



Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD

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INTRODUCTION AND BACKGROUND

In 2009, the Centers for Medicare & Medicaid Services (CMS) contracted with L&M Policy Research (L&M) and its partners, Truven Health Analytics (formerly the health care business of Thomson Reuters) and the National Association of State Directors of Developmental Disabilities Services, to address the growing need among federal and state policymakers and stakeholders for accurate and comprehensive information regarding available services and supports for people with ASD. The *Autism Spectrum Disorders (ASD) State of the States of Services and Supports for People with ASD* report stemmed from the Interagency Autism Coordinating Committee's (IACC's) 2010 and 2011 Strategic Plans.¹ The overall goal of this project was to capture information about services for people with ASD across all federal and state-level agencies and offices that could serve as a useful tool and be updated on an as-needed basis. In addition, the project aimed to identify gaps in data.

Currently, there is no comprehensive, nationwide summary of state services for people with ASD and policies related to people with ASD. Because state-level government agencies play an important public policy role in serving individuals with ASD, the L&M team was tasked with collecting data on existing programs and policies in all 50 states and the District of Columbia to compile this report, *Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People With ASD*. To accomplish this task, the researchers sought to answer the following questions:

- What are states and/or local government doing to provide services for people with ASD?
- What are the types of services and supports that a person with ASD can access?
- How are these supports and services funded?

The data collection tool used for the interviews can be found in appendix A. Prior to conducting the qualitative task with state-level offices and departments, the team received approval from the Office of Management and Budget (OMB) for the federally sponsored data collection task as required by the Paperwork Reduction Act. OMB approved data collection in September 2011. The valid OMB control number for the information collection is 0938-1142. A description of the research team's methodology can be found in appendix B. A glossary of commonly used terms and program references that are captured across many state summary profiles can be found in appendix C. Finally, a summary of insurance mandates and ASD-specific waivers can be found in appendices D and E.

Caveats

Two caveats apply to this document:

1. The information contained in the summary profiles is based on the best available information during the study period.
2. Information on services that were offered through state's Medicaid program focused on 1915c and 1115 programs and not on other authorities (e.g. state plan).

¹ The IACC 2011 Strategic Plan available at <http://iacc.hhs.gov/strategic-plan/2011/index.shtml>.

3. Although some states use the term “mental retardation” (MR) in statute, for the purposes of being consistent with federal statutory changes, the research team, at CMS’s request, replaced references to MR with “intellectual disability” (ID) or “individual with intellectual disability” (IID), as appropriate, in state profile summaries. An exception is made for state program titles including “MR.” All federal references to MR were changed to ID in 2010 with the signing of Rosa’s Law.

CONSIDERATIONS FOR FUTURE ASD STATE OF THE STATES

Because the initial intent of this report was to regularly update the approved template, the research team, based on its experience in producing the summary profiles, has identified several key issues to consider addressing for any future State of the States ASD reports, as follows:

- What are the ASD-specific services adults need? States cite a lack of available services and supports for this cohort.
- What activities and tools are in place to support seamless transition(s) from school to adult services (e.g., vocational rehabilitation, employment, other educational opportunities, tracking service history)?
- How does transition from waiver services happen (for ASD-specific waivers and other waivers)? What is needed to ensure continued support for persons that have aged out of a waiver (e.g., continued case management)?
- What options are available for those on the waiting list for waivers?
- How do states with ASD-specific waivers ensure provider availability and access (e.g., applied behavior analysis therapists)?
- Do all states with a private insurance mandate have providers who will accept private insurance? Is there language in any mandates that might make it prohibitively difficult for people to obtain covered services?
- What are best practices for serving and transitioning those with ASD across the lifespan?

Finally, the research team has concluded that it would be beneficial to reach out to the key national organizations that have a state presence/chapter in order to understand more fully the entire scope of services, their organization, and how services and supports are provided to persons with ASD. Reaching out to such organizations was not part of the scope of work for this project. However, the team initially had the opportunity to discuss the project with a number of national organizations to gauge what a State of the States report should include. The organizations included representatives from

- Autism Science Foundation;
- Autism Society of America;
- Autism Speaks;
- Autistic Self Advocacy Network; and
- Southwest Autism Research & Resource Center.

The following includes some important considerations garnered from the interviews for the summary profiles and any future ASD State of the States reports:

- National stakeholder organizations expressed overall enthusiasm with respect to the State of the States services and supports summary.

- This type of summary will be helpful to families of people with ASD in seeking the types of services and supports that are available in different states.
- A State of the States report will ideally capture the needs of the community. One stakeholder suggested that the deliverable be “fluid . . . something that comes to life and not stagnant numbers on a page.”

Although the official chapters of the preceding organizations are not publicly funded by the states, the research team found these organizations consistently operate as key partners, working in consultation with state-level agencies and programs, and could assist the team in recognizing additional key individuals who should be interviewed for updating and revising a future ASD State of the States report.

ACKNOWLEDGMENTS

L&M would like to thank all of the individuals across all 50 states and the District of Columbia who participated in the discussions for their time and efforts in reviewing and updating their summary profile to ensure accuracy. In addition, the team would like to thank its subcontractors, NASDDDS and Truven Health (formerly Thomson Reuters) and the consultation and guidance CMS provided to the team throughout the data collection process. Finally, the L&M team thanks the members of the Technical Advisory Panel, who provided invaluable insight and direction surrounding the development of the data collection tool.

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STATE SUMMARY PROFILES

ALABAMA

Approach

The L&M research team interviewed eight representatives from the state of Alabama, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Alabama Department of Public Health (DPH); Division of Developmental Disabilities (DDD), Alabama Department of Mental Health; Vocational Rehabilitation Service (VRS), Department of Rehabilitation Services (DRS); Early Intervention System, DRS; and Department of Education (DOE).

State background

The DDD within the Department of Mental Health is home to the Alabama Interagency Autism Coordinating Council (AIACC) as well as the State Autism Coordinator. In 2007, House Joint Resolution 23 established the Alabama Autism Task Force to examine diagnosis and treatment of individuals with autism in the state. Recognizing the need for a source of state data, the task force created the Alabama Autism Collaborative Group to conduct a Statewide Autism Needs Assessment and asked the University of South Alabama to conduct a Statewide Autism Awareness Assessment. Based on the results of these assessments, House Joint Resolution 41 created AIACC to develop a system of care for individuals with ASD. The Alabama Autism Task Force was dissolved in 2009; however, the Riley Ward Alabama Autism Support Act was soon signed into law, keeping AIACC in existence. In addition, Act 592 of 2009 allows for the creation of regional autism centers around the state; however, development of each center is currently dependent on available funding (AIACC, 2009).

The AIACC works to coordinate a lifelong system of support for individuals with ASD. Its goals are to improve funding, training for ASD-specific providers, access to care, political leadership, public awareness of ASD, and true cooperation with the autism community. AIACC includes representatives from many organizations, such as the Alabama Department of Mental Health, the Department of Children's Affairs, the Alabama Institute for Deaf and Blind, the Department of Education, the Department of Human Resources, the Department of Insurance, DPH, the Department of Rehabilitation Services, the Alabama Medicaid Agency, the Autism Society of Alabama, the Alabama Council on Developmental Disabilities, the Alabama Chapter of the American Academy of Pediatrics, and the University Center of Excellence in Developmental Disabilities Education, Research, and Service (AIACC, 2011).

State insurance regulations

Currently, Alabama does not have an insurance mandate for autism services. In 2012, however, Alabama passed the Riley Ward Act instructing health benefit plans to offer coverage for screening, diagnosis, and evidence-based treatments (including applied behavior analysis) for children 9 years old or younger with autism. Covered treatment cannot be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable than those applied to other illnesses under the plan. Policyholders, however, may have to pay a more expensive premium if they opt to accept the coverage (Easter Seals, 2012; National Conference of State Legislatures, 2012).

Additionally, under Alabama’s mental health parity law—House Bill 667—group health benefit plans must provide equitable health coverage for the diagnosis and treatment of mental illnesses as with medical illnesses. Mental illnesses are defined by the International Classification of Diseases and include ASD (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Alabama 1915(c) waivers

Waiver Name	Population Served
AL HCBS Waiver for Persons with ID*	Individuals aged 3+ with ID
AL Living at Home Waiver for Persons with ID*	Individuals aged 3+ with ID
AL SAIL	Individuals aged 18–60 with physical disabilities
AL Individuals with HIV/AIDS & Related Illnesses	Individuals aged 21+ with HIV/AIDS
AL Technology Assisted Waiver	Individuals aged 21+ who are technology dependent
AL Community Transition Waiver (ACT)	Individuals aged 65+ or disabled aged 0–64 who have been in a nursing facility for at least 100 days
AL HCBS Waiver for the Elderly and Disabled	Individuals aged 65+ or physically disabled aged 0–64

**Note: Of particular importance to ASD population*

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Alabama does not have any waivers specific to individuals with ASD at this time.

Other waivers

In Alabama, two HCBS waivers allow people with ASD to receive services. The County Boards of Developmental Disabilities administer the waivers and waiting lists, and all services under DDD are currently provided through waivers. The Alabama Autism Task Force discussed a children’s autism waiver a few years ago, but it was never implemented.

- The *Alabama HCBS Waiver for Persons with ID* provides services to individuals with intellectual disabilities (IDs) who would otherwise require the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). It covers individuals aged 3 and older. This waiver is more comprehensive than the Living at Home Waiver for Persons with ID as it includes residential services (Alabama Medicaid Agency, 2013). Services offered through the waiver include:
 - Residential habilitation
 - Day habilitation
 - Prevocational services
 - Supported employment
 - Therapy services (speech, occupational, physical)
 - Medical supplies
- The *Alabama Living at Home Waiver for Persons with ID* is a support waiver that covers individuals aged 3 and older who require the level of care of an ICF/IID. This waiver covers 569 individuals and offers many of the same services as the HCBS Waiver for

Persons with ID but is not as comprehensive (Alabama Medicaid Agency, 2013). Services offered through the Living at Home waiver include:

- Residential habilitation
- Day habilitation
- Prevocational services
- Supported employment
- Therapy services (speech, occupational, physical)
- Medical supplies

Findings

Services and supports for people with ASD

The DDD in the Department of Mental Health recently changed its name from the Division of Intellectual Disabilities but still provides the same services. The DDD administers services through contracts with community agencies, five regional community services offices, and three comprehensive support services teams that assist with behavioral, medical, psychiatric, and dental services and supports. The DDD has interagency agreements with Child Protective Services (CPS), Department of Human Resources, the DOE, and the Adult Protective Services Division. If a child meets waiver criteria, CPS and DOE help to fund services until age 21; afterwards, DDD works with Adult Protective Services. Eligibility for services is determined by having an IQ of less than 70.

DDD is organized into seven offices: the Office of Administrative and Fiscal Operations, the Office of Psychological and Behavioral Services, the Office of Quality and Planning, the Office of Self-Advocacy Services, the Office of Supported Employment, the Office of Systems Management, and the Office of Waiver Service and Case Management. Of these offices, the Office of Psychological and Behavioral Services, the Office of Self-Advocacy Services, the Office of Supported Employment, and the Office of Waiver Service and Case Management are most helpful to individuals with ASD.

Early intervention

The Alabama Early Intervention System is housed within the Alabama Department of Rehabilitation Services. It serves children from birth to 36 months who are experiencing at least a 25-percent delay in one or more areas of communication, physical, adaptive, cognitive, and social/emotional development (Alabama Department of Rehabilitation Services, n.d.). A diagnosis of autism qualifies a child for early intervention services. Services are delivered based on individual need and a child's Individualized Family Service Plan.

The Early Intervention System works with AIAAC, Help Me Grow, and "Learn the Signs. Act Early." to promote identification. In addition, the Alabama DPH sponsored a 2-hour Webcast with Alabama's "Learn the Signs. Act Early" grantee to help providers become more familiar with early warning signs to promote early identification. The Webcast was broadcast on August 9, 2012, and is available on the DPH Web site. The Webcast was targeted toward pediatricians, nurses, and social workers but is open to all interested parties. Alabama also won a \$15,000 grant from the Centers for Disease Control and Prevention (CDC) and Association of Maternal and Child Health Programs for the Act Early Alabama Awareness and Training Initiative. The grant

provides funding to make the initiative more state specific, create Webinars devoted to training, and create a better network to disseminate information about “Learn the Signs. Act Early.” across the state.

School-aged children

The DOE participates in the AIACC on the Standards of Practice Committee. The DOE contracts with Glenwood Autism and Behavioral Health Center for many services that are specifically intended for children with autism but also help students with other behavioral issues. These services are funded by federal and state dollars and include consultation and training, transition services, and the Preschool Readiness Excellence Program (PREP). Glenwood offers other services for children with ASD; however, they are not funded with federal and state dollars. All of the programs highlighted below are offered at no cost to the individual school or school district.

- Through the contract for *consultation and training*, Glenwood staff can provide diagnostic assessment for children with ASD and consultation services focused on classroom and teaching strategies tailored to specific children. To begin this process, teachers and caregivers must fill out an extensive form providing a personal history of the child and all relevant information, including a current Individualized Education Program (IEP) if available and management steps that have already been taken (Glenwood Autism and Behavioral Health Center, n.d.[a]).
- The *PREP* focuses on children aged 3–5 years that have mental health issues, severe behavioral issues, or ASD. Services are based on expressed need from school districts, individual schools, or agencies. Consultations can last anywhere from 2 to 5 days, with followup services ranging from 3 to 6 months. Services offered within the program include behavioral assessments, development of intervention and communication strategies, parent education, positive programming, and inclusion strategies. The staff will also write a comprehensive report of suggestions based on direct observations and interactions with teachers, aides, and students (Glenwood Autism and Behavioral Health Center, n.d.[b]).

Adults

The VRS within the Alabama DRS provides specialized employment- and education-related services to individuals with disabilities. Services are designed to meet the needs of individuals and can include vocational assessment, evaluation and counseling, job training and placement, and assistive technology. Eligibility is determined by a physical or mental disability that provides a substantial impediment to employment. VRS receives federal funding, and each counselor is given a budget for the provision of eligible services.

In addition, DRS has 30 supported employment providers who provide community-based assessment, job coaching, and extended support to those with the most significant disabilities. Two of the supported employment providers are specifically trained to work with individuals with ASD. One of these providers offers evaluation services designed for this population, and the other provides assistance with evaluations and life coaching to help individuals find and maintain a job and personally adjust to work life.

Systems tracking

The DDD does not currently track individuals with autism but is looking into future plans to do so. However, the University of Alabama at Birmingham School of Public Health, as the bona fide agent of the Alabama DPH, conducts ASD surveillance to estimate the prevalence in Alabama through the Alabama Autism Surveillance Project (AASP). AASP, housed within the university's Department of Health Care Organization and Policy, is a multisource investigation to monitor the number of 8-year-old children with ASD. AASP is a member of the national Autism and Developmental Disabilities Monitoring (ADDM) Network. The ADDM Network is funded by the CDC and outlines a method to ensure that data collection is standardized around the country (CDC, 2012).

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Transition from early intervention to education begins at 27 months, but families can opt out of referral to the local educational agency. If families choose to accept the referral, they have a transition meeting prior to the child's third birthday, and the school develops an IEP by the time the child is 3. The PREP offered through the Glenwood Autism and Behavioral Health Center also offers assistance with transitions from early intervention to special education services.

School-aged to employment

As noted earlier, Glenwood Autism and Behavioral Health Center offers specialized services for student's aged 16 and older to assist with transition out of the DOE. Glenwood provides direct services, such as helping to develop IEP goals, building curriculum focused on best practices of transition, conducting staff training, developing specific strategies, and writing a comprehensive report based on direct observations and interactions with teachers, aides, and students. Glenwood also help schools develop relationships with various community agencies and utilize positive programming and supports (Glenwood Autism and Behavioral Health Center, n.d.).

Project SEARCH (<http://www.projectsearch.us/>) is an initiative modeled after a program at Cincinnati Children's Hospital that promotes collaboration between DRS, DOE, local school boards, and the Department of Mental Health. The program takes high school students and places them in a working environment in hospitals to promote skills development and job fulfillment. The program was initially based on the idea that individuals with developmental disabilities could assist in systematic, entry-level positions in hospitals, such as stocking supply cabinets or sterilizing equipment. In Alabama, the program has two hospital sites and serves all individuals with a developmental disability diagnosis, including individuals with ASD (Project SEARCH, 2012).

In Birmingham, DRS has a program called CONNECTIONS: Connect the World Around Us, which focuses on teaching social skills within the classroom and real-world situations for

students transitioning out of high school. This program is offered during the school year to high schools students and young adults who intend on pursuing employment.

Training for direct service support workers

Other than the training for educators provided by Glenwood Autism and Behavioral Health Center that was outlined earlier, there is currently no statewide training for support service providers.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

AIACC is working to build a new system of care for individuals with ASD in Alabama. One of their goals is to improve communication between agencies and create a cohesive system for individuals of all ages. To support this effort, the AIACC Standards of Practice Committee is working to standardize evaluation and diagnostic assessment tools among agencies to avoid multiple assessments. The Standards of Practice Committee is divided into six workgroups: Services Birth to Five, Services Six to 21, Transition Services, Adult Services, Diagnostic Clinics, and Professional Preparation and Training (AIACC, 2011). In the 2011 Annual Report, the Diagnostic Clinics Workgroup recommended the use of ASD-specific screening and standardized tools for providers and agencies to improve coordination of care. Moreover, the workgroup noted its greatest challenge as improving coordination between the regional diagnostic clinics and the public school systems to reduce unnecessary duplication of evaluation (AIACC, 2011).

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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ALASKA

Approach

The L&M research team interviewed five representatives from Alaska, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Alaska Department of Health and Social Services (DHSS), Senior and Disabilities Services, the Division of Behavioral Health, the Governor's Council on Disabilities and Special Education, the University of Alaska Anchorage Center for Human Development, and the Special Education Service Agency (SESA) Autism Program.

State background

Currently, the state of Alaska's Department of Education has identified 927 students with autism, and almost half (48 percent) are attending schools in Anchorage. In 2006, in response to public testimony regarding the growing need for ASD services across the state, the Governor's Council on Disabilities and Special Education convened an Ad Hoc Committee on Autism. The Committee produced four high-priority recommendations, which were presented to the Alaska Legislature and Administration:

1. Greatly expand autism resources and referral services;
2. Establish universal screening for ASD;
3. Increase the capacity for comprehensive, timely assessments and diagnosis; and
4. Change Medicaid to ensure that children with ASD are able to receive time-limited, intensive intervention services (Governor's Council on Disabilities and Special Education, 2006).

Following these recommendations, the Alaska DHSS and its statewide partners have continued to develop a system of support for children and adults with ASD and their family members and caregivers.

State insurance regulations

In 2012, Alaska enacted S.B. 74, which requires private health care insurers to provide insurance coverage for the diagnosis and treatment of ASD for individuals less than 21 years of age. Diagnosis and treatment coverage includes medically necessary pharmacy care, psychiatric care, psychological care, habilitative or rehabilitative care (including applied behavior analysis), and therapeutic care (which includes services provided by a licensed speech-language pathologist). There is no limit on the number of visits an individual may make to an autism services provider. S.B. 74 also created the Autism Task Force, which will survey the effects of S.B. 74 as well as make recommendations concerning the development of a statewide plan to aid the early diagnosis and treatment of autism. The legislation is effective as of January 1, 2013 (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

The Alaska Medicaid Tax Equity and Fiscal Responsibility Act (TEFRA) program allows children under 19 who require an institutional level of care to qualify for Medicaid, regardless of

parent income. A sliding scale premium is applied based on income, and no copayments are allowed for services to children who are eligible for TEFRA (Centers for Medicare & Medicaid Services [CMS], n.d.). Eligibility for Alaska Medicaid TEFRA is determined by the following criteria:

1. The child must be living in the home of the biological or adoptive parent;
2. Income and resources must be within the specialized Medicaid income limits;
3. The child must meet the Social Security’s definition of disability; and
4. The child must meet one of three possible Level-of-Care categories: Intermediate Care Facility for Persons with Intellectual Disabilities, Nursing Facility (skilled and/or intermediate), or Inpatient Psychiatric Hospital (Qualis Health, n.d.).

State of Alaska 1915(c) Waivers

Waiver Name	Population Served
AK People with Intellectual and Developmental Disabilities*	Individuals of all ages with autism/ID/DD
AK Children with Complex Medical Conditions	Children aged 0–21 who experience developmental disabilities in addition to complex medical conditions and require a nursing facility level of care
AK Psychiatric Residential Treatment Facilities	Children aged 0–21 who meet a psychiatric residential treatment facility level of care (waiver will phase out when participants are no longer eligible)
AK Adults with Physical and Developmental Disabilities	Individuals aged 21–64 who have severe disabilities and require a nursing facility level of care
AK Alaskans Living Independently	Seniors aged 65+ and individuals aged 21–64 with physical disabilities

*Note: Of particular importance to ASD population
Source: CMS, n.d.

Specific ASD waivers

Alaska does not have any waivers specific to individuals with ASD at this time.

Other waivers

Stakeholders indicated that one primary 1915(c) waiver serves all adults and children with intellectual and developmental disabilities. The state is considering application for other Medicaid waivers, including an autism-specific waiver to supplement what is currently available (Governor’s Council on Disabilities and Special Education, 2007).

- The *Alaska People with Intellectual and Developmental Disabilities* waiver is designed to offer a choice between home- and community-based services and institutional care for people who meet waiver service criteria. In order to qualify, an individual has to manifest a developmental disability before age 22 that is likely to continue indefinitely. The developmental disability must result in substantial functional limitations in three or more of the following areas of major life activity:
 - Self-care
 - Receptive and expressive language

- Learning
- Mobility
- Self-direction; capacity for independent living
- Economic self-sufficiency

In addition, the disability must require special supports or other services that are of lifelong or extended duration and are individually planned and coordinated. Services offered through the waiver include:

- Care coordination
- Day habilitation
- Residential habilitation
- Respite
- Supported employment
- Chore
- Environmental modifications
- Intensive active treatment
- Meals
- Nursing oversight and care management
- Specialized medical equipment and supplies
- Specialized private duty nursing
- Transportation (Alaska Senior and Disabilities Services, 2012)

Findings

Services and supports for people with ASD

Early intervention

Alaska's early intervention program, known as the Infant Learning Program, provides services for individuals from birth to age 3 with developmental delays or disabilities and their families through Part C of the Individuals with Disabilities Education Act (IDEA). Preschoolers (aged 3–5) with delays or disabilities receive early childhood special education through IDEA Part B. Eligibility is determined by the general developmental disability criteria as defined by the federal Developmental Disabilities Act, and therefore, the Infant Learning Program does not require an ASD diagnosis. Services include screening and evaluation; development of an Individualized Family Service Plan (IFSP); home visits; physical, occupational, and speech therapy; access to specialized equipment and resources to promote and support development of the child; and assistance with locating resources and services to meet other developmental needs.

Due largely to the continuing work of the Governor's Council Ad Hoc Committee on Autism and the significant progress in resource capacity-building and private insurance regulation, Alaska's spotlight is on workforce development to meet the growing needs of detection, diagnosis, and early intervention for children with ASD. Outgrowths of this work include the integration of a multidisciplinary workforce to detect ASD through the Providence Autism Diagnostic Network and the University of Alaska Anchorage Center for Human Development's Board Certified Behavioral Analyst program.

Alaska has nine military base installations across the state representing the Air Force, Army, and U.S. Coast Guard. The state's large military population has access to a developmental pediatrician and ASD services at the Joint Elmendorf Richardson Base in Anchorage. Interviewees reported that diagnostics and developmental disability services are exceptional for military families of children with ASD.

School-aged children

Depending upon the child's eligibility status, ASD services are financed through the People with Intellectual and Developmental Disabilities waiver and/or the Division of Behavioral Health. A child aged 3–21 years is eligible for ASD services if there is an early childhood developmental delay of 25 percent in two cognitive areas or 20 percent in three or more areas for children aged 3–8 years. A child also may become eligible for services if he or she exhibits a developmental delay significantly affecting verbal and nonverbal communication and social interaction, thereby adversely affecting educational performance and requiring special facilities and equipment. The child must be diagnosed by a psychiatrist, physician, nurse practitioner, pediatric neurodevelopmental specialist, or licensed psychologist and must be certified by an Individualized Education Program (IEP) team as needing special services. The Alaska Department of Education & Early Development Office of Special Education Programs provides programming and placement options, including early intervention and transition services, to help support the educational progress of students with ASD.

In addition, SESA provides assistance to Alaskan school districts and early intervention programs and is currently serving 81 students with ASD in 28 districts across the state. SESA's Autism Support Team is made up of autism specialists who provide support, conduct observations and assessments, develop IEPs, design and implement evidence-based interventions, and train teachers about ASD-specific strategies and interventions. In order to be eligible for SESA services, a student must fall into one or more of the following state developmental disability categories:

- Autism (including Asperger's syndrome);
- Early childhood developmental delay, with a concurrent diagnosis of autism provided by a physician or psychologist; or
- Other health impairment, with a concurrent diagnosis of pervasive developmental disorder not otherwise specified or Asperger's syndrome provided by a physician or psychologist (SESA, n.d.).

Interviewees reported that approximately 100 children are in residential out-of-state psychiatric treatment facilities, and 40 percent have ASD or ASD and intellectual disability. Very few children reside in in-state residential facilities.

Adults

In addition to the waiver services described earlier, the Division of Vocational Rehabilitation offers free and at-cost services to help individuals with job searches and career planning. To be eligible, individuals must have trouble getting or keeping a job because of a mental or physical problem and must need services to prepare for, get, or keep a job. Free services include:

- Assessments
- Counseling
- Referral to other agencies
- Tests and other tools to better understand skills/abilities
- On-the-job training with a real employer
- Short-term job tryouts called “Community Assessments”
- Job search and placement services
- Interpreter, reader, and tutoring services

At-cost services include:

- Training aside from on-the-job training
- Books, training supplies, tools, equipment (including computers), and other supplies
- Living expenses
- Transportation
- Medical care and therapy
- Self-employment
- Devices that help with disabilities
- Services to family members
- Work licenses
- Other goods or services (Alaska Division of Vocational Rehabilitation, 2012b)

Systems tracking

Systems tracking of services and supports for individuals with ASD were not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

SESA is a main hub of ASD service promotion for school-aged children, their teachers, parents, and caregivers. The public school districts receive training and autism-specific behavioral health services through SESA. SESA also operates the Alaska Autism Resource Center, which provides information, referral, training, and consultation via onsite and distance delivery. SESA creates communications to advertise trainings and works with partners to actively recruit speakers for the annual Alaska Statewide Special Education Conference.

Transitions and coordination of services

Early intervention to school

Overall, transitions progress according to IDEA legislation. Children usually move from a home-based program into a preschool at age 3. Around age 2, the Infant Learning Program coordinator

works with the family to review the IFSP, identify areas that will need to be updated, and begin putting together a transition packet. At age 2½, a transition conference takes place with the Infant Learning Program staff, family, childcare providers, service providers, friends, and representatives from the local educational agency and/or community providers, in which the group reviews plans for transition. Transition plans must be developed for all children exiting the Infant Learning Program and evaluated once the child is placed in his or her learning environment. Transition plans address areas such as:

- What is important for the family and child in a new setting;
- Specific outcomes and goals related to preparing the child for transition; and
- Additional information needed to help determine eligibility, including specific assessment tools and who will gather the information; this may include observations in various settings (Alaska Infant Learning Program, 2010).

School-aged to employment

Transition planning from school to adulthood involves exploring postsecondary opportunities and employment options and connecting with adult agencies that provide services at age 22. The transition process occurs according to the IEP at age 16 or younger. At this time, the IEP team helps students identify their post school vision and identifies transition services necessary to support these goals. This information is documented in the IEP as well as a separate transition planning form. Transition services might involve:

- Career interest inventories
- Job shadowing
- Mentoring
- Apprenticeship
- Workplace visits and tours
- Career fairs
- Mock job interviews and job clubs
- Afterschool and summer job placements arranged and supported by school staff
- Community college enrollment

A Division of Vocational Rehabilitation (DVR) counselor may participate in the transition planning meeting at the school in order to provide technical assistance. DVR requires that an Individual Plan for Employment (IPE) is developed and approved before the student transitions from the school setting. The IPE must coordinate with the student's IEP (Alaska DVR, 2012a).

Training for direct service support workers

Most of the training discussed with interviewees is focused on children and early intervention. SESA is the central training arm of public school teachers, providing inservice training on autism awareness, how to include students with ASD in general education classrooms, positive behavioral support and functional assessment, evidence-based teaching strategies, curriculum

modification, social skill development, parent training approaches, and other techniques. In addition, school districts and the general public can access disability and special education resources through the SESA Library.

The Center for Human Development is a Center for Excellence in Developmental Disabilities and is funded by the Alaska Mental Health Trust Authority to provide Board Certified Behavior Analyst (BCBA) training. The BCBA education pathway is directly tied to the Ad Hoc Committee's 2006 plan to increase the strength of Alaska's workforce to meet the growing needs of the ASD population across the state. The center is currently recruiting its fourth cohort of BCBA's for training in 2013.

Another significant source of provider training is the Complex Behavioral Collaborative (CBC), a holistic behavioral stabilization training initiative for direct service support workers who serve Medicaid clients who have challenging and complex behavioral needs and often display aggressive or assaultive behavior. Since early 2012, the CBC has conducted a 6-month consultation and training pilot project called "the Hub," which provides support agencies with technical assistance on serving challenging clients. CBC's partners in the Hub project include the DHSS Division of Behavioral Health and Senior and Disabilities Services, Alaska Pioneer Homes, the Governor's Council on Disabilities and Special Education, the Alaska Commission on Aging, the Alaska Mental Health Board, the Advisory Board on Alcoholism and Drug Abuse, and the Alaska Mental Health Trust Authority.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Governor's Council Ad Hoc Committee on Autism meets quarterly with its subcommittee on education and workforce development. Members regularly identify strengths and gaps across the ASD system relative to professional and family development. The group's work has resulted in the state's increased capacity to diagnose children with ASD for early intervention, assure proper screening and care through a qualified workforce, and provide insurance carrier coverage for ASD diagnostic and treatment services. The group continues to work collaboratively to end the gaps that continue across the state, and according to interviewees, the priority is to find financing solutions that will enable expanded services and supports for ASD in a sustainable manner.

In 2007, the Ad Hoc Committee created a policy paper to provide an analysis of five options for developing early intervention services for young children, which included:

1. Exploring the options for offering autism services under the Deficit Reduction Act;
2. Applying to the Centers for Medicare & Medicaid Services for an autism waiver;
3. Attaching intensive autism intervention services to an overhaul of the entire Medicaid system in Alaska through an 1115 waiver;

4. Offering intensive early intervention as part of the existing Medicaid program (e.g., by designating treatment through the Early Periodic Screening, Diagnostic and Treatment Program; and
5. Mandating that insurance companies provide coverage for autism services.

As of 2012, the passage of SB 74 requires private insurance companies to provide autism service coverage, and according to interviewees, the four other options are still under consideration to finance increased services and supports for ASD in Alaska. The committee is working with the state of Alaska and other self-insured entities to obtain coverage for autism services under their insurance plans.

Other relevant programs and services

- Interviewees identified the *Stone Soup Group* (<http://www.stonesoupgroup.org>) as a key resource for families of children with ASD. The Stone Soup Group is a nonprofit organization that provides information, support, training, and resources to assist families caring for children with special needs up to age 26. Most staff members have children with special needs, some of whom serve as parent navigators who assist families with newly diagnosed children through the Providence Autism Diagnostic Network.
- The *Providence Autism Diagnostic Network* is a multidisciplinary collaborative focused on the early detection of autism in children, providing diagnostic and early intervention services through a combination of psychiatry, psychology, neurology, physical therapy, speech therapy, occupational therapy, and navigation services. The network and its clinics have increased the state's capacity for detection and diagnosis earlier in the lifespan (Providence Health & Services, 2013).
- The *Arc of Anchorage* is a nonprofit organization serving children and adults who experience developmental disabilities or mental health issues, focusing specifically on preserving civil rights of those with disabilities. The Arc of Anchorage is a chapter of The Arc of the United States, a nationwide grassroots organization with nearly 1,000 state and local chapters.
- The *Alaska Center for Autism* offers interactive opportunities for family members of individuals with autism, such as parent-sharing teleconferences, lecture series, Webinars, and onsite events. The center also provides referral and consultation services.
- *Hope Community Resources* (<http://www.hopealaska.org>) is a nonprofit organization that provides community supports to over 1,200 families and individuals who experience disabilities. Services are provided through regional offices, which are located in Anchorage, the Matanuska-Susitna Valley, Dillingham, Kodiak, Juneau, Ketchikan, Seward, Barrow, and the Kenai Peninsula.

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ARIZONA

Approach

The L&M research team interviewed one representative from the state of Arizona to gain information about the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The goal for the interview was to provide greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

The Arizona Autism Spectrum Disorder Task Force was enacted by law in 2010 (SB 1181). The task force is charged with reviewing the coordination of services, identifying problems and recommending solutions regarding the availability of services, identifying current funding sources, recommending opportunities for the sharing of resources and services, identifying evidence-based treatments and best practices, and identifying state models and service systems for persons with ASD. The task force consists of 17 members who include representatives from organizations, members of the Senate, educators, and other providers.

State insurance regulations

H.B. 2847, also known as Steven's Law and signed into law in March 2008, requires group health insurance coverage for the diagnosis and treatment of ASD. The law prohibits health service or medical service corporations from excluding or denying coverage for diagnosis, assessment, treatment, and services for ASD. In addition, the law prohibits the exclusion or denial of coverage for medically necessary behavioral therapy under the supervision of a licensed or certified provider, including applied behavior analysis. The law exempts small business or individual health insurance policies as well as services rendered outside of the state. Behavioral therapy is covered at a maximum of \$50,000 per year up to the age of 9 and at a maximum of \$25,000 per year between the ages of 9 and 16 (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

Specific ASD waivers

Arizona does not have any waivers specific to individuals with ASD at this time.

Other waivers

Arizona does not have any 1915(c) home and community-based services programs. However, the state participates in an 1115 Research and Demonstration Project, the Arizona Health Care Cost Containment System, which offers services for individuals who require nursing home or in-home care. Services are offered through the Arizona Long Term Care System and are intended for individuals aged 65 and older and individuals of all ages who are blind or have a disability that requires ongoing services at a nursing facility level of care (Arizona Health Care Cost Containment System, 2013).

Findings

Services and supports for people with ASD

In Arizona, the Division of Developmental Disabilities provides services and supports to help eligible individuals with developmental disabilities. The division also offers supports for family members and other caregivers.

Early intervention

As required under the Individuals with Disabilities Education Act (IDEA), the Department of Economic Security Arizona Early Intervention Program (AzEIP) and its partner agencies administer, promote, and coordinate early intervention services in the state.

To further enhance AzEIP, the Governor of Arizona has established the State Interagency Coordinating Council for Infants and Toddlers (ICC), made up of family members, providers, state agency representatives, and other community members. The purpose of the ICC is to advise and assist the Department of Economic Security as lead agency for early intervention in the following areas:

- The development and implementation of early intervention policies;
- The full participation, coordination, and cooperation of all appropriate public agencies in early intervention; and
- Federal, state, or local policies that facilitate and/or impede timely service delivery and taking steps to ensure that any policy, rule, or statutory issues are resolved.

Arizona uses team-based early intervention services; a team lead is the primary partner with the family in the provision of services. The team lead has expertise relevant to the child's needs and the outcomes on the Individualized Family Service Plan (IFSP). The team lead's focus is on collaborative coaching of families as the primary intervention strategy to implement functional IFSP outcomes in natural environments. The team lead does not meet all the service needs of the child; rather, other team members support the lead through regular team meetings and joint visits with the family. Families participate in the team meetings through in-person attendance, calling in to a meeting, or posing questions/concerns to the team lead.

School-aged children

In Arizona, the Arizona Department of Education Exceptional Student Services (ESS) is accountable for ensuring that all special education programs, regulations, and procedures are in compliance with IDEA and that eligible children and youth with disabilities are receiving a free appropriate public education. ESS provides customer service and technical assistance while enforcing the state and federal special education mandates to promote continuous improvement throughout the state.

Since 2006, the Arizona Scholarships for Pupils with Disabilities Program provides scholarships to qualifying students with disabilities to attend a qualified public school in another school district or to attend a private school. Parents interested in applying for a scholarship for their child exercise their parental option to place their child in a qualified school. Scholarships are awarded on a "first-come, first-served" basis.

Adults

The Arizona Division of Employment and Rehabilitation Services (DERS), provides a vocational, community-based job training program for adults with ASD aged 18 years and older. Vocational rehabilitation is designed to ensure job development and placement of each enrolled client with a custom job plan and job coach to meet individual employment needs. Each client works one-on-one with an Individual Supported Employment job coach, who provides on-the-job training and support. Southwest Autism Research & Resource Center (SARRC) thoroughly screens each client for appropriateness for employment and works with each client to determine individual strengths and needs and to identify barriers to success. Employment services include, but are not limited to, skills training in résumé building, filling out applications, interviewing, personal hygiene and appropriate dress for work and nonwork settings, and conducting oneself in a professional manner. In addition, job coaches provide continuous support for each client. They monitor each client's progress in an effort to target support and training toward different areas of need throughout the program.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Once a child turns 3, he or she transitions out of AzEIP. Between 6 and 9 months before the child's third birthday, the Family Resource Coordinator for the AzEIP and family begin to develop a transition plan to either preschool special education or other necessary services. At least 3 months prior to the child's third birthday, a transition meeting is held with a representative from the local school district to explain eligibility for special education. If the child is deemed eligible for special education, services are outlined in the Individualized Education Program (IEP) that is developed before the child's third birthday.

School-age to employment

The ESS ensures that all public education agencies in Arizona are able to receive quality technical assistance in the planning, development, organization, implementation, and evaluation of special education secondary transition services. The following components must be included in the IEP (beginning no later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP team):

- **Measurable postsecondary goals**—measurable goal statements in the areas of education/training, employment, and when appropriate, independent living (updated annually)

- **Age-appropriate transition assessments**—assessments provide information on the student’s strengths, needs, preferences, and interests and are used to write achievable, measurable postsecondary goals
- **Transition services**—transition-related services or activities that reasonably enable the student to achieve his/her measurable postsecondary goals (MPGs) and courses that focus on improving academic and functional achievement to reasonably enable the student to achieve his/her MPGs
- **Student invitation**—students at least 16 years of age must be invited to the IEP meeting when postsecondary transition services are being discussed
- **Outside agency invitation (with prior consent)**—a representative of another agency that is likely to provide and/or pay for transition services who has been invited to the meeting after consent from the parent or student who has reached the age of majority

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

SARRC’s mission is to advance research and provide a lifetime of support for individuals with autism and their families. SARRC undertakes self-directed research, serves as a satellite site for national and international projects, and provides up-to-date information, training, and assistance to families and professionals about autism. Through integrative research, educational outreach, model programs, and collaborative initiatives, SARRC sets forth, promotes, and facilitates best practices for early intervention and the long-term care of individuals with ASDs. Over the past decade, SARRC has expanded its direct services to children and parents and refined its clinical and school consultation programs. In 2009, nearly 11,000 individuals were directly impacted by SARRC services—children, adolescents, and young adults with ASDs and their neurotypical peers; family members; and professionals such as teachers, therapists, and medical practitioners. More than 400 SARRC volunteers donated their time, and SARRC staff conducted 250 trainings and presentations and offered services to students and educators in nearly 90 Arizona schools.

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ARKANSAS

Approach

The L&M research team interviewed three individuals from the state of Arkansas. The initial interview in September 2012 was held with the Division of Developmental Disabilities Services (DDS). Following this interview, L&M received recommendations of representatives in other state agencies for further discussion. In these interviews the team sought greater understanding of the services and supports for persons with autism spectrum disorders (ASD) in the following areas: early intervention, developmental disability services, education, vocational rehabilitation, and Medicaid.

State background

DDS is a subset of the Arkansas Department of Human Services (DHS) and the lead resource agency responsible for the coordination of services for individuals with developmental disabilities in Arkansas. The division consists of four main sections: Financial Support Services, Children's Services, Quality Assurance, and Waiver Services. Other service providers in the state include the Department of Education (DOE), the Department of Career Education (DCE), and Partners for Inclusive Communities—a University of Arkansas program in partnership with DDS. These agencies are available to serve the 1 in every 95 individuals with ASD in Arkansas, the seventh highest rate in the U.S. (CDC, 2012).

State insurance regulations

As of 2011, Arkansas requires health benefit plans to provide coverage for the diagnosis and treatment of ASD. Treatment is defined to include applied behavior analysis (ABA), pharmacy care, psychiatric care, psychological care, therapeutic care, necessary equipment to provide evidence-based treatment, and any care that is determined by a licensed physician to be medically necessary and evidence based. ABA services are limited to \$50,000 annually and to children under 18 years of age. As of January 1, 2014, benefits that are required under this mandate and that exceed the essential health benefits required by the Patient Protection and Affordable Care Act are no longer required by health plans if they are offered through the state health insurance exchange (National Conference of State Legislatures, 2012).

Findings from these interviews revealed a major paradigm shift in the way Arkansas will pay for health care in the future. The expectation communicated is that Medicaid and private insurers will begin paying for “episodes” of care rather than for each service performed.

State Home and Community Based Services (HCBS) waivers

The Tax Equity and Fiscal Responsibility Act (TEFRA) waiver, also known as the Katie Beckett option, allows families with children under 18 who require an institutional level of care and would otherwise be ineligible for Medicaid to qualify for the program. A sliding scale premium is applied based on income, and no copayments are allowed for services to children who are eligible for TEFRA (CMS, 2012).

State of Arkansas 1915(c) waivers

Waiver Name	Population Served
AR Autism*	Children aged 18 months to 6 years with autism
AR Alternative Community Services*	Individuals of all ages with a developmental disability
AR Alternatives for Adults with Physical Disabilities	Individuals aged 21–64
AR Living Choices Assisted Living	Individuals aged 65+ or 18–64 with a disability
AR Elder Choices	Individuals aged 65+

*Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Arkansas Autism* waiver provides one-on-one, intensive home-based intervention for young children with ASD. To qualify for services children must be between 18 months and 6 years of age and receive a diagnosis of ASD from three separate providers: a psychologist, a speech-language pathologist, and a medical doctor. Participation in the program is limited to 30 hours per week for 3 years and at no cost to the family if they meet Medicaid eligibility requirements. Waiver applications were made available September 1, 2012, and began serving up to 100 children as of October 1, 2012, using a phase-in enrollment approach over the first waiver year and a waiting list. The program differs from the Alternative Community Services waiver in that it focuses on early childhood intervention for individuals with ASD. Specific services offered through the Arkansas Autism Waiver are as follows:
 - Individual assessment/treatment development
 - Provision of therapeutic aides and behavioral reinforcers
 - Plan implementation and monitoring of intervention effectiveness
 - Lead therapy intervention
 - Line therapy intervention
 - Consultative clinical and therapeutic services.

Other waivers

- The *Arkansas Alternative Community Services (ACS)* waiver is an HCBS waiver administered by DDS and designed for beneficiaries of all ages with ASD or other developmental disabilities who would otherwise require institutionalization. Individuals must be eligible for Medicaid and have limitations in three of six major life activities, including self-care, language, learning, mobility, self-direction, or independent living. Currently, roughly 2,200 individuals receive services under this waiver, and assessments for applications are ongoing with a waiting list. Services available through the program include:
 - Supportive living
 - Respite care
 - Supplemental support services

- Supported employment services
- Environmental modifications
- Adaptive equipment
- Specialized medical supplies
- Case management services
- Transitional case management services
- Community transition services
- Consultation services
- Crisis intervention services

Findings

Services and supports for people with ASD

DDS supports several programs and services for individuals with developmental disabilities although most are targeted to children and youth. These services are generally provided through private, not-for-profit programs whose service areas include all 75 counties of the state.

Currently, there are 96 DDS licensed providers and 43 early intervention providers statewide.

DDS services include Title V: The State Program for Children and Youth with Special Health Care Needs, the Individuals with Disabilities Education Act (IDEA) Part C (early intervention) and Part B (early childhood), wraparound community supports, developmental day treatment, adaptive equipment, and the ACS waiver program described earlier. Arkansas participates in federal Title V funding designed to help children with special health care needs. All children up to age 21 with ASD are entitled to case management and care coordination for an array of available services. In addition, families of children under 18 that receive Supplemental Security Income or TEFRA are eligible for up to \$1,000 for respite care (Arkansas Medicaid, n.d.). Title V funds are limited to \$5,000 per year, and children received an average of \$2,985 between July 2011 and June 2012. Approximately 250 children with ASD receive funding through Title V.

Early intervention

Arkansas delivers its IDEA Part C services—called “First Connections”—through DDS satellite offices and nonprofit providers contracted with the state. The program is responsible for the planning, development, and implementation of statewide services for approximately 3,000 infants and toddlers. Services are available at no cost to children from birth to 3 years of age who have a developmental delay that is 25 percent or more of their chronological age. They are provided in the home or in integrated daycare programs or developmental day treatment clinic services (DDTCS). The program helps to find, coordinate, and fund a variety of services, including:

- Assistive technology
- Speech therapy
- Physical therapy
- Occupational therapy
- Service coordination
- Health and nursing services

- Social work services
- Nutritional services
- Transportation
- Vision and audiology services
- Multidisciplinary education
- Medical diagnostic services
- Psychological services
- Family training, counseling, and home visits
- Respite

Additionally, DDS provides IDEA Part B early childhood services for preschool children aged 3 to kindergarten who have more serious special education needs. These services are offered in 52 licensed DDTCS programs throughout the state and provide individualized, comprehensive education and therapeutic services such as occupational therapy, physical therapy, and speech therapy (AR Medicaid, n.d.). The state finds this model to be a cost-effective way of providing a range of necessary services to children with developmental disabilities.

School-aged children

Once children approach 5 years of age and begin to transition to school, DDS involvement subsides. The school system provides all educationally necessary services, and DDS offers some out-of-school services including targeted case management, respite care, family support, follow-along, integrated supports, community integration companions, and DDS waiver services.

In accordance with IDEA, the Arkansas DOE strives to ensure that students with disabilities receive a high-quality education in the least restrictive setting. Schools are divided into 16 educational co-ops that provide consultants to work with schools around improving care for students with disabilities. Most notable are behavioral consultants who assist schools in conducting functional assessments, developing Individualized Education Programs (IEPs) and programs for students with ASD, and creating early intervention and mental health initiatives. A total of 11 behavioral consultants in Arkansas provide training and technical assistance to teachers and staff. In 2011, these consultants worked with roughly 140 students, 80 percent of whom had ASD.

Adults

A lack of programs and services exist specifically for adults with ASD who are not recipients of the ACS waiver.

Arkansas DCE runs a vocational rehabilitation program called Arkansas Rehabilitation Services (ARS). ARS provides a variety of training, career, and other ancillary services that clients may need for successful employment (Arkansas Department of Career Education, n.d.). Among these services are:

- Diagnosis and evaluation of capacities and limitations
- Guidance and counseling

- Career and technical education
- Job placement
- Physical and cognitive restorative services
- Assistive technology
- Residential career training facility and hospital
- Transition services for high school students with disabilities
- Scholarships and leadership programs for students with disabilities
- Financial assistance to kidney transplant recipients
- Community rehabilitation programs
- Supported employment services
- Supported housing

In addition, there are five state-operated Intermediate Care Facilities for Individuals with Intellectual Disabilities and 30 ten-bed facilities operated through a network of nonprofit organizations. Most of the funding for these facilities options comes from Medicaid or state waivers.

Systems tracking

Systems tracking of services and supports for individuals with ASD were not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Early intervention

The Arkansas Autism Resource & Outreach Center (AAROC) is a 501(c)(3) organization partially funded by Partners for Inclusive Communities and the leading resource for ASD services in Arkansas. AAROC provides a comprehensive Web site that outlines general information about ASD, services throughout the state, and other pertinent information. A key source of referrals to AAROC is the James L. Dennis Developmental Center (DDC) at the University of Arkansas for Medical Sciences—the primary diagnostic center in the state. DDC has several developmental outreach clinics throughout the state that promote early identification of developmental disabilities in the preschool setting (Arkansas Children’s Hospital, n.d.).

Additionally, as part of early intervention services DDS, has 11 coordinators throughout the state who are responsible for outreach to a caseload of 50 to 100 young children. This primarily consists of educating daycare centers and physicians about developmental delays and services that are available. Moreover, the Division of Child Care and Early Childhood Education under DHS has an active outreach campaign as they are responsible for certifying all preschools in Arkansas and ensuring that children with possible delays are referred to DDS.

School-aged children

Educational co-ops engage in some outreach activities, such as participating in autism walks, meeting with local education directors, and sponsoring presentations and discussions about relevant topics. Overall, however, there is less outreach and promotion of services for school-aged children and adults than for young children. One stakeholder indicated that programs serving these populations are burdened by administrative duties, leaving little time for outreach activities. Moreover, long waitlists for these services tend to result in less emphasis on outreach.

Transitions and coordination of services

Early intervention to school

Transitions from early intervention to school-aged programs typically happen in one of two ways. Children who attend DDS preschool programs until they are ready to move to kindergarten tend to have a more seamless transition from early intervention to school. As children age closer to 5, preschools bring in the local educational agency (LEA), which helps to transition children from DDS, to LEA joint services, to the school, where the LEA is the primary provider.

For children not in a DDS-funded preschool program, transitions may occur in a few stages, beginning as early as 9 months of age. DDS service coordinators meet with families to talk about services available for children aged 3 to 5. They provide options such as Head Start, DDS preschools, and/or private therapies as well as meeting with LEA representatives to talk about next steps.

School-aged to employment

As required by federal IDEA legislation, children must have a transition plan outlining postsecondary goals and services by the age of 16. Transition consultants are available in all school districts to assist students with disabilities, educators, parents, agency personnel, and community members in preparing students to transition from school to adult life. The Title V program also provides support to help transition youth with special health care needs to all aspects of adult life, including adult health care, work, and independence. These processes often include rehabilitation services, vocational counseling, and multiagency planning meetings.

For children who are recipients of a state waiver, families along with DDS will explore waiver services for post school life; otherwise, vocational rehabilitation is an option. ARS provides transition services for high school students with disabilities who are moving from high school to further education or work. This includes guidance and counseling, career and technical education, job placement, supported employment in the community, and sheltered workshop options (Arkansas Department of Career Education, n.d.).

Training for direct service support workers

DDS plans and provides continuous training for speech pathologists serving community programs as well as technical assistance to licensed community programs. Through the Community-Based Autism Liaison and Treatment Project, DDS also funds six teams from University of Arkansas for Medical Sciences to train physicians and psychologists throughout the state in recognizing developmental delays to identify children with ASD more quickly. DDS is hoping for grant money to train additional teams and develop better training tools.

Behavioral consultants, through the educational co-op, provide ABA training for those working in the ASD community. In addition, the University of Arkansas organizes lectures and events related to developmental disabilities, and AAROC provides trainings, such as a parent education and positive behavior support training, for those living and working with the ASD population.

Corrections

Those who end up in the corrections system in Arkansas and are found to have a developmental disability are typically referred to DDS. These individuals are sometimes relieved of their charges if they agree to a treatment plan. Until 3 years ago, it was more common for individuals with developmental disabilities to encounter the corrections system. However, DDS has been working with the Division of Youth Services to develop a screening protocol to identify individuals with developmental disabilities that encounter the law at an earlier stage. Ideally, individuals are referred to appropriate services rather than going through the judicial process.

Long-term plans to develop new or expanded supports and services (2–5 years)

Arkansas is exploring use of the Community First Choice Option through Medicaid. The State has not worked out the details of this program but would like to provide HCBS to everyone who qualifies rather than relying on the waivers.

Other relevant programs and services

- The *Arkansas Autism Alliance* (<http://arkansasautismalliance.org>) is a collaborative effort among research scientists and physicians at Arkansas Children’s Hospital Research Institute and the University of Arkansas for Medical Sciences Department of Pediatrics, who share a common interest in the study of autism, its causes, and the provision of the best possible care to children with autism. In addition to clinical care provided through the Dennis Developmental Center, researchers in the alliance are conducting basic, clinical, and translational research to develop a deeper understanding of the psychological, behavioral, and physiological mechanisms that cause ASD and prevent recovery. In addition, the alliance serves as a source of information and education around current issues related to ASD for parents, families, and health care professionals.
- *AAROC* (<http://www.aaroc.org>) is a nonprofit 501(c)(3) organization that supports families through a one-stop resource center where they can seek help after diagnosis to understand best practices in training, resources, and therapies. AAROC provides information through their Web site as well as scheduled trainings and other events.
- *Arkansas Autism* (<http://www.arkansasautism.org/>) is a collaborative effort of parents, friends, and supporters to offer education, support, and care for those affected by ASD. The organization forms the basis for many support groups for families of children with ASD.

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CALIFORNIA

Approach

The L&M research team interviewed two representatives from the state of California's Department of Developmental Services (DDS) to better understand the delivery of services to individuals with autism spectrum disorders (ASD) in the state.

State background

The 21 private, nonprofit regional centers throughout California provide a variety of short- and long-term services to developmentally disabled children and adults. The DDS, which administers state law (the Lanterman Act) and regulation (Title 17) that governs the regional center system contracts with these regional centers. The centers are governed by their own boards of directors and receive funds from DDS. They serve approximately 250,000 individuals and their families statewide by providing service coordination, advocacy, information, support, and referrals to service providers for:

- Young children with developmental disabilities
- Adolescents with developmental disabilities
- Adults with developmental disabilities
- Parents
- Caregivers

Although the Lanterman Act and Title 17 govern regional centers, each regional center operates independently, so many differences exist in the administration of services provided from one regional center to another (Association of Regional Center Agencies, n.d.).

State insurance regulations

In October 9, 2011, when S.B. 946 was signed, California became the 28th state to require insurance coverage of autism services by insurance companies in the state (Easter Seals, 2012). The law requires that every health care plan contract that provides hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism. Behavioral health treatment includes applied behavior analysis and other evidence-based behavior intervention programs. Treatment must be recommended by a licensed doctor or psychologist and provided under a treatment plan. Reimbursement must be made for the services of Board Certified Behavior Analysts as well as the professionals and paraprofessionals who they supervise. The law does not include specific age limits or dollar caps. The law does not apply to health plans that do not deliver mental health or behavioral health services and also does not apply to participants in the Medi-Cal Programs, the Healthy Families Program, or the Public Employees' Retirement System.

In September 1999, California signed into law a mental health parity bill, which requires health insurance coverage for diagnosis and medically necessary treatment for serious mental illnesses, including pervasive developmental disorders or autism, for individuals of any age and serious emotional disturbances of a child under the same terms and conditions as a medical condition.

Covered services include outpatient, inpatient hospital services, partial hospital services, and prescription drugs (if included in the policy).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of California 1915(c) waivers

Waiver Name	Population Served
CA Pediatric Palliative Care	Individuals aged 0–20 who are medically fragile and technology dependent
CA HCBS Waiver for Californians with DD*	Individuals of all ages with autism/DD/ID
CA HIV/AIDS Waiver	Individuals of all ages with HIV/AIDS and aged 65+
CA Nursing Facility/Acute Hospital Waiver	Individuals of all ages who are medically fragile and technology dependent
CA In-Home Operations	Individuals of all ages who are medically fragile and technology dependent
CA San Francisco Community Living Support Benefit	Individuals aged 21+ who require a nursing facility level of care
CA Assisted Living	Individuals aged 65+ and 18–64 with physical disabilities
CA Multipurpose Senior Services Program	Individuals aged 65+

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

California does not have any waivers specific to individuals with ASD at this time.

Other waivers

California has two waivers that can be utilized by individuals with ASD, one of which is an 1115 Demonstration Project.

- The *California HCBS Waiver for Californians with Developmental Disabilities* was implemented in March 2012 to serve individuals in their own homes and communities as an alternative to hospitals, nursing facilities or intermediate care facilities for individuals with intellectual disabilities. Twenty-one regional centers throughout the state provide and/or coordinate community-based services to eligible individuals with autism, intellectual disabilities, or developmental disabilities. The opportunity for self-direction is available for some services. A complete list of waiver services follows:
 - Behavioral intervention
 - Community living arrangements
 - Day service
 - Home health aide
 - Homemaker
 - Prevocational services
 - Respite care
 - Supported employment chore

- Communication aides
 - Community-based training
 - Dental
 - Environmental accessibility adaptations
 - Nonmedical transportation
 - Nutritional consultation
 - Psychology services
 - Skilled nursing
 - Specialized medical equipment and supplies
 - Specialized therapeutic services
- The *California 1115 Research and Demonstration Projects Waiver: California Bridge to Health Reform* was implemented in September 2005. The demonstration is phasing in coverage in individual counties for adults aged 19–64 who have incomes at or below 133 percent of the federal poverty level (FPL) and would be eligible under the Affordable Care Act’s early expansion option for states, as well as adults between 133 percent and 200 percent of the FPL who are not eligible for Medicaid. This waiver also expands the existing Safety Net Care Pool, which ensures continued government support for the provision of care to uninsured individuals by hospitals, clinics, and other providers. It implements a series of infrastructure improvements through a new funding subpool to strengthen care coordination, enhance primary care, and improve the quality of patient care. It also creates a coordinated system of care for older adults and people with disabilities in counties with new or existing Medi-Cal managed care organizations through the mandatory enrollment of the population into Medicaid managed care plans.

Findings

Services and supports for people with ASD

The California Health and Human Services Agency oversees 13 departments and 1 board that provide a range of health care services, social services, mental health services, alcohol and drug treatment services, income assistance, and public health services to all Californians, including those persons with ASD.

Early intervention

California Early Start is a federally funded program through Part C of the Individuals with Disabilities Education Act (IDEA). The program is designed to ensure that eligible infants and toddlers and their families receive evaluation and assessment of their current functioning and coordinated services early enough to make a difference in development. In California, the Early Start program brings together resources and services to help infants and toddlers grow and learn. Early Start also provides support to families to enhance their child’s development. Early intervention services are planned and delivered to help prevent or lessen the need for special services later in the child’s life. The goal is to help answer questions and concerns about each child’s development and to ensure that infants and toddlers are off to the best possible start. There is a wide range of services available through the Early Start program, including medical services for diagnosis and evaluation; physical, occupational, and speech therapy services; special instruction provided by infant education teachers to promote development; and social services to provide family support, counseling, and home visits.

The California regional centers are responsible for providing service coordination, coordinating and arranging for evaluations to determine eligibility, and developing the Individualized Family Service Plan (IFSP). The regional center service coordinator is also responsible for monitoring services and providing periodic review of the IFSP.

School-aged children

Between 2011 and 2012, the California Department of Education (CDE) provided special education services to 686,352 individuals, newborn through 22 years of age. California provides specially designed instruction, at no cost to parents, to meet the unique needs of children with disabilities. This instruction is provided in a variety of settings that allow infants and their families, preschoolers, students, and young adults to be educated with their peers as much as possible; that is, in the least restrictive environment. Special education services are available in a variety of settings, including daycare settings, preschool, regular classrooms, classrooms that emphasize specially designed instruction, the community, and the work environment. The CDE works with colleges and universities to deliver staff development and training that ensures teachers and other service providers are qualified to work with children with disabilities.

The CDE provides state leadership and policy direction for school district programs and services for students who have disabilities. This leadership includes providing families with information on the education of children with disabilities. The CDE works cooperatively with other state agencies to provide everything from family-centered services for infants and preschool children to planned steps for transition from high school to employment and quality adult life. These efforts are supported by evaluation of student outcomes and analysis of current research. The CDE responds to consumer complaints and administers the federal IDEA for students with disabilities in California.

Adults

The California In-home Supportive Services is a program for low-income elderly and disabled individuals, including those individuals with ASD and couples who need assistance in order to remain safely in their own homes. In addition, employment services are available to eligible individuals, which include vocational support, and opportunities through CalWORKS Mental Health.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

In California, by the time a child is 2 years and 9 months old, the IFSP team must conduct a transition meeting. Typically, this meeting will let the team discuss the child's transition needs and formulate a transition plan. From this conversation, the school district and the rest of the

team should come up with an Individualized Education Program (IEP) assessment plan to which the parents can consent. This meeting is held no later than 3 months prior to the child's third birthday in order to give the school district time to come up with an assessment plan (no more than 15 days), give the parents time to consent to the assessment plan (at least 15 days), and give the school district time to assess the child in all areas of suspected disability (no more than 60 days from when the parents consent to the assessment plan). By the time the child is 3 years old, all of the assessments need to be completed, an initial IEP meeting needs to be held, and the IEP needs to be implemented.

School-aged to employment

From age 3 to 22, California children and youth with autism and ASD may receive educational/behavioral interventions and services through special education programs offered by local educational agencies (LEAs). At age 23, persons are no longer entitled to receive special education services although adults with ASD may continue to have need for services and supports throughout their lifetimes, such as housing, employment, income, personal care, transportation, and other assistance in the basic tasks of daily life.

Federal and state special education laws require LEAs to help prepare pupils with disabilities, including youth with autism, for the transition from school into employment, post school education, independent living, and community participation as part of the IEP process. This planning is intended to identify the individual's goals for the future and the services and supports available in the community to help the person meet those goals.

Training for direct service support workers

Through the University of California, Santa Barbara Koegel Autism Center, First S.T.E.P. (Screening, Training, Education Project) was originally a project aimed to increase the early identification of children with ASD and the provision of support services for families with children with this diagnosis.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

The *Koegel Autism Center Assessment Clinic* offers state-of-the-art diagnostic, developmental, and psychological assessment services for individuals with or suspected of having an autism spectrum disorder (including Asperger's syndrome). Typically spanning two half-day testing sessions, these multifaceted, integrated evaluations are tailored to the needs of each child, adolescent, or adult. At the end of the evaluation, families meet with the team for a same-day feedback session in which assessment findings and recommendations are discussed. Each evaluation culminates in the construction of a detailed, yet easy-to-comprehend report that provides a summary of assessment results, diagnostic information, and a comprehensive description of recommendations.

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COLORADO

Approach

The L&M research team interviewed six representatives from the state of Colorado, which included a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. Agencies that were interviewed included the Colorado Department of Education (CDE); the Division of Insurance, Department of Regulatory Agencies; the Colorado Department of Human Services (DHS) Division of Vocational Rehabilitation (VR), Office of Behavioral Health, and Division for Developmental Disabilities; and the Colorado Department of Corrections.

State background

Since 2008, the state of Colorado has taken a number of steps to both improve the availability and integration of services and supports for Colorado residents with ASD as well as solidify the definition of ASD for diagnosis and tracking purposes. Accordingly, the Colorado General Assembly in 2008 created a 24-member Colorado Autism Commission to review the current system of services and supports available to individuals with ASD and outline a set of recommendations for improvements on which the state could focus efforts within the next decade. The resulting report, which serves as a guide for the state, presented a series of 18 recommendations, ranging from coordinating access to services across the state system to providing support for families and caregivers of individuals with ASD (Colorado Autism Commission, 2008). Following the release of the report, the Colorado Developmental Disabilities Council created the Ad Hoc Autism Committee on September 22, 2010, in response to a joint state Senate resolution that a council oversee the implementation of the recommendations outlined in the Colorado Autism Commission's report.

At the same time, the state underwent a process that ultimately resulted in Governor John Hickenlooper signing House Bill (HB) 11-1277 that amended the Exceptional Children's Educational Act on June 9, 2011, aligning Colorado's disability designations with those in the Individuals with Disabilities Education Act (IDEA). IDEA defines "children with disabilities" as individuals from 3 to 21 years old unable to benefit from general education as a result of a range of conditions, including ASD (Colorado Developmental Disabilities Council, n.d.). More specifically, the changes resulting from the governor signing HB 11-1277 included an elimination of the state's previous "physical disability" category, which is now split into "Autism Spectrum Disorder," "Orthopedic Impairment," "Other Health Impairment," and "Traumatic Brain Injury" categories (Steinberg, 2011). Additionally, the new law characterizes ASD as a "tier B" disability, which means that for each student with ASD, the state "administrative unit" receives up to \$6,000 as supplemental education funding. Although the state is in the midst of implementing these changes, the new disability categories and eligibility criteria are not mandated for use until July 1, 2016 (Steinberg, 2011).

State insurance regulations

In addition to the aforementioned shift in disability criteria as well as the implementation of a task force to provide recommendations for improvement in coordination of care across the system, the state recently passed legislation CRS-10-16-104 (1.4), referred to as the Health Insurance Mandated Autism Treatment Law, which requires certain private group health

insurance policies to cover treatment for ASD. The state law applies to policies issued or renewed on or after July 1, 2010, and will impact children from birth to 18 years old with certain insurance policies, as follows:

- Most insurance policies with cards marked “CO-DOI” (Colorado Division of Insurance)
- Colorado group insurance policies
- Insured Employment Retirement Income Security Act plans that purchase Colorado group insurance policies
- Colorado state employee plans (Autism Society of Colorado and JFK Partners, 2011)

Although the law went into effect in 2010, the changes have not been fully implemented to date.

State 1915(c) Home and Community Based Services (HCBS) waivers

According to the Medicaid State Plan, the Colorado Department of Health Care Policy and Financing (HCPF) has administrative authority and responsibility over all of the waivers while the DHS has delegated responsibility as the operating agency to administer some of them.

State of Colorado 1915(c) waivers

Waiver Name	Population Served
CO HCBS Children with Autism*	Children aged 0–6 with a medical diagnosis of ASD
CO Children’s Extensive Support*	Children aged 0–17 with an ICF/IID level of care
CO Children’s HCBS	Children aged 0–17 who are medically fragile
CO Children with Life Limiting Illness	Children aged 0–18 who are medically fragile
CO Children’s Habilitation Residential Program*	Children aged 0–20 with DD
CO Persons Living with AIDS	Individuals of all ages who are living with AIDS
CO Persons with Brain Injury	Individuals aged 16–64 with a brain injury, no maximum age limit for individuals under specialized nursing facility level of care
CO Persons with Developmental Disabilities*	Individuals aged 18+ with DD
CO Persons with Spinal Cord Injury	Individuals aged 18+ with a spinal cord injury
CO HCBS Waiver for Community Mental Health Supports	Individuals aged 18+ without a diagnosis of dementia (including Alzheimer’s disease or a related disorder) who are chronically mentally ill and need a nursing facility level of care
CO Elderly, Blind, or Disabled	Individuals aged 65+ and aged 18–64 with disabilities
CO Supported Living Services	Individuals aged 18+ who can live independently (or with family) with limited supports.

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Colorado Children with Autism (CWA)* waiver serves children up to the age of six and is based on a medical diagnosis of ASD. Services include case management as an administrative activity and behavioral therapy. The waiver has a waiting list, which

interviewees said spoke to the need for additional resources to support Colorado residents through this waiver. For those on the waiting list, a case manager will notify the child's family once he or she moves to 10th on the waiting list, and once the financial application has been completed, the family will be able to receive services. Services available include:

- Case management
- Behavioral therapy (Colorado Department of Health Care Policy and Financing, n.d.[a])

Other waivers

Individuals must meet financial criteria (less than 300 percent of the Supplemental Security Income limit), medical criteria (disability determination), and program criteria (waiver-specific requirements) to be eligible for services provided through the child waivers. In addition to the CWA waiver, the *Children's Extensive Support* (CES) waiver is most pertinent to children with ASD. DHS and HCPF jointly administer the waiver by contracting with community center boards (CCBs), which consist of 20 organizations across the state that serve as long-term care system entry points for individuals with developmental disabilities (Colorado Department of Health Care Policy and Financing, n.d.[b]).

- The CES waiver covers children through the age of 17 who meet the state developmental disability and Intermediate Care Facility for Individuals with Intellectual Disabilities level of care criteria and operates in conjunction with the state plan benefit and *Early and Periodic Screening, Diagnosis, and Treatment* (EPSDT) program (Colorado Department of Health Care Policy and Financing, n.d.[b]). Services provided under the waiver include:
 - Assistive technology
 - Behavioral services
 - Community connector services
 - Home accessibility adaptations
 - Personal care
 - Professional services
 - Specialized medical equipment and supplies
 - Vision services
 - Adapted therapeutic recreational equipment and fees

Findings

Services and supports for people with ASD

Early intervention

In addition to the state waiver programs, HCPF provides services to children with ASD who are eligible for Medicaid through its EPSDT program. Individuals with Disabilities Education Act (IDEA) Part C services are under the Colorado DHS Early Intervention Colorado program. IDEA Part C services are available to infants and toddlers through 2 years of age who have a developmental delay or disability. The Colorado Interagency Coordinating Council advises and assists the state in carrying out the requirements of IDEA Part C. Services are designed to meet

the developmental needs of infants and toddlers based on the Individualized Family Service Plan (IFSP) in the following areas of development: physical, cognitive, communication, social or emotional, and adaptive.

Among the services provided through the Early Intervention Colorado program are:

- Family training, counseling, and home visits;
- Speech-language pathology and audiology services;
- Occupational therapy and physical therapy;
- Early identification, screening, and assessment services;
- Social and emotional services; and
- Assistive technology devices (Chapman & Black, n.d.).

School-aged children

School districts in Colorado use the 2004 IDEA definition of autism to determine eligibility for special education services. A clinical diagnosis of ASD in Colorado does not automatically qualify a student for special education; instead, the team developing the Individualized Education Program (IEP) must consider a number of sources to determine whether a student meets the eligibility requirements, which are not based on a medical evaluation. In general, because local school systems have authority in Colorado (the CDE only provides guidance and training to systems across the state), the research team could not identify a reliable method to catalog the specific services offered to school-aged children through each local educational agency (LEA; Early Intervention Colorado, 2008). Furthermore, Colorado has an opt-out policy available throughout the state that allows families to defer services from the school system if they prefer the school district not know about their children's developmental disabilities.

Adults

According to one individual interviewed, although the state has a number of services and supports available to children, there is a dearth of support once they transition to adulthood. Beyond the employment services provided by the VR (described in more detail below), the research team was unable to glean information about any additional services available to adults with ASD across the state.

Systems tracking

Interviewees indicated the state is able to track individuals in early intervention by disability type through its Community Contract and Management System (CCMSWeb).

Promotion of services and supports for people with ASD

In general, interviewees described limited efforts within the state to promote services and supports, noting in particular a paucity of services for people in rural areas. State interviewees commented that the challenge is to educate providers and caregivers about the interventions for persons with ASD.

The DHS prepares and provides informational material that is disseminated to a number of primary referral sources throughout the state and is available online. For example, one guidebook, “Supporting Development of Newborns and Infants,” describes common signs of developmental disabilities as well as supportive actions the family can take. Interviewees noted that the families of children with ASD often find out about the state waiver options through resource coordinators in early intervention through the state’s Office of Early Childhood (OEC).

School-aged children

Due to the localization of power in the individual Colorado school systems, as described by the state interviewee, the research team was unable to assess whether there are any widespread promotional activities targeted at school-aged children with ASD across the state. To gather the information necessary to make this assessment, the research team would have had to speak to a range of local education leaders across the state of Colorado; as the project is focused on interviews with state-level informants, such interviews would have been outside of the scope of this study.

Adults

Naturally, the main referral points for postsecondary services are the school systems. The CDE and VR jointly contract with a third-party vendor, through a program called the School to Work Alliance Program (SWAP), which provides employment assistance for individuals with disabilities transitioning from school to the working world. Individuals are connected with VR services through a number of other avenues; namely, community service provider referrals, the Internet (particularly through the state Web site), and the phone book. Additionally, the agency has counselors with local relationships through its business outreach program.

Transitions and coordination of services

As previously mentioned, the Colorado Autism Commission outlined a number of recommendations based on identified gaps in the delivery of services to individuals with ASD in the state. Because the state operates under a county system, the records of individuals—whether enrolled in early intervention, school, or VR—must be transferred with that individual.

Early intervention to school

According to interviewees, at the time this research was conducted the Early Intervention Colorado program in the OEC had rewritten its formal policies around childhood transitions and they were undergoing a clearance process for adoption. As a result, interviewees were not able to provide specifics about the new processes in place. Generally, though, one of the local CCBs notifies the administrative unit and state education agency when a child is considered potentially eligible and may qualify for services under Part B of IDEA (Part B provides special education and related services to children and youth aged 3–22.). Once the administrative unit has been notified, the parents decide whether to have their child evaluated for eligibility for IDEA Part B services. All children have a transition plan documented in the IFSP, and if the child is potentially eligible, a transition conference will be held prior to the child’s third birthday. Subsequently, teachers, parents, and providers will meet to create the child’s IEP, developing short-term and annual goals as well as the services provided to the child. Resources and additional options will be outlined in the transition plan for families of children who are not eligible for IDEA Part B services (Early Intervention Colorado, 2008).

For children who have concluded their tenure on the CWA waiver, case managers often notify the school system of the child's previous use of those services, and the transition for the child happens as easily as possible. The Early Intervention Colorado program meets regularly with the CDE to work on transitions although, as noted earlier, the specific steps in the transitions process depend on the local school systems, which have authority over the services provided.

School-aged to employment

The Division of VR provides the majority of transition support for individuals moving from school to employment. As previously described, SWAP contracts with the CDE and VR to provide support to children in this transitional stage, working with individuals who have mild-to-moderate need for assistance with employment. Interviewees explained that SWAP is intended to be more of a "fast-track" program for individuals who do not need as much support in obtaining employment. On the other hand, individuals who fall outside the purview of SWAP and show interest in VR services at the age of 16 will apply for support through VR, which will develop a profile of the individual through information from the student's IEP, school records, school psychologists, personal care providers, and SWAP (if the individual has previously interacted with it). The VR will then work with the individual to obtain appropriate employment following high school graduation.

Training for direct service support workers

One recommendation from the Colorado Autism Commission report was for the state to "establish a statewide training system for all educators and staff." At the time of the interviews, however, the state had not yet done so as it does not require the training of direct support workers. Still, Colorado has minimum provider licensure qualifications.

Interviewees mentioned the following noncompulsory training sessions offered in the state:

- Case manager classes offered through the Autism Society of Colorado, whose mission is to improve the lives of those affected by autism.
- Parent education funding, which provides parents up to \$1,000 per service plan year to be used for a range of educational opportunities (i.e., speaking engagements, conferences, journal articles) to help parents understand the nuances of their child's diagnosis and how best to provide care.
- Training for some law enforcement officials through the Crisis Intervention Teams Association of Colorado, an organization comprising partnerships among the police department, mental health advocacy groups, mental health providers, local universities, and other community stakeholders.

Corrections

According to a representative at the Colorado Department of Corrections, at the time the interview was conducted the agency did not house any individuals with an ASD diagnosis. Still, the agency uses the standard Level of Service Inventory–Revised screening and assessment tool—which is not specialized for ASD—to screen individuals. Individuals flagged for more severe behavioral health issues during the intake process are often placed in one of the agency's "specialized" programs, which includes both a male and female facility focused on stabilizing acute mental illnesses. Although most of the health information the agency receives regarding an

individual transferred to the corrections agency is self-reported, once they are in the system individuals can be tracked by diagnosis through the agency's "quasi-EHR," an interviewee explained.

Individuals transitioning from the state correction facility to employment will work with their parole boards and case managers on their transition plans to find the appropriate services to be accessed upon their release. Only individuals who had prior contact with VR will work with that office on their transition plan.

Long-term plans to develop new or expanded supports and services (2–5 years)

Interviewees highlighted several activities that will be happening over the long term, including a project with the Colorado Collaborative for Autism and Neurodevelopmental Disabilities Options as well as Project CASCADE (Collaborative Addressing System Change in ASD & other Developmental Disabilities).

Other relevant programs and services

- The *Autism Society of Colorado* (<http://www.autismcolorado.org/>) was founded in 1970 and is an advocacy, education, and support organization comprising a number of volunteer stakeholders across the state. According to the organization's Web site, it provides information and referrals to families and individuals seeking support for ASD, performs a number of public awareness and outreach activities, and has advocated for 14 laws that have provided additional funding to individuals with ASD across the state from its founding in 1970 until 2009.
- *JFK Partners* (<http://jfkpartners.org>) is a program through the University of Colorado School of Medicine Departments of Pediatrics and Psychiatry that works with a number of organizations in Colorado's developmental disabilities community, providing training, clinical services, and research. Two autism-related research projects are:
 - Autism Treatment Network: A collaboration between JFK Partners and the Children's Hospital Colorado aimed at improving guidelines for assessing and treating ASD based on best practices pinpointed from a number clinical care evaluations. The program is funded through Autism Speaks and includes a network of 17 locations across the United States and Canada.
 - Autism Intervention Research Network on Physical Health: Targeting Medical Conditions in Children and Young People with Autism. JFK Partners received a 3-year \$12-million grant from Autism Speaks in 2008 to conduct the research.
- The state of Colorado is participating in the *Assuring Better Child Health and Development project* (<http://www.coloradoabcd.org>), which is a nationwide effort funded by The Commonwealth Fund and administered by the National Academy for State Health Policy to increase the use of standardized screening tools in primary care offices.

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CONNECTICUT

Approach

The L&M research team held interviews with three representatives from the Connecticut Birth to Three System, the state Department of Education, the Department of Mental Health and Addiction Services (DMHAS), and the Office of Protection and Advocacy for Persons with Disabilities. Through these interviews, the research team sought to gain greater understanding of the services and supports for persons with autism spectrum disorders (ASD) in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

The agencies and organizations interviewed for this report cover many facets of services and supports for individuals with ASD throughout their lifetime. Further into this profile, more detail regarding the roles and limitations of each of these agencies in terms of service provision. No one agency oversees all services available for individuals with autism. Connecticut has no state task force on autism at this time.

- The *Birth to Three System* is Connecticut's early intervention agency. The program is housed in the Department of Developmental Services (DDS) and serves as the state's coordinator under Part C of the Individuals with Disabilities Education Act.
- The *Connecticut Department of Education* provides preschool (age 3–5) and school-aged services.
- The *Connecticut Department of Mental Health and Addiction Services* provides inpatient and outpatient services, emergency support, and outreach to those with mental illness.
- The *Office of Protection and Advocacy for Persons with Disabilities* provides services, information, and legal representation for individuals or groups with concerns related to developmental disabilities.

State insurance regulations

The Connecticut General Statute §38a-514b requires each group health insurance policy to provide coverage for the diagnosis and treatment of ASD. Treatments include behavioral therapy, prescription drugs, direct psychiatric or consultative services provided by a licensed psychiatrist, direct psychological or consultative services provided by a licensed psychologist, physical therapy provided by a licensed physical therapist, speech and language pathology services provided by a licensed speech and language pathologist, and occupational therapy provided by a licensed occupational therapist. Covered treatments must be (1) medically necessary and (2) identified and ordered by a licensed physician, licensed psychologist, or licensed clinical social worker (American Speech-Language-Hearing Association, n.d.).

Several other bills were introduced in the January 2011 legislative session, on which no further action has been taken to date.

- S.B. 672 was introduced to require out-of state health plans to provide treatment for ASD and referred to the Insurance and Real Estate Committee.

- S.B. 974 and S.B. 978 were introduced to expand group health plans to include “developmental/relationship based therapy” as an alternative therapy for ASD. In March 2011, S.B. 978 was reported out of the Legislative Commissioner’s Office with a favorable report and tabled.
- S.B. 542 was introduced to include ASD within the definition of “developmental disabilities” used by the DDS and referred to the Public Health Committee (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

As in all states, the waivers available to individuals with ASD impact the nature of ASD-related service delivery in the state. Waivers are especially important in ensuring continued care for individuals who have aged out of education services.

State of Connecticut 1915(c) waivers

Waiver Name	Population Served
CT Individual and Family Supports*	Individuals of all ages with developmental and intellectual disabilities
CT Comprehensive Supports*	Individuals aged 3+ with intellectual disabilities and 18+ with developmental disabilities
CT Employment and Day Supports*	Individuals aged 21+ with developmental and intellectual disabilities
CT Katie Beckett	Individuals aged 0–22 with physical disabilities
CT Mental Health Waiver	Individuals aged 22+ with serious mental illness
CT Personal Care Assistance	Individuals aged 18–64 with physical disabilities
CT ABI	Individuals aged 18+ with acquired brain injury
CT HCBS for Elders	Individuals aged 65+

* Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Connecticut does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *Connecticut Individual and Family Supports (IFS)* waiver provides flexible services and supports, with an annual cost list of \$59,000, to supplement natural and informal supports of eligible individuals who live in their own home or their family home. The waiver serves individuals 18 and older with a developmental disability and individuals 3 and older with an intellectual disability, who would require care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) if not for the provision of waiver services. The waiver provides opportunities for self-direction. Services and supports offered include:
 - Adult day health
 - Community companion homes
 - Group day supports

- Individual and group supported employment
 - Live-in companion
 - Prevocational services
 - Respite
 - Independent support broker (for self-directed participants)
 - Behavioral supports
 - Companion supports
 - Continuous residential supports
 - Environmental modifications
 - Health care coordination
 - Individualized day and home supports
 - Goods and services (for self-directed participants)
 - Interpreter
 - Nutrition
 - Parenting support
 - Personal Emergency Response System (PERS)
 - Personal support
 - Senior supports
 - Specialized medical equipment and supplies
 - Transportation
 - Vehicle modifications
- The *Connecticut Comprehensive Supports* waiver provides broad supports to individuals who live in licensed Community Living Arrangements, Community Training Homes, or in assisted living. It can also be used to provide services to individuals who live on their own or with their family and require a level of support not available under the IFS waiver as a result of significant behavioral, medical, and/or physical support needs or in absence of natural supports. The waiver serves individuals 18 and older with a developmental disability and individuals 3 and older with an intellectual disability who would require care in an ICF/IID if not for the provision of waiver services. Opportunities for participant direction are available. A cost limit for this waiver is set at 150 percent of institutional costs. Services provided include:
 - Adult day health
 - Community Training Homes and Community Living Arrangements
 - Group day supports
 - Live-in caregiver
 - Respite
 - Supported employment
 - Independent support broker (for self-directed participants)
 - Adult companion
 - Assisted living
 - Behavioral support services
 - Continuous residential supports
 - Environmental modifications
 - Health care coordination
 - Individual goods and services

- Individualized day and home supports
 - Interpreter
 - Nutrition
 - Parenting support
 - PERS
 - Personal support
 - Senior supports
 - Specialized medical equipment and supplies
 - Transportation service vehicle modifications
- The *Connecticut Employment and Day Supports* waiver provides supports to individuals with a developmental disability or intellectual disability who live on their own or with their family and have strong natural support systems. The waiver targets children under age 21 with complex medical needs and adults over the age of 18 who would require institutional placement without the provision of waiver services. Opportunities for participant direction are available. A cost limit is set for this waiver at \$28,000. Services include:
 - Adult day health
 - Community-based and individualized day support
 - Respite
 - Supported employment
 - Independent support broker (for self-directed participants)
 - Behavioral support services
 - Individual goods and services
 - Interpreter
 - Specialized medical equipment and supplies
 - Transportation

Findings

Services and supports for people with ASD

Early intervention

The Birth to Three System begins identifying children as young as 16 months old and provides services for children with a developmental age of 12 months or less. Screening is done using the Modified Checklist for Autism in Toddlers (M-CHAT) online screening tool. If any indications show that a child might fall on the autism spectrum, parents are offered referrals to providers that are capable of providing a DSM-IV diagnosis if appropriate. Although parents are given the choice to obtain diagnosis anywhere, services are free from Birth to Three System affiliates.

Once in Birth to Three, children with ASD receive between 2 to 25 hours of service, depending on the severity of their delays and their unique needs. Previously, services were only available for those with an intellectual delay, but a pilot program over the last 5 years has enabled children with an ASD diagnosis to receive services without an intellectual delay. Birth to Three works with approximately 300 children at any given time, and approximately 1 child in every 85 they serve has ASD. Additionally, about half of children using Birth to Three services are Medicaid eligible.

School-aged children

Children ages 3 to 21 receive services primarily through the Department of Education. At the age of 3, children with an ASD diagnosis can attend special education preschools that are located in the public schools. A few children receive services at home or in a private daycare, but these arrangements are not common. According to interviewees, children who have Asperger's syndrome are not always eligible for special education, and services for these students could be improved.

Children from birth through 18 years of age can also receive services through the DDS; however, they must have an intellectual disability. As per state statute, intellectual disability is defined as an IQ of less than 70. After age 18, DDS makes an assessment for long-term services and determines if they will continue to provide services; some individuals are deemed ineligible at this point.

One interviewee expressed concern that schools may not be properly trained in the evaluation of children with autism but conduct evaluations nonetheless. As a result, some children with ASD may be misdiagnosed with attention deficit hyperactivity disorder, bipolar disorder, or other mental illnesses. Additionally, some children with mild autism or Asperger's syndrome might go undiagnosed until adulthood. Schools that are ill equipped to handle the needs of children with autism may have programs that are more segregated than those that are better prepared.

Adults

As is the case in other states, services typically become more restricted once individuals reach adulthood. Many adults rely on paid assistants and programs or adult caregiving services. Adults with developmental disabilities may be eligible for HCBS waiver programs, but no one program for autism exists at this point. DMHAS provides behavioral health services to some individuals with autism, serving approximately 500 people with ASD each year with extended services to 200 of those individuals. DMHAS noted a recent increase in requests for services for individuals with ASD who are 30–50 years of age. This is partly attributable to the need for increased support for adults with disabilities as their parents age.

Ten years ago, DMHAS began a Young Adult Services (YAS) program aimed at helping individuals aged 18–25 achieve the necessary skills for adulthood. This program has a separate budget and has grown significantly over the past 5 years. Services are voluntary, but young adults must have prior involvement with the Department of Children and Families. YAS programs have been shown effective for those with ASD who want to step into adult roles but lack the skills to do so. This is particularly true when the individual is involved in the foster care system and lacks a consistent structure and environment. DMHAS also has many resource centers where young adults can socialize and go on outings. These center activities help prepare young adults with the kinds of social skills needed if they go on to live in a residential facility (Connecticut DMHAS, 2013).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Although all the agencies interviewed have some form of promotion and outreach for their services, only representatives from Birth to Three specifically mentioned promotion as a key focus. Promotion of Birth to Three services occurs primarily through health care providers. Having a single point of intake for early intervention services makes it easier to advertise to providers. Birth to Three ranks 11th in the country for percentage of children enrolled in early intervention services.

Transitions and coordination of services

Early intervention to school

Birth to Three maintains a tracking system that connects all offices with the central intake center. All children diagnosed with ASD have an ICD9 code for autism in the computer system, allowing for ease of tracking. Birth to Three coordinates transition to school with all 165 school districts in Connecticut. The program maintains close contact with the preschool coordination office at the Department of Education. There is frequent turnover among the staff in special education preschool programs, so Birth to Three works to improve the transition process as much as possible.

School-aged to employment

As previously mentioned, many services are limited or halted once a child graduates high school. Typically, the school system helps transition the child into adult services; however, the family must be proactive in the process to ensure that a transition plan is in place and executed. The YAS program can help ease individuals into employment or residential living settings.

Training for direct service support workers

The Autism Society of Connecticut provides Autism Orientation Workshops, a 1-hour session overview of autism that addresses the needs and interests of many different audiences. The content of these trainings include what autism is, how it is diagnosed, a history of autism, common characteristics of autism, autism myths, intervention options, family support, and planning for the future (Autism Society of Connecticut, n.d.).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

All the individuals interviewed expected changes and expansion in services and supports for the ASD community in the next few years, both for children and adults. It was noted that the Department of Social Services is conducting a study to identify gaps in services in the ASD community. This will likely influence policy and service options.

DMHAS would like to see their services expand in the next few years to include more life-coaching and behavioral analysis, among other services. This is aligned with reports that much of the ASD community is lobbying for social services and Medicaid to cover behavioral services. It was noted that for all agencies, funding is an issue.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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DELAWARE

Approach

The L&M research team interviewed five stakeholders from the state of Delaware, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Delaware Division of Developmental Disabilities Services (DDDS), the Division of Vocational Rehabilitation (DVR), the Department of Education (DOE) Exceptional Children Resources, the Division of Public Health Child Development Watch (CDW), and Autism Delaware.

State background

The DDDS is the lead coordinating state agency for services and resources for individuals of all ages with ASD. In addition, the DOE, particularly Exceptional Children Resources, is very involved in autism services, operating the Brennen School, Delaware Autism Program. DOE, along with Autism Delaware and the University of Delaware Center for Disabilities Studies, is currently working on a state plan to improve services and supports and potentially create an autism center to serve as the lead agency for ASD services and supports.

State insurance regulations

In August 2012, Delaware passed Senate Bill 22, which requires health insurance plans to provide coverage for diagnosis and treatment of ASD for individuals aged 21 and younger (Delaware Senate, 2012). Covered services include diagnosis, behavioral health, pharmacy, psychiatric, psychological, therapeutic care (including speech, occupational, or physical therapy), and care for individuals with ASD that is determined by the Secretary of the Department of Health and Social Services to be medically necessary based upon review of best practices and/or evidence-based research. Individuals can also receive applied behavior analysis services with an annual spending cap of \$36,000 per year (Easter Seals, 2012).

In addition, in 2009, Governor Jack Markell signed Senate Bill 65, requiring insurance coverage for children with severe disabilities irrespective of “in-network” restrictions. To qualify, children must be under the age of 21 and certified by their treating provider as “severely disabled,” meaning they require specialized treatment or supports due to physical or mental illness or disease. Under the law, insurers must cover care for specialized dental treatment irrespective of lack of contractual or network status in the same amount they would for the same or similar practitioners within their network or geographical area. The law specifically mentions children with ASD as potential beneficiaries (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Delaware 1915(c) waivers

Waiver Name	Population Served
DE Renewal DDDS*	Individuals aged 4+ with autism/ID/DD
DE AIDS/HIV Related Diseases	Individuals of all ages with HIV/AIDS
DE Elderly and Disabled	Individuals aged 65+ or aged 18-64 with a physical disability

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Delaware does not have any waivers specific to individuals with ASD at this time.

Other waivers

In Delaware, there is one waiver that targets individuals with ASD, as well as those with developmental and intellectual disabilities, to receive services. The DDDS administers this waiver. More people are looking for residential placements than current funding supports. Thus, DDDS uses a registry to determine relative need, with those having critical needs enrolled first.

- The *Delaware Renewal DDDS* waiver serves around 850 people. Although available for eligible individuals aged 4 and older, the services are primarily designed for adults receiving residential services. However, DDDS is planning to modify the waiver in the next few years as it has not been updated since the 1980s. Services currently offered include:
 - Case management
 - Prevocational service
 - Supported employment
 - Day and residential habilitation
 - Clinical consultative services (behavioral and nursing)
 - Transportation—residential services

Findings

Services and supports for people with ASD

In addition to DDDS, Autism Delaware is a primary source of resources and information about autism services, supports, and providers (DHSS DDD, 2013). Autism Delaware is a private nonprofit that began as an offshoot of the national Autism Society organization. Autism Delaware serves as a vendor for both DDDS and the DVR and has recently begun working with the Delaware DOE to provide transition services to individuals with ASD who have higher needs. Thus, some of their services are funded by state and national money. To be eligible for state-funded services at Autism Delaware, an individual must have a medical diagnosis of ASD and there must be adequate funding from either a public or private source. In addition, collaboration with the family and community is required; families must be involved in services after school and individuals receiving services must plan to be involved with the community.

Additionally, Autism Delaware also offers non-state-funded clinical services in schools, parent mentoring and support groups, and advocacy services at the state and local levels. One clinical psychologist provides diagnostic work and functional behavioral assessments in the schools. These services are funded through fundraising and private donations.

Early intervention

Early intervention efforts in Delaware began with the Centers for Disease Control and Prevention's "Learn the Signs. Act Early." initiative, which was led by the Division of Public Health and AstraZeneca, a research-based biopharmaceutical company. Now, CDW is the statewide early intervention program for children from birth to three. CDW is housed in the Division of Public Health and leads the operations side of early intervention, while the Birth to Three office, housed in the Division of Management Services, is the administrative authority in charge of all financial activities.

Children are deemed eligible for early intervention services through three pathways:

1. Having an established condition that predisposes the child to developmental disabilities;
2. Having a developmental delay of 25 percent in one or more areas on multidisciplinary assessments (language delays must be 30 percent or greater); and/or
3. Through clinical judgment—at any time, an assessor can determine that a child should receive services even if his/her scores do not reflect it.

CDW offers service coordination through case managers who work with families to develop an Individualized Family Service Plan (IFSP) that outlines goals, concerns, and any services the child and family receives. CDW provides for services such as occupational therapy, physical therapy, speech therapy, some psychological services, and transportation services. CDW also has staff members trained in transition and working with foster/adoptive parents that serve as liaisons to DOE and the Division of Family Services. Funding for early intervention services is provided through a federal grant and the Delaware Division of Public Health.

School-aged children

School-aged children with ASD are supported in multiple settings in Delaware depending on their level of need. Some receive services in their home schools while others receive more specialized services from their school district. There are three Delaware Autism Program sites across the state for students with the highest level of need. School districts refer students to one of the countywide Delaware Autism Program sites when they cannot meet their needs.

The Delaware Autism Program has existed since the early 1980s. There are three main countywide sites, but individual districts can be approved to start their own program; currently, three districts have approved programs. The home school district provides tuition for any of their students enrolled in any one of the countywide programs. Most school districts have expressed interest in better serving students with ASD, so DOE is exploring ways to provide statewide training for school districts. The Delaware Autism Program also provides in-home respite services by state-approved providers for up to 19 days a year. The program absorbs most of the cost, but parents pay a sliding-scale copay based on income (Sussex Consortium, 2012).

In addition, Delaware has a statewide project called the Delaware Positive Behavior Support Project (DE-BSP). The project works to support schools in creating a positive system to lower the need for individual behavioral support services and to increase efficacy of behavioral support by creating a schoolwide support system. DE-BSP is now trying to build capacity to support schools implementing schoolwide support systems. The program started in 1999 and has grown to 141 schools in the 2011–2012 school year. Beginning in 2009, DE-BSP also began offering social skills training through the Delaware Social Skills Pilot. The schools involved in the pilot are given professional development, resources, materials, onsite coaching, and consultation. Other professional development opportunities are offered statewide to support other school staff, parents, and families who are interested in learning more about strategies to support social learning. Currently, 12 schools in 4 districts are involved in the Social Skills Pilot (University of Delaware College of Education & Human Development, n.d.[b]).

The Delaware Adapting Curriculum and Classroom Environments for Student Success (ACCESS) Project also supports teachers to better deliver the general school curriculum to students with intellectual disabilities, including children on the lower end of the autism spectrum. The ACCESS Project believes that all students deserve meaningful access to general education and the opportunity to learn with their peers (University of Delaware College of Education & Human Development, n.d.[a]).

The DOE, along with funding from the Individuals with Disabilities Education Act (IDEA), provides 10 development coaches throughout the state. These coaches support school principals who are running programs to address the needs of students with more severe disabilities. Coaches help ensure that principles understand effective, appropriate programming for students with disabilities and assist them with teacher evaluations.

Adults

DVR, within the Department of Labor, has many services for individuals with disabilities as well as a few services specifically for those with ASD. Eligibility is contingent on having a disability and at least two barriers to employment. Most individuals are referred through the school system although referrals can come from anywhere. DVR offers traditional vocational rehabilitation services as well as unique services, such as support for eligible students at the University of Delaware. DVR also hosts Asperger's syndrome social support groups on evenings and weekends to help individuals develop social skills that are important in obtaining employment.

DVR has a good working relationship with Autism Delaware, which serves as a vendor to provide employment services and opportunities. Autism Delaware runs a community-based program called Productive Opportunities for Work and Recreation that helps individuals with ASD create a plan and budget to achieve employment goals through individualized vocational and recreational support. This support includes job placement, supported employment, job training, social opportunities, and family support. The program is funded by DDDS, DVR, and Autism Delaware (Autism Delaware, 2012).

Systems tracking

Several systems within Delaware track individuals with ASD. Delaware law requires any health care practitioner who diagnoses a child under the age of 18 with autism to report this information annually to the Autism Surveillance and Registration, Delaware's autism registry. In addition, all

children in the school system are tracked to allow DOE to identify students that move across districts or into a countywide autism program. DOE can also extract achievement data from its database (Delaware Health and Social Services Division of Public Health, 2011).

Promotion of services and supports for people with ASD

Interviewees indicated that most individuals hear about ASD services through friends or other word-of-mouth recommendations. In addition, DOE is responsible for identifying children with disabilities throughout the state. For any child that has an issue in school, there is a mechanism in place to link the child with an evaluation and services offered under IDEA.

Transitions and coordination of services

Early intervention to school

Many children transition to special education services from early intervention. Service coordinators are responsible for introducing transition when they first meet with families, even if children are still very young. By the time the child is 2, coordinators will have had in-depth conversations about transition and organized a meeting between the parents, service coordinator, and school district to talk about school services and school eligibility requirements. The purpose of the transition meeting is to determine what is necessary to make a decision or determine eligibility. Service coordinators typically attend the first Individualized Education Program (IEP) meeting as well. Schools in the Delaware Autism Program educate their children from ages 2 to 21, so difficulty of transition is often minimized for these students.

School-aged to employment

Although children commonly receive services through DOE until age 21, transition begins at age 14. For students transitioning from the Delaware Autism Program schools, there is a dedicated transition office. Students who are eligible for vocational rehabilitation services receive a vocational rehabilitation counselor to help outline their future goals and strategies for achieving these goals. In addition, DVR has two specific programs to help students with disabilities transition to post school activities:

- *Project SEARCH* is a business-led, school-to-work program that helps high school students in their final year of school by having them participate in a work environment. The program allows students to build marketable skills in an internship environment and work on interpersonal skills that will be helpful in future jobs (Delaware Department of Labor DVR, 2012).
- *DelTech Supportive Education Program* at the Delaware Technical and Community College is a collaborative program between DVR and the Delaware Technical and Community College to help recent high school graduates with disabilities during their first year of college. The program supports students enrolled in one of the school's remedial programs located on four campuses. To be eligible, students must be working with a DVR transition counselor and have had an IEP (Delaware Department of Labor DVR, 2012).

Training for direct service support workers

Teachers with the Delaware Autism Program must have an undergraduate degree in special education and obtain a certificate, offered through the University of Delaware, in working with children with autism and severe disabilities within 3 years of teaching.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Center for Disabilities Studies at the University of Delaware was awarded a 2-year planning grant in 2011 from the U.S. Department of Health and Human Services Health Resources and Services Administration. The grant is designed to support development of a comprehensive state plan to improve services and supports for individuals with ASD. To date, the center has hosted focus group discussions with parents and caregivers and administered needs assessment surveys to school-aged individuals, adults, and self-advocates. Three workgroups were established—health care, education, and employment/independent living—that continue to meet to develop the state plan (University of Delaware Center for Disabilities Studies, 2012).

Other relevant programs and services

The Governor of Delaware is very involved in initiatives to help people with disabilities find employment. Delaware is in the process of rolling out a vocational program based on a successful program from Denmark—called *Specialisterne*—that was recently highlighted in *The New York Times Magazine* (Cook, 2012). The program will train higher functioning individuals on the autism spectrum in computer-related fields. The training will be 5 to 6 months long, individualized, and highly technical to offer participants the opportunity be hired in many competitive jobs. The state hopes to start recruitment by December 2012 and is hopeful that the program will eventually spread across the country.

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DISTRICT OF COLUMBIA

Approach

The L&M research team interviewed two representatives from Washington, District of Columbia (DC), who offered a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD). In these interviews the research team sought to gain greater understanding of the services and supports available for persons with ASD in the following areas: early intervention, developmental disability services, education, vocational rehabilitation, and Medicaid.

State background

Although DC has some innovative programs to serve those with autism, interviewees indicated more work is needed to improve support for this population. The major source of services and supports in the city—the Developmental Disabilities Administration (DDA)—cannot serve individuals without an intellectual disability, preventing many on the autism spectrum from receiving services.

State insurance regulations

Since 2007, DC Code Ann. § 31-3271 and § 31-3272 has required private insurance plans to cover habilitative services, including occupational and speech therapy for children birth to age 21 with a congenital or genetic birth defect, including ASD. At a minimum, coverage is provided at the same level as other conditions. Private insurers are not required to cover early intervention or school services (National Conference of State Legislatures, 2012).

In addition, limited health insurance coverage may be available under the mental health parity law, which requires health insurers for employers and individuals to offer coverage for the medical and psychological treatment of drug abuse, alcohol abuse, and mental illness. Mental illness is defined according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) and International Classification of Diseases (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

District of Columbia 1915(c) waivers

Waiver Name	Population Served
DC ID/DD*	Individuals aged 18+ with intellectual or developmental disabilities
DC Elderly and Person with Disabilities	Individuals aged 65+ or aged 18–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services (CMS), *n.d.*

Specific ASD waivers

DC does not have an ASD-specific waiver at this time; however, city stakeholders are advocating for an autism waiver.

Other waivers

- The *District of Columbia ID/DD* waiver covers some individuals with ASD; however, not everyone with autism qualifies because the DDA restricts eligibility to those with intellectual and other developmental disabilities. For those 18 and older who are eligible, there are no waitlists and a variety of services are available, including:
 - Day and residential habilitation
 - In-home and behavioral supports
 - Respite
 - Host home (without transportation)
 - Personal care services
 - Prevocational and supported employment
 - Skilled nursing
 - Environmental accessibility adaptations
 - Supported living
 - Art therapies
 - Individualized day supports
 - Family training
 - Dental services
 - Occupational and physical therapy
 - Speech, hearing, and language services
 - One-time transitional services
 - Shared living
 - Transportation
 - Wellness services
 - Vehicle modifications
 - Personal Emergency Response System (CMS, n.d.)

Findings

Services and supports for people with ASD

Several entities serve those with ASD in DC. The Department on Disability Services (DDS) encompasses two administrations: DDA and the Rehabilitation Services Administration (RSA). Both serve those on the autism spectrum as noted above, but individuals must have an intellectual disability to qualify for DDA services. The Office of the State Superintendent of Education (OSSE) and the public school system also provide services.

Early intervention

OSSE is tasked with leading the Child Find program, which requires them to identify, locate, and evaluate children who are in need of early intervention services through their Strong Start program. Along with Part C of the Individuals with Disabilities Education Act (IDEA), DC Public Law 1-2-119 mandates that children with disabilities and their families receive flexible and culturally appropriate services to meet the needs of each individual family. Through Part C of IDEA, OSSE provides a variety of therapies, transportation services, diagnostic services, and family training and support. Services are offered in the least restrictive environment, which may be at home, daycare, or anywhere else children spend their time. Children scoring two standard

deviations below the mean in two developmental areas are eligible for early intervention services (OSSE, n.d.[a]).

OSSE also offers the Play and Language for Autistic Youngsters (P.L.A.Y.) Project for young children aged 18 months and older (<http://www.playproject.org>). The P.L.A.Y. Project was developed in Ann Arbor, Michigan, and includes four components: diagnosis, home consulting, training, and research. Home consultants provide one-to-one interaction with children and strategic direction in areas such as social skills and language and train parents and guardians to provide the intervention (OSSE, n.d.[b]).

According to interviewees, OSSE promotes diagnosis before children age out of early intervention services as the program is often considered the funder of last resort for diagnosis. The Strong Start program contracts with various entities for evaluation, such as the Georgetown Autism and Communications Disorders Clinic; however, there is a waitlist between 8 and 12 months for state-funded diagnostic services.

School-aged children

School-aged children with developmental disabilities are served until age 8 in accordance with Part B of the federal IDEA law. At that time, children must have a diagnosis to continue receiving services through the school system. The DC public school system runs a diagnostic center called Early Stages for children ages 2 years and 8 months to 5 years and 10 months in preschools, public schools, charter schools, and home schools. The program assigns a family care coordinator to guide parents and children through the diagnostic process and development of their Individualized Education Program (IEP) or Individual Service Plan (ISP). A team of experts, including hearing and vision specialists, special educators, psychologists, and therapists complete the diagnostic evaluation (Early Stages, 2013).

Children who qualify can receive all educationally necessary services, including traditional therapies and applied behavior analysis (ABA), during the school day through the school system. At least one special education program is available in each ward of the city as well as an autism team and 17 autism classrooms utilizing ABA (DC Public Schools, 2012b).

The school system works closely with Health Services for Children with Special Needs (HSCSN), the Medicaid managed care program for children with special needs in DC. Enrollment in this program versus Medicaid fee-for-service is voluntary. Each new member receives a thorough clinical assessment, including an environmental scan for social and biological issues that may affect health, as well as a personalized care management plan. Services offered under a personalized care management plan include:

- Care coordination and care management
- Respite
- Medically necessary home modifications
- Mental, behavioral, and developmental services (HSCSN, 2013)

According to one interviewee, many parents realize that children are not eligible for afterschool wraparound services that are commonly available in the states. Several parent groups have begun

advocating for change. The DDS has also begun working to bring the groups together to create a more cohesive advocacy community.

Adults

Adults with disabilities are eligible for vocational rehabilitation (VR) services through the RSA. DC recently began to use the Department of Labor's Employment First approach, meaning that community-based, integrated employment is the first option for adults with significant disabilities (U.S. Department of Labor, n.d.). Upon entering the VR program, individuals develop an Individual Plan for Employment, which sets goals and identifies necessary supports, including:

- Assessment
- Counseling and guidance
- Vocational training
- Job placement and orientation
- Job retention services (DC DDS, n.d.)

Other than VR, no services exist for which individuals with ASD would necessarily qualify. DDA currently serves about 2,000 people with intellectual disabilities, some of whom have ASD as a secondary diagnosis. It provides coordination, day services, community services, and family support and manages admissions to Intermediate Care Facilities for Persons with Intellectual Disabilities (DC DDS, n.d.).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

In 2011, the DC public school system and OSSE made an effort to connect with every major clinic. They ran bus ads and public service announcements on local television and connected with the Centers for Disease Control and Prevention's "Learn the Signs. Act Early." national campaign. Service promotion was largely geared toward early childhood, and interviewees noted positive feedback from the ASD community about the outreach efforts.

Transitions and coordination of services

Early intervention to school

DC has a data system that allows tracking of individual students through the services system. OSSE and the school system meet monthly about the IDEA Part C and B programs and manage a referral list for transitioning children. Transitions occur according to the individual's IEP or ISP. Parents choose where they would like to send their children, but children are typically referred to the Early Stages Diagnostic Center for evaluation and to the school system.

School-aged to employment

Transition to employment generally begins at age 16, per IDEA legislation. The student's IEP helps to determine a transition plan, which often includes involvement from VR. In addition, students may be eligible for one of two transition programs: Bridges—From School to Work or Project SEARCH.

- *Bridges—From School to Work* allows students with disabilities to spend their last year of school in a business environment with VR support with the goal of developing a résumé, references, and real-world experience by the time they graduate. To be eligible for Bridges, children must be able to take public transportation.
- *Project SEARCH* allows students to work three 10- to 12-hour supported employment rotations in their final year of school. This often helps individuals to learn about various occupations and develop employable skills (DC Public Schools, 2012a).

Training for direct service support workers

- The DC public school system has offered a 4-week Autism Training and Support Program for parents of children with ASD (DC Public Schools, 2012b).
- The DCPS Autism Team has offered a lecture series and regularly scheduled school-based trainings on professional development days (DC Public Schools, 2012b).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

One interviewee mentioned the development of a family support ASD waiver that state stakeholders are hoping to make available within the next 3 to 5 years. The DC Healthcare Alliance—a District government-funded insurance program for those not on Medicare or Medicaid—would be part of a waiver proposal.

Other relevant programs and services

- The United States Department of Education's Fund for the Improvement of Postsecondary Education presented Howard University with a grant to improve matriculation rates for those with disabilities in Historically Black Colleges and Universities. Stakeholders commented that they expect this to benefit DC students with disabilities (HBCU Disability Consortium, n.d.).
- DC "More than Words" training sessions are offered to groups of families to help children with ASD improve communication skills.

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FLORIDA

Approach

The L&M research team interviewed six representatives from the state of Florida, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies represented included the Florida Agency for Persons with Disabilities (APD), the Florida Developmental Disabilities Council, the Florida Agency for Health Care Administration, Florida Medicaid, Early Steps, and the Center for Autism and Related Disabilities (CARD).

State background

Although no primary coordinating agency exists for individuals with ASD, the Florida APD and the Substance Abuse and Mental Health Program (SAMH) provide services and resources for individuals across the lifespan. APD, formerly the Developmental Disabilities Program under the Department of Children and Families (DCF), helps individuals utilize waiver services. SAMH is the state's mental health authority, which coordinates issues related to mental health services and policies. SAMH primarily works on adult mental health issues and works closely with APD on most children's mental health issues.

State insurance regulations

In 2008, Senate Bill 2654 was signed into law, requiring coverage for ASD. Individuals must have a diagnosis of autism by the age of 8, and services are covered for the individual until age 18 (or older if he or she is still in high school). Coverage includes screening and behavioral therapy, with an annual monetary cap of \$36,000 for applied behavior analysis and a lifetime monetary cap of \$200,000. This legislation also allows the Office of Insurance Regulation to create a workgroup of health insurers, health maintenance organizations, and self-insured employers to sign an agreement to increase coverage for developmental disorders. Another part of the legislation, called the Steven A. Geller Autism Coverage Act, requires coverage for well-baby and well-child screening for diagnosis of ASD and intervention and treatment as prescribed by a health care provider (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Florida 1915(c) waivers

Waiver Name	Population Served
FL Model Waiver	Individuals aged 0–20 with physical disabilities
FL DD HCBS Tier 2*	Individuals aged 3+ with autism/DD/ID
FL HCBS Tier 3*	Individuals aged 3+ with autism/DD/ID
FL DD Individual Budgeting*	Individuals aged 3+ with DD
FL Project AIDS Care	Individuals of all ages with HIV/AIDS
FL Traumatic Brain and Spinal Cord Injury	Individuals of all ages with brain/spinal cord injury
FL Familial Dysautonomia Waiver	Individuals aged 3–64 who are medically fragile
FL Adult Cystic Fibrosis	Individuals aged 18+ with cystic fibrosis
FL Aged and Disabled Adult	Individuals aged 65+ and aged 18–64 with physical disabilities
FL Assisted Living for the Elderly	Individuals aged 65+ and aged 60–64 with physical disabilities
FL Alzheimer's Disease Program	Individuals aged 65+ and aged 60–64 with physical disabilities
FL Nursing Home Diversion	Individuals aged 65+
FL Channeling for the Frail Elderly	Individuals aged 65+
FL Long-Term Care Managed Care	Individuals aged 65+ and aged 18–64 with physical disability

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Florida does not have any waivers specific to individuals with ASD at this time.

Other waivers

There are three home- and community-based services (HCBS) waivers that allow people with ASD to receive services. The Florida APD oversees the 1915(c) waivers relevant to children with ASD, specifically the Tier 2, 3, and 4 waivers. Eligibility for waiver services is based on the statutory definition of autism and includes those on the lower end of the spectrum, such as those with severe learning disabilities and communication disorders. The aim of the waiver programs is to grant individuals more independence as well as provide respite care and residential programs when needed. Currently, 3,406 people with autism receive assistance from waiver programs and approximately 3,600 individuals with autism are on the waitlist. APD is able to provide some stopgap measures for those on the waitlist, such as supportive employment and adult day training programs. In addition, all individuals on the waitlist have case management to help them utilize alternative benefits until a waiver opening is available. Case managers have an average caseload of 43 cases and work primarily on interagency coordination to ensure continuity of services.

- The *Florida DD HCBS Tier 2* and *Florida HCBS Tier 3* waivers offer the same services but have different requirements and annual monetary caps for services.
 - *FL DD HCBS Tier 2* has an annual monetary cap of \$53,625 and is available to individuals who require residential habilitation in a facility, including behavior-focused residential habilitation at a minimal or higher level or standard residential

habilitation at a moderate or higher level. Individuals who are in supported living or live in their own home and receive more than 6 hours of in-home support services with a cost over \$35,000 are also eligible.

- *FL HCBS Tier 3* has an annual monetary cap of \$34,125 and is available to individuals who live in residential placements or in independent or supported living situations and do not meet the requirements for Tier 2 or 4.

The services included through these waivers are:

- Personal care
 - Residential habilitation
 - Respite
 - Support coordination
 - Supported employment
 - Adult dental
 - Occupational therapy
 - Physical therapy
 - Respiratory therapy
 - Specialized medical equipment and supplies
 - Specialized mental health services
 - Transportation
 - Behavior analysis and assistant services
 - Community guide
 - Companion services
 - Dietician services
 - Environmental accessibility adaptations
 - In-home support
 - Residential nursing
 - Supported living coaching
- The *Florida Individual Budgeting (iBudget)* waiver is the newest waiver that will eventually replace the tiered developmental disability waivers. It is available to those aged 3 and older with developmental disabilities. Individuals began transferring from the tiered waivers to the iBudget waiver in spring 2011 and are expected to be fully transitioned by June 2013. At this time, the iBudget waiver is only for current waiver enrollees (Florida Developmental Disabilities Resources, 2013). The waiver allows recipients to better direct their care and choose services they feel will be most helpful. The hope is that the waiver will help simplify and equalize the funding process for individuals on developmental disability waivers. Individuals will have a support coordinator to help allocate funding and stay within their budget. Services have been reorganized into eight groups called service families, which include Life Skills Development, Supplies and Equipment, Personal Supports, Residential Services, Support Coordination, Therapeutic Supports and Wellness, Transportation, and Dental Services (iBudget Florida, 2012). Services offered under these service families include:
 - Environmental accessibility adaptations
 - Personal Emergency Response Systems
 - Respite care

- Personal supports
- Residential habilitation
- Specialized medical home care
- Supported living coaching
- Support coordination
- Private duty nursing
- Residential nursing
- Skilled nursing
- Dietician services
- Respiratory therapy
- Occupational therapy
- Physical therapy
- Speech therapy
- Behavior analysis services
- Behavior assistant services
- Transportation
- Adult dental services

Findings

Services and supports for people with ASD

CARD has six locations across the state and works with families, caregivers, and professionals to provide resources, such as referrals to other providers and trainings on topics such as communication, social skills, behavior, school and community issues, and adult life issues (University of Florida CARD, n.d.[a]). CARD is funded by the Florida legislature, and its services are free. However, a diagnosis of a qualifying disability, such as ASD, is necessary to receive services. CARD does not provide diagnostic or direct services but helps to refer clients to a health care provider. Referrals are made to a variety of providers and services; for example, hairdressers who work well with individuals with ASD. CARD also helps families navigate and coordinate local, state, and national services and offers a large library of books and videos to provide instruction and information to families and professionals (University of Florida CARD, n.d.[a]).

Early intervention

The Florida Early Steps program primarily runs early intervention efforts. Early Steps is Florida's special education program for children from birth to age 3. Early Steps is an agency operating under the Individuals with Disabilities Education Act (IDEA) legislation (Teaching Resources for Florida ESE, 2009). The program does not provide services specifically for ASD but selects services based on the individual's needs. A diagnosis is not necessary for services; rather, Early Steps evaluates children on physical ability, cognitive ability, gross and fine motor skills, communication, social/emotional skills, and adaptive development to determine eligibility.

The Florida Early Steps program begins offering services to children at birth if there is a suspicion of autism or a related disability. The child is reassessed at age 5, at which time a diagnosis of autism is required to continue services. Early Steps offers home visits and consultations to families to help coordinate and find appropriate care.

School-aged children

Children ages 3 and older primarily receive special education services through the Department of Education. Behavioral services and residential care are provided through waivers from the APD. In addition, CARD continues to provide resource identification and coordination for school-aged children and their families. It also offers technical assistance upon request to schools and daycare facilities in 14 counties across the state (CARD, n.d.[b]).

The Exceptional Student Education (ESE) Endorsement Tuition Support Program provides financial help to exceptional teachers working with students with ASD or prekindergarten disabilities. To be eligible, teachers must have a Florida Teacher Certificate in ESE, teach in a Florida public school, teach children with prekindergarten disabilities or ASD, and be enrolled in a college or university. The program is funded by Part B of IDEA (Bureau of Exceptional Education and Student Services, n.d.).

The Partnership for Effective Programs for Students with Autism is funded by the Florida Department of Education and supports educators and schools through professional development and training. The program is run in collaboration with CARD, which works with educators to provide training and technical assistance. Each educator or school is matched with a CARD staff member to mentor educators and provide support, resources, and specific training based on the needs of the school. The program lasts 2 years, with different goals and outcomes outlined for each year. The first year is focused on outlining goals and practices to use in the classroom, while the second year focuses on ways to expand the project outside the classroom with other teachers and schools (Partnership for Effective Programs for Students with Autism, 2011).

Adults

The Florida Division of Vocational Rehabilitation (DVR), operated through the Department of Education, focuses on ensuring successful employment for adults with developmental disabilities. The process is not unique for individuals with ASD; however, services are tailored to each individual's needs. DVR provides employment skill training, high school-to-college transition support, and up to 150 days of supported employment to qualifying individuals.

CARD acknowledges the challenges associated with coordinating services for adults and transitioning from school to work. As a result, one of CARD's goals is to increase its services to adults. Currently, approximately 20 percent of CARD's population is over the age of 18.

Systems tracking

Early Steps programs are funded through Part C of IDEA, which requires the state to keep a central directory database of children enrolled in services from birth through age 21.

Promotion of services and supports for people with ASD

The Florida Diagnostic and Learning Resources System operates under IDEA and is associated with 19 school districts in Florida. It assists children and their families with accessing resources related to Child Find, human resources development, parent services, and technology. The program helps with early identification of children under the age of 5.

Transitions and coordination of services

Early intervention to school

When a child is under the age of 3, an Individualized Family Service Plan (IFSP) outlines the Early Steps case management approach. Once a child is 3, they transition from an IFSP to an Individualized Education Program. In Florida, there are specific IDEA requirements for transitioning from IDEA Part C (early intervention) to Part B (school-age interventions). The Early Steps program works with the Department of Education to ensure that the child's educational and in-school needs are met and that any noneducational needs, such as unique medical and afterschool needs, are also addressed.

School-aged to employment

CARD initiates transition meetings with individuals and their families at the age of 16 in order to allow ample time for planning post school and post-Early Periodic Screening, Diagnosis, and Treatment service and support. These planning meetings help families understand what resources and agencies they should coordinate with to ensure a smooth transition out of the school system.

Project10: Transition Education Network is funded by the Bureau of Exceptional Education and Student Services to help school districts provide appropriate and timely transitions to adulthood. The Project10 staff work with school districts to identify needs and assist with meeting them. Staff members currently are focused on four areas of interest—capacity building to implement secondary transition services, interagency collaboration, transition legislation and policy, and student development and outcomes (Project10: Transition Education Network, 2013).

Training for direct service support workers

The Early Steps program is piloting an “Autism Navigator” online tool with 24 providers throughout the state. Online Webinars and training modules are available from external Web sites for interested parties; however, they are not mandated.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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GEORGIA

Approach

The L&M research team interviewed 10 representatives from the state of Georgia, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD). The agencies interviewed included the Georgia Council on Developmental Disabilities, Center for Leadership in Disability (CLD), Georgia Department of Education, Division of Family and Children Services of the Department of Human Services, Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD), Georgia Vocational Rehabilitation (VR) Agency, Centers for Disease Control and Prevention (CDC), and the Marcus Autism Center.

State background

The Georgia DBHDD was created in 2009, undertaking many of the activities previously managed under the Division of Mental Health, Developmental Disabilities, and Addictive Diseases. DBHDD serves as the state agency focusing on the policies, programs, and services for individuals with mental illness, substance use disorders, and developmental disorders. It is tasked with coordinating and contracting publicly supported hospital and community services as well as evaluating and monitoring these community programs and services. Another agency that works among the multiple stakeholders is the CLD, which is housed within Georgia State University and is one of two University Centers for Excellence in Developmental Disabilities Education, Research, and Service in the state. The major goals of the CLD include community education and technical assistance, research on evidence-based practices and policies, and sharing information about best practices in services and supports to people with developmental disabilities. The CLD has received a planning grant to work with a large variety of stakeholders and to develop a statewide autism plan to coordinate services and promote the best methods to better respond to the unique needs of children living with autism and other disabilities in the state. In addition to these two agencies, the Atlanta Autism Consortium (AAC; <http://www.hsi.gatech.edu/atl-autism/about>) is an organization aimed to facilitate greater communication among different agencies providing ASD-related services in Georgia. Members of the AAC meet on a monthly basis to discuss various issues and present on current research relating to autism.

State insurance regulations

Since 2001, Georgia state law has required insurers who provide benefits for neurological disorders to provide the same benefits for those with an ASD diagnosis (ASHA, 2012). In 2009, Senate Bill 161 proposed mandates for private health insurance companies to cover the diagnosis and treatment of ASD, including coverage of services up to \$36,000 annually for applied behavior analysis (ABA) therapy. Although the bill was not approved, the Georgia House of Representatives voted to approve the creation of a committee to study autism insurance reform further (Autism Speaks, 2013).

State 1915(c) Home and Community Based Services (HCBS) waivers

Georgia does not have a specific home- and community-based services waiver for ASD at this time. However, the state does provide other home- and community-based services for individuals with developmental disabilities, including ASD.

State of Georgia 1915(c) waivers

Waiver Name	Population Served
GA Pediatric Program	Children aged 0–5 who are medically fragile or technology dependent
GA Community-Based Alternatives for Youth	Children aged 0–17 with serious emotional disturbances and adults aged 18–20 with mental illness
GA New Options*	Individuals of all ages with ID/DD
GA Comprehensive Supports*	Individuals of all ages with ID/DD
GA Independent Care	Individuals aged 21–64 with physical disabilities
GA Elderly and Disabled	Individuals aged 65+ or age 0–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Georgia does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *Georgia New Options* and the *Georgia Comprehensive Supports* waivers are especially pertinent to individuals with ASD. These waivers provide home- and community-based services for individuals of all ages with intellectual or developmental disabilities. *New Options* has an annual cost limit of \$25,000 but *Comprehensive Supports* does not have a waiver cost limit. The *Georgia New Options* waiver was implemented in October 2007. Participant direction opportunities are available in both waivers. With the exception of a community residential alternative service provided by *Comprehensive Supports*, both programs provide the following services:
 - Community living support
 - Support coordination
 - Respite
 - Prevocational services
 - Supported employment
 - Specialized medical equipment and supplies
 - Community guide
 - Behavioral supports consultation
 - Community access
 - Environmental accessibility and vehicle adaptations
 - Financial support services (for participant direction)
 - Transportation
 - Adult occupational, physical, and speech and language therapy
 - Adult dental services
 - Individual directed goods and services
 - Natural support training

Findings

Services and supports for people with ASD

DBHDD provides services to individuals with development disabilities, including ASD, across the lifespan. These services are provided through 25 total contracts with community boards, private providers, and state-operated regional hospitals and include family support, supported employment, respite, and community residential alternative or community living support (Shelp, n.d.). There are generally fewer resources and supports available to populations in rural locations outside of the Atlanta metro region. Overall, service agencies and providers are able to track the government-funded services that individuals receive. However, it is difficult to analyze services to individuals with ASD as a whole, such as how many children with ASD are receiving a certain type of treatment.

Early intervention

Babies Can't Wait (BCW) is Georgia's statewide interagency service delivery system for infants and toddlers (birth through age 3) with developmental delays or disabilities and their families. BCW was established by Part C of the Individuals with Disabilities Education Act, which ensures that eligible children, regardless of their disability, have access to services that will enhance their development. The Georgia Department of Public Health is the lead agency administering BCW although BCW reports its progress to the Office of Special Education Programs (annual reports can be found at <http://www.health.state.ga.us/programs/bcw/index.asp>). Anyone can make a referral to BCW, and once a child is identified, they are referred to services based on their degree of need; for example, whether they should receive services at home versus in day centers. Generally, early intervention services include supports such as family training and counseling, medical diagnostic services, nutrition services, and speech-language pathology (Georgia Department of Public Health, n.d.).

Additionally, Bright from the Start, through the Georgia Department of Early Care and Learning, oversees a range of programs for children from birth to school age. Its activities include administering Georgia's Pre-K program, licensing and monitoring center- and home-based childcare facilities, and providing technical assistance and training to families and childcare providers for children with special needs. Bright from the Start serves as a resource for many children who age out of BCW (Georgia Department of Early Care and Learning, n.d.).

School-aged children

The Division for Special Education Services and Supports offers resources for school districts to provide education to students with disabilities. Targeted areas for services include accessible instructional materials, assistive technology, curriculum alignment, dropout prevention, family engagement, positive behavior supports, and transition. Additional services include ensuring compliance with federal and state regulations for special education and collecting and analyzing data on educational services and outcomes. Furthermore, this division works to provide guidance and oversight on state and federal special education budgets. DBHDD provides services to children as well although these services take place outside of the school environment.

Adults

The Georgia VR Program is tasked with helping individuals with disabilities achieve employment in an integrated setting. The VR operates as an eligibility program rather than an entitlement program and is an independent agency that is attached to the Department of Human Services for administrative support. VR counselors work with individuals with disabilities to develop an employment plan based on the person's abilities and interests. VR may provide services such as skills assessment, vocational training, postsecondary education, assistance with living expenses, transportation, and personal assistance. VR counselors typically work with individuals aged 16 and older, although they may work with younger children if there is risk of school dropout. One of the noted limitations of VR is in providing long-term employment support, which is something from which many individuals with ASD would benefit.

Through the Rehabilitation Act Amendments of 1998, a state's VR Program is required to submit a state plan outlining how it will administer services to individuals with disabilities. This plan includes policies and ideas to achieve state goals as well as an evaluation of the past year's progress. A copy of the most recent state report can be found at <http://www.rsa.ed.gov/about-your-state.cfm?state=Georgia>.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

There are various channels through which individuals become aware of ASD-related services in Georgia. Many agencies interviewed noted an open referral system where anyone can refer an individual to determine if they are eligible for services. Often these referrals come from health care providers and family members. Additionally, many children become connected to services through the school system. As these individuals age, they may become aware of additional services, especially during their transition process. Georgia also participates with the "Learn the Signs. Act Early." campaign, which the CDC launched in 2004 to help parents identify early childhood milestones.

Transitions and coordination of services

Early intervention to school

Transition out of the BCW program occurs before the child's third birthday. The family's service coordinator provides assistance in learning about resources that may be available after this age. These services are typically provided by the Georgia Department of Education and Georgia Department of Early Care and Learning "Bright from the Start" program.

School-aged to employment

Many school systems have VR counselors to help in the transition out of school into the working environment. This is funded in part by the state, with a partial match from federal funds. VR contracts with community rehabilitation providers to help increase capacity. However, certain areas tend to have limited access to these resources, especially more rural areas.

Training for direct service support workers

CLD offers voluntary service-related training as well leadership programs. The CLD is involved with training activities, such as working with school educators and parents on implementing positive behavioral supports in school, broad training offerings for early childhood special educators, and training for parents of young children with ASD on developing effective home routines. CLD also offers courses in public health at the undergraduate and graduate level at Georgia State University (Georgia State University, 2013).

The Marcus Autism Center provides some professional training at a variety of levels, such as for individuals in pre- and post-doctoral internships and continuing education. Some of the topics covered under the predoctoral internship training include ABA, parent-child relationships, cultural and individual differences, and psycho-educational assessments. Much of the training occurs through experience in day treatment programs, outpatient programs, and psychological assessments.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

According to the interviewees, some advocates are in conversation with the state legislature to work toward passing additional autism-related insurance mandates. Additionally, a few agencies commented that greater emphasis will be placed on diagnostic screenings in the coming years. Others suggested there will be greater emphasis on increasing or maintaining resources to provide services to children, which have declined in the past years.

The Georgia Council on Developmental Disabilities published a 5-year strategic plan in July 2011. This plan is not specific to individuals with ASD; rather, it encompasses all types of developmental disabilities. Some of the goals outlined in this report are to (1) develop formal and informal community supports, (2) support efforts from the Real Communities Initiative in their person-centered approach, and (3) implement a Family Support and Real Communities grant, which will provide 50 families a year with intensive support and 100 families with less intensive services (Georgia Council on Developmental Disabilities, 2011).

Other relevant programs and services

The *Marcus Autism Center* (<http://www.marcus.org>) is a nonprofit organization that is affiliated with Emory University School of Medicine and Children's Healthcare of Atlanta pediatric hospital. It is the largest center providing clinical care to children with ASD in the Nation, diagnosing and treating approximately 5,500 children with ASD each year. As a result of its size and affiliations, the Marcus Autism Center has unique opportunities for research. Center studies examine autism populations that may be less represented, such as females and certain racial minorities with ASD. Funding for the Marcus Autism Center is driven by research grants from the National Institutes of Health and CDC, local and state government, and private donations, which make up approximately 20 percent of funding. Some of the unique services offered through the Marcus Autism Center include intensive diagnostic interviews, case management, telemedicine, feeding and swallowing programs for children with extreme selectivity issues, and intensive behavioral programs.

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HAWAII

Approach

The L&M research team interviewed seven representatives from Hawaii'i, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorder (ASD) in the state. The team held a discussion with the Hawaii'i Department of Health (DOH) Developmental Disabilities Division (DDD), the Autism Society of Hawaii, Kapi'olani Medical Center for Women and Children, Tripler Army Medical Center, and University of Hawaii'i at Manoa Center on Disability Studies. The research team also held a followup discussion with the Department of Health's Early Intervention Section (EIS) later that month. Together these two discussions led to a greater understanding of the state's system of services and supports for children and adults diagnosed with ASD, their families, and caregivers.

State background

The state of Hawaii'i's DDD is the central location of supports and services for children and adults with ASD. Apart from DDD, services for individuals with ASD are delivered in a somewhat fragmented manner. Because other agencies have separate sources of funding, this has led to an approach to meet developmental needs circumscribed by area of discipline. Efforts to improve coordination of services have most recently concentrated on development of a funding source to encourage a multidisciplinary, holistic approach toward providing comprehensive services to individuals with ASD, their families, and caregivers.

State insurance regulations

The state of Hawaii'i does not have insurance regulations specific to ASD, but two laws may apply to individuals with ASD. The first is a mental health parity law, which requires insurers to include benefits for mental illness treatment within their hospital and medical coverage; this may include ASD as a covered mental illness (Hawaii'i Revised Statute §431M-2). Second, the state has enacted a law that mandates insurance coverage for child health supervision services from birth to age 5, exempt from deductible provisions and copayments. This mandate requires coverage of developmental assessments during well-baby and well-child visits (Hawaii'i Statute §432:1-602.5).

To fully understand the state of ASD supports and services in Hawaii'i, it is important to examine attempts to introduce ASD-specific insurance regulation measures that have the potential to supply cross-disciplinary service financing that could bridge existing gaps between agency services. Legislators have attempted to pass laws requiring insurance coverage specific to ASD diagnosis and intervention, first in 2008 and most recently in 2012. The 2008 Senate Bill 2532 proposed a mandate for ASD-specific coverage, which did not pass primarily due to findings by the State Auditor's assessment that the social impact would not justify the financial cost of the insurance regulation. Later that year, the Legislature established a temporary Autism Spectrum Disorders Benefits and Coverage Task Force in order to:

- Gather information about the problems faced by parents of children with autism;
- Discuss what can be done to ensure that benefits and services are provided through public and private resources for the special needs of children with autism, including providing services for applied behavior analysis techniques;

- Research other states' health insurance plans that cover ASD; and
- Develop a plan of services that health insurers should be mandated to cover (State of Hawai'i Auditor, 2009).

The task force recommended insurance coverage for ASD, a lower maximum insurance benefit of \$50,000, inclusion of respite care as a covered benefit, and documentation of services by a treatment plan. Pursuant to these recommendations, the Legislature also authorized the State Auditor to review and assess the financial and social impacts of the bill. The audit findings cited low demand for ASD service coverage, an already-existing and adequately accessible level of public health and educational services through the DOH and Department of Education (DOE), and an introduction of unacceptably high costs that would transfer to insurers and consumers if the bill passed. Per the State Auditor's recommendation, the bill was not enacted.

In the 2012 legislative session, a bill was introduced again that would require health insurance coverage for the diagnosis and treatment of ASD (Senate Bill 2631). The second draft of the bill was referred to the House of Representatives Health Committee, Consumer Protection & Commerce Committee, and Finance Committee on March 8, 2012. To date, no further action has been taken.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Hawai'i 1915(c) waivers

Waiver Name	Population Served
HI Home and Community-Based Services for People with Developmental Disabilities*	Individuals of all ages with ID/DD

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Hawai'i does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *Hawai'i Home and Community-Based Services for People with Developmental Disabilities* waiver provides services for individuals with intellectual and developmental disabilities who meet the Intermediate Care Facility for Persons with Intellectual Disabilities level of care to remain living at home and in the community. Other waivers may apply to individuals with ASD depending upon their age and comorbidity status. Services offered under the waiver include:
 - Adult day health
 - Personal assistance/habilitation
 - Respite
 - Residential habilitation
 - Specialized medical equipment and supplies
 - Nonmedical transportation
 - Prevocational services

- Employment supports (individual and group)
- Assistive technology
- Chore
- Environmental accessibility adaptations
- Personal Emergency Response System
- Skilled nursing

Findings

Services and supports for people with ASD

DDD works with various community providers (including military health care providers), the DOE, and other nonprofit agencies to offer the services and supports children and adults with ASD in the state may need.

Early intervention

The EIS of the DOH administers the Early Intervention (EI) program through Part C of the Individuals with Disabilities Education Act, which serves children with developmental delays from birth to 3 years. A child is eligible if he or she exhibits a delay in one or more developmental areas and/or if he or she is biologically at risk with a diagnosed physical or mental condition that will likely result in a developmental delay. Community providers make referrals directly to the program, and a referral line called Hawai'i Keiki Information Service System also accepts direct calls.

Once eligible, children have access to a range of services and a care coordinator. The care coordinator assists the child's family with information gathering, evaluation of the child, development of an Individualized Family Support Plan (IFSP), links to programs and services, family support, and transition planning to a preschool setting. After an IFSP is established, the child may be referred to a child psychologist for an ASD evaluation, if ASD risk has been detected. If a diagnosis can be made, the child receives intensive behavioral services specific to ASD.

The EI program has multiple points of entry available on all six of the permanently inhabited islands of the state. In addition to EIS, entry points are accessible through early childhood services programs, public health nurses, private agencies (e.g., Easter Seals, Kapi'olani Medical Center for Women and Children, United Cerebral Palsy Association of Hawaii, Wai'anae Parent Child Development Center, Salvation Army, Imua Family Support Services), Healthy Start, and Early Head Start (Hawai'i Department of Health Early Intervention Section, 2013). Hawai'i's large military population is able to access services via the Tripler Army Medical Center and through the EI program, and if a child is receiving services from both systems, both programs work together to coordinate care.

School-aged children

Three divisions of the DOH serve school-aged children with ASD: the Family Health Services Division (EIS is housed within this division), the Child and Adolescent Mental Health Division (CAMHD), and the DDD. A developmental disability is defined as a severe chronic disability that is:

- Attributable to a mental or physical impairment or a combination of mental and physical impairments;
- Manifested before age 22;
- Likely to continue indefinitely;
- Results in substantial functional limitations in three or more areas of major life activities: self-care, receptive and expressive language, learning, self-direction, capacity for independent living, economic sufficiency; and
- Reflects the need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services, which are lifelong or of extended duration and individually planned and coordinated (Hawai'i Department of Health Developmental Disabilities Division, n.d.)

A screening test used in the community that is recommended by the Hawai'i chapter of the American Academy of Pediatrics is the Modified Checklist for Autism in Toddlers (M-CHAT). If ASD is suspected, children are referred to a pediatric or child psychology clinic. Interviewees felt that the recommended use of the M-CHAT by the American Academy of Pediatrics has increased identification of possible ASD in children across the state. EI program outreach efforts also rely heavily on pediatrician identification and initiation of referral for further diagnostics and/or intervention services. After further assessment and diagnosis, families can apply for DDD services for their child. If the child is eligible for services, a case manager is assigned to:

- Assess individual supports;
- Identify what supports are necessary to assure the individual's health and safety and well-being;
- Assist individuals in developing a plan to support them in their desired life; and
- Assist individuals in obtaining supports and services needed, including supports provided or funded by the DDD.

Applied behavior analysis (ABA) and other mental health services are available to students through CAMHD, and school-based services are provided by DOE. Families interested in services must first contact the Family Guidance Center (FGC) located in the school district of their home school. FGC staff will then assist families with the process of determining whether their child is eligible for DOH services or whether their child can be better helped by other agencies. If eligible, the student will be assigned a DOH Mental Health Care Coordinator. He or she may continue to receive School-Based Behavioral Health services and support from DOE in conjunction with DOH intensive mental health services.

Alongside behavioral health service provision and coordination, DOE provides special education programming and placement options, including early intervention and transition services, to help support the educational progress of students with ASD. The DOE provides ABA services to many children with ASD. Individualized Education Programs (IEPs) are designed instruction to meet the unique learning needs of students with disabilities. Special education services (e.g., speech and language therapy, occupational therapy, etc.) may be delivered in a variety of settings based on the student's needs (Hawai'i Department of Education, 2012).

Special needs children of military families who attend public schools in the state may take advantage of the services through Project ASSIST (Augmentation of Special-needs Services and Information for Students and Teachers). This includes access to ASD medical evaluation, psychological and educational services for the child and family, social work services, and occupational and physical therapy services (Tripler Army Medical Center, 2008).

Adults

Currently, adults with ASD may have access to adult day health care, personal assistance, respite, habilitation, specialized medical equipment and supplies, and transportation under the HCBS for People with Developmental Disabilities waiver. According to an interviewee, the current community-based services system for adults is based on an institutional level of care, which is not applicable to the majority of adults with ASD who do not require institutionalization but do require intensive behavioral therapy, interventions, family support, crisis services, vocational support, and education across the adult lifespan.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

The EI program is well known across the state and depends mainly on pediatricians' knowledge of the program to actively reach out to parents and families of children with ASD. EI staff members visit doctor's offices to provide informational materials to pediatricians and participate in child-focused health fairs three to four times a year.

Interviewees identified the CDC's "Learn the Signs. Act Early." initiative to help promote ASD supports and services available in Hawai'i. The mission of this initiative is to educate parents, health care professionals, and early educators on developmental milestones, warning signs of developmental delays such as autism, and what to do if there are concerns about a child's development. The campaign has included informational materials, a video, and an online autism case training curriculum for health care providers to earn continuing education credits (University of Hawai'i at Manoa, 2011).

Transitions and coordination of services

Early intervention to school

Transition from EI to a school setting starts at the time the child begins to receive services. At the first IFSP meeting, parents are made aware that their child will transition from EI to the DOE. The care coordinator works with DOE to develop an IEP specific to the child's ASD condition. A transition conference is held when the child is about 30 months old, approximately 6 to 8 months before the child ages out. The EI care coordinator is the central professional involved in the transition who works with the family, childcare providers, service providers, friends, and representatives from the local educational agency (LEA) to review plans for transition. Transition plans must be developed for all children exiting EI and include:

- A review of options for the family;

- Information for the family regarding the process of transition;
- Support available to parents;
- Information to be sent to the LEA and/or other community providers; and
- Specific plans for how the child will successfully transition to the next setting.

School-aged to employment

Interviewees described the transition from school to adult services as a “service cliff”; the transition reflects the state’s widest service gap. Technically, young adults are supposed to have a transition plan, but according to interviewees, that has not happened consistently. A very high functioning person with ASD is able to obtain a job through the Division of Vocational Rehabilitation (DVR) or on their own, but individuals with particularly challenging behaviors may need more intensive services after the transition from school. If eligible for services, the adult with ASD is assessed for DVR needs and then staff members work with the individual to develop an Individual Plan for Employment, which must be approved by a DVR counselor. The plan is reviewed annually as the individual progresses toward or is in employment.

According to interviewees, family members often expect that the individual with ASD will have the same supports and services after age 18 as they had while in school, and they are often caught unaware in crisis situations. Interviewees reported that this is the main focus for future development of ASD support in the state.

Training for direct service support workers

The University of Hawai’i at Manoa Center on Disability Studies offers an Interdisciplinary Certificate in Disability and Diversity Studies in the College of Education. The program creates interdisciplinary experiences to help students acquire skills in joint planning, decisionmaking, and goal setting and to understand contemporary disability issues, research, and effective practices. As previously described, the center is also involved in providing continuing education credits for health care providers through the “Learn the Signs. Act Early.” program. An online training, “Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum,” teaches providers the fundamental components of identifying, diagnosing, and managing ASD through real-life scenarios.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Interviewees identified the pressing need to create one comprehensive waiver for ASD services—and one that is not based on the current waiver’s foundation of an institutional level of care. According to interviewees, it will be critical to ensure cross-divisional and cross-departmental resource allocation to provide a more comprehensive system of services for individuals with ASD, their family members, and caregivers.

Other relevant programs and services

Other organizations not previously mentioned that are working to serve individuals with ASD in Hawai'i include the following:

- The *Autism Society of Hawaii* (<http://autismhi.org>) serves families and individuals with ASD. The Autism Society supported the most recent 2012 proposed legislation to require insurance coverage for ASD diagnostic and treatment services.
- *Autism Speaks in Hawai'i* (http://communities.autismspeaks.org/site/c.iHLPK1PDLof/b.7501069/k.67DF/Autism_Speaks_in_Hawaii.htm) is dedicated to promoting science and research; providing families with information, tools, and resources; increasing public awareness of ASD; and advocating for autism legislation, in addition to fundraising for these areas. Autism Speaks also supported Senate Bill 2631 in the 2012 legislative session.
- *Learning Disabilities Association of Hawai'i* (<http://www.ladahawaii.org>) is the Parent Training & Information Center for the state of Hawai'i that works to enhance education, work, and life opportunities for children and youth with disabilities by empowering them and their families through information, training, and mentoring and by public outreach and advocacy.
- *Autism Awareness Puna* is an autism family support group located in Pahoā.
- *Project Laulima* is a 1-year, Substance Abuse and Mental Health Services Administration–funded, planning grant focused on helping the system of care improve its ability to provide effective services to youth with co-occurring mental health disorders and developmental disabilities. Over the course of the grant year, key stakeholders from Hawai'i's DOE, Department of Human Services, DOH, Hawai'i Families As Allies, and several other child-serving organizations will work collaboratively to develop a strategic plan focused on strengthening their ability to meet the needs of this population (Hawai'i Department of Health Child and Adolescent Mental Health Division, n.d.).
- *Talk About Curing Autism* (TACA; <http://www.tacanow.org/local-chapters/west/hawaii/>) is a national nonprofit 501(c)(3) organization dedicated to educating, empowering, and supporting families affected by autism. The Hawai'i chapter of TACA sponsors meetings and coffee talks across the islands, which feature educational speakers and provide an opportunity for families to network and share resources.

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IDAHO

Approach

The L&M research team interviewed five representatives from the state of Idaho, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. Agencies that were interviewed included the Bureau of Developmental Disabilities (BDD) within the Division of Medicaid, the Department of Education (DOE), the Center for Disabilities and Human Development (CDHD), and the Infant and Toddler Program within the Division of Family and Community Services.

State background

The BDD is one of the main providers of service for individuals with ASD, offering many services across the lifespan through waivers and services offered directly by the Bureau. Idaho currently has no state task force for ASD. However, recent statewide collaboration led to the creation of new waivers in 2011 to serve individuals with ASD. Stakeholder meetings to develop the policy behind the waivers began in 2008 and included individuals from the Idaho Developmental Disabilities Council, the Idaho Association of Developmental Disabilities Agencies, the DOE, the Department of Health and Welfare, the Infant Toddler Program, parents of individuals with ASD, and therapists.

The CDHD, the DOE, the BDD, and the Infant Toddler Program started an Idaho Autism Advisory Committee in 2003 that has continued ever since. They created a state autism action plan and met with several state agencies and physicians to renew services and decide on activities to improve the effectiveness of the services they offer. The state action plan currently focuses on six target areas: diagnosis/assessment and prevalence, effective interventions, family involvement, public policy, personnel preparation, and research (Interagency Planning Group, 2011). The CDHD drives many activities of the state plan and is working to increase their involvement at the national level.

State insurance regulations

Idaho does not currently have an insurance mandate for ASD or a mental health parity requirement for insurance companies (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Idaho 1915(c) waivers

Waiver Name	Population Served
ID Children's DD*	Individuals aged 0–17 with autism/ID/DD
ID Act Early*	Individuals aged 3–6 with autism/ID/DD
ID DD*	Individuals aged 18+ with autism/ID/DD
ID Aged and Disabled	Individuals aged 65+ and aged 18–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Idaho does not have any waivers specific to individuals with ASD at this time.

Other waivers

In Idaho, three waivers target individuals with ASD in addition to intellectual and developmental disabilities. The BDD administers all of the waivers.

- The *Idaho Children's DD* waiver is available to children from birth to age 17 and offers a continuum of care depending on the individual's need. The program works to involve the family in all aspects of a child's services. Participants either design their own service plan or work with a case manager to develop a service plan. If families decide to design their own plan, a case manager is available to help ensure that all requirements are met. The case manager uses a family-centered planning process to find the most appropriate services for each child. The waiver is still being rolled out and currently covers about 500 children, but will eventually include 3,200 children by July 2013. Covered services include:
 - Community support services
 - Crisis intervention
 - Family/interdisciplinary training
 - Financial management services
 - Habilitative intervention
 - Habilitative support
 - Respite
 - Support broker services
 - Therapeutic consultations
- The *Idaho Act Early* waiver is targeted to younger children aged 3 to 6 years and 9 months with developmental disabilities. Children must have ASD or severe behavioral problems to be eligible. The waiver was created to ensure that children with ASD and other developmental disabilities can receive intensive services at an early age. The waiver emphasizes family participation and works to involve the family in all aspects of a child's services. This waiver serves approximately 300 children. Covered services include:
 - Collaboration services
 - Crisis intervention
 - Family/interdisciplinary training
 - Habilitative intervention
 - Habilitative support
 - Respite
 - Support services
 - Therapeutic interventions
- The *Idaho Developmental Disability (DD)* waiver is available to adults aged 18 and older. To be eligible, an individual must require services due to a developmental disability, be able to live in a noninstitutional setting, and would otherwise reside in an Intermediate Care Facility for Individuals with Intellectual Disabilities in the absence of services covered on the waiver. Participants may choose to receive either traditional

services or consumer-directed services but not concurrently (Department of Health and Welfare, 2012b). Services provided by the adult waiver include:

- Adult day health
- Behavioral consultation or crisis management
- Chore services
- Community supported employment
- Dental services
- Environmental accessibility adaptations
- Home delivered meals
- Nonmedical transportation
- Personal Emergency Response System
- Respite
- Skilled nursing
- Specialized equipment and supplies
- Supported residential habilitation

Findings

Services and supports for people with ASD

The BDD offers many services for children and adults through the Developmental Disabilities Program. Many of these services are offered through the waivers, but some can be accessed directly through the state plan. Eligibility for developmental disabilities services is determined by having a disability that appeared before the age of 22 and results in functional limitations in at least three of the following categories: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. The individual must also show a need for lifelong or long-term special care. All individuals with developmental disabilities have access to Developmental Disabilities services regardless of meeting waiver eligibility. Idaho has accomplished this by offering services under the Medicaid 1915(i) authority. Nonwaiver services available for adults with developmental disabilities include developmental therapy and community crisis supports. Nonwaiver services available for children with developmental disabilities include respite, habilitative supports, family education and family-directed services (Idaho Department of Health and Welfare, n.d.[a]).

Early intervention

The Individuals with Disabilities Education Act (IDEA) Part C early intervention services are administered by the Infant Toddler Program within the Department of Health and Welfare. The Infant and Toddler Program serves children from birth to age 3. To be eligible, a child must have either a developmental delay—diagnosed through specific evaluations and assessments—or an established medical condition that is likely to result in a delay. Delays must be at least 30 percent below age norms two standard deviations below the mean in one functional area, or one and one-half standard deviations below the mean in two or more areas as measured in the following five functional categories: cognitive development, physical development, communication, social and emotional development, and adaptive development (Idaho Department of Health and Welfare, n.d.[b]). If a child does not qualify based on a significant developmental delay or an established medical condition, the program has a multidisciplinary team that can provide an “informed medical opinion” to determine eligibility; this accounts for only a small percentage of the children served.

Three hubs are composed of seven regions across the state, and each region has its own coaching team consisting of early interventionists, speech therapists, occupational therapists, physical therapists, service coordinators, developmental therapists, representatives from the Idaho School for the Deaf and Blind, and other specialists based on the needs of the child. Services are provided at little or no cost to families and include:

- Assistive technology devices and services
- Audiology services
- Family training, counseling, and home visits
- Health services
- Medical services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Respite care (short-term)
- Service coordination
- Sign language and cued language services
- Social work services
- Special instruction (developmental therapy)
- Speech/language pathology services
- Transportation and related costs
- Vision services

School-aged children

Eligibility for special education is determined through a three-pronged approach. Students must have an identified disability, they must require specially designed instruction, and there must be an adverse effect on their education in the absence special education services. Autism is considered a defined disability, and students can receive a comprehensive diagnosis of ASD from a school psychologist and language therapist or a licensed psychologist or physician.

Some students receive school-based Medicaid under IDEA to cover certain services that can be delivered in a school environment. To be eligible, students must have a developmental disability and an Individualized Education Program (IEP); they must also meet the criteria for school-based Medicaid. Once a student is deemed eligible, the school can access services and funds to help support the student in meeting their educational goals; the child's IEP team determines services (Idaho Department of Health and Welfare, n.d.[c]).

As of July 1, 2013, the Idaho Medicaid State Plan offers behavioral intervention and behavioral consultation services to children with developmental disabilities and behavior problems as part of Idaho's Medicaid State Plan school-based services (Idaho Department of Health and Welfare, n.d.[c]). To receive behavioral intervention or behavioral consultation services, the child must have a developmental disability as defined by Idaho Code and severe maladaptive behaviors (Idaho Department of Health and Welfare, 2013).

Adults

Most adult support services are offered through the ID DD waiver. However, adults who meet eligibility requirements for developmental disabilities and their families have access to some services directly through the state plan. These include skill development, such as developmental therapy, speech therapy, occupational therapy, physical therapy, and community crisis supports (Idaho Department of Health and Welfare, n.d.[d]).

Vocational rehabilitation services are also available to adults with disabilities through the Division of Vocational Rehabilitation. Eligibility for services is determined by having a disability that causes an impediment to employment. Services include vocational guidance and counseling, assessment to determine strengths and weaknesses, job training, job development, rehabilitation technology, and followup services to ensure that problems or issues are properly handled (Idaho Division of Vocational Rehabilitation, n.d.).

Systems tracking

Idaho's Infant Toddler Program has a monitoring program called the Developmental Milestones program. With parents' permission, a child is signed up to be monitored through developmental screenings and Early Periodic Screening, Treatment, and Diagnosis at specific age intervals to identify children who may have ASD.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Once children age out of the Act Early Waiver, they can apply for the Children's DD waiver. Case managers begin to discuss transition at a child's annual review prior to his or her seventh birthday. The case manager will work with the family and service providers to determine which services are covered under other waivers and to develop a person-centered plan with the family. Within 120 days of the waiver expiring, participants who are eligible and decide to move to another waiver begin the steps to transition. An Independent Assessment Provider works with the family to ensure eligibility and determine a new budget. Participants can elect to stay with the same case manager or transfer to another case manager (Department of Health and Welfare, 2012a).

The DOE conducts a comprehensive assessment to determine whether a child transitioning from the Infant Toddler Program qualifies for special education services. If the child does not qualify,

the team will meet with the family and explain why the child no longer qualifies. Special education services are provided by the public school system, so if a child meets the eligibility for special education, he or she will transition to kindergarten with an IEP. Children can obtain special education services until the semester they graduate or age 21 (whichever comes first).

School-aged to employment

School-aged children often receive services through the DOE and the Medicaid waivers. The typical transition is from the Children's DD waiver to the ID DD waiver, rather than from school-based services to the ID DD waiver. The Children's DD waiver covers children until they are 18 years old. Around this time, the BDD works with families to create a plan for transitioning to the ID DD waiver. The BDD encourages transitioning individuals to work with an adult case manager to discuss what new services are available. By the time a child turns 21, he or she has usually started receiving ID DD waiver services; therefore, many students are set up with community-based services before they leave school.

School districts are required by IDEA to begin transition planning at age 14. Around this time, the IEP team helps the student think about his/her postsecondary education/employment plans. If a child is still receiving services from the school district from the ages of 18 to 21, the school views it as a transition period and works with vocational rehabilitation to provide employment skills.

Idaho completes a post-graduation survey for all students who have graduated and received special education services. This survey is completed 12 months following graduation and 36 months following graduation. The survey focuses on employment and educational outcomes, such as whether the individual is employed (and in what type of employment) and whether they have participated in higher education.

Training for direct service support workers

The state has offered training across the state to physicians and other health care providers to promote the Act Early campaign and raise awareness of autism spectrum disorders to encourage early identification.

The CDHD has many contracts with the DOE to provide training and technical assistance to school-based and infant-toddler teams. Currently, they are working to train school personnel in ASD; they organize several meetings per year to determine goals and objectives and how to best meet those goals.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Idaho's HCBS waivers for children with developmental disabilities are still relatively new. The state has plans to implement a quality improvement strategy to help track key indicators and look at quality assessment. The first evidence-based gathering will happen in January 2013 and look at participant outcomes by meeting with a sample of the population and their families to get

feedback on services. The assessment will also utilize clinical observation to ensure that services are being provided appropriately.

The Idaho Infant Toddler Program was selected as a project state to work with the National Professional Development Center on ASD; the site selected was the first to include home visits. Although many early intervention children do not yet have a diagnosis of ASD, many were identified with early signs using a variety of evidence-based practices for autism. The Infant Toddler Program would like to implement these practices at their early intervention sites statewide.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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ILLINOIS

Approach

The L&M research team interviewed six stakeholders comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Illinois Division of Developmental Disabilities (DDD), Division of Rehabilitation Services (DRS), Bureau of Early Intervention, and the Illinois State Board of Education (ISBE). The first three agencies are housed within the Illinois Department of Human Services (DHS).

State background

The Illinois DDD provides leadership over the design and delivery of services and supports for individuals with developmental disabilities in the state. DDD oversees the Medicaid 1915(c) Home and Community Based Services waivers, which provide services for people with developmental disabilities through 350 providers across the state. The state currently has a waitlist for services, which are based on eligibility rather than entitlement. DDD will receive funding to serve another 6,000 adults over the next 5–6 years as a result of a class action lawsuit (*Ligas v. Hamos*). The funding will provide community service options to adults with developmental disabilities who are living at home or in an Intermediate Care Facility for Individuals with Intellectual Disabilities.

State insurance regulations

In December 2008, the Illinois Senate Bill 934, known as “Brianna’s Law,” was approved. The law requires health insurance coverage up to \$36,000 per year for the diagnosis and treatment of individuals with ASD under the age of 21. Covered therapies include all medically necessary services that help reduce the effects of an illness or improve functionality for daily activities, including psychiatric care, psychological care, rehabilitative care, therapeutic care (speech, occupational, and physical therapy), pharmacy care, and applied behavior analysis therapy. Illinois has had mental health insurance parity legislation since 2005 (HB 59/Public Act 94-0402), which requires insurers to cover serious mental illness, including pervasive developmental disorders, at a level equal to coverage for other health conditions.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Illinois 1915(c) waivers

Waiver Name	Population Served
IL Support Waiver for Children and Young Adults with DD*	Individuals aged 3–21 with autism/DD/ID
IL Residential Waiver for Children and Young Adults with DD*	Individuals aged 3–21 with autism/DD/ID
IL Waiver for Adults with DD*	Individuals aged 18+ with autism/DD/ID
IL HCBS Waiver for Children that are Medically Fragile/Technology Dependent	Individuals aged 0–20 who are medically fragile and technology dependent
IL Persons with Disabilities	Individuals aged 0–59 with physical disabilities
IL Supportive Living Waiver	Individuals aged 65+ or aged 22–64 with disabilities
IL HCBS Waiver for Persons who are Elderly	Individuals aged 65+ or aged 60–64 with physical disabilities
IL HCBS Waiver for Persons with Brain Injury	Individuals of all ages with brain injury
IL HCBS Waiver for Persons with HIV/AIDS	Individuals of all ages with HIV or AIDS

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Illinois does not have any waivers specific to individuals with ASD at this time.

Other waivers

In Illinois, three waivers are especially pertinent to individuals with ASD:

- The *Illinois Support Waiver for Children and Young Adults with DD* provides home-based services for children aged 3–21 with autism, developmental disabilities, and/or intellectual disabilities. Participation in this waiver is limited to 1,400 children, who are selected from the Prioritization of Urgency of Need for Services (PUNS) database. Supports under this waiver include:
 - Adaptive equipment
 - Service facilitation
 - Assistive technology
 - Behavior intervention and treatment
 - Home accessibility modifications
 - Personal support
 - Temporary assistance
 - Training and counseling services for unpaid caregivers
 - Vehicle modifications
- In addition, children aged 3–21 with autism, developmental disabilities, and/or intellectual disabilities may be eligible for the *Illinois Residential Waiver for Children and Young Adults with DD*. This waiver provides residential support services in group

homes licensed by the Department of Child and Family Services. The waiver is limited to 280 individuals per year. Supports provided by this waiver include:

- Adaptive equipment
 - Assistive technology
 - Individual support service advocacy
 - Behavior intervention and treatment
- The *Illinois Waiver for Adults with DD* provides home-based services to individuals 18 and older. New individuals to this waiver are selected from the PUNS database. Currently, the waiver is limited to 19,000 adults. Services available include:
 - Developmental training
 - Adult day care
 - Community integrated living arrangement and community living facility
 - Service facilitation
 - Supported employment
 - Personal support
 - Home accessibility modifications
 - Vehicle modifications
 - Nonmedical transportation
 - Adaptive equipment
 - Assistive technology
 - Personal Emergency Response System
 - Training and counseling services for unpaid caregivers
 - Behavioral intervention and treatment
 - Psychotherapy and counseling
 - Skilled nursing
 - Temporary assistance
 - Physical, occupational, and speech therapy

Findings

Services and supports for people with ASD

Early intervention

The Individuals with Disabilities Education Act (IDEA) Part C early intervention services are offered through the Illinois DHS. Services are provided for eligible children from birth to age 3; one interviewee noted that more than 19,000 children are served under IDEA Part C each year. Early intervention services are designed to help infants and toddlers who have a disability or a 30 percent delay in at least one of five areas of development: movement, learning, dealing with others, behavior, and self-help skills. IDEA Part C services are targeted to meet the developmental needs of infants and toddlers based on the Individualized Family Service Plan and include:

- Assistive technology/aural rehabilitation
- Developmental therapy/special instruction
- Family training and support

- Speech-language and audiology services
- Occupational, physical, and speech therapy
- Psychological/counseling services
- Service coordination and social work services

Early intervention services are not delivered based on diagnosis but rather the child's individualized needs. For children with autism, speech therapy and social-emotional-related services are typically important. Private insurance sometimes helps defray the cost of early intervention services, but families may have to pay a participation fee based on income. The program receives federal funds, but that is the payer of last resort (Illinois Department of Human Services, n.d.).

School-aged children

The ISBE works with school districts to provide special education services to eligible students. ISBE works to provide school districts with compliance and technical assistance services. Compliance services include mediation, administering the due process system, and conducting complaint investigations. Technical assistance includes managing grant programs to schools with special education, operating technical assistance initiatives, and administering personnel development for special education (Illinois State Board of Education, n.d.).

A diagnosis of autism does not automatically qualify a student for special education. School districts have diagnostic tools to help determine the need for services; local school districts set their own diagnostic tools. In 2008–2009, 13,583 Illinois children aged 3–21 with ASD received special education services. This represented approximately 4.3 percent of children with disabilities in special education (Easter Seals, 2012).

Adults

The Illinois DRS is tasked with helping individuals with disabilities achieve quality employment, with an emphasis on community-based employment with competitive wages. The DRS operates as an eligibility program and is housed within the DHS. Vocational rehabilitation counselors work with individuals with disabilities to develop an employment plan based on a person's abilities and interests. Currently in Illinois, vocational rehabilitation serves individuals who meet the "most" or "very significant" needs category. Individuals classified as having the "most significant" needs have at least three limitations out of seven functional capacities and require at least two substantial services in addition to a core set of needs. Individuals determined to have "very significant" needs have two limitations out of seven functional capacities and require at least one substantial service in addition to routine services. Eligible individuals receive services such as evaluation and counseling, job training, job placement, education assistance, equipment, and followup services (DisabilityWorks, 2010).

Systems tracking

Systems tracking of services and supports for persons with ASD system was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals in Illinois may become aware of ASD-related services through several channels. Agencies allow referrals from any source, but referrals typically come from family members, physicians, hospitals, and the school system.

Transitions and coordination of services

Early intervention to school

The early intervention program in Illinois works with local agencies and school districts to transition children at age 3 if they are eligible for continued services. Many children go on to special education services in the schools, but early intervention generally has broader eligibility requirements than special education and developmental disability services. Local early intervention offices work with families to identify systems of support. In 2008, the Illinois Birth-5 Transition Guidance Committee released a family transition workbook called “When I’m 3, Where Will I Be?” The workbook serves as an important resource and planner for families when transitioning from early intervention to school districts and community programs (Illinois Department of Human Services, 2008).

School-aged to employment

In Illinois, students are eligible to receive school-based services until their 22nd birthday. Transition out of the school system typically begins at age 14, but must begin by age 16. Adult waiver services administered through DDD can begin at age 18; this intentionally overlaps with the Children and Young Adults waivers (aged 18–21) in order to provide an easier transition to the adult waiver (for children who receive services from one of the two DDD children’s waiver programs). There is a waitlist for DDD adult waiver services.

Interviewees note a barrier in identifying and obtaining services for individuals that may be high functioning but have subtle issues, such as an inability to recognize potentially dangerous situations (e.g., “stranger danger”). Additionally, individuals sometimes meet the eligibility criteria for vocational rehabilitation services but do not fall into the higher needs categories; therefore, they do not receive services.

Training for direct service support workers

Training requirements in Illinois vary by agency and the type of work an individual performs. For example, DDD requires direct support workers in 24-hour licensed residential homes and certified developmental training programs to have 40 hours of continuing education classroom training and 80 hours of on-the-job training. Within special education, teachers and other professionals with direct contact with students have to be certified in special education. In general, many of the training requirements encompass developmental disabilities in general, with options for ASD-specific training.

In 2008, Illinois State University and other collaborators developed a basic autism training and converted to an online format made available to the public through the early intervention program. The course includes information on ASD prevalence, how ASD is diagnosed, and varying ASD-related educational strategies (Illinois Department of Human Services, 2008).

The Illinois Autism Training and Technical Training Project is an initiative of the State Board of Education under the Illinois Statewide Technical Assistance Center (ISTAC), which aims to provide training and technical assistance to schools. The goal of the project is to build local capacity, increase the number of ASD students who are educated in the least restrictive environment, and promote positive approaches for working with individuals with ASD. Services offered through ISTAC include courses about autism, family support groups, training and coaching for teachers, and accessibility to a lending library with materials regarding ASD. The project is funded by the state and IDEA Part B discretionary funds. Other programs offered by ISTAC include the Illinois PBIS Network, Project CHOICES, ISTAC-Parent and Transition Outreach Training for Adult Living, Illinois Service Resource Center, and Project REACH (ISTAC, 2008).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Overall, respondents noted a constraint on resources that has limited any plans to change or expand ASD services. One plan that has been discussed and promoted by the Illinois Autism Task Force involves more specific licensure requirements, which will help service providers adjust for varying levels of functionality along the autism spectrum.

Other relevant programs and services

- *Illinois Autism Task Force* was established in 2004 and led by the Illinois DHS. The task force brought together multiple stakeholders including representatives from state agencies, health care professionals, parents of children with ASD, and self-advocates. The group was tasked with promoting best practices for diagnosis and treatment of ASD, providing educational opportunities through the state, and working with providers to identify resources and unmet needs. To address issues in lack of coordination and sharing of information across the state, the Autism Task Force wrote a 2005 report to the Governor and General Assembly recommending the development of an Illinois Autism Information Clearinghouse. The clearinghouse is being developed and will provide information on services and collaboration and distributed information on autism services, issues, and training opportunities (Illinois Department of Human Services Autism Clearinghouse, n.d.).
- *The Autism Program of Illinois* (TAP; <http://www.theautismprogram.org/about/who-we-are/>) was created in 2003 by the Public Act 93-0395 and is led by the Hope Institute for Children and Families with funding from the Illinois DHS. TAP serves as a statewide information resource on autism and works with network partners to provide families with access to resources. Additionally, the project trains educators and helps to link health care providers. In 2007, TAP developed the Autism Program of Illinois Service Network, which currently consists of 30 agencies and universities working to provide diagnosis, treatment, support, and other services to families.

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INDIANA

Approach

The L&M research team interviewed two representatives from Indiana to learn about the service system for those with autism spectrum disorders (ASD) across the lifespan, including services available to small children through early intervention, school-aged children through the Department of Education, and adults through vocational rehabilitation and other sources.

State background

Indiana's Family and Social Services Administration (FSSA) is responsible for services to those with developmental disabilities through the Bureau of Developmental Disabilities Services (BDDS). Interviewees indicate that this department is currently "in flux," which affects the service delivery system and the manner in which waiver programs are administered.

FSSA serves those under waiver programs who meet the criteria of having a developmental disability and requiring the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). Indiana's definition of developmental disability includes autism and states that developmental disabilities must manifest before the age of 22, be likely to continue indefinitely, and result in functional limitations in at least three major areas of function (Indiana Division of Disability and Rehabilitative Services, 2012).

State insurance regulations

In 2009, Ind. Code § 27-8-14.2-1 et seq. and § 27-13-7-14.7 became law. The former requires group health insurance to provide coverage for pervasive developmental disorders, including autism and Asperger's syndrome, and individual plans to offer an option for ASD coverage. All coverage must be in accordance with a treatment plan prescribed by a health care provider. The latter defines ASD as a neurological condition, which results in more coverage for ASD. Although the mandate seems relatively comprehensive, stakeholders note that it only applies to insurers that are based in Indiana, and thus does not help many families (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

As mentioned above, the waiver delivery system in the state is changing. Interviewees recommended that the research team wait until the new governor appoints the next head of BDDS; however, the study timeline did not allow for this. The current 1915(c) waivers are reported below.

State of Indiana 1915(c) waivers

Waiver Name	Population Served
IN Community Integration and Habilitation Waiver*	Individuals of all ages with autism/ID/DD
IN Family Supports*	Individuals of all ages with autism/ID/DD
IN Aged and Disabled*	Individuals aged 65+ or aged 0–64 with a disability
IN Traumatic Brain Injury	Individuals of all ages with brain injury
IN Psychiatric Residential Treatment Facilities	Individuals aged 6–17 with serious emotional disturbance or aged 18–20 with mental illness (waiver will phase out when participants are no longer eligible)

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

The *Indiana Autism* waiver was combined with the developmental disabilities waiver, effective September 1, 2012. The combined waiver has been renamed the *Community Integration and Habilitation (CIH)* waiver (described below). At the time that the waivers were combined, all of the people who were receiving services or had been targeted for services but had not yet started receiving services on the *Autism* waiver were seamlessly transitioned to the *CIH* waiver through reserved capacity.

Other waivers

Effective September 1, 2012, the Division of Disability and Rehabilitative Services (DDRS) moved to a single statewide waitlist for waiver services, in which applicants move on a first-come, first-served basis to the Family Supports Waiver, or where capacity exists, enter into waiver services under the CIH Waiver on the basis of need and meeting the criteria of a reserved capacity category. Examples of reserved capacity categories include individuals whose health and welfare is threatened, who have an aging primary care giver, or who are transitioning from 100 percent state-funded services.

- The *CIH* waiver is designed to serve persons with intellectual disability and/or other developmental disabilities, including autism, who would otherwise require care in an ICF/IID. The waiver has no age limit and can serve up to 8,776 participants during Waiver Year Four (October 1, 2012, to September 30, 2013). Participants on the waiver are allowed budgets based on the levels of support necessary to maintain them in the community. Once a level of support has been determined, the participant can select services to meet their needs in the context of this budget limitation. The individual and their support team have multiple opportunities to request review of this budget as well as appeal the budget through the formal state appeal process. The Office of Medicaid Policy and Planning (OMPP) continues to administer and supervise this waiver. The DDRS is responsible for day-to-day implementation of the waiver operations. Finally, the Bureau of Quality Improvement Services develops and implements quality assurance measures. The following services are offered on the CIH Waiver:
 - Adult day services
 - Case management
 - Prevocational services

- Rent and food for unrelated live-in caregiver
 - Residential habilitation and support
 - Respite
 - Supported employment
 - Occupational therapy
 - Physical therapy
 - Psychological therapy
 - Speech/language therapy
 - Behavioral support services
 - Community-based habilitation—group or individual
 - Community transition
 - Electronic monitoring
 - Environmental modification
 - Facility-based habilitation—group or individual
 - Facility based support services
 - Family and caregiver training
 - Intensive behavioral intervention
 - Music therapy
 - Personal Emergency Response System
 - Recreational therapy
 - Specialized medical equipment and supplies
 - Structured family caregiving
 - Transportation
 - Workplace assistance
- The *Indiana Family Supports* waiver also lists autism as an eligibility group, along with intellectual and developmental disabilities. Each participant on the Family Supports waiver is offered a budget of \$16,250 annually; the participant can select any waiver services in the context of this budget limitation. As described above, when participants on the waiting list are determined to be next to receive services, they will begin receiving services under the Family Supports waiver. They can move to the CIH waiver if capacity exists and if they meet the criteria of a reserved capacity category. There is no age limit and services include:
 - Adult day services
 - Case management
 - Prevocational services
 - Respite
 - Supported employment
 - Occupational therapy
 - Physical therapy
 - Psychological therapy
 - Speech/language therapy
 - Behavioral support services
 - Community-based habilitation—group or individual
 - Facility-based habilitation—group or individual
 - Facility based support services

- Family and caregiver training
 - Intensive behavioral intervention
 - Music therapy
 - Participant assistance and care
 - Personal Emergency Response System
 - Recreational therapy
 - Specialized medical equipment and supplies
 - Transportation
 - Workplace assistance
- The *Indiana Aged and Disabled* waiver, administered by OMPP and operated by the Division of Aging, is for adults aged 65 and older and also serves those with disabilities at any age who meet the nursing facility level of care. Services include:
 - Adult day services
 - Adult family care
 - Assisted living
 - Attendant care
 - Case management
 - Community transition services
 - Environmental modifications
 - Health care coordination
 - Homemaker
 - Home delivered meals
 - Nutritional supplements
 - Personal Emergency Response System
 - Pest control
 - Respite
 - Specialized medical equipment and supplies
 - Transportation
 - Vehicle modifications (Indiana Family and Social Services Administration, n.d.[b])

Findings

Services and supports for people with ASD

Early intervention

The Bureau of Child Development Services—a division of FSSA—is responsible for the state’s early intervention services program—called First Steps—available to those from birth to age 3 with a developmental disability (Indiana Family and Social Services Administration, n.d.[a]).

Most families are referred by hospitals or doctor’s offices, but families can also self-refer by contacting their local system point of entry (SPOE). SPOEs are responsible for ensuring that all children and families referred to First Steps are evaluated and enrolled in a timely and culturally competent manner. They are assisted by Local Planning and Coordinating Councils, which comprise a variety of local and community representatives and tasked with evaluating the local service system to identify issues and propose solutions.

Once a family has contacted the SPOE, they meet with a First Steps intake coordinator, who helps family members get an evaluation to determine whether they qualify for services. Families that qualify meet with a case manager to create an Individualized Family Service Plan (IFSP). Children then receive services according to the IFSP, which may include:

- Assistive technology services
- Audiology
- Diagnostic medical services
- Family education
- Health services
- Nursing services
- Nutrition services
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination
- Social work services
- Special instruction/developmental therapy
- Speech language pathology
- Transportation

School-aged children

School-aged children receive all educationally necessary services according to Part B of the Individuals with Disabilities Education Act (IDEA). The rules governing special education services are spelled out in Indiana's special education law—Article 7—which was last restructured in 2008 (Indiana Department of Education, 2011).

Some of Indiana's IDEA Part B funding supports the Indiana Resource Network (IRN; <http://www.irn.indiana.edu/>), which comprises six resource centers throughout the state that give training and assistance to schools in implementing their special education programs. Each resource center has a different focus to enhance special education throughout the state IRN.

Adults

Indiana has 8 independent living centers serving 56 of the state's 92 counties. They serve people regardless of age or disability and are a potential resource for adults with ASD. The centers provide information and referral, independent living skills training, peer counseling, and advocacy for the disabled community (Dubie, Ketzner, & Wheeler, 2006).

Vocational rehabilitation services are available to adults with physical or mental disabilities through the Bureau of Rehabilitation Services (BRS). Individuals apply and are assessed for

eligibility through local BRS offices; assessments must occur within 60 days of application. If a person is deemed eligible, he or she works with a vocational counselor to develop an Individual Plan for Employment and determine which services best fit his or her needs. Services include:

- Vocational counseling and guidance;
- Medical treatment to correct or modify the physical or mental impairment;
- Training (including vocational school, college or university, on-the-job, and other training);
- Rehabilitation technology (e.g., assistive devices and services);
- Placement assistance and followup (including supported employment); and
- Other planned goods and services deemed necessary to address an identified substantial impediment to employment and required to enable the individual to prepare for, enter, engage in, or retain employment (Indiana Family and Social Services Administration, n.d.[c]).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

The Indiana Resource Center on Autism (IRCA) is one of several centers run by the Indiana Institute on Disability and the Community at the Indiana University in Bloomington. The IRCA creates and disseminates materials to raise awareness of ASD and services available for this population. They maintain a Web site with information on Indiana's service system, provide workshops and training, and conduct outreach through listservs, social media, and an e-newsletter (Pratt & Mank, 2012). Further, the Autism Society of Indiana is a great resource for families with Allies across the state and an online search engine, Autism Resource Network of Indiana Online. The Arc provides information to newly diagnosed families and has hosted large events as part of Autism NOW. There is also an Indiana Interagency Autism Coordinating Council to assist with informing policy, coordination of effort and networking of agencies.

Transitions and coordination of services

Early intervention to school

When children are enrolled in First Steps, they are given a student transition number. This is how children are tracked through their academic career, easing the transition from IDEA Part C to IDEA Part B services and from one grade to the next.

School-aged to employment

As required by IDEA, children begin transition by age 16, according to their Individualized Education Program. Representatives from vocational rehabilitation and other agencies are invited to participate in the transition process as necessary.

The Project SEARCH Indiana initiative allows those with disabilities in their last year of high school to participate in a full-time internship. The project is collaboration between BRS and the Center on Community Living and Careers—one of the IRN centers. There are currently nine Project SEARCH locations, and students are guaranteed a job placement by the end of their internship experience or else they receive immediate placement services from a Project SEARCH adult provider partner (Indiana Institute on Disability and Community, 2010).

One of the other six IRN centers—the Indiana Secondary Transitions Resource Center—also has a strong focus on improving transition services. They recently created an online training for school personnel to help students transition more effectively. Their Web site contains links to resources and didactic materials and will soon provide more information on promising practices. An interesting feature of the Web site is the Community Resource Map, which allows those searching for services to choose their geographic location and identify available resources (Indiana Institute on Disability and Community, 2010).

Training for direct service support workers

Another of the six IRN centers—Helping Answer Needs by Developing Specialists in Autism (HANDS in Autism)—provides free and comprehensive training to autism stakeholders throughout the state. Trainings are offered in a variety of locations, including at the Indiana University School of Medicine (where HANDS is based), in local communities, in individual schools, and online. They primarily train school personnel in evidence-based methods, focusing on applied behavior analysis (ABA) and hands-on practice. The center also disseminates didactic material, engages in a variety of awareness efforts, and provides a yearly conference on autism with nationally known speakers.

Their Web site is a comprehensive resource where educators and families can find local services for those with ASD. It includes extensive training in data driven decision-making practices to learn the process of programming and implementing strategies for students with ASD. An integral effort is to provide education and training that will allow for growing of local capacity—this is accomplished with development of demonstration programs in educational districts; facilitation of Local Community Cadres made up of individuals across school, home, medical and community settings; and interactive weeklong summer trainings with opportunities to apply strategies learned with students on the autism spectrum.

IRCA also provides training to school district employees as well as families and caregivers. They have 140 autism leaders, one for nearly every school district in the state. They provided outreach to 19,244 individuals through their 2011–2012 family trainings. The center also helps graduate students in social work and psychology and supported six students in 2011–2012 in obtaining ABA certifications (Pratt & Mank, 2012).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans for services and supports for persons with ASD were not addressed during discussions with state representatives.

Other relevant programs and services

- A program known as Care Trak is available for those with ASD who are likely to run away or wander. The program provides wristbands that allow families to find lost loved ones quickly. Although the program is relatively expensive, grants are available for those who qualify (Indiana Resource Center for Autism, 2012).
- The state is also developing a 911 registry to better serve those with ASD who come in contact with law enforcement. The formats will vary by county but will include the individual's name, address, diagnosis, and some key individual information that a family member may provide (Indiana Resource Center for Autism, 2012).

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IOWA

Approach

The L&M research team was unable to interview any Iowa stakeholders about the service system available for those with autism spectrum disorders (ASD). Instead, the research team used online resources to describe the state's service system (see references) and received state feedback on the completed profile. Overall, the team sought to understand services available to young children in early intervention, school-aged children through the school system, and adults through vocational rehabilitation and other sources.

Due to extensive restructuring throughout the mental health and developmental disabilities service system in Iowa, this profile will primarily focus on the new legislation, rather than how the system has worked to date. According to stakeholders, Iowa is currently focused on the new changes.

State background

The 2012 Iowa state legislature passed two bills that significantly changed the state's mental health and disabilities system. The first—SF 2315—mandates a complete redesign of the state's mental health and disabilities services system. The redesign focuses on creating regional services and names a core set of services that must be available to those who are eligible, regardless of funding source. Currently, and for the foreseeable future, people with ASD are not eligible for state services unless they also have a mental health condition or an intellectual disability. However, the legislation includes a future provision to consider serving those with developmental disabilities who do not also have co-occurring mental health or intellectual disabilities, depending on the impact to the state budget. The second—SF 2247—changed all references to “mental retardation” in the state statutes to the term “intellectual disability” (Iowa Department of Human Services, 2012).

State insurance regulations

The state employee health plan must provide all medically necessary services for individuals under age 21 with ASD who are listed in a service plan and prescribed by a licensed physician, licensed psychologist, licensed social worker, or licensed registered nurse practitioner. Covered services include diagnosis, habilitative services, pharmacy care, psychiatric care, psychological care, and therapeutic care, including applied behavior analysis. There is a maximum annual benefit of \$36,000 (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

Parental income is a determining factor for Medicaid coverage in Iowa. Children with special needs, as defined by the state social security administration, may be eligible for Medicaid if their family income is less than 300 percent of the federal poverty level and parents are unable to obtain affordable insurance for their child from their employer (Iowa Department of Human Services, 2013).

State of Iowa 1915(c) waivers

Waiver Name	Population Served
IA Children's Mental Health	Children aged 0–17 with serious emotional disturbances
IA HCBS Intellectual Disabilities*	Individuals of all ages with intellectual disabilities
IA HCBS AIDS	Individuals of all ages with HIV/AIDS
IA III and Handicapped	Individuals aged 0–64 with physical disabilities
IA BI	Individuals aged 30 days to 64 years with brain injury
IA HCBS Waiver for Persons w/ Physical Disabilities	Individuals aged 18–64 with physical disabilities
IA HCBS Elderly	Individuals aged 65+

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

Iowa does not have any waivers specific to individuals with ASD at this time. Individuals with autism can be served on any waiver if they meet the criteria for that waiver. It is most common for individuals with autism to be served by the HCBS Intellectual Disabilities waiver.

Other waivers

- The *Iowa HCBS Intellectual Disabilities* waiver provides support to people of all ages who are diagnosed with an intellectual disability, require the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities, and meet eligibility criteria for Medicaid. The waiver provides service coordination and individual person-centered planning as well as:
 - Adult day care
 - Consumer directed attendant care—skilled
 - Consumer directed attendant care—unskilled
 - Day habilitation
 - Home and vehicle modifications
 - Home health aide
 - Residential-based supported community living
 - Interim medical monitoring and treatment
 - Nursing
 - Financial management services (for consumer direction)
 - Independent support broker
 - Individual directed goods and services
 - Self-directed community support and employment
 - Self-directed personal care
 - Personal Emergency Response System
 - Prevocational
 - Respite
 - Supported community and residential living

- Supported employment
- Transportation (Iowa Department of Human Services, 2010)

Iowa also offers a consumer choices option for individuals enrolled under one of their HCBS waivers. Those who choose this option work with an Independent Support Broker and a Financial Management Service Team to develop an individual plan. This plan determines how the individual will spend an allotted number of Medicaid dollars. Individuals have the flexibility to choose which services they need as well as recruit and hire their own service providers. This option may not be available to everyone with ASD or a developmental disability (Iowa Department of Human Services, 2006).

Findings

Without input from state stakeholders, it was difficult to determine the method of service delivery available to those with disabilities prior to this time of change. HCBS specialists are assigned across the state in order to provide services.

For the purpose of service delivery, the Department of Human Services (DHS) encouraged contiguous counties to voluntarily form into regions and submit a letter of intent by April 1, 2013. DHS will assist additional counties in creating the new regions, and help them meet all initial requirements for a service region by December 31, 2013. Some of these requirements include the capacity to provide all core required services, a clear regional administrative structure, a community mental health center or a federally qualified health center with mental health services, and inpatient psychiatric services (Iowa Department of Human Services, 2012).

Services and supports for people with ASD

Iowa has two state resource centers, Woodward and Glenwood. They are residential facilities that serve those with intellectual and developmental disabilities. This resource is available to all qualifying Iowa residents.

Early intervention

Each state is required by Part C of the Individuals with Disabilities Education Act (IDEA) to provide services to children aged birth to 3 years. The Visiting Nurses' Service provides Iowa's IDEA Part C services, known as Early ACCESS, and the Iowa Department of Education (DOE) and the Iowa Department of Public Health jointly administer the program. Early ACCESS provides an online state resource directory, organized by location that they update monthly. Parents can get connected to the program by calling a statewide toll free number, or contacting to their local early intervention office. Required statewide services include:

- Service coordination
- Screenings, evaluation and assessments
- Individualized Family Service Plan
- Assistive technology
- Audiology
- Family training/counseling

- Health services
- Medical evaluations to determine eligibility
- Nursing
- Nutrition
- Occupational therapy
- Physical therapy
- Psychology
- Social work
- Special instruction
- Speech language therapy
- Vision
- Transportation (Early ACCESS Iowa, n.d.)

School-aged

Services for school-aged children are primarily furnished through the DOE. Children must receive all educationally necessary services according to Part B of IDEA. Iowa Medicaid also provides applied behavior analysis (ABA) for Medicaid-eligible children who meet level of care certification for this service.

In late 2012, the DOE published a report on autism services throughout the school system. The purpose of this report was to evaluate ASD services throughout the state. They found that no school system has large numbers of students with ASD, 80 percent of these students receive services at or above research standards, and 100 percent of these students are receiving a free and appropriate education. The diverse sets and types of services indicate that students' plans are individualized. The same report also notes that students with ASD show little academic growth year to year. The DOE plans to do additional research to further understand ASD student services and determine what types of training their teachers may need (Iowa Department of Education, October 2012).

The state DOE provides administrative support to the Iowa Autism Council; a member of the DOE also serves on the council. The Council's responsibility is to study issues around ASD in Iowa and offer advice and recommendations to the governor and legislature on policies that concern this population (Iowa Department of Education, 2012c).

Iowa instituted a Children's Disability Workgroup, which completed its work in December of 2012. Their final report included recommendations for the establishment of a "Children's Cabinet" to support the creation of a holistic and integrated statewide service system for Iowa's children (Iowa Department of Human Services, 2012).

Adults

Iowa's Vocational Rehabilitation Services (VRS) has 13 area offices with 32 satellite units that provide services for those with disabilities in the state. Each client, once enrolled with VRS, is assigned a counselor who helps him or her develop an Individual Plan for Employment. Services offered by VRS include:

- Career planning from high school to college work
- Counseling
- Possible financial assistance for training or education
- Adaptive aids and devices
- Career training
- Vocational assessment
- Independent living
- Assistance in planning daily living
- Labor market information (Iowa Vocational Rehabilitation Services, n.d.[b])

For those who have an intellectual disability as well as ASD, the list of core services provided by the new legislation, regardless of funding, will be available to them beginning July 1, 2013.

These include:

- Assessment and evaluation
- Mental health outpatient and inpatient therapy
- Basic crisis response, such as 24-hour access to response and PERS
- Home health aid
- Home and vehicle modification
- Respite services
- Supported community living
- Day habilitation
- Employment support
- Peer and family support
- Service coordination

According to regional person-centered planning, if necessary and funding is available, individual regions may choose to provide additional services once all required core services and an extended set of core services are in place (Iowa Department of Human Services, 2012).

Systems tracking

Iowa does not formally track autism services throughout the state. The education system also has no simple way to follow children by diagnosis because all children with disabilities are listed as “eligible individuals.” The DOE has used various methodologies in three separate efforts since 2009 to find those with ASD being served in the school system. The latest effort found students with “autism” listed as a primary, secondary, or tertiary diagnosis in their Individualized Education Programs (IEPs) in addition to students with keywords, such as schedule, sensory, or sort, that often apply to children with ASD in their IEPs (Iowa Department of Education, October 2012). The same report mentions that they now have a mechanism to track students in their sample.

Promotion of services and supports for people with ASD

Iowa’s online disability resources database provides information by location on disability services throughout the state.

Transitions and coordination of services

Early intervention to school

Between 90 days and 6 months before a child’s third birthday, Early ACCESS convenes a transition meeting. During this meeting, an Early ACCESS representative, local educational agency (LEA) representative, current service providers, and family members meet to discuss next steps. Regardless of whether the child is eligible for IDEA Part B services, Early ACCESS must develop a transition plan either during this transition conference or in subsequent transition meetings. Between 45 and 90 days before a child’s third birthday, Early ACCESS must, with parental permission, notify the LEA if a child is likely eligible for IDEA Part B services (Iowa Department of Education, 2012b).

School-aged to employment

Beginning no later than age 14, a transition plan must be developed for each student. A transition-planning meeting includes the student, family members, possible future service providers, and other members of the regular IEP team. During this time, the team will develop goals, focusing on the student’s desire for his or her future, and a plan to attain these goals. The team must address future living situations as well as employment or further education. Throughout the rest of an individual’s secondary education, he or she receives assessments relevant to his/her postsecondary goals to determine what supports he or she may need moving forward (Iowa Department of Education, 2012d).

In addition, a VRS counselor is assigned to every high school in Iowa. VRS counselors determine eligibility for services, provide career assessments, and help students determine what is available to them in order to succeed after high school. They may be involved in transition planning IEP meetings (Iowa Vocational Rehabilitation Services, n.d.[a].).

Training for direct service support workers

In response to a 1994 judicial decree—the “Connor Consent Decree”—Iowa was required to create the Iowa Training Consortium (<http://www.disabilitytraining.org/>) to support training for those in the disabilities field. They provide trainings both in person and online as well as some

funding for professionals to attend additional conferences. Their online calendar shows trainings from a variety of sources, many of which focus on ASD. One example is an upcoming training called “Behavioral Strategies for the Student/Child with Autism” aimed at teachers, professionals, and parents.

The Iowa DOE created the first two in a coming series of Webcasts to “build awareness and understanding of students with an Autism Spectrum Disorder” among school administrators. These are available on their Web site (Iowa Department of Education, 2012a).

The Autism Center at the University of Iowa provides a variety of trainings to direct service professionals as well as parents throughout the state. They focus on using evidence-based methods and early identification in practice (University of Iowa Children’s Hospital, 2013).

Corrections

As part of the new group of bills passed in the most recent legislature, sections of SF 2312 focus on keeping those with disabilities from improper involvement in the corrections system, or involuntarily commitment to a mental health facility unless absolutely necessary. It states that police must receive training on interacting with those who have mental health issues every 4 years. Further, it explores the issue of involuntary commitment and establishes a workgroup to study this as well as the feasibility of a statewide patient advocate program.

The expanded core services—those that are only required when funding is available per SF 2315—include jail diversion and civil commitment prescreening services (Iowa Department of Human Services, 2012).

Long-term plans to develop new or expanded supports and services (2–5 years)

The expansion bill requires the evaluation of two measures to potentially expand supports in the future. The first, as mentioned above, considers providing state services to those with developmental disabilities who do not also have a co-occurring intellectual disability. The second calls for an evaluation of providing state services to those with traumatic brain injuries aside from those already funded by Medicaid (Iowa Department of Human Services, 2012).

Other relevant programs and services

- The Autism Society of Iowa hosts autism awareness events and fundraisers and they occasionally put on recreational events such as “Jump for Autism” where they rent out a children’s play venue for the day (Autism Society of Iowa, n.d.).
- Several advocacy and advisory groups advocate for individuals with autism of all ages. These include Autism Speaks Iowa, Autism Society of Iowa, and the Iowa Autism Council as well as other disability rights and advocacy groups, such as the Arc, Iowa Developmental Disabilities Council, and various providers of services to persons with disabilities. The autism advocacy groups have a joint Advocacy and Awareness “Day on the Hill” in February where they meet with state legislators to promote insurance reform and legislation that supports individuals with autism. The Governor signed a proclamation declaring April 2013 “Autism Awareness Month.”

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KANSAS

Approach

The L&M research team interviewed five representatives from the state of Kansas, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD). The agencies interviewed included the Kansas Department for Aging and Disability Services (KDADS), Children's Developmental Services of the Department of Health and Environment, Kansas Rehabilitation Services Program (KRSP), and the Technical Assistance System Network.

State background

KDADS was formed on July 1, 2012. In order to make the delivery of state services more efficient, the Kansas Department on Aging merged with programs from the Kansas Department of Social and Rehabilitation Services and the Department of Health and Environment to form the new Kansas Department for Aging and Disability Services.

The Kansas Autism Task Force was created in 2007 and tasked with creating a report for the Legislative Education Planning Committee regarding topics such as the needs of the ASD community, benefits for this population, and accessibility of relevant services. The task force submitted their report in November of 2008, which included recommendations such as expanding the number of children served under the Kansas Autism Waiver and establishing an autism health insurance mandate.

State insurance regulations

In April 2010, Kansas H.B. 2160 was passed and signed into law, requiring the state employee health insurance plan to provide coverage for autism services to individuals younger than age 19. This change affected only members of the state health insurance plan because Kansas requires health insurance mandates to initially apply to state employees for at least one year to evaluate the utilization and cost of the changes. The services covered under H.B. 2160 included diagnostic evaluation, applied behavior analysis, and other treatment prescribed by physicians, psychologists, or clinical social workers. The annual limit on autism treatment is \$36,000 for children under 7 years old and \$27,000 for children between 7 and 19 years of age. Since the approval of this bill, representatives have proposed two other bills seeking to expand autism insurance coverage to families outside of the state employee health plan, but neither of these bills has passed (Autism Speaks, 2010).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Kansas 1915(c) waivers

Waiver Name	Population Served
KS Autism*	Children aged 0–5 with autism
KS SED*	Children aged 4–21 with serious emotional disturbances
KS Technology Assisted	Children aged 0–12 who are medically fragile/technology dependent
KS IID/DD*	Individuals aged 5+ with autism/IID/DD
KS TBI	Individuals aged 16–64 with brain injury
KS Physical Disability	Individuals aged 16–64 with physical disabilities
KS Frail and Elderly	Individuals aged 65+

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

KDADS holds overall responsibility of the state’s HCBS waivers. A variety of the waivers are applicable to individuals with ASD, including the Kansas Autism, Kansas SED, and Kansas IID/DD waivers. Each of these Medicaid waivers has a waiver manager and each forgo certain requirements found in other waivers. For example, Kansas SED waives family financial criteria for eligibility of services.

Specific ASD waivers

- The *Kansas Autism* waiver was implemented on January 1, 2011, and provides services for children aged 0–5 who are diagnosed with autism and who have a functional need for services under the waiver. These services are offered for 3 years and can be extended for an additional year if a review team determines that it is medically necessary. The Kansas Autism waiver is intended to serve as an intervention program, so children under this waiver must demonstrate progress in order to continue on the waiver. Effective January 1, 2013, this waiver runs concurrently with the KanCare 1115 demonstration. Kansas Autism services include:
 - Respite care
 - Intensive individual supports
 - Consultative clinical and therapeutic services (autism specialist)
 - Family adjustment counseling
 - Interpersonal communication therapy
 - Parent support and training (peer-to-peer) provider
 - Other waivers
- The *Kansas SED* waiver is intended to assist youth who may be at risk of inpatient psychiatric treatment. Eligibility for this waiver is for children aged 4–21 although exceptions can be made to allow children who are 3 years old into this waiver. Professional family resource care often involves intensive support services provided outside of the home to treat a crisis situation, whereas independent living skills building often involves helping older children determine their academic or vocational goals. This waiver does not have a waitlist and currently serves approximately 3,700 children (Kansas Health Solutions, 2013). Effective January 1, 2013, this waiver runs concurrently

with the KanCare 1115 demonstration. Services incorporated under the Kansas SED waiver include:

- Wraparound facilitation services
 - Parent support and training
 - Independent living/skills building
 - Attendant care
 - Professional resource family care
 - Short term respite care
- The *Kansas IID/DD* waiver provides services to individuals aged 5 and older with autism, intellectual, and/or developmental disabilities. Services provided under this waiver include:
 - Day supports
 - Overnight respite
 - Personal assistance services
 - Residential supports
 - Supported employment
 - Financial management services
 - Assistive services
 - Family-individual supports
 - Supportive home care
 - Medical alert rental
 - Specialized medical care
 - Wellness monitoring
 - Sleep cycle support

Findings

Services and supports for people with ASD

Early intervention

Under the Individuals with Disabilities Education Act, Part C early intervention services are administered through the Department of Health and Environment through the Kansas Infant-Toddler Services program. To be eligible for early intervention services, children must show a developmental delay of 20 percent or more in two areas of development or a 25 percent delay in one area of development. Additionally, various diagnoses with “established risk” can automatically qualify a child; autism is one of these diagnoses. Some of the services offered through early intervention include physical therapy, vision services, service coordination, speech-language pathology and audiology services, family training, assistive technology devices, and other health services needed to enable the child to benefit from early intervention. Services are individualized, based on the child’s needs and family’s goals, rather than based on a specific diagnosis. Approximately 8,500 children were served under early intervention in 2012 (Kansas Department of Health and Environment, 2013).

School-aged children

Special education services are administered through the Kansas State Department of Education (KSDE) and functions to provide a variety of services to children who need modifications in their educational programs. In the academic year of 2010–2011, approximately 2,624, or 3.9 percent, of students with disabilities aged 3–21 who were receiving special education services had autism (Easter Seals, 2011). Special education services are provided according to the child’s Individualized Education Program (IEP), which is developed to take into account certain factors, such as how the child learns best, the academic and developmental needs of the student, and goals for the child. Some of the services provided through special education include social work services, speech-language pathology, psychological services, parent training, medical services for diagnostic and evaluation purposes, orientation and mobility services, interpreting services, and vocational education. An overarching goal is for services to be provided in the least restrictive environment for the student (Kansas Department of Education, 2011).

Adults

KRSP provides vocational rehabilitation (VR) services to help individuals with disabilities become employed and self-sufficient. KRSP services are housed within the Kansas Department for Children and Families. For eligible individuals, a VR counselor works with the individual to develop an Individualized Plan for Employment. All individuals eligible for VR services receive vocational counseling and guidance at no cost. Other services are provided depending on the individual’s need, and individuals may contribute to the payment for these services depending on their financial ability to do so. Some of the services provided through VR include physical and mental restoration services, speech therapy, work skills training, daily living skill training, on-the-job training, personal assistance services, and supportive employment (Kansas Department for Children and Families, 2012). One interviewee noted that, where applicable, VR seeks to identify a vocational theme, which involves identifying an individual’s skills and interests and expanding on this for further job opportunities. An example is an individual who liked to wash dishes at home; instead of obtaining a job in a restaurant, he worked in a parts manufacturing plant, which required parts to be extremely clean before being installed in airplanes.

Stakeholders have suggested that people with ASD may be underserved in the VR community. In fiscal year 2012, individuals with autism represented about 2.3 percent of all individuals served by KRSP. In accordance with the Rehabilitation Act of 1997, the VR program is required to submit a state plan outlining how it will administer services to individuals with disabilities. This plan includes policies and ideals to achieve state goals, as well as an evaluation of the past year’s progress. A copy of the most recent state report can be found at: <http://www.rsa.ed.gov/about-your-state.cfm?state=Kansas#t5>.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals may become aware of ASD-related services in Kansas through a variety of channels. This includes referrals through physicians, local health departments, other families, and various programs, such as early head start and home visitation programs. Some interviewees noted that

services are more accessible in metro areas of the state because of greater availability of service providers in these areas.

Transitions and coordination of services

Early intervention to school

Transition out of the Kansas Infant-Toddler Services program occurs at least 90 days before the child's third birthday. The program works with the local education and state education agency to develop a transition plan for each child. They work to identify other community resources or systems of support children may be eligible for when they age out of early intervention. Often, families will move from an Individualized Family Service Plan for early intervention to an IEP for special education. Kansas has a "Step Ahead at Age 3" pamphlet that provides guidance to families about transitioning from early intervention to early childhood and other community services (Families Together, 2010).

School-aged to employment

Many school systems have VR counselors to help in the transition from school to the working environment. This transition often begins 18 months before the student exits the school system. Some interviewees noted difficulty students have obtaining a good balance between academic and community experiences as they exit special education but that employment is often the primary goal when these students leave the school system.

Training for direct service support workers

In general, training for direct support workers varies by agency and type of work the individual practices. The Kansas Technical Assistance System Network (TASN) is tasked with supporting the systematic implementation of evidence-based practices throughout Kansas. TASN is administered by Pittsburg State University and the Center for Technical Assistance for Excellence in Special Education of Utah State University. TASN develops the communication and work alignment among all technical assistance providers in this network. The Autism and Tertiary Behavior Supports (ATBS) project is incorporated under TASN; its goal is to help school districts build local capacity by providing developmental training and technical assistance. Certain school districts can request training specific to their needs, and TASN ATBS staff provide direct consultation for individual students after a district has exhausted its resources.

Kansas University houses a Center for Autism Research and Training, which works to promote research and training regarding the causes and treatment of ASD. Some of their training topics have involved the accurate use of screening tools for early detection of ASD and training on the delivery of evidenced-based practices to manage ASD.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

One major upcoming change in Kansas is the move of individuals with developmental disabilities from Medicaid to managed-care health plans. The transition was set to be implemented, but was delayed due to concerns over the potentially dramatic change to how individuals receive services. For example, individuals expressed concern about the role of their current caseworker if insurance companies took over this role (Cooper, 2012).

Additionally, the KRSP is currently conducting its comprehensive statewide needs assessment, which will review the work and progress of the organization as well as the goals the agency will set in meeting the needs of individuals with disabilities.

Other relevant programs and services

- The *Kansas Governor’s Commission on Autism* is tasked with providing recommendations to the Office of the Governor with information about the needs, issues, and available services for the autism community in Kansas. The committee is made up of 15 individuals from a variety of backgrounds who are appointed by the Governor. One of the goals of this commission is to create local diagnostic and outreach centers (Kansas Department for Aging and Disability Services, 2013).
- *Families Together* (<http://famiestogetherinc.org>) is an organization that serves as a state parent training and information center for families who have a youth with disabilities. It functions as an informational resource in the state, providing support, workshops, and referrals to families. Examples of topics covered by this organization include employment and outreach to minorities. Additionally, Parent-to-Parent Support is a program offered through Families Together that matches experienced parents to parents who are new to disability services. Overall, funding for this organization is provided through a grant from the Department of Health and Human Services.

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KENTUCKY

Approach

The L&M research team interviewed six representatives from the state of Kentucky, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Kentucky Division of Developmental and Intellectual Disabilities (DDID), Kentucky First Steps Early Intervention, the Kentucky Office of Rehabilitation, the Kentucky Commonwealth Council on Developmental Disabilities, Kentucky Autism Training Center (KATC) at the University of Louisville, and the University of Kentucky Human Development Institute—University Center for Excellence in Developmental Disabilities.

State background

The Kentucky Commission on Autism Spectrum Disorders was established by H.B. 296, which was signed into law by Governor Ernie Fletcher in 2005. The commission met for a year to review and assess the training, treatment, and services for individuals with ASD, which resulted in a 2006 state plan with recommendations to the Governor, the Kentucky Council on Developmental Disabilities, and the Legislative Research Commission. The Commission dissolved 1 year later, at which time a subcommittee was appointed by the Kentucky Council on Developmental Disabilities to monitor the implementation of the state plan. This subcommittee is charged with preparing an annual report on the status of the state plan until 2015 (Easters Seals, 2012). According to the most recent 2012 state plan, no consolidated state agency or single access point coordinates autism services; rather these services are delivered through a patchwork of programs and providers, thereby neglecting the complex needs of individuals with ASD (Kentucky Commonwealth Council on Developmental Disabilities, 2012).

State insurance regulations

In April 2010, Governor Steve Beshear signed into law H.B. 159, requiring health insurance companies to provide coverage for the diagnosis and treatment of ASD. Covered services include habilitative/rehabilitative care, pharmacy care, psychiatric care, psychological care and therapeutic care. There is a maximum annual benefit of \$50,000 for individuals aged 1–6 and a maximum monthly benefit of \$1,000 for individuals aged 7–21.

In May 2012, the Kentucky Department of Insurance issued an advisory opinion directing health insurers to start covering services rendered by supervised applied behavior analysis (ABA) providers, noting that autism treatment would be “severely compromised” without their services. The state order clarified the 2010 insurance mandate, noting that ABA services rendered by frontline “supervisees” with the direction of Board Certified Behavior Analysts or Board Certified Assistant Behavior Analysts must be covered by health insurance companies (Autism Speaks, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Kentucky 1915(c) waivers

Waiver Name	Population Served
KY Michelle P. Waiver*	Individuals of all ages with ID/DD
KY Supports for Community Living*	Individuals aged 3+ with ID/DD
KY Model Waiver II	Individuals of all ages who are technology dependent
KY Acquired Brain Injury	Individuals aged 18+ with brain injury
KY Acquired Brain Injury—Long Term Care	Individuals aged 18+ with brain injury
KY HCBS	Individuals aged 65+
KY Home and Community-Based Services Transitions Waiver	Individuals aged 65+ and aged 18+ with a disability who have transitioned from a nursing facility

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Kentucky does not have any waivers specific to individuals with ASD at this time.

Other waivers

Two HCBS waivers provide support for individuals with intellectual and developmental disabilities, including ASD.

- The *Kentucky Michelle P.* waiver is administered by the Department for Medicaid Services and designed as an alternative to institutional care for individuals of all ages with intellectual and developmental disabilities. To be eligible, individuals must have a developmental or intellectual disability, meet the level of care requirements for an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), and meet Medicaid financial eligibility requirements. The waiver serves approximately 8,000 residents, many of whom are on a waitlist for the Supports for Community Living Waiver; there is currently no waitlist for the Michelle P. Waiver. Services offered include:
 - Adult day health care
 - Case management
 - Community living supports
 - Environmental/minor home adaptation
 - Homemaker services
 - Supplemental occupational, physical, and speech therapy
 - Supplemental specialized medical equipment
 - Personal and attendant care
 - Physical therapy
 - Respite
 - Speech therapy
 - Supported employment
 - Self-direction supports for goods and services, financial management services, and community guide

- Family training
- Supervised residential care (Kentucky Department for Medicaid Services, 2013)
- The *Kentucky Supports for Community Living (SCL)* waiver is administered by the Division of Developmental and Intellectual Disabilities. The waiver is designed as an alternative to institutional care and allows individuals with developmental and intellectual disabilities to remain in the community in the least restrictive setting. To be eligible, individuals must have a developmental or intellectual disability, meet the requirements for residence in an ICF/IID, and meet other Medicaid requirements. The SCL waiver includes many of the same services as the Michelle P. Waiver but is more comprehensive. The waiver serves approximately 3,600 individuals; another 2,200 are on a waitlist. Due to the extensive waitlist, interviewees indicated that the SCL waiver currently serves adults only, often those at risk of homelessness (Kentucky Department for Behavioral Health, Developmental and Intellectual Disabilities, 2013c). Services include:
 - Case management
 - Community access
 - Day training
 - Personal assistance
 - Residential support
 - Respite
 - Shared living
 - Supported employment
 - Occupational therapy
 - Physical therapy
 - Speech therapy
 - Self-direction supports community guide
 - Goods and services
 - Natural supports training
 - Transportation
 - Assessment/reassessment
 - Community transition
 - Consultative clinical and therapeutic service
 - Environmental accessibility/adaptation services
 - Person-centered coaching
 - Positive behavior supports
 - Specialized medical equipment and supplies
 - Vehicle adaptation

In addition, a consumer-directed option under the HCBS waivers allows eligible members to choose a provider for their nonmedical, nonresidential waiver services, offering greater freedom of choice, flexibility, and control over supports and services. Members can choose to direct all or some of their nonmedical waiver services.

Findings

Services and supports for people with ASD

The DDID is housed within the Department for Behavioral Health, Developmental and Intellectual Disabilities and is responsible for acquiring and dispersing resources and grants, providing information and technical assistance, monitoring and ensuring accountability, and setting the standards for best practice for individuals with developmental and intellectual disabilities across the state. DDID is made up of the Supports for Community Living Waiver Branch and the Community Support Branch. The SCL Waiver Branch provides staff support and oversight of the SCL waiver program, whereas the Community Support Branch provides staff support, technical assistance, and monitoring of 14 contracting Regional Community Mental Health/Intellectual Disability Centers (CMHCs). CMHCs provide services such as case management, community access, supported employment, and respite; however, services vary by region (Kentucky Department for Behavioral Health, Developmental and Intellectual Disabilities, 2013a).

Individuals with ASD can receive funding for services through one of the HCBS waivers, through the CMHCs, or through the state-funded Hart-Supported Living Program. The latter allows all individuals with a disability to plan and design a set of services that meet their needs and is consistent with the principles of supported living. Eligibility for the Hart-Supported Living Program is defined by the Americans with Disabilities Act, as “persons with a physical or mental impairment that substantially limits a major life activity such as caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working.” If an individual’s plan is approved, funds are made available to implement services. Examples of services offered through the Hart-Supported Living Program include adaptive/therapeutic equipment, home and vehicle modifications, personal care/companion services, homemaker services, community resource developer, respite, leisure/recreation, live-in support, support broker/personal agent, consultation, transportation, and employment-related expenses. There is no waitlist for these services, but resources are limited, and individuals apply each year to receive available funds (Kentucky Department for Aging and Independent Living, 2013).

Early intervention

First Steps serves as Kentucky’s early intervention program, providing services for children from birth to age 3 and their families. The program is housed in the Department for Public Health and consists of 15 regional offices, which serve as points of entry into the system. Physicians and parents commonly refer children around the age of 2, and from there eligibility is determined in one of two ways:

1. Having a developmental delay of 2.0 standard deviations below the mean in one skill area or 1.5 standard deviations below the mean in two skill areas, including communication, cognition, physical, social, and emotional or self-help; or
2. Automatic entry for children who receive a diagnosis of a physical or mental condition that has a high probability of developmental delay (Department for Public Health, 2013).

Services are offered through contracted providers according to an Individualized Family Service Plan (IFSP) and occur in the home, at a child development center, or another clinical setting. First Steps provides the full array of federal early intervention services, including service

coordination, psychological services, counseling, transportation, respite, special instruction, assistive technology, and occupational, physical, and speech therapy. The program uses a primary service provider model in which the family selects one provider to serve as the key individual working with the child and family; others on the team are less involved and often provide co-treatment with the primary provider. Roughly 4,800 to 5,000 children have an active IFSP in place on any given day.

School-aged children

School-aged children with ASD receive special education services in accordance with the Individuals with Disabilities Education Act (IDEA). Through the Child Find program, local school districts are tasked with locating, identifying, and evaluating all children aged 3–21 who may be eligible for special education services. The Admission and Release Committee, also known as the Individualized Education Program (IEP) team, is responsible for making decisions regarding identification, evaluation, and placement of children with disabilities. This team consists of the child, parents/caregivers, general education teachers, special education teachers, psychologists, placement specialists, representatives from preschool programs, representatives from state agencies, and related service personnel. Once a child is deemed eligible for special education services, the team develops an IEP and makes decisions on appropriate services, supports, and the least restrictive educational placement (University of Louisville Kentucky Autism Training Center, 2010). The number of children aged 3–21 with ASD who are receiving special education services in Kentucky went up from 1.09 percent (1,032) of children with disabilities in 2000 to 3.84 percent (3,927) of children with disabilities in 2010–2011 (Easter Seals, 2012).

The Kelly Autism Program (KAP) through Western Kentucky University provides services for school-aged children with ASD. KAP elementary, middle, and high school programs offer educational support to school staff in writing and implementing IEPs that meet participants' academic, communication, sensory, and social/behavioral needs. In addition, elementary school students participate in afterschool sessions to improve social, emotional, behavioral, sensory, and communication skills; middle and high school students receive tutoring in literacy, math, communication, technology and daily living activities.

Social skill development is an important focus of KAP. The program holds daily group sessions with elementary and middle school students to improve areas such as focusing on tasks, getting along with others, problem solving, and friendship skills. High school students can get involved in the "Teen Council," which provides high school students an opportunity to learn and practice leadership and group participation skills with peers. Additionally, many recreation and leisure activities are held during the school year to promote socialization (Western Kentucky University, 2012).

Adults

In addition to the waiver services described earlier, the Kentucky Office of Vocational Rehabilitation (OVR) funds direct services for individuals with disabilities through 52 offices around the state. These local offices employ 140 vocational rehabilitation counselors that review applications, determine appropriate service agencies, and work with eligible candidates to develop and implement an Individual Plan for Employment (IPE). The goal of the IPE is to

identify and maintain the most appropriate and integrated employment or educational setting based on informed choice of the individual. OVR also contracts with a network of Community Rehabilitation Programs to provide direct services such as:

- Assessment for determining eligibility and vocational rehabilitation needs
- Counseling and guidance
- Vocational training and other training services
- Supported employment
- Personal assistance services
- Interpreter and note taking services
- Telecommunications, sensory, and other technological aids and devices
- Rehabilitation technology
- Job placement and job retention services
- Employment followup and post-employment services (Kentucky Office of Vocational Rehabilitation, n.d.[a])

One of the greatest risk factors for not finding employment in Kentucky is a diagnosis of autism, even though individuals with ASD have been shown to perform at a higher level than other disability groups according to interviewees. Limited social skills are likely a contributing factor and, therefore, social skills training is an important part of vocational services. Vocational counselors commonly refer clients with ASD to vendors who offer this type of service. For example, KAP runs a successful postsecondary employment program that includes job and social skills training, job coaching, and group social/leisure activities to promote independence and improve socialization (Western Kentucky University, 2012).

The Perkins Vocational Training Center (<http://www.cdpvtc.ky.gov/>) is a component of OVR where students with disabilities can receive a variety of classes and therapies to achieve employment and independence. Students can live on campus or commute to class to complete an occupational training program, a college program, or earn their GED. According to interviewees, the Perkins Center can serve as a stepping-stone between high school and college for students with disabilities who are interested in, but not ready to pursue, a college education.

To be eligible for OVR services, individuals must have a physical or mental impairment that results in substantial impediment to employment, benefit from vocational rehabilitation in terms of employment outcomes, and require vocational rehabilitation in order to obtain and maintain employment. However, there is currently an order of selection and not all eligible individuals receive services; at this time there is only enough funding to serve those with functional limitations in two or more areas (Categories 1–3 of 5). Individuals with ASD generally fall into these qualified categories.

Systems tracking

Medicaid is able to track services billed through the Medicaid Management system by diagnosis.

Promotion of services and supports for people with ASD

The KATC is housed at the University of Louisville and serves as the leading source of information for individuals of all ages with ASD, their families and caregivers, and professionals in the state. KATC was established in 1996 through the Kentucky General Assembly to serve as a statewide resource for families and educators. Among the resources available through KATC are:

- KATC Web site and online community—provides information about disability resources, education, and KATC services, and hosts discussion forums and live chats;
- KATC Newsletter—provides current information on ASD and is posted on the Web site, emailed, and distributed at meetings and trainings;
- Kentucky Family Guide to Autism Spectrum Disorders—includes information on a wide range of topics, including evidenced-based practices;
- Amanda L. King Resource Library—a collection of materials accessible at no cost to families and professionals; and
- Kentucky Autism Supports Directory—users can search for information about specific community resources.

Early intervention

Kentucky received a grant in 2008 to begin implementing the “Learn the Signs. Act Early.” campaign developed by the Centers for Disease Control and Prevention. Several organizations across the state helped to launch the outreach program, including the KATC, the Human Development Institute, the Kentucky Department of Education, the Kentucky Cabinet for Health and Family Services, and several autism advocacy groups. The campaign featured public service announcements, workshops, Webinars, and downloadable materials to help caregivers understand typical developmental milestones and encourage early screening and diagnosis among providers. Additionally, the grant funded a training series for early intervention field staff in various screening tools, such as the “Ages and Stages Questionnaire and Modified Checklist for Autism in Toddlers (M-CHAT) (Kentucky Cabinet for Health and Family Services, 2012).

School-aged children

The Department of Education received a grant in 2009 that established a partnership between KATC, the Kentucky Department of Education, the Special Education Cooperatives, and local school districts. The group worked together to establish an “Autism Cadre” of roughly 750 members from school districts across the state to promote best practices for ASD in schools. The goals of the group are to (1) provide ongoing training to district-level staff on evidence-based practices, which can then be brought to the local level, (2) establish networks of support between professionals from different districts and special education cooperative regions, and (3) establish local problem-solving teams at the district level across Kentucky. Cadre members represent a variety of roles within school districts, including speech-language pathologists, occupational therapists, general education teachers, special education teachers, early childhood diagnosticians, psychologists, autism specialists, consultants, and preschool teachers. In a 2011 survey, nearly all participants indicated that the cadre trainings improved their ability to provide evidenced-based practices in the classroom.

Adults

The OVR works closely with high schools across the state as students begin to transition to postsecondary options. Referrals are made to local OVR offices by the school system for all students with a disability that may prevent them from obtaining and maintaining a job.

Transitions and coordination of services

Early intervention to school

The transition process for children moving from early intervention to special education services follows the requirements of IDEA. When a child turns 2, an early intervention service coordinator sends a notification to the Department of Education, who then notifies the appropriate school district of the child's involvement in First Steps. Between the ages of 2.5 and 3, a transition conference occurs with the school district, family, early intervention coordinator, and service providers to inform the family of their options and begin to establish a plan for services. The early intervention program provides information about each child to the school district with parental consent; this often includes assessments, progress reports, length and type of services, and other narrative information, and presents an important snapshot for the school system. Interviewees noted some shortcomings in the process, but overall a relatively smooth transition from early intervention to school for most children; the state works to ensure that the same evidenced-based practices are utilized across systems to avoid major disruptions.

School-aged to employment

Typically, the transition process from school to postsecondary options occurs within 2 years of graduation; however, students can be referred earlier if appropriate. Students work with OVR transition counselors to identify their individualized vocational interests and capacities, develop an appropriate vocational goal, and determine the services necessary to attain that goal.

For students who wish to work but require a higher level of assistance, the Community-Based Work Transition Program provides personalized supports through a job coach during the last 2 years of high school. Students are provided with 160 hours of individual career exploration and training in their community. Up to 80 hours are devoted to exploring career interests and options in the first year and another 80 hours for job training and transition assistance in the second year to help the student maintain employment in his or her chosen career path (Kentucky Office of Vocational Rehabilitation, n.d.[b]).

Training for direct service support workers

The DDID offers education, training, and resources that are grounded in best practices to its support providers. An online training calendar provides information on upcoming opportunities. Additionally, DDID Education and Resource Development professionals offer mentoring for those working in the field to promote professional development (Division of Developmental and Intellectual Disabilities, 2013b).

Through the Autism Cadre, the Kentucky Autism Training Center and its partners are working to set up model ASD-specific training programs for educators across the state and providing individualized consultation to schools. KATC also offers many educational opportunities for families and providers through conferences, workshops, and professional development sessions.

The Human Development Institute, in collaboration with DDID and OVR, directs the Supported Employment Training Project, which provides training and technical assistance for professionals who support people with disabilities in finding jobs. The training involves 7 days of events that are required for all supported employment personnel statewide (Human Development Institute, 2012b).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Kentucky Commonwealth Council on Developmental Disabilities is looking at ways to expand its “The Future Is Now” program, which has shown great success in its first 3 years of implementation. The program is run by The Arc of Kentucky and assists families of individuals with disabilities in planning for the future and securing the services necessary to support that vision. The program involves an attorney and a financial planner who guide the family in taking concrete steps to plan for the future of their family member. The Council hopes to continue growing the program; however, they have had difficulty finding a sustainable funding source.

Other relevant programs and services

- The *Supported Higher Education in Kentucky* supports students with intellectual disabilities in inclusive educational settings using person-centered planning. The program also trains professionals in secondary education, higher education, and disability services to effectively serve a broader audience of learners and implements certificates and academic recognition that promote improved educational and employment outcomes. Currently, the program partners with Northern Kentucky University, Bluegrass Community and Technical College, Eastern Kentucky University, Western Kentucky University, and Murray State (Human Development Institute, 2012c).

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LOUISIANA

Approach

The L&M research team interviewed eight representatives from the state of Louisiana, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Louisiana Office for Citizens with Developmental Disabilities (OCDD), Early Steps, the Louisiana Department of Education (DOE), Louisiana Rehabilitation Services (LRS), and the Louisiana Developmental Disabilities Council.

State background

In June 2008, legislation was introduced in the Louisiana House and Senate Committees on Health and Welfare requesting the formation a joint committee to study ASD and develop a comprehensive statewide system to address the needs for individuals with autism. If approved, the study would examine and make recommendations regarding home- and community-based support services, training, consideration of an autism waiver, early screening, diagnosis, prevention, and other areas of interest. To date, no further action has been taken on HCR 69 (Easter Seals, 2012).

State insurance regulations

H.B. 958 was signed into law in July 2008, requiring coverage for the diagnosis and treatment of ASD in individuals under the age of 17. The mandate applies to group health plans with 50 or more employees; individual and small group plans are exempt. Covered services include habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care, and therapeutic care, including applied behavior analysis (ABA). Benefits are subject to a maximum of \$36,000 per year and a lifetime benefit of \$144,000 per year.

In June 2012, Governor Bobby Jindal signed H.B. 771, expanding Louisiana's autism insurance reform law. The lifetime maximum benefit of \$144,000 was removed and the age limit was raised to 21. Beginning in 2013, families paying expensive insurance premiums can continue coverage for the screening, diagnosis, and treatment of ASD for children aged 16–20 (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Louisiana 1915(c) waivers

Waiver Name	Population Served
LA New Opportunities Waiver*	Individuals aged 3+ with autism/ID/DD
LA Children's Choice*	Individuals aged 0–18 with autism/ID/DD
LA Supports Waiver*	Individuals aged 18+ with autism/ID/DD
LA Residential Options Waiver*	Individuals of all ages with autism/ID/DD
LA Coordinate System of Care—SED Children	Individuals aged 0–17 with SED and aged 18–21 with mental illness
LA Community Choices	Individuals aged 65+ or aged 21–64 with a physical disability
LA Adult Day Health Care	Individuals aged 65+ or aged 22–64 with a physical disability

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Louisiana does not have any waivers specific to individuals with ASD at this time.

Other waivers

The OCDD under the Department of Health and Hospitals (DHH) is charged with administering community-based services through the Medicaid HCBS program. The Bureau of Health Services Financing, within DHH is responsible for the Medicaid program and is accountable for oversight for all waiver programs. There are four home- and community-based individual support waivers that serve people with ASD. To be eligible for the HCBS waivers, individuals must meet age requirements, have a developmental disability (as defined by Louisiana state law *R.S. 28:451.1-455.2*), meet the level of care for an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID), and meet financial and nonfinancial Medicaid requirements. Waiver opportunities are dependent upon funding and are offered on a first-come, first-served basis through the Request for Services Registry (RFSR). Currently 9,600 individuals receive waiver services and another 9,000 are on the RFSR waitlist.

- The *Louisiana New Opportunities Waiver (NOW)* is the most comprehensive of the HCBS waivers and includes a variety of supports and services to help an individual aged 3 and older to live as independently as possible. The NOW waiver serves 9,000 individuals. Direct resource allocations are based on assessed level of need. Services follow a person-centered process and include:
 - Support coordination
 - Center-based respite
 - Day habilitation
 - Employment-related training
 - Support employment
 - Supported living
 - Supplemental skilled nursing
 - Supplemental specialized medical equipment and supplies

- Adult companion care
- Community integration and development
- Environmental accessibility adaptations (including home and vehicle)
- Housing stabilization service
- Housing stabilization transition service
- Individual and family support
- One-time transitional services
- Personal Emergency Response Systems
- Professional services
- Remote assistance
- Substitute family care
- The *Louisiana Children’s Choice* waiver offers additional support to children with developmental disabilities who live at home with their family or with a foster family. Children’s Choice offers a small package of services to individuals aged 0–18; there is a cap of \$16,410 annually. Services offered through the waiver include:
 - Support coordination
 - Family support services
 - Center-based respite
 - Environmental accessibility adaptations (home and vehicle)
 - Family training
 - Housing stabilization service
 - Housing stabilization transition service
 - Supplemental specialized medical equipment and supplies
 - Specialized therapies, including:
 - ABA therapy
 - Aquatic therapy
 - Art therapy
 - Hippotherapy/therapeutic horseback riding
 - Music therapy
 - Sensory integration
- The *Louisiana Support* waiver offers focused, individualized vocational services to people aged 18 and older that otherwise would require the level of care of an ICF/DD. The waiver is capped at \$26,000 and meant to provide specific, activity-focused services, rather than ongoing care. These include:
 - Support coordination
 - Day habilitation
 - Habilitation
 - Prevocational services
 - Supported employment
 - Housing stabilization service
 - Housing stabilization transition service
 - Respite
 - Personal Emergency Response System

- The *Louisiana Residential Options Waiver (ROW)* is the newest of the HCBS programs, offering individuals of all ages support in moving from an ICF/DD or nursing facility to a community-based setting. According to interviewees, ROW was intended as a conversion model to encourage community home providers to close the roughly 400 six- to eight-bed ICF/IIDs and provide services in a less restrictive setting. Although the waiver provides comprehensive services, it currently serves only 25 individuals. Services are similar to those provided under the New Opportunities Waiver and include:
 - Host home services
 - Supplemental dental services
 - Support coordination
 - Respite services—out of home
 - Day habilitation
 - Supported employment
 - Shared living services
 - Supplemental nursing
 - Supplemental assistive technology and specialized medical equipment and supplies
 - Dental
 - Companion care
 - Community living supports
 - Environmental accessibility adaptations (including home and vehicle)
 - One-time transitional services
 - Personal Emergency Response System
 - Professional services
 - Substitute family care
 - Transportation—community access

Findings

Services and supports for people with ASD

The Louisiana OCDD serves as the lead agency and single point of entry into the developmental disabilities services system for individuals with ASD across the lifespan. In addition to managing the home- and community-based waiver programs, OCDD oversees public and private residential and nonresidential services, administers Individual and Family Supports and Flexible Family Funds, and manages the state's Community Support Teams.

- The *Individual and Family Supports* program provides state-funded services that are not available from any other resource to allow people with developmental disabilities to live in their own homes or with their families. Many individuals who are on the RFSR waitlist receive this support. The funding is flexible and provides for services such as personal care, respite, equipment, and rent/utilities (Office for Citizens with Developmental Disabilities, n.d.[b]).
- The *Flexible Family Fund* program is intended to assist families of children from birth to age 18 with the most severe disabilities. The program provides a monthly stipend of \$268, which can be used on any number of services and supports to help children remain in their home. There is currently a waitlist for these funds. Both the Individual and Family Supports and Flexible Family Fund program have been in existence for more than

20 years; Louisiana was one of the first states to pass community and family supports legislation (Office for Citizens with Developmental Disabilities, n.d.[b]).

- OCDD also manages nine *Community Support Teams* that provide supports and services to people with developmental disabilities who need intensive treatment intervention to remain in their community setting. The teams provide initial and ongoing assessment, psychiatric services, family support and education, support coordination, and other services critical to an individual's success. Services are provided in the community rather than in an office-based setting and combine skill teaching and clinical management (Office for Citizens with Developmental Disabilities, 2013).

Early intervention

OCDD is home to Early Steps—Louisiana's early intervention program. Early Steps provides IDEA Part C services to families and children from birth to age 3 who have developmental delays or a medical condition likely to result in a developmental delay. Children with a delay of 1.5 standard deviations from the mean in two areas of development are eligible for services, including cognitive, motor, vision, hearing, communication, social-emotional, or adaptive development. The program receives approximately 10,000 to 11,000 referrals each year from a variety of sources, most commonly families, physicians, and the referral hotline. Early Steps services are provided in the child's natural environment, such as the home, childcare, or another appropriate community setting, and include:

- Assistive technology
- Audiology
- Health services
- Medical services (evaluation only)
- Nutrition services
- Occupational, physical, and speech therapy
- Psychological services
- Service coordination
- Social work services
- Special instruction
- Transportation (to and from Early Steps services only)
- Translation interpreter services (foreign language and sign language)
- Vision services (Office for Citizens with Developmental Disabilities, n.d.[a])

School-aged children

The Louisiana DOE provides special education services for all children aged 3–21 with disabilities. Programs and services are provided by local school districts according to a student's Individualized Education Program (IEP) and include:

- Adapted physical education
- Assistive technology
- Extended school year
- Games Uniting Mind and Body
- Homebound services
- Occupational, physical, and speech/language therapy in the educational setting
- Orientation and mobility
- School psychology
- School social work
- Transition services
- Educational interpreter services
- School-based Medicaid services (Louisiana Department of Education, n.d.[a])

The Louisiana State University Human Development Center (HDC) has partnered with DOE to run the Louisiana Autism Spectrum and Related Disabilities (LASARD) Project. The goals of the LASARD Project are to (1) improve educational practices and outcomes for students with ASD and related disabilities and (2) develop statewide capacity to provide high quality educational programs for these students. Currently, nine school districts participate in the project, each of which contracts directly with HDC for training and technical assistance from LASARD facilitators. In addition, the LASARD Project is developing the Louisiana Autism Quality Indicators for Schools, a tool that will help schools evaluate and improve the quality of their programs for students with ASD. To complement the assessment tool, the LASARD Project is developing ASD-specific electronic professional development modules focused on key areas such as:

- Transition Practices for Students with ASD
- Assistive Technology
- Behavior Intervention Practices for Students with ASD and Related Disabilities
- Communication
- Inclusive Practices for Students with ASD and Related Disabilities
- Collaboration & Teaming
- Social Skills Instruction for Students with ASD and Related Disabilities

- Curriculum and Instruction
- Environment Supports for Students with ASD and Related Disabilities (Louisiana State University Human Development Center, 2012)

Adults

In addition to services provided through OCDD, the LRS works with adults aged 18 and older with disabilities to obtain or maintain employment and achieve independence in their communities. The LRS has eight regional offices throughout the state through which many services are provided. They also contract with Community Rehabilitation Programs to provide more intensive services, such as supported employment. Rehabilitation counselors and clients develop an Individual Plan for Employment, which combines the professional expertise of counselors with the needs and choices of clients. Some of the services offered through the regional LRS include:

- Vocational evaluations
- Vocational guidance and career counseling
- Job placement
- Training up to and including college
- Assistive technology (e.g., computers, software)
- Personal assistance services (e.g., personal care attendant, scribe, reader, interpreter)
- Books and supplies
- Transportation
- Mental health counseling
- Transition services (Louisiana Rehabilitation Services, 2011)

To be eligible, individuals must meet the following federal criteria: (1) have a physical or mental disability which results in a substantial impediment to employment; (2) be able to benefit from vocational rehabilitation services in terms of employment; and (3) require vocational rehabilitation services to prepare for, enter, engage in, or retain gainful employment (Louisiana Rehabilitation Services, 2011). Due to budget constraints, LRS operates under an Order of Selection; individuals must meet Category 1 of 5 (having the most significant needs) in order to receive services. This requires functional limitations in at least four out of eight areas. According to interviewees, most individuals with ASD fall into this category; in 2011, 348 out of the 393 individuals with ASD referred to LRS were in Category 1. Moreover, 123 of these individuals received supportive employment services. It is important to note that some individuals with autism may not have been categorized as having ASD because their primary diagnosis is something else.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals and families learn about services and supports for ASD through several channels. As efforts for early identification and screening improve, knowledge of and entry into the service system begin at a younger age. Early Steps has regional community outreach specialists responsible for coordinating activities and events to increase awareness of developmental delays and early intervention services. Additionally, the Louisiana Developmental Disabilities Council provides funding to Families Helping Families (FHF; <http://www.fhfgbr.org/>), a predominately parent-run organization that provides information, referral, education, and training for families and individuals with disabilities. FHF has 10 regional centers throughout the state that coordinate outreach events, advertise services, and conduct other activities to spread the word about supports, services, and issues related to disabilities. Interviewees note that early identification and connection to services is a continuous struggle, particularly in rural areas. The Louisiana Developmental Disabilities Council 5-year strategic plan outlines funding and technical assistance to increase capacity of the regional FHF centers as well as efforts to educate hospitals and health care providers on available resources to individuals with developmental disabilities.

Transitions and coordination of services

Early intervention to school

Transition from early intervention to school occurs according to the requirements of the Individuals with Disabilities Education Act (IDEA). Transition is discussed at every opportunity as soon as a child is eligible for early intervention services. As a child nears his or her third birthday, a notification is sent to the local educational agency (LEA), and the early intervention coordinator and family discuss services in more detail. This can involve in-person meetings with the transition coordinator and visits to school programs. By the child's third birthday, an official transition conference takes place in which a representative from the LEA attends. The family, LEA representative, transition coordinator, service providers, and others discuss necessary and available services and supports. Additionally, the family determines what information will be exchanged between early intervention and school staff.

School-aged to employment

Transition services for individuals leaving school begin by age 16 or earlier as required by IDEA. This includes development of the transition services plan, a coordinated effort among the student, parents, schools, and adult service providers to achieve a desirable future for the student. The Louisiana Transition Services Web site is available as a guide for students, families, educators, and service providers to improve post school outcomes for students with disabilities (Louisiana Department of Education, n.d.[b]).

According to interviewees, transition services from school to employment are in need of improvement. Louisiana does not provide the state match due to lack of funds to draw down all available federal dollars for vocational rehabilitation. Consequently, employment services in the schools are lacking and students are often placed in sheltered workshops, rather than integrated employment settings.

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Louisiana is one of 23 states participating in the State Employment Leadership Network, a joint initiative of the National Association of State Directors of Developmental Disabilities Services. In July 2011, the OCDD, along with several state partners, launched an Employment First Initiative with the goal of improving the lives of people with disabilities by promoting employment (Office for Citizens with Developmental Disabilities, 2011). The official position statement of OCDD is as follows:

“Employment will be the primary outcome for all persons receiving OCDD services who are of working age. Employment is characterized by typical jobs with competitive compensation that are fully integrated into the workplace. A more thorough implementation statement with further detailed definitions, desired outcomes and operational procedures will be released as they are finalized.”

Accordingly, OCDD has set targets for all of their regional offices to improve employment outcomes for individuals with disabilities. Additionally, the Louisiana Developmental Disabilities Council, the DOE, and the LRS are currently meeting to discuss how to improve transition to more integrated employment for students with disabilities.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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MAINE

Approach

The L&M research team held discussions with two representatives from Maine: one from the Developmental Disabilities Council (DDC) and another from the Autism Spectrum Disorder Steering Committee. Due to extensive restructuring of positions in the state, we were unable to obtain interviews with members of the Department of Education, Department of Health and Human Services, and others key to implementing services for those with Autism Spectrum Disorders (ASD).

State background

The prevalence of Pervasive Developmental Disorders (PDD), including Autism Spectrum Disorder (ASD), has skyrocketed in Maine, increasing over 540 percent between 2000 and 2009. During this time, MaineCare (Maine's Medicaid program) reported paying claims for 4,156 individuals with PDD (Maine DHHS, 2013).

Maine has taken steps to serve this growing population over the years, including creating the PDD Systems Change Initiative in 2008. The initiative is being led by the Maine Department of Health and Human Services (DHHS), Department of Education (DOE), and Department of Labor (DOL) and staffed by the Office of Developmental Disabilities. Their goal is to analyze systems that individuals with PDD and their families utilize and make them more effective and efficient. Specifically, their purpose is to implement the five task strategic plan recommended by the Joint Standing Committee on Health and Human Services. These tasks include:

1. Develop a statewide early identification and surveillance system to identify children with PDD at the earliest possible time;
2. Explore and recommend standard assessment and treatment protocols for children with PDD;
3. Refocus the Adult Service System to respond to the changing needs of children with PDD who are exiting school;
4. Investigate post-secondary and vocational opportunities for people with PDD and recommend a plan of action and;
5. Develop and implement a point of accountability for overall system performance.

In 2009, DHHS and DOE performed a meta-analysis of peer-reviewed studies to determine the effectiveness of various interventions for children with ASD. They found that most research focuses on early intervention, leaving a dearth of information about education interventions, school-age youth, adolescents, and adults with ASD. They also noted that Maine does not have sufficient resources to effectively deliver evidence-based treatments throughout the state (Maine DHHS, 2013).

Maine has received two grants from the federal government that will go toward enhancing ASD services for children in the state. The first is a 5-year \$11,277,362 federal child health quality improvement grant, which Maine refers to as Improving Health Outcomes for Children (IHOC). The goal of this grant is to improve health outcomes of Medicaid-eligible children through the

use of quality measures and information technology. It will be used in part to fund implementation of medical home pilots, some benefiting children with ASD. The other is a 3-year \$300,000/year state Autism Implementation Grant (AIG) that will allow the PDD Systems Change Initiative to continue working toward its five goals (Maine DHHS, 2013).

State insurance regulations

Three regulations are currently in place that affect the insurance landscape for ASD in Maine. Enacted in January 2011, the most sweeping statute requires that all individual and group plans cover the diagnosis and treatment of children with ASD from 0 to 5 years of age. Further regulations require that some group contracts provide benefits for certain mental illnesses (including ASD) that are no less extensive than those for physical illnesses. In 2009, the state legislature also required that DHHS provide for Board Certified Behavior Analysts (BCBAs) to deliver supervisory services in several capacities for people with mental disabilities or ASD (National Conference of State Legislatures, 2012). One issue with the mandate is that many providers are not accustomed to billing for BCBA services and do not accept private insurance because MaineCare is their primary payer.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Maine 1915 (c) Waivers

Waiver Name	Population Served
ME Services for Children with ID and/or PDD*	Children aged 5–21
ME Home and Community Services for Adults with ID or AD*	Adults 18+ with intellectual disabilities and/or ASD
ME Support Services for Adults with ID or AD*	Adults 18+ with intellectual disabilities and/or ASD
ME Elderly and Adults with Disabilities	Adults aged 65+ or aged 18–64 with a physical disability
ME Consumer Directed Personal Assistance Services	Adults aged 65+ or aged 18–64 with a physical disability
ME Home and Community Based Services for Adults with Other Related Conditions	Adults aged 21+ with cerebral palsy, epilepsy, and other related conditions

*Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Maine Home and Community Services for Adults with ID or AD* is one of two primary waivers that qualify for waiver services adults over the age of 18 who have a documented autistic disorder or pervasive developmental disorder or intellectual disability. The program is meant to be comprehensive with a cost limit at 200 percent of average institutional costs. Available services include:
 - Community support
 - Home support
 - Work support
 - Communication aids

- Consultation
 - Counseling
 - Crisis assessment and intervention
 - Employment specialist services
 - Home accessibility adaptations
 - Nontraditional communication assessment and consultation
 - Nonmedical transportation
 - Occupational therapy (maintenance)
 - Physical therapy (maintenance)
 - Specialized medical equipment and supplies
 - Speech therapy (maintenance)
- The *Maine Support Services for Adults with ID or AD* waiver primarily supports adults with intellectual disabilities or an autistic disorder who are living with their families and offers accompanying services designed to provide the support necessary to assist individuals and their families to live as independently as possible. A waiver cost limit is set at 50 percent of the state’s average Intermediate Care Facility for Individuals with Intellectual Disabilities costs. Available services include:
 - Respite
 - Community support
 - Employment specialist services
 - Work support
 - Home accessibility adaptations
 - Transportation

As of January 2011, the two adult programs had a combined waitlist of 628 individuals, including 189 at risk for health and safety issues (Maine DHHS, 2013).

- The *Maine Services for Children with ID and/or PDD* waiver is designed to provide services for children 5–21 years old diagnosed with ID, ASD, Rett syndrome, child disintegrative disorder, or PDD-NOS. The waiver targets children who have significant behavioral health needs and traditionally have been placed in institutional settings for extended periods. A waiver cost limit is set at 100 percent of institutional costs. Available services include:
 - Home support
 - Respite
 - Communication aids
 - Consultation
 - Home accessibility adaptations
 - Transportation

Findings

Services and supports for people with ASD

Maine has a strong focus on early intervention for young children (typically under the age of 6) as well as services for school-aged youth. However, once people with ASD exit the school system, fewer services exist to help them through their adult lives. Further, because Maine is a

rural state, service providers often drive long distances to clients, time for which they are not compensated. Therefore, even if someone is entitled to a variety of services, providers may not be willing to offer them (DDC, personal communication, June 2012).

Early intervention

As noted earlier, there is a strong emphasis on research, services, and supports for young children with ASD and their families. Early detection is a primary focus of the federal IHOC grant. In 2008, Maine began universal screening for ASD on all children using the Modified Checklist for Autism in Toddlers (M-CHAT). MaineCare encourages and incentivizes doctors to screen all children during recommended well-child visits by providing enhanced rates for those using the M-CHAT guidelines set forth by the American Academy of Pediatrics. Additionally, Women, Infants, and Children, Head Start, Home Visiting, and Public Health Nursing programs partially screen for and counsel families on getting the necessary evaluations and followup (Abt Associates, 2011).

Aside from the state waiver program, Maine has a number of publicly funded services for children under age 6 with ASD who are eligible for MaineCare. The Division of Children's Behavioral Health Services (CBHS) provides an array of early intervention services including screening, diagnosis and evaluation, case consultation for parents and caregivers, developmental therapies, and specific treatment directed to address children's needs (Maine DHHS, 2013). Those who are ineligible for MaineCare, and the Katie Beckett exception for people with disabilities should be able to receive services through their private health insurance; however, there are often not enough qualified professionals to provide services that children need.

- Children with ASD qualify for pre-education help through Child Development Services (CDS), CBHS, and/or MaineCare in the form of therapeutic preschool, one-on-one in traditional preschool, or special education pre-K programs. Under the federally mandated Individuals with Disabilities Act (IDEA), CDS provides IDEA Part C early intervention (birth to 2) and IDEA Part B early childhood (age 3 to 5) services through the Department of Education. This includes screening and evaluation; case management and direct instruction for children and families; special education in areas of physical, cognitive, speech/language, social/emotional, and adaptive skills; and access to local resources. IDEA Part C services utilize individual family service plans (IFSP) and occur in the natural environment. Similarly, IDEA Part B services are based on Individualized Education Programs (IEPs) and are provided in the least restrictive setting possible.

In addition, the Division of Early Childhood works to ensure that all infants, preschoolers, and young children, with and without disabilities, have an opportunity to receive high quality care and education in inclusive schools and childcare settings. To this end, the Child Care Plus ME program provides onsite inclusion consultation and temporary supports in these settings (Maine DHHS, 2013).

One difficulty with early intervention in Maine is that several agencies provide services and supports and children may end up with an individualized family service plan, individual treatment plan, and individual service plan. They often go from CBHS, CDS, and/or MaineCare to a regional case management agency, to various other providers for services. This daunting process requires ongoing parental involvement that if interrupted, may result in children not receiving the services they need (Cronin, 2009). There are plans to streamline these services, and

two pilots have been established in the state through IHOC and AIG funds to determine best practices for coordination and communication.

School-aged children

For children aged 6–20 who are eligible for MaineCare or Katie Beckett and score more than two standard deviations below the mean on a functional development assessment, CBHS offers a comprehensive list of services. Among these services are:

- Targeted case management utilizing a wraparound process to coordinate plans and services so that children receive all of the necessary supports (over 2,690 youth received case management in 2009);
- Rehabilitative and community support (Section 28), which offers skill building in daily living, communication, and behavioral management utilizing evidence-based applied behavior analysis (over 1,050 youth with PDD received these services in 2009);
- Mental health treatment programs to provide counseling and strategies for improving functioning at home, in school, and in the community (over 1,511 youth with PDD received these services in 2009);
- Short-term residential services for children in need of short-term care outside the home;
- Crisis intervention for children in need of immediate stabilization during crisis situations;
- Outpatient services including counseling and medication management;
- Respite care to provide temporary relief for families of children with PDD; and
- Flexible funding for short-term assistance with safety devices, assessments, emergency needs, transportation, adaptive equipment, therapeutic recreation, and family support (Maine DHHS, 2013).

For children above the age of 6 and ineligible for MaineCare or Katie Beckett, finding services is generally more difficult. Parents cannot offer private pay for CBHS services and the insurance mandate does not extend to children over the age of 5. Therefore, families must try to get all necessary services through the school system and, if they have the means, find and privately pay for services that are not educationally necessary. Moreover, because Maine is rural and lacks both developmental pediatricians and facilities, families often travel out of state. For example, families on a long waitlist for diagnostic services may travel to Boston to be seen more quickly. Additionally, children who are in need of longer term residential care must go out of state because there are no institutions for developmental disabilities in Maine.

DOE established the Maine Unified Special Education Regulation (MUSER), which implements IDEA and governs how school IEP meetings are held. These regulations focus on giving the best services to individuals in the least restrictive environment. Ideally, children are mainstreamed when possible and given just enough time in self-contained classrooms, homebound tutoring, hospital programs, residential schools, and so on to meet their individual needs. Services available through the school system include:

- Audiology
- Counseling

- Psychological services
- Interpreting services
- Transliteration for students who are deaf
- Medical services (to identify students' disabilities)
- Occupational therapy
- Orientation and mobility services
- Parent counseling and training
- Physical therapy
- Recreation
- School health services
- Social work services
- Assistive technology
- Rehabilitation counseling
- Transportation services (Southern Maine Parent Awareness, 2009)

Adults

Overall, Maine suffers from funding limitations that significantly restrict availability and access to services for adults with PDD. In addition to the state waiver programs described earlier, the Office of Aging and Disabilities Services (OADS) under DHHS handles general case management on a statewide level for all persons with PDD. As it does with children's programs, the DHHS requires that adults have a diagnosis of PDD and score more than two standard deviations below the mean on a functional development test to be eligible for case management services, which include:

- Person-centered planning—this is a major focus of care in Maine that emphasizing what individuals want and how they can achieve their goals. Case managers ensure that participants and teams understand which services are being provided and why;
- Quality improvement/assurance—reviews patient care and evaluates whether it is meeting the needs of individuals;
- Crisis services—includes a hotline and crisis teams to help individuals stabilize and remain in their homes;
- Public guardianship—OADS will become a guardian if there is no one to take over guardianship;
- Representative payees—these are often case managers when individuals are determined to need help with financial affairs and do not have someone to represent them;
- Adult protective services—arranges for services to protect vulnerable individuals who are in situations of abuse, neglect, or exploitation;

- Advocacy—informs individuals of their rights and upholds them through grievance proceedings; and
- Limited professional support not covered by MaineCare (Maine DHHS, n.d.).

OADS provides MaineCare employment services to over 900 individuals with developmental disabilities who work in businesses throughout Maine. Quality employment, sufficient wages, benefits, and integrated workplaces are available to recipients of MaineCare waiver services. Individual planning for these adults include employment counseling and career development. Businesses such as Procter and Gamble, Hannaford Supermarkets, Wal-Mart, Mardens, Lowe's, and many small Maine businesses have hired individuals with developmental disabilities into their workforce. OADS and its stakeholders continue to work toward increasing the numbers of residents with developmental disabilities who work in integrated, competitive employment.

DHHS, DOL, and the Muskie School of Public Service partnered to develop a Web site, www.employmentforme.org. This is a one-stop shop to link people with disabilities to employment services and help them understand eligibility for services such as an employment coach, workplace accommodations, or other supports. In addition, the Web site explains the Americans with Disabilities Act and responsibility to comply and encourages employers to hire people with disabilities.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

There are several key players for the promotion of services; most of which are the same entities that provide services.

- The *Autism Society of Maine* (<http://www.asmonline.org/>) is a nonprofit organization that serves individuals with autism, families, professionals, and communities by providing education, advocacy, referrals, and resource development to support of informed choice of treatments and services.
- The *Center for Community Inclusion and Disabilities Studies* through the University of Maine offers interdisciplinary education, community service, applied research, and information on developmental disabilities.
- *Child Development Services* under the DOE ensures the provisions of special education rules statewide.
- *Children with Special Health Care Needs* under the DHHS seeks to improve the health and well-being of children with special health care needs by developing and sustaining community-based systems of care.
- The *Office of Aging and Disability Services* under the DHHS (formerly the Offices of Elder Services and Cognitive and Physical Disabilities Services) provides leadership and support in Maine's comprehensive system of support to individuals with cognitive and physical disabilities.

- The *Bureau of Rehabilitation Services* under the DOL works to bring about full access to employment, independence, and community integration for people with disabilities.
- *Maine Administrators of Services for Children with Disabilities* advocates for the right of all students to receive a free and appropriate public education, provides opportunities for professional growth to Maine educators, and offers leadership in shaping policies and practices.
- The *Maine Association of Community Service Providers* is an association of organizations that provide supports and services to children and adults with developmental and other cognitive disabilities and advocates from the provider perspective.
- The *Maine Chapter of the American Academy of Pediatrics* is a membership organization of 220 pediatricians and subspecialists who are dedicated to improving the lives of children and adolescents in Maine.
- The *Maine Parent Federation* (<http://www.mpf.org/>) provides information, advocacy, education, and training to benefit families of children and adults with disabilities and special health care needs.
- The *Public Health Nurses Program* is a group of registered professional nurses working to improve, preserve, and protect the health and quality of life for all Maine citizens.
- Also, an unofficial group of six developmental pediatricians meet regularly to discuss best practices.

Transitions and coordination of services

Although some plans are in place, coordination of services among different providers requires transition periods that are often difficult for families to understand and can lead to gaps in services. This is particularly salient when children age out of entitlement years into adulthood.

Early intervention to school

Responsibility for special services shifts from CDS to local school districts, but children continue to be covered under MUSER regulations. Once in school, transitions are based on the student's IEP. In 2009, the Maine DOE convened a workgroup that examined transitions for school-aged children with ASD. One of their key concerns was a gap in standardized methods for communicating information about an individual from teacher to teacher. In addition, they identified a lack of formal preparation for students as they transition from year to year (Maine DHHS, 2013).

School-aged to employment

The beginning stages of transition are largely determined by the IEP. The school system works with kids beginning no later than their 14th birthday to begin planning for transitions to adulthood. At this time, they join their own IEP meetings and begin to focus on classes and extracurricular activities (life skills, budgeting, personal care, precollege, etc.) that will help them meet their goals. The school is responsible for inviting representatives from state and community agencies to IEP meetings so that families can begin to decide which services they will need in the future and how to apply for them (Southern Maine Parent Awareness, 2009).

One major issue with transitions from school to adult services is a lack of funding in the adult world. Children are transitioned out of school and into employment programs in two separate steps. Often children are not able to gain waiver services right away, if at all, and employment support programs will not move past the evaluation stage until they know that they have waiver funding. If families are not strong advocates and waiver applications are never approved, young adults often are left with no services.

Training for direct service support workers

Maine is taking several steps to educate and train professionals who provide direct service to individuals with PDD. As noted earlier, the state is implementing part of its AIG funds to improve early identification and treatment for ASD. Specifically, Head Start, Home Visiting, and Public Health Nursing programs are receiving training on how to use the M-CHAT to diagnose young children, how to support and discuss screening results with families, and how to communicate results to primary care physicians (PCPs). Moreover, the state is providing guidance to PCPs on making quick and easy referrals to diagnostic and early intervention professionals as well as training hospital staff on the ASD population and why screening and referrals are important.

Over the next few years AIG funds will also serve to provide training to physicians on how to more effectively treat children and youth with ASD to improve health care and outcomes (Maine DHHS, 2013). In addition, OADS provides for ongoing education about ASD-specific topics to case managers and other direct services providers as well as clinical consultation for crises teams (Maine DHHS, 2013).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

With IHOC and AIG funds in place, Maine has the opportunity to work toward achieving the overarching goal of the PDD Systems Change Initiative—to improve the services and systems that individuals with ASD and their families utilize. Specifically, part of these grant monies will go toward (1) implementing new and enhancing existing pilot projects; (2) developing a comprehensive data system and; (3) educating consumers and families on the medical home concept.

ASD services have been evolving and improving over the past few years, making it increasingly difficult to coordinate across various entities. With this in mind, over the next few years, Maine will establish two pilot projects to improve early identification and intervention by enhancing communication and coordination across systems. Likewise, they will enhance the activities of the ongoing Patient Centered Medical Home pilot to include coordination of services that are specific to the ASD population.

In an effort to facilitate better coordination and higher quality care, Maine is rolling out the Facilitating Autism Screening and Treatment Data System. The system will help integrate the aforementioned pilot projects and allow Head Start, Home Visitors, Public Health Nurses, and

primary care physicians to communicate effectively, identify children in need of services quickly, coordinate services among several groups, and as a positive externality, provide useful data to policy makers.

Finally, with the support of AIG funds, the Maine Parent Federation and Autism Society of Maine are developing and circulating a Medical Home Curriculum, which will allow families to understand the concept of a medical home. The idea is that families with greater capacity to actively participate in the medical home model will benefit from more continuous and coordinated care (Maine DHHS, 2013).

Other relevant programs and services

The *Center for Communication Inclusion and Disability Studies* at the University of Maine was awarded a 4-year grant to provide expertise and resources on a wide range of topics relevant to individuals with ASD and their families. Some of this work includes: providing autism-specific technical assistance to staff within early childhood programs, schools, high education institutions, employers, and state and community agencies; training for early intervention providers in the use of the evidence-based Developmental, Individual-Difference, Relationship-Based Model for children with ASD; and a two-day advanced training for individuals who provide employment supports to individuals with ASD.

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MARYLAND

Approach

The L&M research team interviewed six representatives from the state of Maryland, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Developmental Disabilities Administration (DDA), the Maryland Department of Education, the Office of Genetics and Children with Special Health Care Needs, the Maryland Department of Disabilities, the Maryland Department of Rehabilitative Services (DRS), and Towson University.

State background

Governor Martin O'Malley created the Maryland Commission on Autism on May 7, 2009. This Commission is tasked with making recommendations to the governor and relevant state agencies regarding services for autism across all state levels. The Commission is made up of 26 members from a variety of backgrounds, including state agency representatives, health care providers, adults with ASD, parents of children with ASD, legislators, and insurers. The Commission formed nine workgroups in the areas of health and medical services, transitioning youth, adult services, funding and resources, research partnerships, evidence-based practices, workforce development, data, and early intervention and awareness. In September 2012, the Commission published its final report, outlining 12 recommendations across many areas of service and support. Many of these recommendations focus on partnerships and coordination, such as the formation of an Autism Coordinating Council to help implement the other recommendations (Maryland Commission on Autism, 2012).

Historically, Maryland has treated Autism as a developmental disability, as opposed to an intellectual disability. This is partly because Maryland chooses not to identify specific populations by type of diagnosis, in an effort to make services more inclusive. As is the case for many states, the state school system accounts for a majority of ASD diagnoses. In 2010, the Maryland school system served close to 9,000 students with autism, representing an estimated 8.2 percent of all special education services in Maryland (Health, 2010).

State insurance regulations

Maryland does not have a specific insurance mandate for ASD. However, the state requires health insurers that provide hospital, medical, and surgical benefits to provide coverage for habilitative services for children with a congenital or genetic birth defect, including autism. Covered services include occupational therapy, physical therapy, and speech therapy. Maryland also has a comprehensive mental health parity law that ensures insurance coverage for broad based mental health disorders. Mental health benefits must be equal to other health benefits, and there is no limit for psychiatric care annually or throughout the lifetime (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Maryland 1915(c) waivers

Waiver Name	Population Served
MD Waiver for Children with Autism Spectrum Disorder*	Individuals aged 1–21 with autism spectrum disorders
MD New Directions Independence Plus*	Individuals of all ages with ID/DD
MD Community Pathways*	Individuals of all ages with ID/DD
MD Model Waiver for Fragile Children	Individuals of all ages who are medically fragile (initial eligibility and enrollment must occur prior to age 21)
MD Living at Home	Individuals aged 18–64 with physical disabilities
MD TBI	Individuals aged 22+ with brain injury
MD Older Adults	Individuals aged 65+ or aged 50–64 with physical disabilities
MD Medical Day Care Services	Individuals aged 65+ or aged 16–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

The Department of Health and Mental Hygiene (DHMH) is Maryland’s single state Medicaid agency, and provides oversight of all waivers in the state. However, many of the waivers applicable to individuals with ASD are administered by different state agencies.

Specific ASD waivers

- The *Maryland Waiver for Children with Autism Spectrum Disorders* is administered by the Department of Education. This waiver allows eligible children aged 1–21 to receive services necessary to stay in their homes and communities. This waiver is popular because it measures the child’s income rather than the families’ income. However, when children either graduate from high school or turn 21, they are no longer eligible for the waiver. Roughly 3,700 children are on the waiver registry, indicating interest in the waiver. Services covered include:
 - Residential habilitation
 - Respite
 - Adult life planning
 - Environmental accessibility adaptations
 - Family training
 - Intensive individual support
 - Therapeutic integration (Maryland DHMH, 2008)

Other waivers

- The DDA administers the *Maryland New Directions Independence Plus* waiver. It is a self-directed waiver that allows participants with developmental or intellectual disabilities of all ages to manage their individual budgets, decide which services to utilize, and choose providers. Individuals on the waiver are assigned a support broker to manage the system and act as an advocate on behalf of the participant. Individuals also

receive assistance from a fiscal management service to help pay their bills, take care of paperwork, and provide monthly budget statements. Services offered include:

- Community supported living
 - Respite
 - Supported employment
 - Employment discovery and customization
 - Community learning services
 - Live-in caregiver
 - Transportation
 - Environmental accessibility adaptation
 - Family and individual support services
 - Transition services
 - Support brokerage (for self-directed services)
 - Assistive technology and adaptive equipment
 - Resource coordination
 - Day habilitation
 - Medical day care
 - Behavioral supports (Centers for Medicare & Medicaid Services, n.d.)
- The DDA also administers the *Maryland Community Pathways* waiver. Community Pathways covers approximately 9,000 individuals with intellectual or developmental disabilities of all ages who require the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities. The waiver intends to enhance community integration through meeting employment goals and the choice of participating in meaningful daily activities at home and in the community. Services offered include:
 - Resource coordination (targeted case management)
 - Community residential habilitation
 - Day habilitation
 - Supported employment
 - Residential habilitation
 - Family and individual support services
 - Community supported living arrangements
 - Assistive technology and adaptive equipment
 - Employment discovery and customization
 - Community learning services
 - Environmental modifications
 - Respite
 - Transportation
 - Behavioral supports
 - Live-in caregiver
 - Medical day care
 - Transition services (Centers for Medicare & Medicaid Services, n.d.)

Findings

Services and supports for people with ASD

The DDA offers family or individual support services throughout the lifespan to eligible individuals with an intellectual or developmental disability. Eligibility for services in Maryland is based on having a chronic condition and a higher need for health care and related services, rather than having a specific diagnosis. Some of these services include behavioral support, day services, residential services, and supported employment. DDA also offers low intensity support services that are designed for a one-time, temporary crisis or a low-level need. This service functions on a first come, first served basis with individuals receiving up to \$3000 for the year. This service is typically spent for summer programs or respite. In general, the state is able to track service utilization history (Maryland DHMH, n.d.).

Early intervention

In Maryland, the Division of Special Education/Early Intervention Services provides leadership and support to create a comprehensive system for children with disabilities from birth to age 21. The Early Childhood Intervention and Education Branch serves as the state's Individuals with Disabilities Education Act (IDEA) Part C and B authority. The Branch oversees two programs: the Maryland Infants and Toddlers Program serves children from birth to age 3 and Preschool Special Education Services serves children aged 3–5.

Eligibility for the Maryland Infants and Toddlers Program is determined by atypical development, a diagnosed condition, or a 25 percent developmental delay. Children under age 3 are not classified based on disability, and the school system is allowed to use the criteria of developmental delay through age 7. Infant and toddler services are family-centered and have a home-based approach. When children reach age 3, they may have the option to extend their Individualized Family Service Plan, which allows children to stay in early intervention until their fourth birthday. Approximately 70 percent of participants elect to use this extension.

School-aged children

Preschool Special Education Services are available to children aged 3–5 who qualify under Part B of IDEA; autism is listed as an eligible disability. Children can receive screening services through the local school system's Child Find program and then work with the Individualized Education Program (IEP) team to determine the most appropriate services. Available services include special instruction, speech therapy, language therapy, physical therapy, occupational therapy, assistive technology devices and services, psychological services, and others that are deemed necessary. The IEP team also identifies the least restrictive environment for education, such as a local preschool special education classroom (Maryland State Department of Education, 2003).

In 2011, Special Education served 8,829 children aged 3–21 with an ASD classification. The Children with Autism Spectrum Disorder Waiver serves many children until age 21 and offers services in addition to what is offered in school. It also helps with service availability by offering another funding source for services that were previously only offered by school districts.

Adults

The Department of Rehabilitative Services (DORS) determines eligible individuals for vocational rehabilitation to be those having a significant physical, mental, or cognitive disability that affects their ability to work. However, individuals with the “most significant” disabilities are served first, so even if someone is eligible, he or she might not immediately receive services. DRS offer services such as vocational guidance and counseling, career assessment, job training, vocational training, college or technical training, supported employment, job search and placement services, physical restoration, and mental restoration. The overarching goal is to help participants obtain employment in a job that matches their skills and interest. Cases are closed after an individual has been successfully employed for 90 days (Division of Rehabilitation Services, 2013b).

The DORS recently conducted a 2-week program called Autism Program: Planning Success for Employment, which helps individuals with ASD explore employment readiness skills such as self-advocacy, decisionmaking, work expectations and responsibilities, and career interests. Six participants took place in the event and were able to visit many work sites, such as hotels, movie theaters, and barbershops to learn about work opportunities (Division of Rehabilitation Services, 2013a).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Preschool Partners provides support to families of children aged 3–5 and maintains connections across different sources, including preschool programs and community services. They help children transition from the Infants and Toddlers Program (ITP) to the local school system. The Maryland State Department of Education made funding available to local ITPs to expand services provided through local family support networks (Pathfinders for Autism, 2011b). Key individuals involved in the transition process include the child, parents/caregivers, early intervention coordinators, representatives from the local education authority, and current and future service providers. Some key transition activities include:

- Developing a transition plan which includes activities, events, responsibilities, and timelines;
- Identifying key personnel from current and future programs;
- Modifying the child’s current program to be more similar to the future environment;
- Having future service providers observe the child in the current environment;

- Scheduling special education meetings and IEP reviews; and
- Transferring records or other information to the future program

School-age to employment

Maryland regulations call for post-high school transition planning to begin at age 14 and include the student, family, IEP team, and adult service providers and agencies. Postsecondary goals typically include any combination of the following: employment, postsecondary education, employment training, independent living, and community participation. Students share their interests and work with school staff when developing their IEP. From these goals, the school examines which services and courses may be helpful toward achieving these goals and the student's goals and interests are reassessed on an annual basis (Pathfinders for Autism, 2011a).

The Governor's Transitioning Youth Initiative (GTI) provides funding for supported employment and day programs for eligible youth who are exiting the school system. The DRS and the DDA run the program. DRS sponsors short-term services, such as summer job placement, help identifying individual strengths and interests, learning skills to maintain a job, and assistive technology. DDA supports long-term services for 1 year beginning at age 21. This includes job coaching while working to assist with learning new job skills, help maintaining or advancing employment, and other services in accordance to an individual's employment needs (Maryland State Department of Education, 2010). DRS can offer similar services to eligible youths outside of the GTI and is also involved with Project SEARCH, a school-to-work internship program for students in high school. Overall, roughly 35 percent of DRS caseloads involve transitioning youths, who are often referred by the school system.

The Maryland Higher Education Commission created a Web site (<http://www.mdgo4it.mhec.maryland.gov>) for students interested in attending a postsecondary institution that provides information on preparing for college, the application process, financial aid, and campus life. Some financial aid sources are available for students with disabilities, such as DRS tuition assistance to students requiring postsecondary education to reach an IEP employment goal and scholarships for students with disabilities (Maryland Transitioning Youth, n.d.).

Training for direct service support workers

The Office of Genetics and Children with Special Health Care Needs funds developmental screening training across the state. The training educates providers on standardized instruments for screening and involves a specialist who helps physicians incorporate these screenings into their practices. There is currently no mandate for physicians to participate, though an incentive is that the training counts for Continuing Medical Education credits.

The DDA is partnering with the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute to assist community providers in their skills and knowledge to support individuals with ASD (Maryland Commission on Autism, 2012). In addition, many local school systems have their own training that they support and fund. In 2010, a booklet with articles about different aspects of the autism service delivery was released and made available to parents and providers by the Department of Education.

- The Department of Education supports some graduate certificate programs in autism, including a program at Johns Hopkins University. Additionally, Towson University is developing a curriculum for a Bachelor of Arts degree related to working with individuals with developmental disabilities. The goal is to develop future experts to work in communities.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Overall, funding is an issue in the state. Maryland has permission to increase the number of participants enrolled in the autism waiver, but there is not enough state funding to do so. However, to supplement the HCBS waiver program, there is some discussion around implementing a supports waiver in the next 2 to 3 years. This waiver would serve as a resource for individuals who may not qualify for a comprehensive waiver, but still have intensive needs. Funding was identified to provide onetime assistance for crisis resolution to individuals and families at high risk of a crisis situation. The individual would receive \$10,000 in support services, such as respite care and applied behavior analysis therapy.

If additional funds were available, one of the goals of the state would be to analyze services aimed at youths between 18 and 21 years old. The National Survey of Children with Special Health Care Needs is conducted every 4 years. Maryland anticipates utilizing the next iteration of data to provide feedback, especially related to transitions services for youth to adulthood. In the 2009/2010 survey, Maryland ranked 40th in the Nation for providing this service, with approximately 36.8 percent of youths receiving transition to adult services, including transition to doctors who treat adults, changing health needs, and maintaining health insurance.

Other relevant programs and services

- Maryland offers some recreational activities, including sensory-friendly movie nights, which are movie screenings geared toward families with a child with a disability. During these screenings, the lights are left on, the film volume is lowered, and participants are allowed to talk and move around during the movie.
- Maryland Department of Disabilities and the Maryland Department of Business and Economic Development sponsored meetings with the founder of Specialisterne, a Danish company that utilizes the unique skills of individuals with ASD to perform software testing and quality control for technological companies (Maryland Department of Disabilities, 2010). There has been discussion to bring this business model to Maryland.

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MASSACHUSETTS

Approach

The L&M research team spoke with six Massachusetts stakeholders. Interviews were held with persons from the Massachusetts Department of Developmental Services (DDS), Early Intervention (EI) Program, Vocational Rehabilitation (VR) Services, Department of Elementary & Secondary Education Special Education, and MassHealth (Massachusetts Medicaid) in order to gain understanding of the range of services available to those with autism spectrum disorders (ASD).

State background

DDS is the largest agency in the Executive Office of Health and Human Services (EOHHS). Under this same umbrella is MassHealth (the state Medicaid agency), which makes EOHHS the second largest agency in the state after the Executive Office of Education. The ASD division of DDS is relatively small, with a budget of \$4.6 million, three full-time case managers, and one part-time program manager. DDS has begun to track how many individuals with ASD receive services through the adult waiver programs. They estimate between 30 and 40 percent of the adults receiving waiver services have ASD.

Other than DDS, individuals with ASD receive services through two other branches of EOHHS: the Massachusetts Rehabilitation Commission (MRC) and the Department of Public Health (DPH). In addition, the school system provides services for children aged 3–21, in accordance with the Individuals with Disabilities Act (IDEA) legislation. The number of students receiving services for ASD through the school system is growing, and as of 2011, Massachusetts schools provided services to 13,228 students with ASD (Riley, 2012).

State insurance regulations

Two statutes pertain to coverage for ASD in Massachusetts. The first requires specified individual, group, and state employee health plans and health maintenance contracts to provide benefits on a nondiscriminatory basis for the diagnosis and treatment of ASD, including habilitative/rehabilitative, pharmacy, psychiatric, psychological, and therapeutic care. In addition, individual and group policies of accident and sickness insurance or health maintenance contracts that include hospital and surgical insurance are required to provide mental health benefits for the diagnosis and treatment of ASD that are equal to benefits provided for physical conditions (National Conference of State Legislatures, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Massachusetts 1915(c) waivers

Waiver Name	Population Served
MA Children's Autism Spectrum Disorder*	Children aged 0–8 with ASD
MA Community Living*	Individuals aged 22+ with intellectual disabilities
MA Adult Supports*	Individuals aged 22+ with intellectual disabilities
MA MFP Residential Supports	Individuals aged 65+ and aged 1–64 with physical disabilities
MA MFP Community Living	Individuals aged 65+ and aged 18-64 with physical disabilities
MA Intensive Supports*	Individuals aged 22+ with intellectual disabilities
MA Acquired Brain Injury Non-residential Habilitation	Individuals aged 22+ with acquired or traumatic brain injury
MA Acquired Brain Injury with Residential Habilitation	Individuals aged 22+ with acquired or traumatic brain injury
MA Traumatic Brain Injury	Individuals aged 18+ with traumatic brain injury
MA	

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Massachusetts Children's ASD* waiver is run by DDS and designed to provide services to help children with ASD remain in their homes and actively participate in their families and communities. The waiver serves up to 157 children with ASD aged 0–8. The following services are provided under the waiver:
 - Community integration
 - Habilitation/Education
 - Family training
 - Respite
 - Homemaker
 - Home modifications and adaptations
 - Vehicle modifications
 - Assistive technology
 - Individual goods and services
 - Occupational therapy, physical therapy, and speech therapy
 - Behavioral supports and consultation

To be eligible for the *Children's ASD Waiver*, children must:

1. Have a confirmed diagnosis of ASD;
2. Be under the age of 9;
3. Be a resident of Massachusetts;
4. Meet the level of care required for services in an Intermediate Care Facility for Individuals with Intellectual Disability as assessed by DDS;

5. Be eligible for MassHealth standard coverage, based on family income;
6. Be chosen by the family to receive services in the home and community;
7. Be safely served in the community; and
8. Have a legally responsible representative able to direct the services and supports of the waiver (DDS, 2012).

Other waivers

- The *Massachusetts Community Living* waiver is for individuals with disabilities who can live in their own home or in someone else's home and do not need 24-hour support. For individuals who live outside of the family home, these services are necessary due to a lack of adequate natural supports or a sufficient array of community services to support their health and welfare in the community. For individuals who reside with their families the waiver will provide for a level of support to assist the individual to acquire the skills necessary to work and access the community or to provide substantial assistance to the family/caregiver to allow the individual to remain at home. Through the coordination of natural supports, Medicaid services, generic community resources and the services available in this Waiver, individuals are able to live successfully in the community. The waiver has a cost limit of \$70,000 per year. This waiver provide participant direction opportunities. A wide variety of services are offered under this plan, including:
 - Day supports (center-based, community-based, and individualized)
 - Day habilitation supplement
 - Individualized home supports
 - Respite
 - Home modifications and adaptations
 - Vehicle modifications
 - Assistive technology
 - Family training
 - Peer support
 - Occupational, physical and speech therapy
 - Stabilization
 - Behavioral supports and consultation
 - Supported employment (group and individual)
 - Transportation
 - Individual goods and services
 - Specialized medical equipment and supplies
 - Live-in caregiver
 - Chore services
 - Adult companion services
- The *Massachusetts Adult Supports* waiver is intended for individuals with I/DD who can live in their own homes or in a family home with strong natural or informal supports. Without the waiver services individuals would be at risk for more intensive supports or institutional care at an Intermediate Care Facility for the Intellectually Disabled. For individuals who live outside of the family home, these services are necessary due to a lack of adequate natural supports or a sufficient array of community services to support

their health and welfare in the community. Opportunities for participant direction are available. Services offered include:

- Day supports (center-based, community-based, and individualized)
 - Community and day habilitation
 - Individualized home supports
 - Respite
 - Family support navigation
 - Supported employment (group and individual)
 - Day habilitation
 - Adult companion
 - Assistive Technology
 - Behavioral supports and consultation
 - Chore service
 - Home modifications and adaptations
 - Individual goods and services
 - Occupational, physical and speech therapy,
 - Peer support
 - Specialized medical equipment and supplies
 - Stabilization
 - Vehicle modification
 - Transportation (DDS, n.d.)
- The *Massachusetts Intensive Supports* waiver provides a comprehensive array of supports to adults aged 22 and over who meet the ICF-ID level of care and require supervision and support 24 hours, 7 days per week to avoid institutionalization. Individuals may reside in out-of-home settings or in their family home. The waiver provides opportunities for participant direction. Waiver services include:
 - Day supports (center based, community based and individual)
 - Supported employment (group and individual)
 - Individualized home supports
 - Live-in caregiver
 - Residential habilitation
 - Respite
 - Day habilitation supplement
 - 24-Hour self directed home sharing support
 - Adult companion
 - Assistive technology
 - Behavioral supports and consultation
 - Chore
 - Family training
 - Home modifications and adaptations
 - Individual goods and services
 - Occupational, physical and speech therapy
 - Peer support
 - Specialized medical equipment and supplies

- Stabilization
- Transitional assistance services
- Transportation
- Vehicle modification

Findings

Services and supports for people with ASD

DDS works in collaboration with various community providers, school systems, and other EOHHS agencies to offer the services and supports children and adults with ASD in the state may need.

Early intervention

The statewide EI program is headed by the Division for Perinatal, Early Childhood, and Special Health Needs under EOHHS. Children aged 0–3 are commonly referred by a family member, doctor, or childcare provider and then evaluated to determine whether they meet criteria on a developmental assessment. Other sources of referral include Women, Infants, and Children, hospitals, and child protective services. The “net is cast wide,” and children can be eligible under three categories: (1) an established diagnosis, including ASD, (2) a 30 percent developmental delay in any category, or (3) clinical judgment. Doctors are encouraged to screen all children for ASD twice before the age of 2.

Once eligible, children have access to a range of services, which are determined by an Individual Family Service Plan (IFSP) and may include home visits, center-based individual visits, community child groups, EI-only child groups, parent groups, and specialty provider services. Children with ASD qualify to receive continued early learning services from age 3 to 5 under Part B of IDEA. The program is paid for by a combination of annual fees (for families that are able to pay), private insurance, DPH, and MassHealth (Department of Public Health, 2013).

In addition to the general EI program, children with ASD are eligible to receive special intensive therapies. Massachusetts allows private companies to bid for the right to offer ASD-specific services; there are currently 10 programs statewide. Staff members from these programs use structured, highly individualized treatment programs to promote social skills and communication to improve learning. Most offer only ABA with few offering a range of therapies.

School-aged children

Children receive educationally necessary services according to an Individualized Education Program (IEP) developed in teams from each school district. Parents have the right to request an independent educational evaluation (IEE) for their child if they disagree with the IEP team’s assessment. They are asked to pay on a sliding scale basis, and any family making less than 100 percent of the federal poverty level receives an IEE at no cost. Services offered through the school system may include special teaching services, consultative services, training for teachers, and other supportive services such as transportation, psychological services, counseling, and orientation and mobility services (Federation for Children with Special Needs, 2013).

In addition to school-based services, children under age 18 are eligible for DDS services if they have a diagnosed developmental disability and display severe functional impairment. Currently, DDS serves more than 8,600 children and families in the state. Some programs and services offered include:

- Service coordination to arrange and monitor services and supports that DDS delivers or provides for;
- Family support services to help families care for their child, including education and training, support groups, family support coordination, supports planning, and respite. However, one DDS interviewee noted that there are not nearly enough DDS respite services for families, compared with the number of children with ASD in the state. They heavily encourage families to take advantage of respite services under Part B of IDEA if possible;
- Specialty services including the Family Leadership Series focusing on leadership and policy-making, Autism Support Centers that provide information and referrals, and afterschool programs to better integrate children with disabilities into community programs and activities;
- Camp programs providing integrated summer day and overnight camping experiences for children (contract with providers who offer vacation programs and summer experiences);
- Intensive Flexible Family Support Program, which is an intensive, targeted, and time-limited program for families experiencing stress that puts the child at risk of an out-of-home placement; and
- Medically Fragile Family Partnership Program, which provides comprehensive wraparound supports to families with children with significant cognitive, physical, and complex health care needs (DDS, 2013).

Adults

Eligible adults with ASD are able to receive services through DDS and MRC. Adults aged 18 and older must have an I/DD with an IQ under 70 in order to qualify for DDS services. This means that not everyone with ASD is eligible, but once they qualify, as one interviewee noted, “short of leaving the state or dying they are in DDS.” For those who meet eligibility criteria, DDS offers a comprehensive service menu, which includes:

- Day services
- Residential services
- Family support (e.g., respite and recreation)
- Prevocational and employment services
- Residential facilities
- Community-based living arrangements (e.g., group homes)

MRC offers VR to anyone with a disability in three functional areas regardless of diagnosis, as long as it is demonstrated that VR will help a consumer gain employment. Counselors determine

eligibility based on medical records, psychiatric records, and interviews, and roughly 90 percent of those who apply receive services. VR typically includes:

- Career counseling
- Plan development
- Tuition assistance for college or trade school
- Vocational training
- Placement services
- Job coaching and supported employment

Participants who are successfully employed after 90 days of job coaching and supported employment will no longer receive VR; however, individuals who need additional support can continue to receive services. MRC is working with DDS to develop a memorandum of understanding establishing that after 90 days of job coaching and supported employment, DDS will take over any additional employment services that individuals need. MRC has been successful in exceeding their employment outcome goals for the past 2 years.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Early intervention

EI is a well-known program in Massachusetts and connected to many entities including social service agencies, childcare providers, and pediatricians. EI has formed a number of task forces that are focused on education and training, early intervention, outreach, and the creation of culturally competent screeners. The outreach task force aims to increase public awareness of developmental disabilities by designing materials, promoting and disseminating educational materials to the general public, and maintaining resources on a Web site. Additionally, Massachusetts is part of the Centers for Disease Control and Prevention's national "Learn the Signs. Act Early." campaign to inform parents, educators, physicians, and daycare workers how to recognize the signs of developmental disabilities early and across cultures and socioeconomic backgrounds (<http://www.maactearly.org/index.html>).

School-aged children

Autism Support Centers disseminate information statewide about programs and services available to individuals with ASD and their families. They provide free (or low-cost) services including referrals, activities and events, educational and therapeutic programs, and community partnerships for children with ASD and their siblings, families, and friends. Among these organizations are:

- Community Resources for People with Autism (western MA)
- Community Autism Resources (southeastern MA)

- Autism Resource Center of Central Massachusetts
- Family Autism Center (metro south MA)
- Autism Alliance of Metro West (metro west MA)
- The NEARC's Autism Support Center (northeastern MA)
- TILL, Inc., Autism Support Center (Greater Boston, MA)

MRC has several modes of outreach for adults and adolescents transitioning to adulthood. For example, MRC assigns a counselor to each public school and works with temporary agencies to outreach to potential clients and employers. They have been quite successful in reaching individuals with ASD that are in need of post school support. MRC also refers clients to DDS if they feel that individuals can benefit from their services.

Transitions and coordination of services

The research team received varied responses from interviewees on the status of transitions and coordination of services in Massachusetts. Some stakeholders felt that transitions and coordination are relatively seamless, whereas others noted that services are somewhat fragmented.

Early intervention to school

Overall, transitions progress according to IDEA legislation; however, due to wider eligibility standards in early intervention program, children sometimes reach a “cliff” in services at age 3. At age 2, the EI service coordinator works with the family to review the IFSP, identify areas that will need to be updated, and begin putting together a transition packet. Around age 2.5, a meeting takes place with the EI service coordinator, family, childcare providers, service providers, friends, and representative from the local educational agency (LEA), in which the group reviews plans for transition. Transition plans must be developed for all children exiting EI and include:

- A review of options for the family;
- Information for the family regarding the process of transition;
- Support available to parents;
- Information to be sent to the LEA and/or other community providers; and
- Specific plans for how the child will successfully transition to the next setting (Department of Early Education and Care, 2010).

School-age to employment

Transition planning from school to adulthood involves exploring postsecondary opportunities and employment options and connecting with the adult agencies that provide students with services when they graduate or turn 22 years of age. The transition process occurs according to the IEP and begins by age 14. At this time, the IEP team helps students identify their post school vision and identifies transition services necessary to support these goals. This information is documented in the IEP as well as a separate transition planning form. Transition services might involve:

- Career interest inventories
- Job shadowing
- Mentoring
- Apprenticeship
- Workplace visits and tours
- Career fairs
- Mock job interviews and job clubs
- Afterschool and summer job placements arranged and supported by school staff
- Community college enrollment

Before students with severe disabilities “age out” of services, schools complete a Chapter 688 referral, which is provided to DDS, MRC, and the Department of Mental Health. This referral ensures that students who require ongoing supports and services from one or more public agency are part of the eligibility process for receiving services and supports as adults (DDS, 2010).

Additionally, MRC is working with school systems to receive referrals when students are in their junior year, with the goal of having supported employment at the time of graduation. Because this program is relatively new, MRC currently receives referrals closer to the time of graduation.

Training for direct service support workers

Interviewees described a few opportunities for education and training for individuals working with the ASD population:

- DDS provides training for their service providers to understand the history of I/DD, learn about positive behavioral supports, and get certified in CPR and first aid. This training is not specific to ASD; however, one interviewee noted that those working with children involved in the ASD waiver experience “tough” training qualifications.
- The school system has an online training module for individuals working with children with ASD; it is similar to the online training center that EI has created for childcare workers, physician, and families.
- MRC has held several trainings for staff over the past year in collaboration with a Massachusetts senator. About 120 staff members have attended these sessions to learn about the types of supports that people with ASD and other disabilities may need to maintain employment.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Autism Commission is currently writing a report due at the end of the year that will help stakeholders in Massachusetts understand more about how ASD services and supports are

functioning, and provide recommendations about how to streamline and improve them. Therefore, most stakeholders are unsure about the steps they will take in the upcoming years.

Other relevant programs and services

Other organizations, not previously mentioned, are working to serve individuals with ASD in Massachusetts.

- *Advocates for Autism of Massachusetts* (<http://www.afamaction.org>) is a coalition of individuals, families, and organizations from across the state advocating on behalf of people with ASD, with the goal of forming a collective voice in support of legislation, funding, and public awareness around ASD.
- *Asperger's Association of New England* (<http://www.aane.org>) works with individuals, families, and professionals to help people with Asperger's syndrome and other ASD profiles to build meaningful, connected lives by providing information, education, support, and advocacy.
- The EI program compiled a survey from 2001 to 2005 that demonstrated that African-American and Hispanic children were identified at later ages than their Caucasian peers. They created a training program targeted at those who work with minority children and were successful in reducing the disparity in racial identification. Massachusetts is tackling the disparity across cultures, particularly with parents who do not speak English. They have developed a project with community liaisons in different areas of Boston to create vignettes explaining cultural differences to pediatricians who administer developmental screens. The vignettes help pediatricians understand how certain cultures may react to a diagnosis of ASD and how to present the screening in a more culturally appropriate manner. EI has distributed the vignettes to autism centers throughout the state.

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MICHIGAN

Approach

The L&M research team interviewed eight representatives from the state of Michigan comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. Through these interviews, the research team sought to obtain greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

Services and supports for those with ASD in Michigan began to undergo a rapid change at the end of 2012. In July 2012, the governor announced the appointment of members to the newly formed State Autism Council. The council developed a state plan to expand and integrate ASD services, which was approved and made public in December 2012. Specifically, eligibility for applied behavior analysis (ABA) therapy expanded to more individuals with ASD (Michigan.gov, 2012). Effective April 1, 2013, ABA is included as a state Medicaid plan service in Michigan.

State insurance regulations

The state of Michigan requires that all HMO and private insurance plans (excluding the employer funded plans) cover medically necessary treatment for children with ASD. The bill was passed in March 2012; prior to this time little coverage existed for ASD (American Speech-Language-Hearing Association, 2012). Treatment services covered under the mandate are behavioral health (including ABA), pharmacy, psychiatry, psychology, and therapeutic care. Maximum required benefits for ASD-related costs decrease as children age. Currently, the state of Michigan's Medicaid program is involved in legal proceedings surrounding their failure to provide ABA to all children with an autism diagnosis (Martin, 2012; Michigan.gov, 2012). The lawsuit is close to settlement and Michigan is developing the necessary 1915(i) state plan amendment and 1915 b Specialty Services and Supports waiver amendment to add ABA as a covered service under Medicaid for children aged 18 months through 5 years of age.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Michigan 1915(c) and (b) waivers

Waiver Name	Population Served
Children's Waiver*	Children aged 0–17 with autism/ID/DD
Children with Severe Emotional Disturbances	Children aged 0–20 with SED
Habilitation Supports Waiver*	Individuals of all ages with DD
MI Choice	Individuals aged 65+ or aged 21–64 with a physical disability

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

Michigan does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *Michigan Children's Waiver* is run by the Michigan Department of Community Health (MDCH). The purpose of the waiver is to help children under the age of 18 with developmental disabilities or who are otherwise in need of an Intermediate Care Facility for Individuals with Intellectual Disabilities level of care, to remain in their homes (Michigan Department of Community Health, 2012). Services offered through the Children's Waiver program include:
 - Family and nonfamily training
 - Specialty services (e.g., music, recreation, art therapy)
 - Community living supports
 - Enhanced transportation
 - Respite care
 - Environmental accessibility adaptations
 - Specialty medical equipment and supplies
 - Fiscal intermediary services
- The *Michigan Habilitation Supports* waiver is designed to help individuals that have a developmental disability and otherwise would require an institutional level of care to live in their communities. Services provided include:
 - Goods and services
 - Supports coordination
 - Community living supports
 - Environmental modifications
 - Prevocational services
 - Supported employment
 - Out-of-home nonvocational habilitation
 - Respite
 - Family training
 - Personal Emergency Response System
 - Private nursing (for age 21 years and older)
 - Medical equipment and supplies
 - Enhanced pharmacy
- This waiver operates in conjunction with a state 1915(b) *Managed Specialty Services and Supports* waiver, which offers a flexible menu of mental health services to Michigan residents who require specialty services and supports due to mental health needs.

Findings

Services and supports for people with ASD

Individuals with ASD must be diagnosed with a developmental disability in order to receive MDCH services. MDCH also provides early intervention services in collaboration with the Department of Human Services (DHS) and the Department of Education (DOE).

Michigan has the ability to track any diagnosis and the state has been conducting more data analysis as they prepare for the new ABA Medicaid benefit are able to pull data by diagnosis to determine which services are being provided to children and adults on the autism spectrum.

Early intervention

Michigan's early intervention program, "Early On," is housed in the DOE and is a collaborative effort of the DHS and the state mental health and public health authorities under MDCH. The state operates a tiered system in terms of eligibility for the Individuals with Disabilities Education Act (IDEA) Part C early intervention services. Children who score one standard deviation below the mean in one of five developmental areas qualify for early intervention services.

The typical mode of referral to early intervention is through a primary care physician. The proposed Medicaid policy includes that at each well-child visit, physicians monitor development, and they are encouraged to administer the Modified Checklist for Autism in Toddlers at 18- and 24-month checkups. If a developmental delay is suspected, a physician will refer the family to early intervention services or a specialist for a more comprehensive evaluation. Children who are identified as having a delay can receive services through the Early On program and are also referred to their local Community Mental Health agency (Wayne State University, 2012). Children needing the new ABA Medicaid benefit will be referred directly to the Pre-paid Inpatient Health Plan, which is comprised of one or more Community Mental Health Services Program. Services most commonly offered through early intervention include speech therapy, occupational therapy, and physical therapy.

School-aged children

Michigan is the only state that serves children in the school system until age 26; however, the state encourages earlier transition out of school services if appropriate. Students with disabilities receive services according to IDEA. Children with ASD are referred to school services and receive special education services if they meet the criteria for autism under the special education criteria. Currently, children receive all educationally necessary therapies during the school day. Additionally, DOE promotes a peer-to-peer program in schools to help children learn appropriate social behaviors; a movement is underway to incorporate this into the curriculum for all students with disabilities.

Adults

Adults with ASD who qualify under the Michigan Mental Health Code with a developmental disability currently are eligible for a wide array of services provided under the 1915(b)/(c) Medicaid Managed Care Specialty Services and Supports Waiver. Aside from waiver programs, adults with ASD may be eligible for vocational rehabilitation, Medicaid Health Plan services, and programs through local centers for independent living. Michigan Rehabilitation Services is the vocational rehabilitation agency; it provides career counseling, vocational education, training, job placement, and assistance in other areas related to employment (Michigan Rehabilitation Services, 2013).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Many agencies and organizations promote services for individuals with ASD, including state and local organizations, physicians, schools, and university-sponsored ASD programs.

- Each Pre-Paid Inpatient Health Plan providing Medicaid specialty managed care services and supports has a customer service unit that provides information on available services for all age groups and how to access them.
- The state early intervention team conducts outreach to all primary referral systems and advertises their services on local cable stations, billboards, buses, or in local establishments (e.g., fast food restaurants).
- Each of the 56 regional school districts has its own outreach programs as well as an interagency coordinating council. The latter brings together various providers to discuss community issues and forms a structure to connect local agencies with information about resources.
- The Developmental Disabilities Institute of Wayne State University created a series of online navigator guides on how families can find services for children with ASD.
- Finally, as part of the new state plan, an Autism Resource Center and a resource site created by the Michigan Autism Alliance will be available as a source of information and support to individuals and families with ASD.

Transitions and coordination of services

Early intervention to school

According to interviewees, the transition to education services is as seamless as possible given different eligibility criteria for IDEA Part C (early intervention) and IDEA Part B (early education) services. Because Early On is run in part by DOE, the school system is the provider for IDEA Part C and IDEA Part B. The primary difference between the two programs is the location of service delivery; early intervention services are provided in the most natural environment (e.g., the home or daycare center), and education services are provided in the school.

School-aged to employment

Transitions generally begin at age 16 in Michigan, extending until age 26 if necessary, and are guided by the Individualized Education Program for each student. In addition, the Michigan DOE has a grant-funded initiative—Michigan Transition Outcomes Project (MI-TOP)—to develop additional resources to ensure that all children leave high school with the skills they need to gain employment or succeed in their chosen next steps. The program works with children before they enter high school to develop skills they need to gain employment, such as cognitive skills and software abilities. The MI-TOP Web site (<http://mi-top.cenmi.org/Home.aspx>)

provides information for families on how to make the most of transition services that are available.

Training for direct service support workers

MDCH is currently promoting a statewide training on the “culture of gentleness” that has proven successful for those working with the ASD population. It began as a program for clinicians but has expanded to include group home staff and other relevant professionals. All trainings are done at the local or regional level, and a provider or mental health professional can request training in their area. Currently, MDCH is developing a training program for parents as well.

The Michigan DOE funded the Statewide Autism Resources and Training (START) project (<http://www.gvsu.edu/autismcenter/>). The START project forms district teams and provides technical assistance and training to school districts at the K–12 and early childhood levels. Modules focus on educating teachers, administrators, and paraprofessionals who work with children with ASD, to better understand autism and how to improve skills in typical problem areas, such as social communication and teamwork.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Interviewees indicated an April 1, 2013, target to roll out a new Medicaid State Plan Benefit to provide ABA services for children with ASD aged 18 months through 5 years through the Pre-Paid Inpatient Health Plans. With the start of the program, trainings will be offered for both direct service workers and clinicians to learn to determine eligibility and deliver ABA services.

Other programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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MINNESOTA

Approach

The L&M research team spoke with three representatives from the state of Minnesota, comprising a range of perspectives related to the delivery of services for individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Minnesota Department of Health (DOH), the Minnesota Department of Human Services (DHS) Division of Children’s Mental Health and Disability Services Division, the Minnesota Department of Education (DOE), and the Minnesota Governor’s Council of Developmental Disabilities.

State background

The state of Minnesota created an ASD Task Force in 2009 to report on and develop recommendations for the improvement of care delivery in the following areas:

- Services provided by state and political subdivisions;
- Sources of public and private funding for treatment and ways to improve efficiency in using funds;
- Methods to improve coordination in the delivery of service among public and private agencies, health providers, and schools, and to address any geographic discrepancies in the delivery of services;
- Availability of and training for medical providers and educators who identify and provide services to individuals with ASD; and
- Treatment options supported by peer-reviewed, scientific research for individuals with ASD (ASD Task Force, 2011).

Beginning in January 2010, the state task force met every month to review the state of care delivery in Minnesota and develop its final report to be submitted to the state legislature in January 2012. Because our research team conducted interviews with state officials in November 2011, we were unable to probe on the specifics of the report. Still, the research team reviewed the final report following its release on January 15, 2012. Among the recommendations outlined in the report was the development of a statewide ASD “early identification and information awareness campaign” in addition to increased training for physicians in diagnosing ASD during early childhood (ASD Task Force, 2011).

State insurance regulations

Although Minnesota does not require that insurance carriers cover treatment for ASD, it mandates that all group policies and group subscriber contracts that provide benefits for inpatient hospital mental or nervous disorder services provide coverage for treatments that occur outside of the hospital. Additionally, the state requires insurance carriers that provide inpatient hospital and medical expenses to cover residential treatment of emotionally disabled children by a licensed health professional (American Speech-Language-Hearing Association, 2013).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Minnesota 1915(c) waivers

Waiver Name	Population Served
Minnesota Community Alternative Care	Individuals aged 0–64 who are chronically ill or medically fragile
Minnesota Community Alternatives for Disabled Individuals	Individuals aged 0–64 with a physical disability
Minnesota Developmental Disabilities Waiver*	Individuals of all ages with DD or related conditions
Minnesota Elderly Waiver	Individuals aged 65+
Minnesota Brain Injury Waiver	Individuals of all ages with acquired or traumatic brain injuries

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Minnesota does not have any waivers specific to individuals with ASD at this time.

Other waivers

The *Minnesota's Developmental Disabilities Waiver* provides a transition to home- and community-based services to children and adults with developmental disabilities or a related diagnosis. Initial eligibility is based on living in an Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/DD) and continuing to require an institutional level of care absent the waiver. Participants must be eligible for the state Medicaid program but require services beyond what is available in the state plan, including but not limited to residential habilitation (Minnesota Department of Human Services, 2013a). The comprehensive range of services includes:

- 24-hour emergency assistance
- Adult day care
- Assistive technology
- Caregiver living expenses
- Case management
- Chore service
- Consumer directed community supports
- Crisis respite
- Day training and habilitation
- Environmental accessibility and adaptations
- Extended home care services
- Home delivered meals
- Homemaker services

- Housing access coordination
- Personal support
- Prevocational and supported employment services
- Residential habilitation (in-home family support, supported living services)
- Respite
- Specialist services
- Transportation
- Transitional services

For individuals on the waiting list, resources are prioritized based on several factors: unstable living conditions as a result of the primary caregiver’s incapacity, prevention of out-of-home placement of a child, local ICF/DD closures, immediate risk resulting from out-of-home placement, and immediate risk resulting from ICF/DD placement.

Findings

Services and supports for people with ASD

The state of Minnesota does not have a standard definition of autism, and eligibility for services is determined at the county level. According to interviewees, the state agencies administer the services that are delivered at a local level through 54 community health boards, “which are essentially our local health departments that get a lot of our Title V and state money,” one interviewee said. For the last 10 years, the Minnesota System of Interagency Coordination has worked on improving the interaction among state agencies at the local level, as most of the state agencies are responsible for determining policies and focusing on statewide assessment and quality improvement. Like all states, Minnesota’s Early Periodic Screening, Treatment, and Diagnosis (EPSDT)—called Child and Teen Checkups—complements the state 1915(c) waiver programs by providing services to children from birth to age 20 who are eligible for the state Medicaid program. Minnesota DHS administers the EPSDT program, which served 400,000 children throughout the state in 2009 (DOH, n.d.).

Early intervention

The state’s early intervention program, provided through the DOE, is called Help Me Grow and includes two programs:

- *Help Me Grow: Infant and Toddler (Part C of the Individuals with Disabilities Education Act)* is available for children from birth through age 2 years who have been diagnosed with certain physical or mental conditions that will likely result in a delay. Core services include service coordination, early childhood special education, and related services such as speech services, occupational therapy, and physical therapy.
- *Help Me Grow: Preschool Special Education (Part B of the Individuals with Disabilities Act)* is available for children aged 3–5 years who meet the state eligibility criteria for a developmental delay or other disability. Services are tailored to the needs of each individual through an Individualized Education Program (IEP).

Children can receive services through the early intervention program in their home, childcare setting, or school (DOE, n.d.). According to interviewees, DHS can generally track the number of individuals receiving services through IDEA Part C and B but does not “really have the resources” to conduct analyses of service utilization across specific metrics.

School-aged children

Because the local schools provide services and supports to children with ASD, and Minnesota DOE only oversees activities at the local level, the research team did not delve into services provided to school-aged children on a school-by-school basis. However, in general, many children with ASD have an IEP, which outlines their strategy for school support and is updated regularly. One interviewee estimated that about 40 to 45 percent of students with a primary ASD disability are enrolled in mainstream classrooms, whereas the rest receive some combination of special education, speech therapy, and occupational therapy. School staff members typically use a standard mental health screening to identify children with ASD.

In addition to supporting families and schools and promoting interagency planning related to service delivery for children aged 3–21, the DOE tracks the services students use through specific student identification numbers. According to one interviewee, “we’ve seen an increase in the last 10 years” in the number of children with ASD accessing services. The state can use the data tied to the tracker numbers to drill down at the local level and get a better sense of service utilization by age, ethnicity, and federal poverty level status.

Adults

In general, there are fewer services in the state available to adults with ASD. The research team did not speak with the Minnesota Department of Employment and Economic Development.

In addition to the aforementioned waiver programs, Minnesota offers Semi-Independent Living Services (SILS) to individuals with developmental disabilities to support community living. The program provides training and assistance related to social, recreation, and transportation skills; rights and responsibilities of living in the community; maintaining personal appearance; money management; obtaining and maintaining a home; and self-administering medication. To be eligible for SILS, individuals must be aged 18 or older, have a developmental disability, be unable to function independently without SILS, and not be at risk for placement in an ICF/DD.

Under Minnesota’s Consumer Support Grant, individuals who are not part of a waiver program may be eligible for limited funds to assist with home care services, such as home health aide, personal care assistance, and private nursing. Individuals must be eligible for the state Medicaid program, have a functional limitation that requires ongoing support to live in the community, live in a natural home setting, and be eligible to receive home care services from a Minnesota home health care agency. In general, the amount available to individuals is based on home care assessment ratings, statewide utilization for home care services, and availability of funding (DHS, 2011).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Both the Development Disabilities Council (DDC) and DHS play vital roles in promoting services and supports to people with ASD across Minnesota. As the central advocacy organization in the state, DDC is essential in reaching out to individuals with developmental disabilities—particularly historically underserved subpopulations—to (1) provide an introduction to the system through which they can access services and (2) alert them to their rights. DHS has developed trainings, information lines, assistance lines (they are currently in the midst of enhancing the help information line), and Web tools that provide residents with a wealth of information related to the availability of services in the state.

Early intervention

Interviewees mentioned two state programs in particular that promote early intervention services to families of children with ASD statewide.

- *Parent Advocacy Coalition for Educational Rights (PACER) Center* (<http://www.pacer.org>) was founded in 1977 by parents of children with disabilities to provide guidance and support to families facing similar issues. According to the organization's Web site, its mission is to "expand opportunities and enhance the quality of life of children and young adults with disabilities and their families."
- *The Arc of Minnesota* (<http://www.thearcofminnesota.org/>) is a private, nonprofit, statewide organization that seeks to promote and protect the rights of individuals with intellectual and developmental disabilities in the state. The organization oversees a number of local chapters that connect families with resources and advocate on their behalf. Although the Arc was originally founded to serve children with intellectual disabilities, it has expanded to assist individuals throughout the lifespan.

School-aged children

Interviewees noted that the Minnesota Parents Know program is a major source of resources for parents of school-aged children in addition to newborns and toddlers. The program allows parents to connect with other parents and provides them with a number of child development resources as well as information regarding pertinent state programs.

Adults

The research team did not hear about any activities to specifically promote services to adults with ASD other than The Arc, as noted above.

Transitions and coordination of services

In general, children receiving services through more than one state agency can have an interagency intervention plan, which requires agencies to convene a meeting with the family and the individual receiving services to develop a plan for service coordination.

Early intervention to school

In August 2011, the state opened the Office of Early Learning to coordinate the activities of early childhood programs at the state level. Through the office, important connections to programs and services such as DOE's early childhood and parenting education programs; DOH's Childhood Systems Grant; Women, Infants and Children; Temporary Assistance for Needy Families; and

foster care; and DHS' child development services and childcare assistance can be better aligned in order to improve children's outcomes and readiness for school. However, the research team was unable to get a sense of the impact this organization has had because it was in its nascent state at the time interviews were conducted.

School-aged to employment

Transitions from school to employment generally involve efforts of Minnesota DOH and DOE and the local school system. According to interviewees, transition planning begins as early as age 14, and the steps taken in that transition plan "depend on what the child's needs are." Individuals working on the transition plan may include developmental disability social workers, county case managers, and local public health nurses, depending on the child's condition. Transition plans "evolve over a period of years," one interviewee said. For individuals interested in moving toward employment, the organization Project SEARCH provides internships for individuals with disabilities and is particularly targeted at children with ASD.

Training for direct service support workers

Although interviewees did not mention any statewide mandatory training for direct service providers, they discussed a few voluntary avenues through which interested parties can seek additional education:

- The University of Minnesota Leadership Education in Neurodevelopmental and Related Disabilities program (<http://lend.umn.edu/about/index.htm>) is a leadership training across 12 disciplines that focuses on engagement and support for individuals with ASD as well as other neurodevelopmental disabilities. The Maternal Child Health Bureau of DHS funds the program.
- Minnesota DOE runs a 3-day annual symposium every summer that focuses on training through best practices.
- The Minnesota Autism Project and Network provides technical assistance and training statewide. Specifically, the project conducts two annual trainings—one in the fall and one in the winter.
- The Minnesota Autism Conference is held each spring and features national and international speakers as well as local speakers who share best practices. The conference includes a special section that caters to individuals with ASD and their families (Autism Society of Minnesota, n.d.).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Interviewees did not discuss any specific long-term plans regarding service delivery to the state's ASD population, but mentioned a few more general areas they would like the state to focus on in the coming years. One interviewee mentioned widespread interest in the areas of prevention and intervention through earlier identification via "research-based practice." Another commented on the need for future allocation of resources toward access to information for both providers and

families. Interviewees also mentioned that the state will continue to focus its efforts around health care homes and pursue any ASD grants that become available at the federal level.

Other relevant programs and services

- The *Autism Society of Minnesota* was established in 1971 and comprises families, educators, caregivers, and professionals focusing on advocacy, support, collaboration, and education around issues related to ASD throughout the state.
- The *Highland Friendship Club* (<http://www.highlandfriendshipclub.org/>), established in 2002, encourages children and teens with disabilities to create a social network of friends by providing a number of activities and forums for such interactions, such as art classes, music classes, fitness classes, and “Friday Fun Nights.”
- The *Autism Advocacy & Law Center* (<http://www.autismlawcenter.com>) is an advocacy organization for individuals with disabilities that was established in 2009.
- The state of Minnesota is participating in the *Assuring Better Child Health and Development Project*, which is a nationwide effort to increase the use of standardized screening tools in primary care offices (Minnesota Department of Human Services, 2013b).
- *Minnesota Governor’s Council on Developmental Disabilities iPhone Applications*, an award-winning free mobile device application that helps people with ASD communicate during emergencies. The iPhone app uses a 5-point, color-coded scale that can be customized to the specific situation of an individual or family. Customization can include different levels of emergencies, photos and responses, or familiar voices. Individuals are able to communicate and take steps to be safe without the need to be verbal.

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MISSISSIPPI

Approach

The L&M research team interviewed nine representatives from the state of Mississippi, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Mississippi Department of Mental Health (MDMH) Bureau of Intellectual and Developmental Disabilities (BIDD), a representative from Project TEAAM (Together Enhancing Autism Awareness in Mississippi), and the Mississippi Department of Rehabilitation Services.

State background

In 2011, legislation passed that established the Mississippi Autism Advisory Committee, tasked with the development of a strategic plan to address the needs for individuals with ASD. To date, no further action has been taken on HCR 69 (Easter Seals, 2012).

State insurance regulations

In 2011, SB 2146 was introduced to require all health plans to provide for diagnosis and treatment of people under the age of 21 with ASD. Applied behavior analysis (ABA) is covered to a maximum of \$50,000 a year. As a result, SB 2146 required the MDMH to develop standards for credentialing autism service providers. This bill was referred to the Committee on Insurance, but failed to move forward. During the spring 2011 legislative session, a similar bill, SB 2757, was introduced requiring health plans to provide coverage for persons with autism. SB 2757 also failed to make it out of the committee (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Mississippi 1915(c) waivers

Waiver Name	Population Served
MS Intellectual Disabilities/DD*	Individuals of all ages with autism/DD
MS Psychiatric Residential Treatment Facilities	Individuals aged 0–22 with mental illness and SED (waiver will phase out when participants are no longer eligible)
MS Independent Living	Individuals aged 65+ and individuals aged 16–64 with physical disabilities
MS Elderly and Disabled	Individuals aged 65+ and individuals aged 21–64 with physical disabilities
MS Assisted Living	Individuals aged 65+ and individuals aged 21–64 with physical disabilities
MS TB/Spinal Cord Injury	Individuals aged 0–64 with a physical disability related to a spinal cord injury or a traumatic brain injury

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

Mississippi does not have any waivers specific to individuals with ASD at this time.

Other waivers

One home- and community-based individual support waiver serves people with ASD in Mississippi. The *Mississippi Intellectual Disabilities/DD Waiver* was implemented on July 1, 2008, and allows for people with developmental disabilities, such as autism, to remain living at home and within their community. There is no age requirement for the waiver, but individuals must meet an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD) level of care. Services include:

- Adult day services
- Prevocational supports
- Residential habilitation
- Respite
- Support coordination
- Supported employment
- Behavior support and intervention
- Home and community supports
- Specialized medical supplies
- Therapy services

Findings

Services and supports for people with ASD

The MDMH is responsible for the development and implementation of services to meet the needs of individuals with intellectual/developmental disabilities. This public service delivery system is comprised of five state-operated comprehensive regional centers, a state-operated facility for youth who require specialized treatment, 15 regional community mental health/mental retardation centers, and other nonprofit community agencies/organizations that provide community services (Mississippi Department of Mental Health, n.d.[b]).

The State Plan for Services and Supports for Individuals with Intellectual/Developmental Disabilities is developed annually by the BIDD in conjunction with the BIDD State Plan Advisory Council. The plan guides the BIDD in developing, implementing, and maintaining a comprehensive system of services and supports. All services and supports certified by MDMH are described in the BIDD Services Directory for 2011.

Early intervention

The primary agencies involved in early intervention service delivery are the Mississippi Department of Health First Steps Early Intervention Program, the lead agency for early intervention; the MDMH; the Mississippi Department of Education (MDE); and the Office of the Governor, Division of Medicaid.

The MDMH is the largest service provider of early intervention services. In accordance with the Individuals with Disabilities Education Act (IDEA) Part C, children are eligible for IDEA Part C early intervention services if they are at risk for developing delays, or have delays in any of the five developmental domains based on evaluation. The five domains are cognitive, communication, adaptive, social, and physical, including fine and gross motor skills. Prior to enrollment in the program, a developmental evaluation is completed to determine the area(s) of delay. An Individualized Family Service Plan (IFSP) is written with family input to address the child and family's service needs (Mississippi Department of Mental Health, n.d.[a]). Programs are offered through various providers in Mississippi including the Boswell Regional Center, Ellisville State School, Hudspeth Regional Center, North Mississippi Regional Center, South Mississippi Regional Center, Delta Community Mental Health Services and Willowood Developmental Center. MDMH early intervention programs offer comprehensive, multidisciplinary evaluations and annual assessments as well as occupational therapy, physical therapy, speech/language therapy, developmental therapy, psychological services, family education and support, socialization, assistive technology, and transition services.

The Office of the Governor, Division of Medicaid pays for the medically necessary services for persons determined to meet the Medicaid eligibility requirements. Services for which reimbursement is available are those approved by the Mississippi Medicaid State Plan for Medicaid services. Under the Early Periodic Screening Diagnosis and Treatment Program reimbursement is available for services deemed necessary on the IFSP.

School-aged children

Mississippi defines autism as a developmental disability that affects communications and social interactions, usually manifested before the age of 3, which adversely affects a child's educational performance. To be eligible to receive special education services, a student must undergo a comprehensive assessment. The assessment includes physical and emotional tests as well as achievement tests to see if the student is performing below their age norms. Teachers may also be asked to provide a narrative or developmental history of the student. During the 2011 legislative session, SB 2122 was introduced regarding ASD classrooms. The legislation would have required the State Board of Education in collaboration with the MDE to review the prevalence of ASD in Mississippi schools and develop ASD classrooms designed to meet the specific needs of children with ASD. The classrooms were not intended to supplant current programs for children with special needs, but rather supplement currently offerings. S.B. 2122 was referred to the Committee on Education and Appropriations and died in committee.

The BIDD also has certified special education teachers and State Department of Education–approved programs at the four regional centers for individuals with mental retardation/developmental disabilities that serve persons below the age of 22 years.

Adults

The MDMH is responsible for the development of community services/supports for adults with mental retardation with state dollars and federal grant funds. The services and supports offered provide opportunities for adults to choose supports that increase their independence, productivity, or integration/inclusion in their own community. Community Services/supports options for adults with developmental disabilities that are available through DMH include:

- Case management
- Community living for adults
- Work/employment services
- Support services

Mississippi also has comprehensive regional centers that provide a full array of services for persons with developmental disabilities. For those individuals who require residential living arrangements with the level of care found at an ICF/DD, admission may be recommended. However, the person must first be found eligible and appropriate for ICF/DD placement, and then, ultimately, it is the individual's and family's choice as to whether this setting will best meet their needs for services and supports. In addition to providing a supervised 24-hour setting, the regional facility provides active treatment for those individuals. This may involve a range of personal care, training, educational, vocational, recreational, social, medical, and counseling services based on individual strengths and needs. These services include a variety of needed support services to meet special needs.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals and families learn about services and supports for ASD through several channels, which include referrals from providers and agencies.

Transitions and coordination of services

Early intervention to school

The MDE is responsible for statewide coordination of the planning and implementation of the identification, location, and evaluation of children with disabilities from birth to age 21.

Transition from early intervention to school occurs according to the requirements of the IDEA through MDE. MDE assures the implementation of policies and procedures for a smooth transition for those who are exiting the early intervention program and are eligible for IDEA Part B services. Six months prior to the child's third birthday, plans are made to transition to appropriate services including but not limited to public school, Head Start, childcare, or therapies. A transition meeting with the family, service coordinator, current service providers and school or Head Start personnel is scheduled for the child's third birthday.

School-aged to employment

Transition services for individuals begin as required by IDEA. This includes development of the transition services plan. The Mississippi Department of Rehabilitation Services has a Transition Services Program, whereby Vocational Rehabilitation (VR) counselors work with eligible secondary school students with disabilities to enable them to transition from school to subsequent work environments (Mississippi Department of Vocational Rehabilitation, 2008). VR works closely with the MDE and local school districts in planning and implementing a variety of

programs designed to provide training and assistance for students with disabilities to support them in making the difficult transition from school to work.

The following transition services are available to eligible high school students with disabilities:

- Career exploration and employability skills program;
- Job readiness training;
- Regular vocational technical training; and
- On-the-job training.

The decision as to the appropriate services for a student will be made by the student, through informed choice, and in coordination with the VR counselor and the school system. Each transition case is individualized, and the services will be coordinated as to what is appropriate in each case.

Training for direct service support workers

TEAAM holds an annual conference on autism that includes training for families and providers.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Mississippi interviewees mentioned that there will be more of a focus on the development of the strategic plan by the Autism Advisory Committee, including training of professionals who work with persons with an ASD diagnosis as well as working on ASD-specific training for teachers and licensure requirements for ASD-specific providers.

Other relevant programs and services

- The *Autism Advisory Committee* was created during the 2011 session, when the Mississippi legislature enacted H.B. 1125 to create an Autism Advisory Committee to study, make recommendations, and develop a strategic plan on how best to educate and train students with autism or ASD to maximize their potential productivity with the workforce and to develop an annual plan. The plan will be due in July of each year. The first report was issued July 1, 2011.
- In 2007, the *Caring for Mississippi Individuals with Autism Task Force* was organized to evaluate the needs of individuals with autism, in particular the areas of medical, education, and early intervention, and to propose recommendations for improving services for autism in the state. The task force comprised 15 members who represented state agencies, parents, and other professionals with an interest in autism. The task force found that care and services for people with autism were inadequate. To address this problem, the task force proposed recommendations, such as a waiver that would provide services to individuals with autism. The task force also recommended that all teachers and special education professionals receive better training about ASD and that

community colleges offer classes on ASD so that graduates are better prepared to work with individuals with autism. A final report was submitted to the governor and legislature on December 1, 2007. S.B. 2058 was introduced to reinstate the task force to continue its work through July 1, 2009. The bill was introduced on January 6, 2009, and referred to the Public Health and Welfare Committee. No further action was taken.

- *TEAAM* is a nonprofit organization dedicated to improving the lives of Mississippians with ASD by cultivating and enhancing family and community supports.

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MISSOURI

Approach

The L&M research team interviewed four representatives from the state of Missouri, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Missouri Division of Developmental Disabilities' (DDD) Office of Autism Services, the Division of Vocational Rehabilitation (VR), the Individuals with Disabilities Education Act (IDEA) Part C Early Intervention Program, and the Department of Elementary and Secondary Education.

State background

The DDD, under the Missouri Department of Mental Health, provides leadership over the design and delivery of services and supports for individuals with developmental disabilities in the state. More specifically, the DDD Office of Autism was established in 2008 to provide leadership in program development for children and adults with ASD, to include establishment of program standards and coordination of program capacity. The Office of Autism Services (<http://dmh.mo.gov/dd/autism>) oversees the Medicaid 1915(c) Home and Community Based Services (HCBS) waivers.

State insurance regulations

In June 2010, Governor Jay Nixon signed H.B. 1311 into law, requiring insurance companies to provide coverage of medically necessary autism therapies that are evidence based, including behavioral health treatment such as applied behavior analysis (ABA). The limit for ABA coverage for children with ASD up to age 18 is \$40,000 per year, or more if medically necessary. Insurance coverage for non-ABA therapies is not subject to age limits or monetary caps. Insurers cannot impose visit limits on any coverage under the new law, other than the dollar cap on ABA. The law's effective date was January 1, 2011.

Missouri also passed the "Mental Health and Chemical Dependency Insurance Act," which includes autism as defined in the International Classification of Diseases. Under the law, mental illnesses are subject to the same coverage provided for physical or medical illnesses (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

The DDD administers five HCBS waivers for individuals with developmental disabilities, including autism. These waivers are the main source of funding for people who live in the community, such as group homes, supported living, or with their families. Eligibility for each waiver is determined by DDD Regional Offices, and eligibility for Medicaid is determined by the Missouri Department of Social Services—Family Support Division.

State of Missouri 1915(c) waivers

Waiver Name	Population Served
MO Children with DD*	Children aged 0–17 with ID/DD
MO Autism*	Children aged 3–18 with autism
MO Partnership for Hope*	Individuals of all ages with autism/ID/DD
MO DD Community Support*	Individuals of all ages with ID/DD
MO DD Comprehensive*	Individuals of all ages with ID/DD
MO Independent Living	Individuals aged 18–64 with physical disabilities
MO Medically Fragile Adult	Individuals aged 21+ with DD
MO AIDS	Individuals aged 21+ with HIV/AIDS
MO Adult Day Care	Individuals aged 18–63 with physical and other disabilities
MO Aged and Disabled	Individuals aged 65+ or aged 63–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Missouri Autism* waiver began in July 2009 for children with ASD. To be eligible for the waiver, children must:
 1. Be between the ages of 3 and 18;
 2. Have a diagnosis of ASD, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders;
 3. Be living in the community with family;
 4. Be experiencing behavioral and/or social or communication deficits that interfere with participation in community activities, require supervision, and make it difficult for the family to provide care in the home;
 5. Have been determined to meet the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID); and
 6. Have been determined by a DDD Regional Office to need services and supports that will not exceed \$22,000 annually.

The *Autism* waiver includes a behavior analysis service that is not already available in one or more of the other DDD HCBS waivers. The behavior analysis service has three components: senior behavior consultant, behavior intervention specialist, and functional behavior assessment. The Autism Waiver can serve up to 175 persons and provide participant direction of services. The services provided under the waiver include:

- Personal assistant
- Assistive technology
- Behavior analysis service
- Community specialist services
- Environmental accessibility adaptations/vehicle modifications
- In-home respite
- Out-of-home respite

- Person-centered strategies consultation
- Professional assessment and monitoring
- Specialized medical equipment and supplies (adaptive equipment)
- Support broker
- Transportation

Other waivers

In addition to the MO Autism waiver, DDD administers four 1915(c) HCBS programs for people with intellectual and developmental disabilities that are especially pertinent to individuals with ASD.

- The *Missouri Children with DD* waiver, formerly known as the *Sarah Jian Lopez Waiver*, is a Medicaid model waiver administered by DDD. Typically, Medicaid guidelines require parental income and resources to be considered in determining a child's financial eligibility for Medicaid when the child lives at home with the parents. This requirement, called deeming parental income to the child, is waived for children who participate in the Children with DD Waiver. This provision allows participants eligibility for all State plan Medicaid services in addition to waiver services. To be eligible for the waiver, children must:
 1. Be under the age of 18;
 2. Live with their parents/family;
 3. Be determined to have a permanent and total disability;
 4. Be eligible for ICF/IID level of care;
 5. Be at risk of needing ICF/IID services if waiver services are not accessed;
 6. Not be eligible for Medicaid under regular guidelines; and
 7. Meet financial guidelines.

The *Children with DD* waiver provides participant direction of services and offers the following services:

- Behavior therapy
 - Community specialist services
 - Crisis intervention
 - Day habilitation
 - Environmental accessibility adaptations
 - In-home respite
 - Out-of-home respite
 - Personal assistant
 - Specialized medical equipment and supplies (adaptive equipment)
 - Support broker
 - Transportation
- The *Missouri Partnership for Hope* waiver is a new county-based waiver that is the result of a partnership between the Missouri Association of County Developmental Disabilities Services, the DDD, and the MO HealthNet Division. Early research on best practices and waiver development was supported by a grant from the Missouri Foundation for Health to the Missouri Association of County Developmental Disabilities Services. The MO

Partnership for Hope waiver can serve adults and children of all ages and has an annual total service cost limit of \$12,000 per participant. To be eligible, participants must:

1. Be eligible for Missouri Medicaid;
2. Meet eligibility criteria for DDD services;
3. Meet the ICF/IID level of care;
4. Reside in a participating county;
5. Meet crisis or priority criteria; and
6. Have been determined by a DDD Regional Office to need waiver services that will not exceed \$12,000 annually.

Currently, 95 counties plus the City of St. Louis participate in the *Partnership for Hope* waiver. Services included are:

- Assistive technology
 - Behavior analysis service
 - Community employment
 - Community specialist
 - Day services
 - Dental
 - Employer provided job supports
 - Environmental accessibility adaptations
 - Job discovery
 - Job preparation
 - Occupational therapy
 - Personal assistant
 - Physical therapy
 - Positive behavior support
 - Professional assessment and monitoring
 - Specialized medical equipment and supplies (adaptive equipment)
 - Speech therapy
 - Support broker
 - Temporary residential
 - Transportation
- The *Missouri Community Support* waiver is designed for persons of all ages who have a place to live in the community, usually with family. However, if the family is unable to provide all of the services the person requires, the waiver can provide additional support. The waiver has an individual annual cap on the total amount of services of \$22,000. The person must meet the ICF/IID level of care and be at risk of needing ICF/IID care if waiver services are not provided. Participant direction opportunities are provided in this waiver. Services include:
 - Assistive technology
 - Behavior analysis service
 - Communication skills instruction
 - Community employment

- Community specialist services
 - Counseling
 - Coworker supports
 - Crisis intervention
 - Environmental accessibility adaptations/vehicle modifications
 - Independent living skills development
 - In-home respite
 - Job discovery
 - Job preparation
 - Occupational therapy
 - Out-of-home respite
 - Physical therapy
 - Personal assistance
 - Person-centered strategies consultation
 - Professional assessment and monitoring
 - Specialized medical equipment and supplies (adaptive equipment)
 - Speech therapy
 - Support broker
 - Transportation
- The *Missouri DD Comprehensive* waiver is the only waiver in Missouri that provides residential services, although not all participants need these services. To be eligible, a person must meet the level of care of an ICF/IID and must be at risk of needing ICF/IID services in the absence of waiver services. In addition, there must be a determination that the individual's needs cannot be met through the Community Support Waiver. The DD Comprehensive Waiver provides all of the same services as the Community Support Waiver but also includes residential services. Participant direction opportunities are provided in this waiver. The full list of services includes:
 - Assistive technology
 - Behavior analysis service
 - Communication skills instruction
 - Community employment
 - Community specialist
 - Community transition
 - Counseling
 - Coworker supports
 - Crisis intervention
 - Environmental accessibility adaptations/vehicle modifications
 - Group home
 - Host home (shared living)
 - Individualized supported living
 - In-home respite
 - Job discovery
 - Job preparation
 - Occupational therapy
 - Out-of-home respite

- Physical therapy
- Personal assistance
- Person-centered strategies consultation
- Professional assessment and monitoring
- Specialized medical equipment and supplies (adaptive equipment)
- Speech therapy
- Support broker
- Transportation

Self-directed supports and coordination is an option of service delivery in Missouri. Persons with disabilities and their families who choose self-directed services hire and supervise their own personal assistants. A service coordinator can continue to assist the family by helping to explain the program and preparing a spending plan as well as conducting home visits to check in. A fiscal agent is available if needed to issue paychecks, collect taxes, and other tasks to relieve the family of this responsibility. A support broker is also available if the individual or family needs help making decisions or hiring or supervising a personal assistant.

Findings

Services and supports for people with ASD

Early intervention

Missouri offers early intervention services in accordance with IDEA Part C. First Steps is an early intervention program designed to serve children from birth to age 3 with developmental delays. The program is a collaborative effort of four state agencies—the Departments of Elementary and Secondary Education (DESE), Health, Mental Health, and Social Services. Eligible children are those between the ages of birth and 36 months who have been determined to have a diagnosed condition with a high probability of developmental delay or disability or who have a 50 percent developmental delay in one or more of the following areas: cognitive, communication, adaptive, physical (including vision and hearing), and social/emotional development. Children who have a medical diagnosis of ASD automatically qualify for early intervention services in Missouri.

First Steps offers coordinated services through the support of federal and state dollars, public and private insurance reimbursement, and family cost participation. The program provides screening, evaluation, and intervention services. For children with ASD, typical services include speech therapy, occupational therapy, ABA, and special instruction (developmental therapy).

School-aged children

The DESE oversees the administration of special education services in Missouri. A student who qualifies for special education has an Individualized Education Program (IEP) that documents the educational services and supports he or she needs in order to learn at school. School-aged children with a medical diagnosis of ASD often qualify for special education services. However, a medical diagnosis of an ASD given by a doctor or a licensed psychologist does not necessarily qualify children for special education services. The school is required by law to consider the medical diagnosis and any reports, but the school does not have to agree with the recommendations. The school is also required to conduct an evaluation and determine whether

there is a need for special education, which may include additional testing. If a student does not initially qualify for special education services but begins to have difficulty later on, the parent can request a reevaluation.

School districts have the option of identifying a child as eligible under the category of Young Child with a Developmental Delay (YCDD) or one of the other eligibility categories that have historically been used for school-aged children. In order to be eligible under the YCDD category, the child's development must be at or below 1.5 standard deviations in any two areas of development or at or below 2.0 standard deviations in one area of development, and the child must need special education and related services. Areas of development used to determine eligibility include: physical, cognitive, communication, social/emotional, and adaptive development.

Adults

DDD funds many services including in-home services, speech therapy, physical therapy, occupational therapy, behavior therapy, crisis intervention services, and respite care. Both medical and behavioral assistance can be provided in a person's home or during other activities in the community. DDD also funds out-of-home services to people in residential or community settings, both in smaller supported living arrangements and in larger residential centers. In addition, there is a special county tax in Missouri to provide for people with developmental disabilities in the community. These services may include funding to assist with housing, employment supports, or other services. In some areas in Missouri, the Parks and Recreation Department, YMCA, or other local organizations may provide recreation supports for adults.

DDD has a statewide employment initiative to increase the number of people with disabilities in integrated work settings. Employment coordinators are available in each regional office to provide technical assistance to individuals, families, providers, and support coordinators. In addition, the Missouri Division of VR provides supports for people with disabilities to help them find and keep a job. VR provides job guidance and counseling, job-seeking skills, job placement, and vocational training as well as assistance with transition from school to the workforce, supported employment, and assistive technology services.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals in Missouri may become aware of ASD-related services through several channels. DDD promotes the availability of the National Early Childhood Technical Assistance Center (NECTAC), which provides online knowledge and resources regarding diagnosis, programs, guidelines, and evidence-based practices for children with ASD. In addition, the Office of Autism Services developed a publication—*Navigating Autism Services: A Community Guide for Missouri*—which includes information on how to navigate the services and supports in Missouri and covers special topics such as assistive technology, childcare and respite family supports, safety and emergency planning, and handling mental health crisis (<http://dmh.mo.gov/docs/dd/navigationguide.pdf>).

Transitions and coordination of services

Early intervention to school

The First Steps service coordinator explains to families the transition process from early intervention and reviews available community programs and options for the child after age 3. Community programs may include Head Start, local public or private preschool programs, childcare, home-based care, and Early Childhood Special Education (ECSE). All First Steps children are potentially eligible for ECSE services; therefore, First Steps is required to notify ECSE when a child is approaching age 3. This notification assists ECSE with Child Find efforts and ensures a smoother transition from First Steps to ECSE. Once ECSE receives a referral, ECSE eligibility is determined 90 days or more prior to the child's third birthday.

School-aged to employment

In Missouri, students who meet specific guidelines concerning economic, social, and health care needs are able to receive services after the age of 18. This includes service coordinators who help people with disabilities and their families to identify and obtain needed services and supports, including assistance with completing paperwork. They make referrals to other community agencies and often attend school IEP meetings. The individual or family will work with the service coordinator to develop a person-centered plan that outlines action plans, explores natural supports, and discusses additional services that may be needed post graduation.

DDD provides a resources toolkit that assists families in planning for the youth transitioning from high school to independence in their homes and communities. This resource aims to enhance joint service delivery and collaboration between Centers for Independent Living (CILs), local educational agencies, and VR. The toolkit walks the user through a comprehensive transition planning process: exploration, empowerment, and employment and training. In addition, the toolkit includes information on disability-related laws, the team approach, and agency listings.

In addition, the University of Missouri offers an extension course that provides an overview for families and community professionals about the important life skill areas for a successful transition to adult life. Topics for this module include community living skills, health and safety, education and training after high school, employment, and adult services and benefits. Information on these transition topics is also available on the university's Website (<http://asdtransition.missouri.edu/roadmap.html>).

Training for direct service support workers

The Missouri College of Direct Support (<http://www.moddrc.org/direct/index.html>) is a partnership of agencies that have joined together to create a training and certification program for direct support workers in Missouri. Fourteen provider agencies are collaborating to pilot the College of Direct Support Internet-based training curriculum for people in direct service roles.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Overall, respondents noted that the main goals over the next several years are to follow and implement the Show-Me State Plan for ASD.

Other relevant programs and services

- In 2008, the Missouri General Assembly created the *Commission on Autism Spectrum Disorders*, which is charged with making “recommendations for developing a comprehensive statewide plan for an integrated system of training, treatment, and services for individuals of all ages with autism spectrum disorder.” The commission has displayed unwavering commitment to fulfill that task in the coming months.
- The Department of Mental Health’s DDD funds five regional autism projects that collectively provide services to approximately 2,500 families statewide. Individuals are referred to autism projects through their regional office. The programs and services are designed to assist in skill development of individuals with ASD and provide needed training and support for families. The first project was established in 1991 as a result of families in rural Missouri approaching legislators to ask for autism-specific family support. They requested needed services so that their family members could remain at home and receive supports close to home. The five Missouri Autism Projects are overseen by the Missouri Advisory Committee on Autism and by Regional Parent Advisory Councils, which consist of individuals with autism and families of people with autism.
- *Project ACCESS* was created in 1985, as (one of) the first state resource centers for autism in the Nation. Funded entirely by the Missouri Department of Elementary and Secondary Education, Project ACCESS at Missouri State University provides autism resources to public schools across Missouri serving students with autism and other pervasive developmental disorders (Missouri Department of Early and Secondary Education, n.d.). This includes onsite and telephone consultations as well as online support. In addition, Project ACCESS designs autism-specific professional development opportunities and trains credentialed professionals to present these courses through Missouri’s Regional Professional Development Centers. These trainings are offered to Missouri school district staff and educators who work with youth aged 0–21 with ASD or related disabilities. Onsite child-specific consultations can be arranged through the use of Missouri Autism Consultants, and district staff can be trained to be In-District Autism Consultants.
- The *Thompson Center for Autism and Neurodevelopmental Disorders* at the University of Missouri—Columbia was established in 2005 to promote research, teaching, and service innovations to improve the lives of children with ASD and other neurological conditions. The center serves as a resource for families and professionals, providing help through clinical services, research, and professional training.

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MONTANA

Approach

The L&M research team interviewed six representatives from the state of Montana, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Montana Developmental Disabilities Program (DDP); Montana Vocational Rehabilitation (MVR); the Montana Council on Developmental Disabilities; the Montana Autism Education Project; and Parents Let's Unite for Kids.

State background

The Montana Developmental Services Division (DSD), under the Montana Department of Public Health and Human Services, is the lead agency in charge of contracting and coordinating services for individuals with disabilities across the lifespan, including those with ASD. There are two primary programs within DSD: the DDP and the Children's Mental Health Bureau. The DDP administers the Medicaid Home and Community Based Services waivers for individuals with developmental disabilities as well as other nonwaiver services. DDP also manages the Part C Family Education and Support program—Montana's early intervention program—which provides entitlement services in accordance with Part C of the Individuals with Disabilities Education Act (IDEA) for children from birth to age 3 and their families. A common theme throughout all of DDP's services is a focus on self-determination and individual choice.

The Montana Council on Developmental Disabilities is currently carrying a bill in the 2013 legislative session to remove the words "mental retardation" from all legislative language.

State insurance regulations

In May 2009, Governor Brian Schweitzer signed into law S.B. 234, also known as "Brandon's Law," requiring health insurance coverage for ASD for children aged 18 years or younger. Coverage must include habilitative or rehabilitative care, medications, psychiatric or psychological care, therapeutic care (including applied behavior analysis), and other specified treatment. Coverage is limited to a maximum benefit of \$50,000 for children aged 8 and under and \$20,000 for children aged 9 to 18. According to interviewees, the autism legislation is severely limited in that the mandate only applies to Montana-based companies, leaving many children and families without coverage for autism services (National Conference of State Legislatures, 2012).

Montana also has a mental health parity law, which includes coverage for severe mental illnesses. As of July 2009, health insurance or disability insurance must provide a level of benefits necessary for the care and treatment of severe mental illness, including autism. Benefits include inpatient hospital services, outpatient services, rehabilitative services, and medication as well as services by licensed clinicians whose services are part of a treatment plan prescribed by a licensed physician (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Montana 1915(c) waivers

Waiver Name	Population Served
MT Children's Autism Waiver*	Children aged 1–4 with autism
MT Bridge-PRTF Waiver	Children aged 6–7 with serious emotional disturbances
MT HCBW for Individuals with DD*	Individuals of all ages with ID/DD
MT Community Supports*	Individuals aged 18+ with ID/DD
MT HCB Waiver for Adults with Severe Disabling Mental Illness	Individuals aged 18+ with mental illness
MT Big Sky Bonanza	Individuals aged 65+ and aged 0–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Montana Children's Autism Waiver (MT.0667.R01.01)* began in 2009 as a way to provide evidenced-based, intensive programming for a small number of children with autism and their families. Currently, the waiver serves 50 children aged 1–8 years diagnosed with ASD who have delays in adaptive behavior. Children cannot enroll if they are older than 4 and must transition out of waiver services by the age of 8. Another 58 children and families are on a waitlist. The program utilizes techniques based on applied behavior analysis to improve communication skills, social interaction, and activities of daily living, while reducing problematic behaviors commonly associated with autism. To support this effort, the program includes individualized program design and monitoring, case management, 20 hours a week of instruction for the child, and other ancillary supports. The average cost of service is approximately \$42,000 per year for each child (Emerson & Garfinkle, 2012). The full array of services includes:
 - Program design and monitoring
 - Case management
 - Children's autism training, including applied behavior analysis
 - Respite
 - Environmental modifications and adaptive equipment
 - Occupational, physical, and speech therapy
 - Transportation
 - Individual goods and services (Montana Developmental Services Division, n.d.)

As a supplement to the *Children's Autism Waiver*, the Department of Public Health and Human Services has contracted with the University of Montana to provide technical assistance and professional development for providers and to conduct an evaluation of the program's success. The Interim Committee Report in January 2012 showed very positive results; most notably, participants' rate of development in social skills, communication skills, and adaptive functioning nearly tripled. Additionally, of the four children aging out of the program, two had an autism symptom severity rating in the normal range and one in the mildly autistic range (Emerson & Garfinkle, 2012).

Other waivers

Two other 1915(c) HCBS waivers provide services to individuals with developmental disabilities in Montana, including those with ASD. These programs have a combined enrollment of approximately 2,600, and there is currently a waitlist for services.

- The *Montana HCBW for Individuals with DD (MT 0208. R04.02)* waiver, also known as the Comprehensive Waiver, provides a wide range of supports for people of all ages with developmental disabilities who would otherwise require an institutional level of care to maintain independence and quality of life. Services offered through the Comprehensive Waiver include:
 - Adult companion services
 - Adult foster support
 - Assisted living
 - Board Certified Behavior Analyst services
 - Caregiver training and support
 - Children’s case management
 - Community transition services
 - Day and residential habilitation
 - Dietician services
 - Environmental modification and adaptive equipment
 - Homemaker services
 - Individual goods and services
 - Live-in caregiver
 - Meal services
 - Occupational, physical, and speech therapy
 - Personal care
 - Personal Emergency Response System
 - Personal supports
 - Private duty nursing
 - Psychological and counseling services
 - Respiratory therapy
 - Respite
 - Supports brokerage
 - Supported employment
 - Transportation (Montana Developmental Services Division, n.d.)
- The *Montana Community Supports (MT 0371.R02.02)* waiver is designed to provide more limited support than the Comprehensive Waiver. Individuals typically appropriate for this waiver are adults aged 18 and older who live at home with their families and have caregiving needs that are largely met by unpaid family members or adults who live alone and require modest levels of support or supervision. Service needs under this waiver must be at \$7,800 or less per year, unless private nursing duty or emergency assistance is required. Services available include:
 - Adult companion services
 - Day and residential habilitation
 - Educational services

- Environmental modification, adaptive equipment, specialized medical equipment
 - Health, health maintenance, safety supports
 - Homemaker services
 - Individual goods and services
 - Live-in caregiver
 - Personal care
 - Personal Emergency Response System
 - Personal supports
 - Private duty nursing
 - Respite
 - Social, leisure, and recreational supports
 - Supports brokerage
 - Supported employment
- Montana also has a growing self-directed services option for individuals enrolled in any of the HCBS waivers. Through the self-directed program, individuals choose one of two options: (1) hire a provider agency to manage their services—known as the Agency with Choice Option, or (2) choose to manage their own services or have a family member do so—known as the Employer Authority Option. In both cases, participants have increased control over and responsibility for the “what, when, who, and how services are provided” but still have access to a support broker and fiscal agent as well as state case manager to help monitor ongoing service delivery and individual budgets (Montana Developmental Disabilities Program, n.d.).

Findings

Services and supports for people with ASD

Early intervention

Through IDEA Part C family education and support program, early intervention services are administered by the DDP. To be eligible, children must:

1. Have a diagnosed physical or mental condition that has a high probability of resulting in developmental delay, even though the delay may not exist at the time of diagnosis; or
2. Be experiencing developmental delays in one or more of the following areas of development: cognitive, physical, speech and language, social and emotional, and self-help (Parents Let’s Unite for Kids, 2007).

Services are delivered as part of an Individualized Family Service Plan (IFSP), which is developed in collaboration with the family, in which the parent or caregiver typically leads the planning of services. Services available include:

- Assistive technology
- Audiology and vision
- Counseling and home visits
- Family education

- Family support coordination
- Medical and health related services
- Nursing
- Nutrition
- Occupational, physical, and speech therapy
- Psychological
- Social work
- Special instruction
- Transportation

School-aged children

The Division of Special Education (DSE) within the Montana Office of Public Instruction is the authority responsible for ensuring that children with disabilities receive a free and appropriate public education in the least restrictive environment. DSE provides training and technical assistance and monitors special education services provided by public schools and state-operated programs.

Most children with disabilities between the ages of 3 and 21 receive support through school-based special education services. To be eligible for IDEA Part B preschool services, a child must meet the criteria for one of the disabling conditions recognized by IDEA and Montana state code, which includes autism. Once eligible, services are provided according to an Individualized Education Program (IEP), which details a child's plan for special education and other services. The IEP is reviewed periodically to determine whether special education services are still necessary or need to be updated. Some of the support services available to supplement special education include:

- Assistive technology
- Audiology
- Counseling
- Orientation and mobility services
- Physical, occupational, and speech/language therapy
- Psychological services and assessment
- School nursing
- Social work services
- Transportation
- Other services as needed (Parents Let's Unite for Kids, 2005)

The Montana Office of Public Instruction is also home to the Montana Autism Education Project—a statewide autism training and support program for educators, parents, and other professional. The project implemented an online-based training program a few years ago—Autism Training Solutions (ATS)—in an effort to reach the greatest number of educators across the state. The project purchased subscriptions to the training for a number of school districts. After only 1 year of implementation, the training showed great success: ATS was voluntarily adopted by 57 school districts across rural and urban areas, and more than 90 percent of participants noted ATS was effective in their classroom. In addition, the small project staff also travel throughout the state to provide free onsite training and workshops, including popular “iPad summits.” They also maintain a blog with information on current trainings and relevant issues (Autism Training Solutions, n.d.).

Adults

In addition to administering the Comprehensive and Community Supports waivers, the Montana DDP contracts with private, nonprofit organizations to provide services to adults with disabilities (Montana Developmental Services Division, 2013). The following services are available to adults who meet the state criteria for developmental disability, which includes autism:

- Adult intensive habilitation serves people with severe disabilities who may present challenging behaviors and need self-help skills. The programs enable individuals to engage in paid work if possible. If the individuals are not able to work, structured training and integrated community activities are provided. These activities are designed to help individuals move toward greater independence and active participation in their community.
- Facility-based work services are provided to roughly 700 individuals and provide paid work as well as job skill and functional life skill training. Participants generally engage in producing a product or delivering a service as a paid employee of a contracting agency.
- Supported employment provides job training, job placement, and ongoing support while individuals are employed in the general workforce. The goal of support employment is workplace integration, allowing participants to work alongside nondisabled employees. About 325 adults participated in state-funded supported employment last year, 25 of which have ASD.
- Combination supported work/facility-based work programs provide employment services including functional academics, job skill training, and supported employment. Roughly 280 people participate in these programs.
- Senior programs provide training and activities to Montana’s elderly disabled population, including socialization skills, leisure skills, community activities, and maintenance of self-help skills. About 120 seniors participate in these programs.

In addition, MVR promotes work and independence for individuals with disabilities by providing assistance with finding, obtaining, and maintaining quality employment. Eligible individuals are those who want and need MVR services and have a physical or mental disability that prevents them from getting or keeping a job. Services provided include:

- Career counseling and guidance
- Evaluation
- Job development and placement
- Medical or psychological services
- Post-employment services
- Rehabilitation technology
- Referrals
- Training (Montana Vocational Rehabilitation, 2013b)

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Montana began participating in the Center for Disease Control and Prevention's "Learn the Signs. Act Early." campaign in 2008 to improve early identification of autism and other developmental disabilities. The state is currently engaging in an Act Early Ambassador pilot project, designed to develop a network of state-level experts to improve the early identification process. Each of the 25 Act Early Ambassadors commits to conducting two activities over the next year in one of five areas: education and training, partnership development, ACT curriculum training, outreach/public awareness, or working with the Act Early state team (Association of University Centers on Disabilities, 2012).

In addition, Child Find requires that IDEA Part C and public school special education programs have a practical method of locating, evaluating, and identifying all children aged 3–21 who have a disability and need special education services. This includes all children who live within a public school district's boundaries, including children receiving early intervention services, those enrolled in Head Start or private schools, and those attending public schools within the district. The Child Find process requires implementation of preschool transition from IDEA Part C to IDEA Part B special education services, preschool screening activities that outreach to the whole community, and school-based pre-referral activities for school-age children. Child Find procedures vary between districts depending on the needs and resources of the community, but commonly they involve partnering with community-based agencies and publicizing screening activities in local media (Montana Office of Public Instruction, 2002).

Transitions and coordination of services

Early intervention to school

The transition process from early intervention to special education services progresses according to the requirements of IDEA. The IFSP team meets 3 to 6 months before a child's third birthday to discuss transition from IDEA Part C to IDEA Part B services. If a child needs preschool special education, joint planning meetings with the local educational agency occur at least 90 days before the move from early intervention to school. The purpose of the meetings is to

- Provide the family an opportunity to meet the public school staff and begin to develop mutually supportive relationships;
- Review the child's priority outcomes through the beginning of the next school year;
- Describe the steps and anticipated outcomes of the transition process;
- Consider future needs and placements;
- Discuss how to help prepare the child and family for changes in service delivery;
- With written parental consent, share records (assessments, evaluations, IFSPs, other useful information) with the public school preschool special education program; and
- Develop a plan for transition (Parents Let's Unite for Kids, 2007).

School-aged to employment

According to IDEA, the process for transitioning out of special education services must begin by age 16 but can start as early as age 14 for those needing more extensive planning. Public schools are required to write Individualized Transition Plans (ITPs) that are designed to help the student transition smoothly from school to adulthood. The ITP is similar to the student's IEP but also includes information on community-based instruction, vocational education, future placements, performance criteria in future environments, skills in nonacademic domains, and annual goals that are linked to future needs. The ITP emphasizes functional skills needed to prepare for adult living, such as daily living skills, learning strategies and study skills, and vocational skills (Parents Let's Unite for Kids, 2008).

Students are eligible to apply for Montana Vocational Rehabilitation services during their final year of high school. Before that time, MVR counselors serve as consultants regarding vocational planning, and students, teachers, and parents are encouraged to contact MVR. Since 2011, vocational rehabilitation counselors have been assigned to hold regular office hours in the largest high schools around the state. This developed out of a 2007 Disability Employment and Transitions demonstration in which vocational rehabilitation counselors held regular office hours in the three public high schools in Missoula. Following the demonstration, students and their support team members (parents, teachers, therapists, etc.) reported considerable improvement in the quality of services (Montana Vocational Rehabilitation, 2013a).

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Montana Children's Autism Waiver program is developing a data collection system based on the evaluation protocol designed by the University of Montana. The system will allow the Department of Public Health and Human Services to sustain the ability to aggregate, summarize,

analyze, and report data and outcomes. Additionally, to supplement the Children's Autism Waiver, the state is working on implementing distance technologies to reach hard-to-serve families, continued professional development for personnel, and standardized transition planning so that children making significant progress through waiver services do not lose their skills (Emerson & Garfinkle, 2012).

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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NEBRASKA

Approach

The L&M research team interviewed a total of six representatives from the state of Nebraska to gain a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Nebraska Division of Developmental Disabilities (DDD), the Nebraska Division of Medicaid and Long-Term Care, the Nebraska Planning Council on Developmental Disabilities, Nebraska Vocational Rehabilitation, and the Nebraska Department of Special Education and Communication Disorders.

State background

The Nebraska Department of Health and Human Services (DHHS) is the organization with ultimate responsibility for the delivery of services and supports for individuals with developmental disabilities in the state. DHHS is divided into various divisions, including the DDD and the Division of Medicaid and Long-Term Care, which oversee Nebraska's 1915(c) Home and Community Based Services waivers. More specifically, some of the responsibilities of the DDD include implementation of three HCBS waivers for adults and children with developmental disabilities (DD), certification, technical assistance, and coordination and payment for state developmental disability service providers. Overall, some respondents in Nebraska noted a lack of providers in rural regions of the state; however, this was not specific to DD service providers but rather to health care providers in general.

State insurance regulations

In Nebraska, some coverage for autism-related services is provided under the state's mental health parity law, which requires plans that offer mental health coverage to cover mental health conditions, including autism, as defined by the International Classification of Diseases. Nebraska does not have a specific health insurance mandate for ASD (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Nebraska 1915(c) waivers

Waiver Name	Population Served
NE Autism*	Individuals aged 0–17 with autism
NE HCBS Waiver for Children w/ DD and their Families*	Individuals aged 0–20 with ID/DD
NE HCBS Waiver for Aged and Adults with Disabilities	Individuals aged 0–64 with physical disabilities and individuals aged 65+
NE TBI	Individuals aged 18–64 with brain injury
NE Day Services Waiver for Adults w/ DD*	Individuals aged 21+ with autism/ID/DD
NE Comprehensive DD Waiver for Adults*	Individuals aged 21+ with autism/ID/DD

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Under the direction of the Nebraska Legislature, the Nebraska DHHS developed and received approval from CMS for the *Nebraska Autism* waiver. The waiver is overseen by the Division of Medicaid and Long-Term Care within DHHS. However, the legislation required private matching donations to fund the waiver. In July 2010, the primary donor of this waiver decided not to proceed with a planned financial donation. As a result, the NE Autism waiver remains ready to be implemented, but can only do so after receipt of sufficient funds. The primary service on this waiver will be early intensive behavioral intervention services (Nebraska Department of Health & Human Services, 2011).

Other waivers

The Nebraska DHHS is the organization that ultimately encompasses the state Medicaid waivers. The DDD oversees three waivers applicable to the ASD population. Of these waivers, one is aimed at children and two are designed for adults.

- The *Nebraska HCBS Waiver for Children w/ DD and their Families* waiver provides support to individuals aged 0–20 with intellectual and developmental disabilities (I/DD) and their families. However, individuals continuing in special education beyond their 21st birthday may continue on the waiver until the special education services end. Students are also entitled to complete their final semester rather than leave school on their 21st birthday. This waiver includes the following services:
 - Community living and day supports
 - Companion home residential habilitation
 - Extended family home residential habilitation
 - Integrated community employment—individual employment support
 - Prevocational habilitation
 - Behavioral risk service
 - Habilitative childcare
 - Home modifications
 - Homemaker services
 - Group home residential habitation
 - Respite
 - Specialized childcare
 - In-home residential habilitation
 - Medical risk services
 - Team behavioral consultation
 - Vocational planning habilitation service
 - Workstation habilitation services
- The *Nebraska Day Services Waiver for Adults with DD* provides a variety of services for an individual aged 21 and older with ID/DD, including autism. Services include:
 - Assistive technology and supports
 - Behavioral risk services
 - Community inclusion day habilitation
 - Community living and day supports
 - Home modifications

- Integrated community employment
 - Medical risk services
 - Prevocational workshop habilitation
 - Respite
 - Personal Emergency Response System
 - Retirement services
 - Team behavioral consultation
 - Vehicle modifications
 - Vocational planning habilitation
 - Workstation habilitation
- The second adult waiver is the *Nebraska Comprehensive DD Waiver for Adults*, which provides the same services as the Nebraska Day Services Waiver for Adults with DD but also includes a variety of residential services. The full list of services includes:
 - Assistive technology and supports
 - Behavioral risk services
 - Community inclusion day habilitation
 - Community living and day supports
 - Companion home residential habilitation
 - Extended family home residential habilitation
 - Group home residential habilitation
 - Home modifications
 - In-home residential habilitation
 - Integrated community employment
 - Medical risk services
 - Prevocational workshop habilitation
 - Respite
 - Personal Emergency Response System
 - Retirement services
 - Team behavioral consultation
 - Vehicle modifications
 - Vocational planning habilitation
 - Workstation habilitation

Findings

Services and supports for people with ASD

Early intervention

The Early Development Network is the statewide early intervention program that is responsible for overseeing Part C services of the Individuals with Disabilities Education Act (IDEA). Young children under age 3 are eligible for early intervention services if they exhibit developmental delays or have a diagnosis for certain medical conditions that are known to affect development. With the family's permission, a child referred to the Early Development Network will undergo an assessment from a multidisciplinary evaluation team to determine the child's eligibility of services. If the child is eligible for early intervention services, a service coordinator will work with the family to develop an Individualized Family Service Plan (IFSP), which outlines goals

for the child as well as the services that are necessary to achieve those goals (Nebraska Early Development Network, 2010). Among the services provided by the Early Development Network are:

- Assistive technology and audiology
- Family training, counseling, and home visits
- Health, nutrition, nursing, and vision services
- Medical services for diagnostic or evaluation
- Occupational, physical, and speech therapy
- Service coordination
- Social work and psychology services
- Special instruction
- Transportation

School-aged children

The Nebraska Office of Special Education is housed within the Nebraska Department of Education and is tasked with providing IDEA Part B services to students eligible for these services. In the 2010–2011 academic year, 2,085 children with autism received special education services, which represented approximately 4.7 percent of all children receiving special education in the state (Easter Seals, 2012).

The Nebraska Autism Spectrum Disorders Network (<http://www.unl.edu/asdnetwork/>) was created in 2002 and is funded by the Nebraska Department of Education through IDEA Part B Set-Aside funds. The ASD Network hosts various training and workshops for school districts in the state. Although parents are allowed to attend these training sessions, the typical audience often includes team educators, occupational therapists, and personally therapists. The ASD Network seeks to build and enhance the capacity for schools and families to provide for children across the spectrum. The ASD Network divides Nebraska into five regions, each of which has a regional coordinator who organizes trainings according to the requestor’s specific needs and goals.

Adults

Nebraska Vocational Rehabilitation (VR) is tasked with helping individuals with disabilities join the workforce. The organization is housed within the Nebraska Department of Education and is under the direction of the Assistant Commissioner of Education. Services offered by VR are delivered under the supervision of local office directors through multiple sites in Nebraska. Additional VR staff can travel directly to sites such as health centers, community programs, schools, and so on to provide services directly (Nebraska Department of Education, n.d.[a]). Some of the services offered through vocational rehabilitation include:

- Assessment
- Higher education assistance
- Personal assistance services

- Rehabilitation technology services
- Supportive employment
- Transportation

Nebraska VR has had a long-standing relationship with the Assistive Technology Partnership (ATP). ATP often conducts onsite assessments for people referred from VR and works to identify where assistive technology and modification may be beneficial. Lastly, the State Rehabilitation Council (SRC) (<http://www.vocrehab.state.ne.us/src/index.html>) was established in 1992 as an independent council to analyze and advise VR's performance.

Systems tracking

The DDD does not track services specific to individuals with ASD.

Promotion of services and supports for people with ASD

Individuals in Nebraska may become aware of ASD-related services in the state through many channels. Many agencies have an open referral system in place where anyone can refer individuals to determine whether they are eligible for services. These referrals typically come from physicians, family members, hospitals, and the school system. Some agencies noted promotional efforts through brochures, radio and television advertisements, job or community fairs, and conferences held by other agencies.

Transitions and coordination of services

Early intervention to school

Transition from early intervention to special education occurs according to the requirements of IDEA. If the child is still in need of specialized services after age 3 and is eligible for special education, he or she will move from an IFSP to an Individualized Education Program (IEP). Meetings for this transition begin between 9 months and 90 days before the child turns 3 years old (Nebraska Early Development Network, 2010).

School-aged to employment

In Nebraska, students in special education who are 21 years old and younger are eligible to receive school-based services until they leave the school system. Transition out of the school system often includes movement toward vocational services and employment. The Department of Education and Nebraska VR frequently work together to include VR as part of a student's IEP.

In addition, Nebraska VR currently operates ten Project SEARCH sites across the state. Project SEARCH helps high school students with disabilities learn vocational and competitive skills to help them enter the workplace and become more independent in the work environment. Rather than attending their typical school environment, Project SEARCH students attend classes at local businesses and work in internship positions during the school week. Students focus on job skills with the assistance of a job coach, such as working with coworkers, the importance of being on time, and proper workplace grooming (Nebraska Department of Education, n.d.[b]).

The Transition Advisory Committee and the Transition Practitioners Committee were created to discuss issues around transitioning in the state and develop appropriate initiatives and responses. These committees are made up of a variety of stakeholders such as parents, direct service providers, and advocacy and agency representatives (Nebraska Transition, 2007).

Training for direct service support workers

Training requirements in Nebraska vary by agency and the type of work an individual is involved in. For example, Nebraska VR hosts biannual training on medical topics such as brain injury and autism. The Nebraska Planning Council on Developmental Disabilities highlighted the training efforts of regional councils, which help provide leadership and training opportunities for individuals with DD as well as their families and service providers.

Additionally, Parent Training and Information (PTI) Nebraska (<http://pti-nebraska.org/>) is an organization that functions as a statewide resource to provide information, training, and support to families of children with disabilities. PTI Nebraska offers a variety of training workshops in topics such as early intervention services, transitioning from early intervention to special education services, and self-advocacy. One of the trainings developed by PTI Nebraska was a Web-based curriculum on the IEP, which can be taken by individuals at their leisure. Finally, PTI Nebraska houses the Family-to-Family Health Information Center, which is a federally funded center that assists families of children with disabilities in making beneficial health care decisions.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Overall, respondents commented on the general movement of the state toward self-advocacy and the push for communities to develop inclusive practices for individuals with DD. The Nebraska State Plan for Developmental Disabilities outlines five main goals over the coming years: community inclusion, employment, quality assurance, self-advocacy, and health. Some of the efforts for community inclusion involve identifying recreational opportunities for individuals with developmental disabilities and maintaining regional councils to engage in local advocacy and capacity building.

Other relevant programs and services

- *The Autism Center of Nebraska (ACN)* (<http://autismcenterofnebraska.org/>) is a developmental disabilities service provider that is contracted by the DDD within the Nebraska DHHS. The ACN provides services and supports to help individuals achieve higher independence in their lives. These services include such things as respite, residential services, vocational services, and transition services. The ACN specializes in providing services to individuals with autism; however, it also serves individuals with other developmental disabilities.

- *The Munroe-Meyer Institute (MMI)* (<http://www.unmc.edu/mmi/index.htm>) is a Nebraska University Center of Excellence for Developmental Disabilities Education, Research, and Service (UCEDD). MMI offers family-centered services for individuals with disabilities with the intent of promoting inclusion to the community. Additionally, MMI provides technical assistance and consultation to schools and agencies providing services to individuals with disabilities. Funding for MMI comes from a variety of sources, including patient revenues, federal and state funds, state and school contracts, and private funds.

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NEVADA

Approach

The L&M research team interviewed six representatives from the state of Nevada, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Division of Mental Health and Developmental Services (DMHDS), the Rural Regional Center, the Autism Treatment Assistance Program (ATAP) within the Aging and Disability Services Division (ADSD), and the Bureau of Vocational Rehabilitation (BVR) within the Nevada Department of Employment, Training and Rehabilitation.

State background

In 2007, Governor Jim Gibbons signed A.B 629 into law, creating the Nevada Autism Task Force. The task force comprised 14 individuals and met for 1 year before submitting its recommendations report (Easter Seals, 2012). Following the report, the Governor created the Nevada Commission on Autism Spectrum Disorders in 2008 to continue the work of the task force. The commission meets biannually with the Governor to discuss updates and consists of three members who are appointed by the Governor and eight subcommittees including:

1. Data and Statistics
2. Teen and Adult Supports—Employment
3. Teen and Adult Supports—Community Living
4. Education—Early Intervention
5. Education—3–22 years old
6. Funding, Workforce, University Programs, and Professional Training
7. Insurance
8. Adult Services (Nevada Department of Health and Human Services, 2006)

State insurance regulations

In 2009, A.B. 162 was signed into law, mandating private health insurance companies to provide coverage for screening and treatment of ASD. Coverage is mandated for children up to age 18 or 21 if they are enrolled in high school. Covered treatments include habilitative or rehabilitative care, pharmaceutical care, psychiatric care, psychological care, and therapeutic care. There is an annual monetary cap of \$36,000 a year for applied behavior analysis therapy (Easter Seals, 2012). The insurance mandate covers only certified behavior analysts, and certification can be costly, which inhibits many analysts from becoming certified.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Nevada 1915(c) waivers

Waiver Name	Population Served
NV HCBW for Persons w/ ID & Related Conditions*	Individuals of all ages w/ intellectual disabilities
NV HCBW for Persons with Physical Disabilities	Individuals aged 65+ or aged 0–64 with physical disabilities
NV Assisted Living	Individuals aged 65+
NV Frail Elderly	Individuals aged 65+

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Nevada does not have any waivers specific to individuals with ASD at this time.

Other waivers

One home- and community-based services waiver in Nevada allows people with ASD to receive services.

- The *Nevada HCBW for Persons with ID and Related Conditions* is administered by the Department of Health and Human Services through the DMHDS and the Division of Health Care Financing and Policy. The waiver helps individuals across the lifespan who would require institutional care at an Intermediate Care Facility for Individuals with Intellectual Disabilities. Services provided include:
 - Day habilitation
 - Direct services and support
 - Prevocational services
 - Supported employment
 - Behavioral consultation, training, and intervention
 - Community integration services
 - Counseling
 - Direct support management
 - Nonmedical transportation
 - Nursing services
 - Nutrition counseling services

Findings

Services and supports for people with ASD

In the 2011 legislative session, the program for individuals with ASD, known as the Autism Treatment Assistance Program (ATAP), was moved from the DMHDS to the ADSD. Children who were already being served in DMHDS continue to receive services and supports there until they age out of the autism-specific services. The ADSD is serving new applicants as well as individuals on the waitlist.

In addition to waiver services, DMHDS offers many supports through state general funds, including nutrition therapy and community outreach. They also work with the federal Family Preservation Program, which provides support to individuals with developmental disabilities younger than 6 years and individuals with intellectual disabilities older than 6 years. The general funds typically serve individuals on a waiver waiting list; however, there is also a waiting list for many of these services. To be eligible, individuals must be clinically identified as having an intellectual disability with adaptive skills deficits in two areas, or a related condition, such as ASD, and adaptive skills deficits in three areas.

Three regional centers in Las Vegas, Reno, and Carson City coordinate and provide community services under DMHDS. The center in Carson City is the Rural Regional Center, which covers the other 14 counties and 95,000 square miles in the state (Nevada Department of Health and Human Services, 2013b). Nevada has a shortage of providers across the state, with higher concentrations of providers in the larger cities of Las Vegas and Reno. This creates barriers to the availability and accessibility of services in many parts of the state such that many communities do not offer certain services due to limited providers.

Early intervention

Early intervention services in Nevada are provided to children from birth to age 3 by the Nevada Department of Health and Human Services, Nevada Division of Public and Behavioral Health. Eligibility is determined by having either a developmental delay or diagnosed condition such as ASD. Early intervention services are usually provided in the home or in the child's natural environment and include:

- Assistive technology
- Audiology
- Family training and counseling
- Medical services for diagnostic purposes
- Nutrition counseling
- Occupational, physical, and speech/language therapies
- Psychological therapies
- Service coordination
- Social work services
- Transportation services (Nevada Department of Health and Human Services, 2011b)

School-aged children

Early childhood special education services are provided to children with disabilities aged 3–5 through the local school districts (Nevada Department of Education, 2012b). A multidisciplinary team helps create an Individualized Education Program (IEP) that determines which services will be most helpful for a student. The Office of Special Education works to develop educational success for all students using evidence-based practices, providing professional development for

teachers and other staff, and providing technical assistance (Nevada Department of Education, 2012a).

ATAP is available to children under the age of 19 with a diagnosis of ASD. ATAP offers a family budget depending on the child's age and allows families to select, hire, and bill their providers using an online tool. The family is in charge of which services to utilize and when to schedule sessions. The program currently serves 137 children, with 265 children on the waitlist. Individuals can stay on the program for approximately 7 years, 4 of which involve comprehensive services; the other 3 years focus on transition. ATAP contains multiple levels of plans:

- The *Comprehensive Plan* typically starts before the age of 6 and lasts about 4 years, covering 25 hours of service per week.
- After that, children can move to the *Targeted Extensive Plan*, which covers between 10 and 15 hours a week and targets specific behaviors.
- The *Collaborative Plan* involves training done at the school.
- The *Basic Plan* trains parents and helps individuals transition out of the program.

A Board Certified Behavior Analyst (BCBA) supervises all plans, and care managers work with families and BCBA's to monitor improvement through quarterly visits and annual videos. Usually children graduate down to less rigorous plans, but they must improve on the items in their behavior plan to remain in the program. The turnover of individuals in the program is slow, so ATAP uses a priority assessment to decide who will move into the program. Trainings and programs are available to families on the waitlist, including a 40-hour online technical training to educate families on applied behavior analysis. ATAP started as a pilot program in 2008 and was made permanent in the 2011 legislature. Most of the funding is drawn from Healthy Fund Nevada, with some general funds.

Adults

The BVR within the Nevada Department of Employment, Training and Rehabilitation employs 46 vocational rehabilitation counselors around the state, including JobConnect, a statewide network that connects businesses with employees. The BVR has no ASD-specific programs; rather it works with the entire disabled community. The BVR offers a range of employment services including assessments of job-related skills, assistance with job searches, job placement and retention, collaboration with employers and agencies, transportation services, career counseling and guidance, and postemployment services (Nevada Department of Employment, Training and Rehabilitation, n.d.[a]).

In the northern region of the state, the BVR and the University of Reno collaborate to help create employment opportunities for individuals who are severely impacted by disabilities. A team comprised of vocational rehabilitation workers, a University of Reno representative, the regional center case worker or manager, and anyone who is significant to the individual work together to develop a customized employment plan.

Systems tracking

Nevada law designates that a single diagnostic tool, ADOPH, be used by all agencies. This same law requires that the early intervention program, the Department of Education, and the BVR report statistics on individuals with ASD to the ADSD. However, there is currently little feedback and analysis, as the first reporting will occur in in 2013.

Promotion of services

The Nevada Department of Education and the Department of Human Resources sponsor a resource and referral system called Project ASSIST. Project ASSIST helps interested individuals find information about different organizations and programs that can provide supports and services for individuals with disabilities up to age 21 (Nevada Department of Health and Human Services, 2013a).

Additionally, BVR works closely with the Employment Security Division and other agencies to get people into the vocational rehabilitation system, refer them to jobs, and share resources with private organizations such as JOIN, a job training agency designed to help individuals gain or improve the skills for the local labor market.

Transitions and coordination of services

The DMHDS organizes quarterly meetings between all service providers and individuals involved in a child's life. These team meetings serve as the center of service coordination and help ensure that resources are being used efficiently and overlap and transition is as smoothly as possible.

Early intervention to school

After age 3, children are no longer eligible for early intervention services. Six months before a child's third birthday, an early intervention service coordinator will help plan transition to another agency. A transition plan meeting with the service coordinator, school district, service provider(s), and family will take place 90 days before the child's third birthday to discuss preschool special education services or other options (Nevada Department of Health and Human Services, 2011a).

School-aged to employment

Vocational rehabilitation services are available to high school students with disabilities that serve as a barrier to employment. Students do not need to be enrolled in special education services, and a separate evaluation is conducted to determine eligibility. Students either are referred to vocational rehabilitation or apply directly. Transition generally begins in the last 2 years of high school and includes assessments of job-related skills, collaboration with the school district, career counseling and guidance, assistance with college or trade school education, assistive technology, on-the-job training, and services to help retain employment (Nevada Department of Employment, Training and Rehabilitation, n.d.[b]).

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

DMHDS has worked with the Department of Corrections, the courts, law enforcement, and first responders to organize trainings related to individuals with disabilities involved in the justice system, both as victims and offenders. DMHDS is notified if a homeless person is thought to have a developmental disability. In addition, a judge at a mental health court in Carson City refers individuals who have been arrested to the developmental services system; this relationship has been in place for about 10 years. DMHDS also organizes transition services and creates a service coordination team, which includes the parole officer.

Long-term plans to develop new or expanded supports and services (2–5 years)

ATAP is planning to ask the legislature for funding to cover the entire waiting list. They are also looking at ways to improve the continuum of care by making the transition out of early intervention and into school and developmental disability services more seamless.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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NEW HAMPSHIRE

Approach

The L&M research team held an initial discussion with the Administrative Director of the New Hampshire Council on Autism Spectrum Disorders to discuss the services and supports for persons with autism spectrum disorders (ASD) in New Hampshire. The L&M research team interviewed three representatives from the state of New Hampshire, comprising a range of perspectives related to the delivery of services to individuals with ASD in the state. The goal of these interviews was to obtain greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

At least 932 students in New Hampshire have a diagnosis of ASD; 107 new residents were diagnosed in 2011, the vast majority of which were under age 9 (New Hampshire Department of Health and Human Services, 2010b). According to interviewees, the New Hampshire service system for individuals with ASD is extremely fragmented. Although many people in the state are dedicated to serving this population, each program operates in its own “silo.” One stakeholder noted that she has attended planning meetings where three different care managers were in place for one child. This disjointed system makes it difficult for families to receive a comprehensive set of services.

The New Hampshire Council on Autism Spectrum Disorders (<http://www.nhcouncilonasd.org/>) was created by the state legislature in 2008 to provide coordinated leadership in addressing the health care, education, and service needs of individuals who experience autism or a related disability. In addition, New Hampshire has a Developmental Disabilities Council (<http://www.nhddc.org/>) that develops a state plan every 5 years to establish specific goals, objectives, and strategies to address the most important issues affecting people with developmental disabilities. The Council has enough funding for a part-time director.

State insurance regulations

H.B. 569, also known “Connor’s Law,” was introduced in 2009 amending the current mental health parity law to require health insurance companies to provide coverage for the diagnosis and treatment of ASD. The law covers habilitative or rehabilitative care, pharmacy care, psychiatric care, psychological care, or therapeutic care, as provided by a licensed physician or psychologist. Children aged 0–12 are allowed a maximum benefit of \$36,000 and children aged 13–21 a maximum benefit of \$27,000. An insurer may require a treatment plan stating that the treatment is medically necessary and is consistent with nationally recognized treatment standards. During the 2011 session, a bill was introduced that would repeal requirements that health insurance provide coverage for early intervention therapy as well as diagnosis and treatment of pervasive developmental disorders or ASD. H.B. 309 was referred to Interim Study in March 2012 and no further action has taken place (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

New Hampshire has a Katie Beckett provision allowing children under the age of 19 with disabilities to qualify for Medicaid even if their parents’ income is over the threshold. All

children with ASD may not qualify under this exemption (NH Department of Health and Human Services, 2010c).

State of New Hampshire 1915(c) waivers

Waiver Name	Population Served
NH In-Home Supports for Children with DD*	Individuals aged 0–21 with ASD/ID/DD
NH BDS Development Services*	Individuals of all ages with ASD/ID/DD
NH Acquired Brain Disorder Services	Individuals aged 22+ with brain injuries
NH Choices for Independence	Individuals aged 65+ or aged 18–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services (CMS), n.d.

Specific ASD waivers

New Hampshire does not have any waivers specific to individuals with ASD at this time.

Other waivers

The *NH In-Home Supports for Children with DD* waiver provides services to children from birth to age 21 with autism, intellectual disabilities, and developmental disabilities, who require long-term services and supports. About half of the children on this waiver are diagnosed with an ASD. The selection process is based on a ten-point scale determined by an individual's needs. The waiver cannot be used for therapeutic services that would otherwise be covered by Medicaid or private insurance. Typically this waiver is used to keep children who are on the verge of institutionalization in the home. An individual cost limit is set at \$30,000. The opportunity for participant direction is available. Services include:

- Consultations
- Enhanced personal care
- Environmental and vehicle modifications
- Family support/service coordination
- Respite care (CMS, n.d.)

The *NH BDS Developmental Services* waiver provides services for individuals across the lifespan who have autism or an intellectual or developmental disability, are Medicaid eligible, and meet the Intermediate Care Facility for Individuals with Intellectual Disabilities level of care. The waiver's services and supports allow for participant direction and emphasize choice, control and involvement in service planning, individualized budget development, and service delivery. Services include:

- Day services
- Residential habilitation/personal care services
- Respite

- Service coordination
- Supported employment
- Assistive technology support services
- Community support
- Crisis response
- Environmental and vehicle modification services
- Participant directed and managed services
- Specialty services

Findings

Services and supports for people with ASD

The Bureau of Developmental Services (BDS), under New Hampshire's Department of Health and Human Services (DHHS), contracts with 10 nonprofits, called area agencies, which provide services to individuals with developmental disabilities according to their geographic locations. Various programs are available through BDS, the school system, and vocational rehabilitation depending on the age and needs of the participant (New Hampshire Department of Health and Human Services, n.d.).

Early intervention

According to interviewees, New Hampshire casts a wide net for early intervention services. If children have at least a 33 percent developmental delay, they will receive some type of intervention through the state's Family Centered Early Supports & Services (FCESS). This agency is responsible for providing the Individuals with Disabilities Education Act (IDEA) Part C services. Children under age 3 who have an official diagnosis of ASD may receive \$4,500 every 6 months from ESS's Autism Proposal Fund. This fund was created recognizing that children with ASD may need different services—such as applied behavior analysis—than those available in the general early intervention program.

Anyone, including parents, who thinks that children may qualify, can refer them to early intervention. Services include:

- Assistive technology
- Audiology services
- Family support, education, and counseling
- Health and nursing services
- Medical services for diagnosis and evaluation
- Nutrition counseling and assessment
- Occupational therapy
- Physical therapy

- Psychological services
- Service coordination
- Social work services
- Special equipment
- Special instruction
- Speech/language therapy
- Transportation services
- Vision services (NH Department of Health and Human Services, 2010d)

Children receive screening and other services through the statewide network of Title V Children with Special Health Care Needs (CSHCN) clinics. These work closely with FCESS, focus on child development, and employ a variety of professionals including developmental pediatricians, coordinators, psychologists, and allied health professionals to assist with diagnosis and other statewide programs. Stakeholders indicated that children with ASD frequently utilize the feeding and swallowing consultation provided by the Title V CHSCN clinics.

School-aged children

Schools are the primary service provider for children aged 3–22. Children must have available all educationally necessary services as required by IDEA. According to our interviewees, positive behavior supports are a well-established part of the school service system.

Interviewees indicate that in addition to school-based and waiver services, children may receive some services from their local area agencies. This typically consists of 10 hours per month of respite care.

Adults

Adults with developmental disabilities are eligible for services through the 10 area agencies, including:

- Case management
- Day services that are similar to occupational therapy and social development
- Employment services, such as job training
- Personal care services
- Community support
- Family services
- Crisis services (New Hampshire Department of Health and Human Services, 2010a)

In addition, the Bureau of Vocational Rehabilitation (BVR) is a resource for those with disabilities to find employment. BVR contracts with two separate entities to provide services; one is in Massachusetts, and the other is in New Hampshire. Their services focus on providing employment skills through:

- Job coaching;
- Targeted programming;
- Life skills; and
- Improving cognitive function.

BVR also provides funding for an ASD-specific program, which helps develop clerical skills for employment in the insurance industry. However, interviewees indicate that BVR services are not optimal for those with ASD, citing the fact that the vocational rehabilitation program often ends its services just as those with ASD are beginning to have trouble with their employment situation, which sometimes leads to job loss. BVR has plans to improve targeted services to this population.

Systems tracking

In 2008, with the passage of He-M 501, New Hampshire became the second state in the Nation to establish a legislatively mandated statewide registry for ASD. All providers who are qualified to diagnose ASD must report each new diagnosis of a New Hampshire resident to the registry run by DHHS. The state plans to use data from this registry to improve current knowledge of ASD and improve services throughout the state (New Hampshire Department of Health and Human Services, 2010b).

Promotion of services and supports for people with ASD

Early intervention

Interviewees told the research team that the Title V CSHCN clinics provide materials to families with all relevant supports and services.

School-aged children

A number of agencies and program help to promote ASD services to school-aged children. These include:

- Local education agencies responsible for the state's Child Find program. They are required to identify any child between the ages of 2.5 and 21 who may be eligible to receive disability services, whether they are preschool age, in a public school, or in a private school. Once identified, these children are referred to an Individualized Education Program (IEP) team (New Hampshire Department of Education, 2008).
- New Hampshire Partners in Health (<http://www.nhpih.dartmouth.edu/index.html>) is a useful resource for children aged 0–21. They provide individual family advocacy to help families find needed supports and services. Program representatives will also join IEP meetings and coordinate with BDS.

- The Developmental Disabilities Council offers “resource consultation”; they are able to provide families with guidance about the system of care that they need to navigate and explain state resources.
- Easter Seals has three people available throughout the state to help explain the service system to families. They do not offer care planning but are a resource that families can call to determine what types of services to ask for and where to find them.

Adults

Interviewees indicated that families typically hear about BVR services through local schools during transition planning or through their local area agency.

Transitions and coordination of services

Early intervention to school

The transition process from early intervention begins at age 2. At this time, the child’s Individual Family Service Plan includes a transition plan. Between 9 months and 90 days before a child’s third birthday, the child’s EES care coordinator will make a referral to the local school system if they believe that he or she will be eligible for school services. Parents meet with the local educational authority to discuss their options and find out whether the school needs more information to determine whether or not a child is eligible. Finally, once eligibility is determined, parents and other stakeholders work together to develop an IEP to enumerate the services and supports that a child will receive (The Parent Information Center on Special Education, 2008).

One issue in transition is a dearth of services for the preschool group. Anecdotally, one interviewee mentioned that families typically only receive about 10 hours of weekly programming, even if a child has a diagnosis of autism. They may be eligible for an additional 10 monthly hours of respite from the local area agency or have private insurance that covers home-based programming. Otherwise, waiver services are the only publicly available option.

School-aged to employment

Transition planning begins at age 14 for those with disabilities. At the IEP meeting, additional stakeholders, such as representatives from BVR or other adult services, may join to help determine which services are necessary after graduation. This plan is revised yearly and governs the supports that children receive post graduation as well as the remaining high school classes and programs they participate in to best prepare them for their next steps (New Hampshire Department of Education, 2008).

One program that is helping to make transition easier for some young adults is called Project SEARCH. Interviewees specified that several of the participants have ASD. Students opt to complete their senior year in high school through this project as opposed to a school setting. They spend time immersed in a host business 5 days a week. The goal is for the student to learn practical skills in the classroom as well as on-the-job training by participating in several internships and experiences. The hope is that the program will lead to employment for those with disabilities (NH Department of Health and Human Services, 2010e).

Training for direct service support workers

The NH Autism Council created a set of core competencies that direct support professionals or paraprofessionals need in order to successfully work with those with ASD. The council set up some best practice guidelines, and the University Center for Excellence in Developmental Disabilities Education and Council on Developmental Disabilities run a yearly conference to help disseminate the information. This type of training is not a requirement.

In addition, respite providers in the state may take a Web-based competency training, which includes information about working with those with ASD.

Corrections

In 2010, HB 1559-FN established a database for people with disabilities within the Division of State Police so that anyone in contact with law enforcement who is in the database can get appropriate help as quickly as possible.

Long-term plans to develop new or expanded supports and services (2–5 years)

Interviewees indicated that the state is currently developing a survey to assess the needs of families of children and young adults with ASD. The survey includes questions about diagnosis, education services, community services, and recreational opportunities.

In addition, BVR is planning its first steps to develop a program to more specifically target the ASD population. They plan to begin by offering specific ASD trainings to employment and BVR staff as well as hiring psychologists with ASD specific credentials to provide consultation to vocational rehabilitation counselors.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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NEW JERSEY

Approach

The L&M research team interviewed four representatives in New Jersey, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies represented included the New Jersey Department of Human Services (DHS) Division of Developmental Disabilities (DDD), the New Jersey Department of Health (DOH) Division of Family Health Services, the New Jersey Department of Education Office of Special Education Programs, and the New Jersey Department of Labor and Workforce Development Division of Vocational Rehabilitation Services.

State background

A 2012 national study by the Centers for Disease Control and Prevention found that roughly 1 in every 88 children in the United States has autism or a related disorder (Centers for Disease Control and Prevention, 2012b). Strikingly, the rate in New Jersey was one in 49, the second highest in the country (Centers for Disease Control and Prevention, 2012a). Some researchers attribute the high rate in part to the state's sophisticated education services and high awareness of ASD indicators.

A subset of the New Jersey DHS, the DDD, is the lead resource agency that coordinates programs for those with ASD. In 2009, the Adults with Autism Task Force released a report recommending that DHS create a specific Office on Autism within the DDD. The office serves as a central space for issues related to ASD, promotes collaboration with other agencies, and encourages sharing of best practices in training staff and supporting individuals with ASD (New Jersey Department of Human Services, 2008a). Additionally, the Office on Autism, along with the DHS, Children and Families, Community Affairs, Education, Health, and Labor and Workforce Development, created a comprehensive resource guide for individuals and families with ASD (New Jersey Department of Human Services, 2011).

In July 2012, a dramatic realignment within the state government split services previously housed in DDD and moved them into separate departments. Early intervention (EI) services continue under the DOH and children's services are under the Department of Children and Families (DCF). Transition planning is provided by DDD in collaboration with DCF from age 16 to 21, at which point DDD takes over adult day services. The official deadline to transfer these services to their new divisions and departments was January 2013 (Family Support Center for New Jersey, n.d.).

State insurance regulations

As of 2009, according to S. 1651/A. 2238, specific health insurance policies and health benefit plans must provide coverage for screening and diagnosing of ASD and other developmental disabilities as well as certain therapies that are included in the treatment plan. If the primary diagnosis is ASD or another developmental disability and the individual is under age 21, behavioral interventions based on applied behavior analysis (ABA) are covered. Additionally, medically necessary occupational, physical, and speech therapy services are covered for individuals of all ages (National Conference of State Legislatures, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of New Jersey 1915(c) waivers

Waiver Name	Population Served
NJ Community Care Waiver*	Individuals of all ages with DD
NJ Community Resources for People w/ Disabilities	Individuals of all ages with physical disabilities
NJ AIDS Community Care Alternatives Program	Individuals of all ages with HIV/AIDS
NJ Global Options for Long Term Care	Adults aged 65+ or aged 21–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD Waiver

New Jersey does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *New Jersey Community Care* waiver has been in effect since 1982. The waiver is administered by DDD and provides for services and supports that individuals with developmental disabilities require to live in the community. To be eligible for services, individuals must:
 1. Meet the DDD eligibility threshold;
 2. Meet DDD criteria for Title XIX Level of Care for an Intermediate Care Facility for Individuals with Intellectual/Developmental Disabilities;
 3. Meet income and asset threshold for the New Jersey Medicaid Waiver; and
 4. Be reached chronologically on the waiting list for waiver services or meet DDD's emergency criteria.

Once enrolled on the waiver, individuals are entitled to receive services that will meet their assessed needs. These services include:

- Case management
- Individual supports
- Day habilitation
- Respite
- Supported employment
- Community transition services for individuals who self-direct
- Support coordination for individuals who self-direct
- Assistive technology devices
- Environmental and vehicle adaptations
- Personal Emergency Response System
- Transportation (NJ Division of Developmental Disabilities, 2008b)

State 1115 demonstration

- The *New Jersey Comprehensive Waiver* is an 1115 demonstration that was approved by the Centers for Medicare & Medicaid Services on October 1, 2012. The demonstration changes the financing, coordination of care, and other major aspects of Medicaid and CHIP. Although it combines many existing programs, it also has created two new pilot projects that will directly affect the ASD population. The DCF administers both of these pilot projects under the realignment of services.
 - The first pilot project is for children under the age of 12 with pervasive developmental disorders. The program will serve up to 200 children and is designed to provide behavioral support, such as ABA, and to keep services offered by Medicaid on par with those required in the insurance mandate.
 - The second pilot project—the Children’s Placement Enhancement Program—already exists in DDD as an intensive state-funded program that provides in- and out-of-home support for children under age 21 with co-occurring mental illness and developmental disability. The pilot will be a way to receive federal reimbursement for the program, which is currently funded by the state.

The *Comprehensive Waiver* includes the new Supports Program, which will provide services to adults (21 and over) who are eligible for developmental disabilities services and Medicaid, but are currently not enrolled in the Community Care Waiver. The program will provide employment services, day services, and individual and family support services for adults living at home with their families or on their own (New Jersey Division of Developmental Disabilities, 2008d).

Findings

Services and supports for people with ASD

The DDD Office on Autism promotes interagency cooperation among multiple state government entities to provide services to those with developmental disabilities at every age and in a linear and connected fashion. Individuals may participate in a variety of programs depending on the age of the participant.

Early intervention

The EI system is administered through the New Jersey DOH, Division of Family Health Services and implements the state’s system of services for individuals from birth to age 3 with developmental delays or disabilities as well as their families. There are four regional points of entry into the early intervention system, namely Family Link, Helpful Hands, Mid-Jersey Cares, and Southern Regional. Most children are referred by a health care provider or through a toll-free hotline that directs people into the system from anywhere in the state.

Eligibility is determined in one of two ways: (1) if a child has at least a 33 percent delay or a score of 2.0 standard deviations below the mean in one functional developmental area or (2) if a child has at least a 25 percent delay or a score of 1.5 standard deviations below the mean in two or more of the following developmental areas:

- Physical (including gross motor, fine motor, and sensory)
- Cognitive
- Communication
- Social or emotional
- Adaptive

The EI program helps with evaluation and assessment and works with the individual and family to meet developmental outcomes through the creation of an Individualized Family Service Plan (IFSP). If deemed appropriate through the IFSP, services may include assistive technology, audiology services, family training and counseling, developmental intervention, medical services, nutrition, occupational therapy, and physical therapy (New Jersey Department of Health, 2013).

School-aged children

The Department of Education Office of Special Education Programs (OSEP) is responsible for implementing state and federal laws and regulations governing special education, and school districts are responsible for providing educational evaluations and supports to students with developmental disabilities. OSEP also funds four Learning Resource Centers (LRCs) around the state that provide schools and parents with information, materials circulation, technical assistance, consultation, and production services. The LRCs also organize workshops, training institutes, and statewide conferences for families, educators, and other interested parties.

The Department of Children and Families Office of Education provides intensive 12-month educational services for children with developmental disabilities aged 3–21. The program offers comprehensive educational and behavioral supports with the goal of returning students with severe or unique needs to their original schools and increasing participation in the community (New Jersey Department of Children and Families, 2013).

Adults

For adults with ASD, person-centered plans help to identify individual interests and find the best ways to pursue those interests through support systems and resources. DDD provides case management for eligible individuals and funds a number of additional services, such as day services, supported employment, in-home supports, and residential services (group homes, supervised apartments, and supportive housing). These nonentitlement services depend on availability of resources and are provided by more than 280 community agencies and seven developmental centers throughout the state. Currently, more than 42,000 individuals are being served by DDD, the vast majority of which reside in the community, either with family or in a community residence (New Jersey Department of Human Services, 2008d).

The New Jersey Department of Labor & Workforce Development, Division of Vocational Rehabilitation Services (NJDVRS) offers vocational rehabilitation services to adults with disabilities, which lead to successful employment outcomes. NJDVRS serves individuals with physical, mental, and cognitive impairments including those with ASD. Individuals are determined eligible for NJDVRS if their disability poses an impediment to employment and as such the individual will require services in order to prepare for, obtain, and maintain employment. The number of NJDVRS consumers with ASD has continued to increase over the past few years due to a more heightened awareness of ASD. The number of those served however, may still be underrepresented due to the nature of the “disability coding” utilized by state VR agencies including NJDVRS. The services provided to NJDVRS consumers are individualized and based on informed choice. Services are not based on the individual’s diagnosis but rather the unique strengths and limitations of the individual as well as the vocational goal. Vocational guidance and counseling is the core service provided by trained master-level counselors and involves career assessment, vocational planning, job preparation, and job placement. Other services provided may include job coaching, skills training, tuition funding, assistive technology devices, and more. All services provided must serve the vocational goal and employment plan (New Jersey Department of Labor and Workforce Development, n.d.[a]).

NJDVRS is currently funding a vocational program and career center specific to adults on the Autism spectrum and has been soliciting other vendors to provide ASD specific services as well.

System tracking

New Jersey has a comprehensive tracking program for children and adults with ASD. Children under the age of 5 with a birth defect are required by law to be added to the Special Child Health Services Registry, and children aged 5–21 are often reported to the registry with parental consent, although it is not required. In addition to birth defects, the Special Child Health Services Registry also includes the Autism Registry whereby licensed health care professionals must register any child under age 22 diagnosed with ASD. Families cannot decline registration, but have the option to be in the registry without identifiable personal information. The adult registry is voluntary but available to anyone with an ASD diagnosis.

The Special Child Health Services Registry, which is mainly funded by the Center for Disease Control and Prevention as well as the New Jersey’s Autism Medical Research and Treatment Fund, serves as the primary access point to county-based special child health case management services. Registered children under the age of 3 are referred to EI services. EI service coordinators help facilitate transitions to Early or Special Education and eventually to the Special Child Health Case Management Unit if the child is known to EI first. These case managers help with transition to adulthood until age 22, when individuals are transferred to the DHS for assistance throughout adulthood. The registry does not provide identifiable information to other departments or agencies but allows for aggregate information.

In addition, there is a confidential Emergency Preparedness Registry that allows emergency response agencies to better prepare for and track individuals with functional needs during disasters and emergencies. Individuals with functional needs and their family members provide information related to specific assistance that may be necessary during adverse conditions. Emergency management officials review the information regularly.

Promotion of services and supports for people with ASD

The DDD Office on Autism serves as a hub for information pertaining to New Jersey services to ASD and offers links and contact data for other government departments with relevant programs. The programs bring together families that serve as an important support system for each other. In addition, the Child Find Program is a national free referral service for children with developmental delays and disabilities from birth to age 21. Child Find helps connect interested individuals with local Special Child Health Case Management Units, local school districts, and other community services.

Transitions and coordination of services

Early intervention to school

When children transition from EI to preschool, EI service coordinators organize a preschool transition planning conference. The meeting involves a member of the child study team who reviews the IFSP, provides parents with information on district registration requirements and available programs for preschoolers, and explains how to request that the District Board of Education invite the early intervention service coordinator to the initial Individualized Education Program (IEP) meeting. The initial IEP meeting often includes family, friends, teachers, child study team representatives, EI service coordinators, and other individuals important to the well-being of the child.

School-age to employment

Transitions from school to employment are included in the IEP, with discussion starting around age 14. Transition plans are reassessed every year until graduation or exit from high school. At age 16, schools conduct a transition assessment that aims to identify individuals' postsecondary goals in further education, training, employment, and independent living. "Person-centered planning" is used in determining young adults' interests and the necessary supports for pursuing those interests.

A primary goal of DVRS is to include a transition counselor in every school. Once children are age 14, counselors are available to meet with students and their families to begin planning for services (New Jersey Department of Labor and Workforce Development, n.d.[b]). In addition, students transitioning to adulthood learn about vocational rehabilitation services through public forums, the DVRS Web site, and other outreach programs. DVRS has a specific focus on reaching underserved and minority populations, including people with more complex needs. Students can apply for DVRS services up to 2 years before they leave secondary school.

DDD provides training programs related to helping students transition to the adult service system (New Jersey Department of Human Services, 2008c).

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

In New Jersey, the Criminal Justice Advocacy Program uses intervention, advocacy, case management, education, training, and personalized justice plans to help individuals with developmental and intellectual disabilities navigate the criminal justice system. The program works with individuals who encounter the criminal justice system to help them understand the process and their options. The program runs training programs for target audiences including defense and prosecuting attorneys, court officials, judges, police officers, parole officers, and community service agencies. Additionally, the program helps to present Personalized Justice Plans as alternatives to incarceration; these plans often focus on community-based alternatives with an emphasis on community monitoring (The Arc of New Jersey, n.d.).

Long-term plans to develop new or expanded supports and services (2–5 years)

In June 2012, the New Jersey Governor's Council for Medical Research and Treatment of Autism named Montclair State University the Coordinating Center of the Autism Spectrum Disorder Center of Excellence. This 5-year program has set funding and is dedicated to research around understanding, preventing, and treating ASD. The coordinating center supports three newly funded clinical research sites across the state (Montclair State University, n.d.).

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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NEW MEXICO

Approach

The L&M research team interviewed two representatives from the state of New Mexico, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the New Mexico Developmental Disabilities Supports Division and the Division of Health. Extensive research was done on other agencies across the state and the services and supports that they offer.

State background

The Developmental Disabilities Supports Division (DDSD) within the Department of Health (DOH) is the main provider of services and supports for individuals with ASD (New Mexico Department of Health, n.d.[a]). Most services are delivered through the Developmental Disabilities Waiver, which serves individuals across the lifespan. Although individuals of all ages are eligible for the waiver, a multiple-year waitlist hinders the waiver from effectively covering young children. There is no interagency task force on ASD in the state, so DDSD has stepped into the role of coordinating services and supports.

State insurance regulations

In 2009, Senate Bill 39 was signed into law, mandating health insurance coverage for the diagnosis and treatment of ASD for individuals up to age 19 or 22 if the person is still in high school. The insurance coverage is limited to prescribed treatments and has an annual and lifetime cap of \$36,000 and \$200,000, respectively. As of 2011, the limits are adjusted for inflation every January (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of New Mexico 1915(c) waivers

Waiver Name	Population Served
NM Developmental Disabilities*	Individuals of all ages with DD
NM Mi Via-ICF/MR*	Individuals of all ages with autism/DD/ID
NM Mi Via NF	Individuals aged 65+ and aged 0–64 with physical disabilities
NM Coordinated Long-Term Services	Individuals aged 65+ and aged 0–64 with physical disabilities
NM AIDS	Individuals of all ages with HIV/AIDS
NM Medically Fragile	Individuals of all ages who are medically fragile

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

New Mexico does not have any waivers specific to individuals with ASD at this time.

Other waivers

Two HCBS waivers in New Mexico allow people with ASD to receive services.

- The *New Mexico Developmental Disabilities* waiver is run by DDS and provides services to individuals of all ages with developmental disabilities—including ASD—who would otherwise require the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities. As of 2011, 3,690 individuals were covered on this waiver. There is an approximate 7-year chronological waitlist for waiver services. Because the waitlist is long, most individuals are about 18 years old by the time they access the waiver. However, DDS can expedite or create emergency allocations based on eligible crisis situations. DDS is also going through a renewal process to allocate funding more quickly and make services more efficient. Services include:
 - Case management
 - Behavioral support consultation
 - Respite
 - Nutrition counseling
 - Supplemental dental care
 - Nonmedical transportation
 - Personal support technology/onsite response service
 - Crisis support
 - Supported employment, including job development and job coaching
 - Day habilitation
 - Occupational therapy for adults
 - Physical therapy for adults
 - Speech and language therapy for adults
 - Customized in-home supports
 - Assistive Technology
 - Residential habilitation
 - Preliminary risk screening and consultation related to inappropriate sexual behavior
 - Socialization and sexuality education
 - Environmental modifications
 - Supplemental dental care
 - Personal support services
 - Independent living transition services
 - Crisis supports
 - Adult nursing
 - Intense medical living supports
 - Nonmedical transportation (New Mexico Department of Health, 2012)
- The *New Mexico Mi Via-ICF/MR* waiver is a collaborative effort between the New Mexico Aging and Long-Term Services Department, the Human Services Department, and the DOH to serve individuals with a developmental and intellectual disability or a specific related condition. The Mi Via-ICF/MR waiver further targets certain medically fragile groups. The Mi Via waiver is a self-directed waiver in which participants can develop their own Service and Support Plan, based on assessed level of need, with the help of a consultant. Individuals can access many of the same services as the

Developmental Disabilities Waiver as well as some services offered through the Medically Fragile waiver (New Mexico Department of Health, n.d.[b]). Waiver services include:

- Consultant support
- Customized community and in-home supports
- Employment supports
- Homemaker/direct support services
- Respite
- Supplemental home health aide services
- Supplemental skilled therapy for adults
- Supports for self-direction
- Assisted living
- Behavior support consultation
- Community direct support
- Emergency response services
- Environmental modifications
- Nutritional counseling
- Private duty nursing for adults
- Related goods
- Specialized therapies, including but not limited to cognitive rehabilitation therapy, hippotherapy, and play therapy
- Transportation

Findings

Services and supports for people with ASD

The DDSO organizes many services for individuals across the lifespan with ASD. Most of these services are offered on the Developmental Disability waiver; however, services and supports are available to those on the waiting list. A state general fund helps provide services for people on the waitlist. Some services, such as respite, day habilitation, supported employment, and some therapy services can be accessed through state Medicaid funds.

Individuals and families sometimes encounter difficulty finding service providers in certain areas of the state; ability to access services is often dependent on where one lives and the involvement of the school district. For example, adaptive skill building classes are available only in certain counties, but the DOH provides some funding to DDSO to help with technical assistance for adult providers.

Early intervention

Early intervention services are housed within DDSO and run through the Family Infant Toddler (FIT) program. The program works to help families meet the needs of their children through family-centered services that are based on relationships between the family and child and take place in children's natural environments. Once children are referred to FIT, they receive a free evaluation. If they are determined eligible for services, FIT helps create an Individualized Family Service Plan (IFSP), which is reviewed every 6 months and offers service coordination along

with the services outlined in the IFSP. The FIT program contracts with more than 30 local early intervention agencies across the state to provide services, which include:

- Adaptive equipment
- Audiological services
- Family education
- Counseling
- Home visits
- Health services
- Nursing services
- Nutrition services
- Psychological services
- Occupational therapy
- Physical therapy
- Speech therapy
- Vision services
- Transportation services
- Transition planning to the preschool education program (Family Infant Toddler Program, n.d.[b])

Services are paid for with a combination of New Mexico state general funds, an annual grant from the U.S. Department of Education, Medicaid, and private insurance. The FIT Interagency Coordinating Council is mandated under Part C of the Individuals with Disabilities Education Act (IDEA) and helps the agency identify monetary resources, prepare applications, assist with transition to preschool and other educational services, and prepare and submit an annual report to the governor (Family Infant Toddler Program, n.d.[a]).

The University of New Mexico Center for Development and Disability also has an adaptive skills program for children aged birth to 5. Many children come to the University to get an evaluation, but the coaching often takes place in the child's natural environment, typically the home.

School-aged children

School-aged children with ASD receive special education services in accordance with IDEA. The New Mexico Department of Special Education has worked to highlight best practices for developing Individualized Education Programs (IEPs) for students with ASD. Some of the best practices that they recommend include extended educational programming, daily schedules with minimal unstructured time, positive behavior support strategies, parent and family training and support, communications interventions, social skills supports, and professional education and staff support. For school-aged children on the Developmental Disabilities Waiver, case managers

put a lot of emphasis on working with the IEP team, especially during transition years (New Mexico Public Education Department, 2011).

The DOH received funding from the state legislature to establish an adaptive skill-building course for children aged 5–18 after school. Four providers at the University of New Mexico provide services and adaptive skills classes for children and their families. DOH also has some recreational respite programs in which children can sign up for a 10-week program with activities every Saturday that include art, theater, and other activities.

Adults

The Department of Vocational Rehabilitation (DVR) offers services for adults with ASD. To be eligible, individuals must have a physical or mental impairment that impedes employment, show that they will benefit from a positive employment outcome, and require vocational rehabilitation services in order to prepare for and engage in gainful employment. Vocational rehabilitation helps participants to find a career that fits the individual based on personal interests, skills, and abilities. DVR offers one-on-one job placement services, provides access to assistive technologies, and helps the individual prepare for an entry-level job that will launch a career path. They offer many types of training and planning, such as school-to-work transition planning, rehabilitative engineering, job coaching and training, independent living services, and postemployment services. DVR assists individuals until they have been successfully employed for 90 days (New Mexico Public Education Department, n.d.).

Individuals on the Developmental Disabilities Waiver are required to access DVR resources first to see whether they can receive vocational rehabilitation services. Otherwise individuals can access available employment services through the Developmental Disabilities Waiver.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

If children are already on the Developmental Disabilities Waiver, their case manager works extensively with the school to help create an IEP and utilize the best services available.

School-age to employment

Transition typically begins 5 years prior to graduation, with an emphasis on the last 2 years before graduation. Individuals must transition out of school prior to their 22nd birthday. Transition planning is focused on designing an educational program to prepare students for postsecondary education plans. Ideally, individuals are on the waiver by the time they graduate;

if students are on the waiver before leaving school, they can transition to DDS waiver services the summer before their last year of school to soften the transition.

Training for direct service support workers

The DDS offers a series of classes that direct service providers are required to take; however, they are not specific to individuals with ASD. In addition, the University of New Mexico offers individualized technical assistance and statewide trainings related to ASD for parents, providers, teachers, and other interested parties. They also have Web-based programs for individuals who cannot attend the training sessions.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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NEW YORK

Approach

The L&M research team interviewed three representatives from the state of New York's Office for People with Developmental Disabilities (OPWDD). The goal for the interviews was to obtain greater understanding of services and supports available to those with autism spectrum disorders (ASD) throughout the state. Interviews focused on early intervention, school-aged services, vocational rehabilitation, and other adult services.

State background

In New York, OPWDD is responsible for providing services for individuals with ASD across the lifespan. According to interviewees, autism is a possible eligibility criterion for OPWDD services, but individuals must also be two standard deviations away from the norm in adaptive functioning. Since 1990, OPWDD has seen a 500 percent increase in the number of individuals with ASD, which currently represents 17 percent of their service population (New York State Office for People With Developmental Disabilities, n.d.).

In response to this growing population, New York State created the NY State Interagency Task Force on Autism, which was co-led by OPWDD and the New York State Education Department. The task force completed its work in 2009 and submitted a report in January 2010 to help the state address the needs of those with ASD despite shrinking budgets. The member agencies included:

- State Education Department
- Office of Mental Health
- Office of Children and Family Services
- Office of Temporary Disability Assistance
- Department of Health
- Office of Alcohol and Substance Abuse Services
- Council on Children and Families
- Commission on Quality of Care and Advocacy for Persons with Disabilities
- New York State Insurance Department
- Developmental Disabilities Planning Council

Additionally, the Autism Platform was created in 2008 in response to the growing ASD population. The Autism Platform is “a comprehensive slate of state initiatives intended to specifically address the needs of people on the autism spectrum within a service system that supports individuals with a wide range of diagnoses.” This platform was amended in 2010 to match the recommendations of the task force (New York State Office for People With Developmental Disabilities, 2012a).

State insurance regulations

As of November 1, 2012, private health insurance companies must provide coverage for the screening, diagnosis, and treatment of ASD according to S.5845/A6305A. If the policy covers prescription drugs and therapeutic care for other conditions, it must also cover those for ASD, in addition to psychological care, psychiatric care, and behavioral health treatment provided by a licensed health care provider. There is a \$45,000 cap for applied behavior analysis (ABA) services. The law also prohibits an insurance company from terminating coverage or refusing to renew, adjust, amend, issue, or execute a policy solely because the individual has been diagnosed or received treatment for ASD. In addition, the law includes a provision, New York [ISC] §3216, precluding insurers from denying or in any way limiting a policy because someone has a diagnosis of ASD. Health insurance policies that would cover hospital, surgical, or medical care may not deny or exclude coverage for any of these services on the basis of an autism diagnosis (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of New York 1915(c) waivers

Waiver Name	Population Served
NY CAH I/II	Children aged 0–17 with a physical disability
NY CAH III*	Children aged 0–17 with ID/DD/ASD and who are also medically fragile
NYS OPWDD CAH IV*	Children aged 0–17 with ID/DD/ASD and who are also medically fragile
NY CAH VI*	Children aged 0–17 with ID/DD/ASD and who are also medically fragile
NY Bridges to Health for Children w/DD*	Children aged 0–20 with ID/DD/ASD
NY Bridges to Health for Children w/SED	Children aged 0–18 with SED or aged 19–20 with mental illness
NY Bridges to Health for Children who are Medically Fragile	Children aged 0–20 who are medically fragile
NY OMH SED	Children aged 5–21 w/ SED or mental illness
NY OPWDD Comprehensive*	Individuals of all ages with ID/DD/ASD
NY Traumatic Brain Injury	Individuals aged 18+ with traumatic brain injury
NY Long Term Home Health Care Program	Individuals aged 65+ or aged 0–64 with a physical disability
NY Nursing Home Transition and Diversion Medicaid Waiver	Individuals aged 65+ or aged 18–64 with a physical disability

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

New York does not have any waivers specific to individuals with ASD at this time.

Other waivers

Five waivers include autism as an eligible diagnosis. The waivers that cover individuals with autism are as follows:

- The *New York CAH III* waiver is one in a series of Care at Home (CAH) waivers that serve children under the age of 18 who are medically fragile with a diagnosed intellectual or developmental disability, including ASD, who would otherwise need the level of care provided by an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). This waiver serves 200 children and provides:
 - Case management
 - Respite
 - Assistive technology
- The *New York OPWDD-CAH IV* waiver is for children under the age of 18 who have a diagnosed intellectual or developmental disability or are medically fragile, including ASD. Participants also need to meet the requirement of an ICF/IID level of care. The capacity of this waiver is 200 and includes:
 - Case management
 - Respite
 - Assistive technology
- The *New York CAH VI* waiver is the final in the series of CAH waivers that serves those under the age of 18 with a diagnosed intellectual or developmental disability (including ASD) or who are medically fragile, who would otherwise need an ICF/IID level of care. This waiver also serves 200 children and includes:
 - Case management
 - Respite
 - Assistive technology
- The *New York Bridges to Health (B2H) for Children with Developmental Disabilities* waiver allows children under the age of 21 with developmental disabilities in foster care or the justice system to receive additional services. Children may stay on the waiver after they leave the foster care or justice system. To qualify, children must have a diagnosed intellectual or developmental disability, including autism, and require an ICF/IID level of care. An array of services has been tailored to meet the needs of this population including:
 - Day habilitation
 - Health care integration
 - Skill building
 - Special needs community advocacy and support
 - Accessibility modifications
 - Adaptive and assistive equipment
 - Crisis avoidance and management
 - Crisis respite
 - Family/caregiver supports and services
 - Immediate crisis response services
 - Intensive in-home supports and services
 - Planned respite
 - Vocational services

- The *New York OIDDD Comprehensive* waiver serves those of any age who would otherwise require an ICF/IID level of care and are diagnosed with an intellectual or developmental disability, including ASD. The waiver supplements natural supports and community-based resources to allow the participant to be as independent and, when feasible, as self-directing as possible. The goal is to allow participants to live in the home of their choice, engage in the community, and maintain good health and meaningful relationships (Perrin, 2011). The waiver offers a wide range of services including:
 - Day habilitation
 - Live-in caregiver
 - Prevocational services
 - Pathway to employment
 - Supported employment
 - Residential habilitation
 - Respite
 - Financial management choices
 - Consolidated supports and services
 - Support brokerage
 - Assistive technology
 - Adaptive devices
 - Community habilitation
 - Community transition services
 - Environmental modifications
 - Family education and training
 - Intensive behavioral services
 - Plan of care support services

Findings

Services and supports for people with ASD

In addition to the waiver services outlined above, the New York State Department of Health (DOH) provides early intervention (EI) services and the New York State Education Department (NYSED) provides special education and vocational rehabilitation services. OPWDD can also provide services at any age, but is primarily responsible for those who have already aged out of school.

Early intervention

Very young children are eligible for EI services through DOH. In this case, local public health agencies provide a caseworker to develop an Individualized Family Services Plan (IFSP) and guide the family through appropriate avenues to receive services. Services are provided in the home or the child's daycare and include:

- Family education and counseling
- Home visits
- Parent support groups
- Special instruction

- Speech pathology and audiology
- Occupational therapy
- Physical therapy
- Psychological services
- Service coordination
- Nursing services
- Nutrition services
- Social work services
- Vision services
- Assistive technology devices and services

To apply for EI, individuals must go to their municipal Early Intervention Official (EIO), which administers the program. They can also contact the DOH Bureau of Early Intervention to be connected with their EIO (New York State Department of Health, n.d.).

School-aged children

When children turn 3, NYSED assumes the responsibility for providing them with a free and appropriate education in the least restrictive environment according to the Individuals with Disabilities Education Act (IDEA). The educational system works with parents and others to create an Individualized Educational Program (IEP) and provides all services according to this document, including school aides and any therapy deemed necessary to help the child be educationally successful.

In addition, OPWDD, the NYSED, and New York City's Department of Education are partnering to provide behavioral assessment and intervention services to students in public school settings who present with severe behavioral challenges. The program serves students with developmental disabilities including ASD, who display severe aggression and/or self-injurious behaviors that pose a significant health and safety risk. A clinical team of experienced, doctoral-level behavioral psychologists and Board Certified Behavior Analysts supplement resources within the school by assessing students and developing and implementing behavior intervention plans. All assessment and treatment occurs in the school setting in collaboration with teachers, staff, and caregivers. In September of 2009, the Autism Platform's goal of providing intensive behavior services in public schools was realized; preliminary evaluations showed tremendous success as well as teacher and caregiver satisfaction (New York State Office for People With Developmental Disabilities, 2012b).

The *New York Times* recently highlighted the special education preschool program in New York. The program has existed much longer than IDEA, and the state has used private contractors to provide these services, which has become very expensive. This year alone, NYSED plans to spend approximately \$1 billion on the special education preschool program, which amounts to roughly \$40,000 per child. Due to these astronomical figures, the state may choose to reform its preschool education in the coming years (Halbfinger, 2012).

Adults

OPWDD provides and certifies services through local developmental disabilities regional offices. These offices work with provider agencies to coordinate services within a region, which include:

- Speech therapy
- Occupational therapy
- Nutrition services
- Social work and psychology
- In-home habilitation
- Day services
- Residential services
- Supported employment
- Respite (NYACTS, 2012)

Adults with disabilities may also be eligible for the Adult Career and Continuing Education Services—Vocational Rehabilitation (ACCES-VR) program through NYSED. This comprehensive program works with both individuals and businesses for placement and followup and mediates problems that occur in employment situations to ensure that individuals with disabilities meet their employment goals. ACCES-VR also administers funding for 39 Independent Living Centers, which help individuals with developmental disabilities live independently in their communities. These centers are nonresidential, are primarily governed and staffed by people with disabilities, and provide peer counseling, life skills training, referral services, and information to promote self-advocacy (New York State Education Department, 2011).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

A 2008 law required DOH to set up recommendations for early detection. Children are screened with the M-CHAT at 18- and 24-month well-child pediatrician appointments and are referred for a full diagnosis if their score suggests they are at risk for ASD. Those under age 3 are referred to early intervention through their individual municipal governments (New York State Department of Health, 2013). DOH also developed an extensive outreach plan that has occurred through public libraries for the past 2 years in the month of April during Autism Awareness Month to provide information to the general public on ASD.

New York Adults and Children on the Autism Spectrum (<http://www.nyacts.org>) offers comprehensive web Web-based resources for individuals with ASD across the lifespan. It provides information on autism, services and supports, relevant federal and state legislation, and other state autism initiatives.

In addition, NYSED has made efforts to engage parents by creating an autism section of their Web site and offering annual autism conferences. They also have 13 parent centers located across the state to assist parents of individuals with disabilities in developing advocacy skills and understanding their children's disabilities and educational rights (New York State Education Department, 2013).

The 2010 report from the Interagency Task Force on Autism noted that New York needs to broaden its outreach efforts. The state relies heavily on internet-based tools to promote ASD services. Although their current Web sites are useful, the task force stressed the importance of providing other forms of outreach to families that may not have Internet access (New York State Office for People With Developmental Disabilities, 2012c).

Transitions and coordination of services

Early intervention to school

Children transition from EI to school according to their IFSP. The state provides preschool special education for children aged 3–5 with developmental disabilities and similarly school-aged special education for individuals aged 5–21. An IEP is developed for children eligible for school-aged special education services. Related services are included on the IEP and provided in the school setting whenever possible. Available related services and supports include:

- Assistive technology
- Counseling
- Hearing and vision education services
- Occupational therapy
- Paraprofessional services
- Parent training and counseling
- Physical therapy
- School health services
- Speech therapy
- Transportation (Advocates for Children of New York, 2012)

School-age to employment

By law, the transition process begins before age 15, but can start as early as age 12 in New York. Students and parents help to structure the transition segment of the IEP, which is updated annually, and school districts conduct vocational assessments, including a review of school records, comprehensive assessments, and interviews with parents and students to determine career aptitude and interests (New York State Office for People With Developmental Disabilities, n.d.). NYSED also provides a transition specialist for students leaving school. Because NYSED runs the ACCES-VR program, students do not need to transition out of one agency and into another (NYACTS, 2012).

In 2010, Cornell University established the Transition Services Professional Development Support Center (PDSC). Although not fully implemented, PDSC will provide a Web-based transition tool for all school districts; the tool will focus on five quality indicators, such as student-focused planning and interagency coordination. PDSC will also create an online forum for districts to discuss transition improvement with other districts (DeLorenzo, 2010).

Training for direct service support workers

The Autism Platform outlined a number of current and future training initiatives targeted toward professionals, caregivers, and others interacting with individuals with ASD. Among these initiatives are:

- *A Residential Services Training Curriculum.* In February of 2011, OPWDD finalized a comprehensive staff-training curriculum to be used in four community-based homes for adolescents and adults with ASD that are currently in development. This training will focus on communication, social interaction, and sexuality. It will be available to OPWDD regional staff and volunteers accessible via online modules or DVD.
- *Targeting the Big Three.* As a result of a Family Services Community Grant from Autism Speaks, OPWDD implemented this program in March 2010. The program is a train-the-trainer model that includes a 5- to 6- week curriculum geared toward families and caregivers of those with ASD based on the principles of ABA. State and voluntary agency clinicians are trained to deliver the program to its target population.
- *First Responders Sensitivity and Awareness Training.* In 2007, one of OPWDD's Developmental Disability Services Offices held training sessions focused on autism and first response. The training included sessions for parents, advocates, and first responders, including police, firefighters, and emergency medical technicians. In 2011, Niagara University developed a version of this training for statewide implementation.
- *Positive Relationships Offer More Opportunities to Everyone.* This is a training program geared toward OPWDD clinical and direct support staff who work with individuals with disabilities. The goal is "to shift the philosophy of staff from behavior control and crisis intervention to that of fostering positive and functional relationships, environments, communication, and respect." PROMOTE training for staff in state operated and voluntary programs will begin in 2013; full implementation is expected in 2014.
- *Navigating Multiple Services Training.* This will be an online video to assist families in navigating the New York State Service System and finding support for their loved ones with disabilities. The project is a collaboration between OPWDD and nine other state agencies (New York State Office for People With Developmental Disabilities, n.d.).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Some of the initiatives of the Autism Platform that will enhance the service and outreach system in the state are outlined below.

- A volunteer expert panel is currently reviewing the 1999 ASD assessment and diagnostic guidelines for children aged 3 and under.
- The platform is calling for new training initiatives, including:
 - Training for Medicaid service coordinators;
 - Promotion of trainings for multicultural service providers; and
 - Expansion of emergency preparedness training for individuals with developmental disabilities throughout the state (New York State Office for People With Developmental Disabilities, 2012a).

Other relevant programs and services

The New York State Commission on Quality of Care and Advocacy for Persons with Disabilities is an agency that offers advice and training on disability issues, and provides advocacy services and ensures accountability of the state's mental hygiene system (NYACTS, 2012).

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NORTH CAROLINA

Approach

The L&M research team interviewed one representative from North Carolina in order to learn about the service system available for individuals with autism spectrum disorders (ASD) throughout the lifespan. In addition to information gathered from the interviewee, the team used online resources to fill in gaps in knowledge. Overall, the team attempted to learn about services available to young children in early intervention, school-aged children through the school system, and adults through vocational rehabilitation and other sources.

State background

In 2003, North Carolina drastically altered its service system by dividing its sections in the Department of Health and Human Services' (DHHS) Division of Mental Health, Developmental Disabilities, and Substance Abuse Services by function rather than diagnoses. The division is divided into five sections along functional lines. These sections include Community Policy Management, Resource/Regulatory Management, Advocacy and Customer Service, Operations Support, and Clinical Policy (North Carolina DHHS, 2013).

North Carolina has a state-mandated Council on Developmental Disabilities (NCCDD). The council has been in place since 1962 and maintains a membership of which at least 60 percent of the council includes family members of or individuals with a developmental disability. The council awards grants, studies and participates in creating policy, and creates a 5-year plan to help set funding priorities. Their most recent plan was published in 2011 (NCCDD, 2012).

Individuals with ASD do not automatically qualify for state funding; they must also have a developmental disability. The state definition of developmental disability largely resembles the federal definition but includes similar disabilities acquired by traumatic brain injury (TBI) later in life. The definition can be found in North Carolina General Statute 122C-3(12a) and requires that the disability be exhibited before age 22 (except in the case of TBI), will likely continue indefinitely, and causes functional limitations in at least three of five areas of major life activities. Children under the age of 10 who have a substantial developmental delay or a congenital or acquired condition without functional limitation in at least three areas may qualify if there is a high probability they will meet the criteria for developmental disability later in life (NCCDD, n.d.).

State insurance regulations

There is no ASD insurance mandate; however, there may be some coverage for individuals with ASD under the mental health parity law. Insurance plans must provide coverage for mental illnesses—including autism as defined by the DSM IV—as they do for physical illnesses. Insurance plans can set their own criteria for medical necessity but must cover a minimum of 30 combined inpatient/outpatient visits per year (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

North Carolina has a Katie Beckett exemption for children with disabilities. This means that for qualified children, their parents' income will not factor in to their eligibility for Medicaid,

making it more likely they will be accepted in to the program and potentially receive waiver services (North Carolina DHHS, 2013).

State of North Carolina 1915(c) waivers

Waiver Name	Population Served
NC Community Alternative Program for Children	Individuals aged 0–20 who are medically fragile
NC Comprehensive Waiver*	Individuals of all ages with autism/DD/ID
NC Supports Waiver*	Individuals of all ages with autism/DD/ID
NC Community Alternatives Program for Disabled Adults	Individuals aged 65+ or aged 18–64 with disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

North Carolina does not have any waivers specific to individuals with ASD at this time.

Other Waivers

- The *North Carolina Comprehensive* waiver is administered by the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services and the Division of Medical Assistance with the help of Local Management Entities. The program was created to provide home- and community-based services to those with intellectual disabilities (IDs) or developmental disabilities (DDs) that are eligible for an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) level of care. The waiver provides the opportunity for participant direction. The full list of services includes:
 - Adult day health
 - Behavior consultation
 - Community transition
 - Crisis services
 - Crisis respite
 - Day supports
 - Home and community supports
 - Home modifications
 - Individual caregiver training and education
 - Individual goods and services (for participant direction)
 - Long-term vocational supports
 - Personal care services
 - Personal Emergency Response System
 - Residential supports
 - Respite services
 - Specialized consultative services
 - Specialized equipment and supplies
 - Supported employment
 - Transportation
 - Vehicle adaptations (North Carolina DHHS, 2010a)

- The *North Carolina Supports* waiver is administered by the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services and the Division of Medical Assistance with the help of Local Management Entities (LMEs). It was created to provide home- and community-based services within a \$17,500 annual cost limit to those with IDs or DDs who are eligible for an ICF/IID level of care. The services provided are similar to the Comprehensive Waiver but do not include residential supports. Participant direction opportunities are available. The full list of services includes:
 - Adult day health
 - Behavior consultation
 - Crisis services
 - Crisis respite
 - Day supports
 - Home and community supports
 - Home modifications
 - Individual and caregiver training
 - Individual goods and services (self-direction only)
 - Long-term vocational supports
 - Personal care services
 - Personal Emergency Response System
 - Respite services
 - Specialized consultative services
 - Specialized equipment and supplies
 - Supported employment
 - Transportation
 - Vehicle adaptations (North Carolina DHHS, 2010b)

Findings

Services and supports for people with ASD

LMEs are responsible for managing, coordinating, facilitating, and monitoring the provision of mental health, developmental disabilities, and substance abuse services in the area that they serve. Services are delivered by private entities that contract with the LMEs. They range from large nonprofits such as The Arc, the Autism Society of North Carolina, and Easter Seals to individual providers. (North Carolina DHHS, 2012).

Early intervention

The North Carolina Early Intervention Branch (<http://www.beeearly.nc.gov/index.php/>) is under the DHHS Division of Public Health and serves as the lead agency for the state's Individuals with Disabilities Education Act (IDEA) Part C services—the Infant-Toddler Program. Services are provided through 18 local Children's Developmental Service Agencies (CDSAs). Depending on the individual needs of the child, some services may include:

- Service coordination
- Physical therapy
- Occupational therapy

- Speech therapy
- Family support
- Assistive technology

School-aged children

School-aged children are primarily served through the Department of Public Instruction (DPI). DPI provides all educationally necessary services according to Part B of IDEA and according to each child's Individualized Education Program (IEP). The department emphasizes that children with ASD may need a specific set of accommodations including particular types of transition between activities or a certain classroom structure. They also publish an autism best practices list on their Web site (Public Schools of North Carolina, 2013).

Outside of school, children who are eligible to receive CAP funding through Medicaid may access the variety of services mentioned in the waivers section. This includes various types of therapies, respite care, home supports, and other services.

Adults

The DHHS Division of Vocational Rehabilitation Services (VRS) is a primary service provider for adults with disabilities (services are contracted). In fiscal year 2011, VRS assisted with successful employment for 6,303 of their clients. Some services available through VRS include:

- Disability determination
- Counseling
- Transportation
- Independent living skills
- Job coaching and other employment skills (North Carolina DHHS, 2013)

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

According to state stakeholders, LME-MCOs are primarily responsible for outreach, which is conducted on a regional basis. The state offers a series of helplines, including one for children with special health care needs, which are publicized and help families find the appropriate service providers for family members with disabilities.

The Infant-Toddler Program Web site (<http://www.bearly.nc.gov/index.php/>) states a goal of increasing parents' and families' awareness of their rights according to Part C of IDEA. At their comprehensive Web site families can find their local CDSAs and learn about developmental milestones and the early intervention program.

Transitions and coordination of services

Early intervention to school

Beginning around a child's second birthday, parents meet with their Early Intervention Services Coordinator (EISC) to develop a transition plan. Nine months before a child's third birthday, the EISC, parents, current service providers, and potential future service providers hold a transition conference to discuss next steps. At this point, with parental permission, a child may be referred to preschool services through DPI. Parents then meet with a representative from their local education authority and develop an IEP. If a child is eligible for services, parents can help determine which, if any, preschool program is appropriate for the child (North Carolina Infant-Toddler Program, 2007).

School-aged to employment

Transition to adulthood in North Carolina begins at age 14. At this time, the student and a team of relatives, teachers, guidance counselors, a transition coordinator, adult services providers, and others assemble to define the student's future goals and create an Individualized Transition Plan to attain these goals (Autism Society of North Carolina, 2013c).

Training for direct service support workers

The Autism Society of North Carolina holds an annual educational conference for families and those who work with people on the autism spectrum. The conference workshops are practical and focused on working specifically with individuals with ASD. The goals of the trainings vary but include enhancing communication, positive behavior supports, and social skills development (Autism Society of North Carolina, 2013b).

The Division of Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH) is a group of university-based centers headquartered in Chapel Hill that developed an influential method of teaching in the ASD community. TEACCH provides trainings to teachers and service providers. They focus on creating a physical learning environment as well as lesson structures conducive to teaching individuals with ASD (University of North Carolina at Chapel Hill School of Medicine, 2013).

The Autism Spectrum Disorders Program through DPI has the goal of providing effective training to those working with children who have ASD. Their Web site states, "Creating local experts that support the school-based teams is [important]." They have no current trainings posted online; however, they do have several Web-based resources (Public Schools of North Carolina, 2013).

Corrections

North Carolina has a Justice Systems Innovations Team through the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services that is committed to producing promising practices to keep those with DD out of the justice system or receiving appropriate treatment when they do have contact with Justice System. Much of this involves training and working with policemen, magistrates, and other stakeholders in the justice system. A Victims with Disabilities Task Force meets approximately every 6 weeks; its mission is to support collaboration among agencies, and it advocates for victims with disabilities to promote justice

and prevent violence. The Justice Systems Innovations Team worked with the state Justice Academy to update the 8-hour training for all law enforcement on intervening with persons who have mental illness and/or DD. Also, the 5-day Crisis Interventions Team training for police across the state includes at least 1 hour about DDs and best practices when coming into contact with people who have IDs and DDs. In one North Carolina county, a tragic accident involving the death of someone with ASD who encountered law enforcement spurred creation of an additional segment of training on ASD in one of the Justice Academy courses on Special Populations.

Through funding from the NCCDD, The Arc of NC created a training called Partners in Justice to educate stakeholders about issues around working with people with developmental disabilities. Since the program's inception, they have been able to train more than 670 human service workers, 285 attorneys and judges, 640 self-advocates, 563 law enforcement officers, 454 magistrates, and 69 community corrections and prison social workers (The Arc of NC, n.d.).

For those with developmental disabilities who do enter the justice system, a facility in Pender County tailors to the needs of this group. The facility features some special services, such as additional career training and a farm program. The prison system tracks the number of inmates with DDs on a monthly basis, which is consistently reported to be around 300.

Our interviewee related anecdotes that would indicate that the transition from incarceration back to community may result in service breakdown at times through the LMEs. However, whereas only a few years ago, 80 percent of persons released from state prisons had neither a probation officer nor any assistance in transition to community, with current legislation almost all prisoners released to the community, including those with autism, are at least assigned the support of a probation officer.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

- The *Autism Society of North Carolina* regionally provides opportunities for leisure activities. They also offer a summer camp for children on the autism spectrum called Camp Royall. Each summer, nearly 350 people with ASD attend weeklong traditional residential camps. This is the largest summer camp for those with ASD in the world. Session fees are on a tiered schedule depending on income, and there are some opportunities for scholarship (Autism Society of North Carolina, 2013a).
- North Carolina is home to *TEACCH* (<http://teacch.com/>), which serves the needs of the autism community in a myriad of ways including clinical services such as diagnostic evaluations, parent training and parent support groups, social play and recreation groups, individual counseling for higher-functioning clients, supported employment, and national and international training and consultation for teachers, residential care providers, and other professionals. TEACCH methods are used throughout the country and around the world. Many of their services are available for a fee; a few are eligible for coverage under Medicaid waivers.

- North Carolina is a participant in the Centers for Disease Control and Prevention (CDC) *Autism and Developmental Disabilities Monitoring Project (ADDM)*. Their most recent survey was in 2008, examining the records of 36,913 8-year-old children in 11 counties. They found that 525 of those children were diagnosed with ASD, or roughly 1 out of every 70 8 year olds; this is slightly higher than the other ADDM sites (CDC, 2012).

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NORTH DAKOTA

Approach

The L&M research team interviewed one representative from the state of North Dakota to discuss services and supports for persons with autism spectrum disorders (ASD). In addition to information gathered from this interviewee, the team used online resources to fill in gaps in knowledge. Through these interviews, the research team sought to gain greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

North Dakota has initiated multiple ASD service development strategies across the state over the past 4 to 5 years. The state legislature formed an Autism Spectrum Task Force in 2009, which was preceded by a Minot State University–led workgroup formed in 2008. The workgroup developed a state logic model plan that supported the next steps toward the task force’s 2010 Initial State Plan. The 2010 Initial State Plan was developed on the basis of a statewide needs assessment survey. Thereafter, the task force continues to review and periodically update or otherwise amend the state plan so that it best serves the needs of individuals with ASD.

State insurance regulations

The State of North Dakota has a mental health parity law that mandates that insurers provide coverage for the diagnosis and treatment of mental illnesses, under which ASD may fall.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of North Dakota 1915(c) waivers

Waiver Name	Population Served
ND Autism Spectrum Disorder Birth through Four*	Children aged 0–4 with PDD
ND Children’s Hospice	Children aged 0–21 who are medically fragile
ND Medicaid Waiver for Medically Fragile Children	Children aged 3–17 who are medically fragile
ND Traditional MR/DD HCBS*	Individuals of all ages with ID who meet the ICF/ID level of care
ND Technology Dependent Medicaid Waiver	Individuals aged 18+ who are technology dependent
ND Medicaid Waiver HCBS	Individuals aged 65+ and aged 18–64 with physical or other disabilities including brain injury and dementia.

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- North Dakota’s *Autism Spectrum Disorder Birth through Four* provides support to approximately 30 children aged 0–4, who live with a primary caregiver. The waiver supports the primary caregiver to maximize child development and prevent out-of-home

placements. Participant direction opportunities are available. Services offered through the waiver include:

- Environmental modifications
- Equipment and supplies
- In-home supports
- Intervention coordination

Other waivers

- The *North Dakota Traditional Mental Retardation and Developmental Disabilities HCBS* waiver is designed to offer home- and community-based services for qualifying individuals in the least restrictive environment. Individuals eligible for this waiver must meet the Intermediate Care Facility for Individuals with Intellectual Disabilities level of care and have a diagnosis of Intellectual Disability or a related condition. According to interview findings, this waiver serves approximately 4,200 individuals. The services include:

- Adult day health
- Day habilitation
- Extended services
- Homemaker services
- Residential habilitation
- Extended home health care
- Adult family foster care
- Behavioral consultation
- Environmental supports/modifications
- Equipment and supplies
- In-home supports
- Infant development
- Parenting support
- Transportation costs for financially responsible caregivers
- Family care option

Findings

Services and supports for people with ASD

Early intervention

North Dakota's early intervention program is for children aged 0–2. The program offers in-home visits with professionals who provide developmental screenings, developmental information, referrals to local, state and national organizations, and coaching to parents on how to best support their children (North Dakota Department of Human Services, 2010b). An Individualized Family Service Plan (IFSP) is developed with the family and professional team, in accordance with the requirements of Part C of the Individuals with Disabilities Education Act (IDEA). A child may be eligible in three ways.

- The child must be 25 percent below age norms in two or more of the following developmental areas:

- Cognitive development
 - Gross motor development
 - Fine motor development
 - Sensory processing (hearing, vision, touch)
 - Communication development (expressive or receptive)
 - Social or emotional development
 - Adaptive development
- The child must be performing 50 percent below age norms in one or more of the following developmental areas:
 - Cognitive development
 - Physical development, including vision and hearing
 - Communication development (expressive and receptive)
 - Social or emotional development
 - Adaptive development
 - The child is considered “high risk,” which means the child, from birth through age 2
 - Has a high probability of becoming developmentally delayed based on a diagnosed physical or mental condition; or
 - Has a high probability of becoming developmentally delayed based on informed clinical opinion, which is documented by qualitative and quantitative evaluation information.

At approximately 2.5 years of age, the child is reassessed to determine eligibility for either HCBS waiver services, ASD waiver services, and eligibility for IDEA Part B services at parental discretion.

School-aged children

Eligibility for developmental disability services among school-aged children depends on demonstration of six features of developmental disability and/or behavioral indicators from three categories, including:

- Atypical development of social competence;
- Disturbance of communication; and
- Atypical range of interests, patterns of behavior, and/or responses to sensory stimuli.

The assessment team may also choose to use a medical diagnosis of autism if the disability significantly impacts educational performance (North Dakota Department of Public Instruction, Department of Human Services, and the North Dakota Autism Task Force, 2003).

Adults

The state of North Dakota has two state-operated facilities, North Dakota State Hospital and North Dakota Developmental Center, which provide comprehensive support for people with intellectual and developmental disabilities.

Systems tracking

Currently, no statewide tracking system is in place in North Dakota although legislation is being proposed to create a statewide agency.

Promotion of services and supports for people with ASD

The developmental disability system serves as a contact and entryway for families and caregivers of children with ASD.

Transitions and coordination of services

Early intervention to school

The Department of Public Instruction coordinates with the early intervention program to direct transition from early intervention to school, and the transition progresses according to IDEA legislation. If able, children usually move from home-based programs into a preschool at age 3, and the assessment and planning process starts at age 2 to 2.5 years. The IFSP team works with the family to review the IFSP, identify areas that will need to be updated, and begin putting together a transition plan. A transition planning conference takes place with the IFSP team, family or caregivers, and representatives from the local educational agency. The group reviews plans for transition, which must be developed for all children exiting early intervention services and must be evaluated once the children are placed in their new learning environment.

School-aged to employment

According to federal IDEA legislation, transition planning is required for all special education students who are graduating from or aging out of the school environment. An Individualized Education Program (IEP) team includes transition planning in the first IEP, which is in effect when the child is 16 years of age—younger if deemed appropriate (North Dakota Department of Public Instruction, n.d.).

For individuals who are eligible, the Department of Public Instruction coordinates with the Department of Vocational Rehabilitation to direct transition from school to employment for young adults aged 19–21 years. In order to be eligible for vocational rehabilitation services, the individual must have a physical or mental impairment that affects the individual's ability to obtain or maintain employment (North Dakota Division of Vocational Rehabilitation, 2010). Services include (but are not limited to):

- Diagnosis and evaluation
- Vocational counseling and planning
- Information and referral
- Adaptive equipment
- Physical and mental restoration services
- Employment maintenance
- Transportation

- Vocational training, including supported employment
- Job placement and followup

The Department of Public Instruction hosts a biannual transition conference to discuss, monitor and improve students' transition from secondary school to higher education, employment, and adult services. The transition is also supported by the North Dakota Disability Services Council (<http://www.und.nodak.edu/org/nddsc/>), which is a partnership between North Dakota Colleges and Universities Disability Services Council and the Office of Special Education. One of the programs that are supported by the council is "Think College" (<http://www.thinkcollege.net>), an initiative of the Institute for Community Inclusion at the University of Massachusetts Boston. Think College provides intellectually disabled students with transition life skills and coaches who accompany the students during their classroom experience on a state college campus.

Training for direct service support workers

Ten licensed intervention coordination providers work with families on the ASD waiver. In general, recruitment and retention of trained providers to work with school-aged children in North Dakota public schools has been difficult. This is particularly challenging in North Dakota's rural areas, which are sparsely populated with lower numbers of children with ASD. To meet the need in rural areas, special education providers travel long distances, which can be difficult to traverse during the winter season.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

The *Pathfinder Parent Center* (<http://www.pathfinder-nd.org/>), a nonprofit organization that serves as the statewide parent training and information center, is funded by the U.S. Department of Education. The center serves more than 2,000 parents of children who have learning challenges or disabilities, aged 0–26. Services include parent education, training, IEP development assistance, effective communication techniques, conflict resolution, and referrals.

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OHIO

Approach

The L&M research team interviewed five representatives from the state of Ohio, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Ohio Department of Developmental Disabilities (DODD), the Ohio Center for Autism and Low Incidence (OCALI), the Ohio Rehabilitation Services Commission (RSC), the Interagency Work Group on Autism, and the Department of Health Bureau of Early Intervention.

State background

The Ohio Interagency Work Group on Autism (IWGA), led by the Ohio DODD, is the entity that coordinates programs and services of many state agency partners that serve individuals with ASD. IWGA grew out of the time-limited Ohio Autism Taskforce, which was created in House Bill 95 in 2003. IWGA membership consists of the Governor's office, Ohio Medical Assistance (Medicaid), the Office of Budget and Management, the Ohio Center for Autism and Low Incidence, the RSC, the Ohio Department of Mental Health, the Ohio Department of Education (ODE), the Ohio Department of Job and Family Services, the Ohio Department of Health, and the Ohio Department of Developmental Disabilities. DODD is the lead agency of the workgroup and convenes monthly meetings. IWGA's 2011–2012 strategic framework plan concentrated on the areas of policy development, capacity building, continuity across systems, and outcome measurement (Ohio IWGA, n.d.). A new set of Autism Recommendations released August 2012 serves as a blueprint for the work of the IWGA (<http://www.ocali.org>).

State insurance regulations

Ohio currently has no insurance mandate for autism coverage. Several bills have been introduced since 2009, but none have been enacted. Recently, two new bills were introduced. House Bill 598 and companion Senate Bill 381 call for the inclusion of pervasive developmental disorders into insurance coverage provided under the Mental Health Parity Act of 2007. Another bill, House Bill 376, would prohibit a health insurance corporation or an individual or group policy of sickness and accident insurance from refusing to provide coverage for screening and diagnosis of ASD or for any medically necessary services including habilitative/rehabilitative, pharmacy, psychiatric, psychological, therapeutic, and counseling (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Ohio 1915(c) waivers

Waiver Name	Population Served
OH Individual Options Waivers*	Individuals of all ages with ID/DD
OH Level One*	Individuals of all ages with ID/DD
OH SELF Waiver*	Individuals of all ages with ID/DD
OH Transitions Developmental Disabilities*	Individuals of all ages with ID/DD
OH Home Care	Individuals aged 0–59 with physical disabilities
OH Passport	Individuals aged 65+ or aged 60–64 with physical disabilities
OH Assisted Living	Individuals aged 65+ or aged 21–64 with physical disabilities
OH Transitions II Aging	Individuals aged 65+ or aged 60–64 with physical disabilities
OH Choices	Individuals aged 65+ or aged 60–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Ohio does not have any waivers specific to individuals with ASD at this time.

Other waivers

Four waivers provide services to people with ASD in Ohio. The County Boards of Developmental Disabilities administer the waivers and manage the waiting lists. Each waiver requires an Intermediate Care Facility for Individuals with Intellectual Disabilities level of care.

- The *Ohio Individual Options Waiver* is a comprehensive waiver for people of any age with intellectual disabilities, developmental disabilities (including ASD), or both. The waiver has no monetary cap; however, individuals are assessed and placed into one of nine funding categories in which they can develop budgets to meet their needs; 16,000 people use this waiver. Services include:
 - Homemaker/personal care
 - Respite
 - Adaptive and assistive equipment
 - Adult family living
 - Adult foster care
 - Community respite
 - Environmental accessibility adaptations
 - Adult day support
 - Vocational habilitation
 - Supported employment
 - Transportation
 - Home delivered meals
 - Interpreter

- Nutrition
- Remote monitoring equipment
- Residential respite
- Social work (Ohio DODD, 2011a)
- The *Ohio Level 1 Waiver* is much smaller in scope. It is primarily a day services waiver for individuals of all ages with intellectual disabilities, developmental disabilities (including ASD), or both. An annual cap of \$5,000 is in place for additional services outside of day services, such as respite, equipment, or homemaker/personal care. Services include:
 - Community inclusion
 - Residential respite
 - Support brokerage
 - Homemaker personal care
 - Clinical/therapeutic intervention
 - Community respite
 - Functional behavior assessment
 - Adult day support
 - Vocational habilitation
 - Supported employment
 - Integrated employment
 - Nonmedical transportation
 - Remote monitoring and equipment (Ohio DODD, 2011b)
- The *Ohio Transitions DD Waiver* was recently shifted to DODD from the Department of Jobs and Family Services. This waiver is for individuals of all ages with intellectual disabilities, developmental disabilities (including ASD), or both. The waiver provides for many services but is the only waiver administered by DODD that includes nursing services. Services include:
 - Adult day health center services
 - Personal care aide services
 - Emergency response
 - Home delivered meals
 - Home modifications
 - Out-of-home respite
 - Supplemental adaptive and assistive devices
 - Supplemental transportation
 - Nursing services (CMS, n.d.)
- The *Ohio Self Empowered Life Funding (SELF) Waiver* began enrolling individuals with intellectual disabilities, developmental disabilities (including ASD), or both on July 1, 2012. With this waiver, individuals can direct how they receive services. The SELF waiver has an annual monetary cap of \$25,000 for children and \$40,000 for adults. Services include:
 - Clinical therapeutic intervention
 - Functional behavior assessment

- Integrated employment
- Community inclusion
- Support brokerage
- Goods and services (Ohio DODD, 2012)

Findings

Services and supports for people with ASD

Ohio has a three-pronged infrastructure, supported in statute, to systematically and comprehensively plan and implement services and supports that create opportunities for individuals with ASD to have meaningful and successful lives. This infrastructure includes: (1) the IWGA, which provides a formal process for various state agencies to work together to inform autism policy development and implementation; (2) the OCALI (<http://www.ocali.org/>), which serves as a central source for the state for high-quality autism information, professional development, and technical assistance; and (3) OCALI's Advisory Board, which provides a formal process for parents, individuals, advocacy groups, and other stakeholders to contribute to the state's autism policy development and implementation. Ohio's infrastructure is built on multiagency collaboration and partnerships that unite the private and public sector.

Ohio's IWGA is led by DODD and meets monthly to bring together the Governor's office, Ohio Medical Assistance (Medicaid), the Office of Budget and Management, the Ohio Center for Autism and Low Incidence, the RSC, the Ohio Department of Mental Health, the ODE, the Ohio Department of Job and Family Services, the Ohio Department of Health, and the Ohio Department of Developmental Disabilities to better coordinate services across agencies. This group, closely tied to high-level state administrators, serves as a catalyst for change and improvement in Ohio's complex system of services and supports. The IWGA encourages a strong network of communication among individuals, families, service providers, and state leaders (Ohio IWGA, n.d.).

OCALI serves as the information clearinghouse for ASD in Ohio and serves families, educators, and professionals by providing high quality information and resources. OCALI is funded primarily through ODE and DODD but also has collaborative relationships with other state agencies and private organizations such as Easter Seals, the National Association of State Directors of Special Education, and the Individuals with Disabilities Education Act (IDEA) Partnership.

OCALI houses seven centers: (1) the Autism Center, (2) the Disabilities Center, (3) the Universal Design for Learning Center, (4) Assistive Technology Centers, (5) Lifespan Transitions Center, (6) Family Center, and (7) the Center for Systems Change, which focuses on information dissemination, capacity building, and systems change. Although OCALI does not offer direct assistance to children with ASD, it offers many services that include training, technical assistance, assessment resources, consultations, and professional development for family members and other individuals who support individuals on the autism spectrum across the lifespan. They also have an extensive lending library of books and materials on ASD and low-incidence disabilities (http://www.ocali.org/project/lending_library) as well as a master calendar (<http://www.ocali.org/project/calendar>) of important events around the state. OCALI operates a Supports and Service Database, which can locate service providers available to address the

specialized needs of people with disabilities of all ages. It is a searchable database available via computer or smartphone. Information is organized according to age group (0–3, 3–21, and 22+) and according to service type (e.g., education, legal, medical, parent support, vocational, etc.). By entering an individual’s zip code, the user can determine the distance the individual or family needs to travel to access an identified service provider.

OCALI has two very informative Internet module systems, Autism Internet Modules (<http://www.autisminternetmodules.org/>) and Assistive Technology Internet Modules (<http://www.atinternetmodules.org/>), which serve as Internet-based platforms for evidence-based practices in ASD for people around the world. These Internet modules are used in every state and in approximately 140 countries. There are currently 38 modules on different topics. OCALI works directly with the National Professional Development Center on ASD, among other national organizations, to identify evidence-based practices.

OCALI’s Advisory Board consists of individuals with autism and other disabilities, family members, and some of Ohio’s key autism leaders, practitioners, and advocates. The Board, working in concert with OCALI and the IWGA, brings a high level of both personal and professional expertise that adds value to decisions made regarding the state’s system of services and supports.

Several state agencies and their local counterparts provide a myriad of services and supports for Ohioans with ASD. The Ohio Department of Health administers Ohio’s early intervention program (IDEA Part C) and the Children with Special Health Care Needs program, and the ODE provides special education services (IDEA Part B). The Ohio Department of Mental Health provides resources for behavioral health care, and the Ohio Department of Job and Family Services provides public assistance and serves as Ohio’s family, health, and workforce support system. Ohio Medical Assistance is the lead for the state’s Medicaid program. The RSC offers services for vocational training, counseling, and employment guidance. The Department of Developmental Disabilities administers several Medicaid waivers and provides governance and structure for the local county board programs in the provision of services and supports for Ohioans with developmental disabilities from birth through adulthood. It is very likely that individuals with ASD and their families will access services through most of these agencies in order to meet their children’s and family’s needs across the lifespan.

Early intervention

Ohio, like other states, serves children (aged 0 to 21) with developmental disabilities, including ASD, under the provisions of IDEA Part C and Part B. Help Me Grow (HMG) is Ohio’s early intervention program for infants and toddlers aged 0–3 with developmental disabilities including ASD and their families. HMG is administered by the Ohio Department of Health. Per federal IDEA Part C regulations, HMG is a comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services (<http://www.ohiohelpmegrow.org/>).

In October 2012, Governor John Kasich’s office announced the commitment of Health Transformation Innovation Funds to support key programs that will expand early identification and intervention for Ohio’s youngest children with ASD. The two programs, administered by DODD include:

- *The Autism Diagnostic Education Project (ADEP)* trains pediatricians to correctly identify the early signs of autism, to aide in early intervention. ADEP facilitates unique partnerships between community-based primary care practices and professionals who provide early intervention and early childhood services to increase opportunities for children to receive timely and comprehensive evaluations. ADEP was originally piloted through funds from the Ohio Department of Health (ODH) and administered by the Ohio chapter of the American Academy of Pediatrics. ADEP has formed these Diagnostic Partnerships in 30 counties across Ohio. The Health Transformation Funds will support the existing partnerships and allow for more expansion in resource-poor regions of the state.
- *The Specialized Training for Early Intervention Professionals Project* will provide funds to train professionals in serving infants and toddlers in a play-based approach that nurtures the critical parent/child relationship early in the child's development. The training is part of the Play and Language for Autistic Youngsters Project (<http://www.playproject.org/>) and will bring a new level of specialized expertise within the County Boards of Developmental Disabilities' early intervention programs. These trained professionals will be better equipped to assist and empower families, encourage and nurture the child's social interaction, and ultimately increase the likelihood of the child enjoying a successful and inclusive life. Nearly 100 intervention specialists across 34 counties have received training and followup coaching. Funding will be used to reach at least 80 percent of the state over the next 3 years.

School-aged children

Ohio serves children aged 3–21 with disabilities, including ASD, in alignment with IDEA Part B federal regulations. The ODE is the administering agency with the involvement of more than 600 local school districts statewide. A child identified as having ASD or other developmental disabilities may access special education services provided through the public school system if determined eligible through comprehensive assessment. These IDEA Part B services may include an evaluation at no cost to the parents, an Individualized Education Program (IEP), and a full range of individualized services as specified by IDEA.

ODE administers an Autism Scholarship Program for children aged 3–21 that allows parents who qualify for the scholarship to send their child with ASD to a special education program outside of their school district to receive services. There is no cap on the number of scholarships available through this program. The scholarship money cannot be used to supplement public education, but must be used to obtain education and supportive services outlined in the IEP. The maximum scholarship amount per year is \$20,000 (ODE, n.d.[a]).

The Ohio Medicaid Schools Program is a joint program between the Ohio Department of Job and Family Services and ODE that helps utilize federal Medicaid matching funding for specific direct services provided by schools districts and community schools (ODE, n.d.[b]).

The Ohio RSC helps young people with disabilities aged 14–22 transition from the classroom to the workplace or college. RSC vocational rehabilitation counselors, educators, and family members help develop individual plans of employment that are focused on the individual and based on goals, skills, and strengths (Ohio RSC, 2011).

County Boards of Developmental Disabilities also offer services to school-age children as well as their families. County boards can help families access Medicaid waivers, family support services, and parental support and education opportunities (Ohio IWGA, 2013b).

Recently, an Executive Order signed by Governor Kasich (March 2012) has set into motion the Employment First Initiative. This initiative has ramifications for the way Ohio serves youth with disabilities exiting high school with a focus on preparation and skill development for community employment. More information follows below.

Adults

On June 25, 2012, Governor Kasich signed Senate Bill 316 into law. The legislation includes statutory provisions making Ohio an Employment First state. This legislation is in addition to an Executive Order signed in March 2012 calling for DODD to take the lead in developing an Employment First Task Force to improve collaboration among the Departments of Developmental Disabilities, Mental Health, Education, Job and Family Services, and the Ohio Rehabilitation Services Commission to increase employment opportunities for people with developmental disabilities, including ASD. The DODD has also established an Advisory Committee made up of business leaders, stakeholders, self-advocates, and others in the developmental disabilities field to contribute to the development of policy recommendations to assure that meaningful community employment is the preferred option for students with disabilities exiting high school. The Employment First Initiative challenges Ohio to create opportunities and prepare Ohioans with developmental disabilities to take part in the community workforce whenever possible, rather than in more traditional “sheltered workshop” settings. The Employment First initiative is challenging Ohio to think more creatively about how adults with disabilities are served and supported (Ohio DODD, n.d.).

County Boards of Developmental Disabilities offer a range of services for adults with developmental disabilities including ASD. The Ohio Eligibility Determination Instrument (OEDI) must be used to determine eligibility for these services. The OEDI looks at how well a person functions in daily life. To be eligible, someone must be determined to have a qualifying diagnosis and have a functional limitation in at least three major life activities including: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Adult Services options are provided according to a person’s assessed needs and preferences, which are identified through a planning process. Adult services may include, but not be limited to:

- Community/supported employment;
- Vocational training;
- Adult day activities including social, leisure, and recreational activities; and
- Sheltered employment.

These services are to be provided by a qualified and willing provider of the individual’s choice. These services are generally planned through a Person-Centered Planning Process (Ohio IWGA, 2013c).

The RSC also offers many services to adults with developmental disabilities through its Bureau of Vocational Rehabilitation, Bureau of Services for the Visually Impaired, and Bureau of Disability Determination. These services include vocational training, counseling and guidance to outline employment goals, assistance with resume writing and interviewing skills, and providing employers with support, technical assistance and placement services. RSC focuses on customized employment and uses a systematic approach for individuals with complex needs. The ASD population often requires customized support to best serve an individual's impairment to employment. RSC has time-limited services and only works with individuals as they prepare for and gain employment. This means that the Commission might be involved with someone for only a few months, or as long as a few years, if they become involved in the transition from high school to college and then to employment. The County Boards of Developmental Disabilities and DDD provide long-term services across the lifespan and adult services that supplement the employment support of RSC (Ohio RSC, 2011).

Systems tracking

Governor Kasich's Office of Health Transformation (OHT) has been established to streamline Ohio's Health and Human Service (HHS) system. A key initiative of the OHT is a project to integrate HHS information capabilities across all of the state's HHS systems. This includes eligibility, claims payment, and decision support systems. The ultimate goal is to integrate business intelligence across the HHS enterprise so information about the whole person being served is available in the right place at the right time to get the best results for that person. This person-centered approach is a departure from the agency-centered solutions of the past. Through these efforts, Ohio is taking steps to more accurately track and share data across its multiple service systems (Ohio Governor's Office of Health Transformation, n.d.).

Aligning with this work, Ohio recently received an Early Learning Challenge grant, which will be used to improve services and supports that serve high-needs children younger than age 5. Some of the funds will be used to design a single identifier system that starts earlier than preschool and will assign an identifier to any young child receiving services from any public service agency. This identifier would then become part of a mechanism used to track children across all services and agencies (ODE, 2013).

Promotion of services and supports for people with ASD

Ohio's history of addressing autism spectrum disorders has been driven by the strong network of families and advocates. Ohio has nearly 70 different autism family support and advocacy groups. This, coupled with a collaborative spirit, has brought together committed groups of parents, individuals, legislators, state leaders, and service providers to bring autism to the forefront of state policy discussions.

Ever-evolving research and new information about autism paired with a growing prevalence rate have presented new challenges that have called for Ohio to intensify its efforts. Thus, a new set of Ohio Autism Recommendations was released in August 2012 as a logical and necessary step to meet these challenges. The new recommendations promote services and supports for Ohioans with ASD, requiring multisystem solutions and an attentive focus on issues that cross the lifespan. The recommendations will serve the state as a blueprint and guide the work of Ohio's IWGA and OCALI.

Additionally, the Ohio Developmental Disabilities Council (<http://ddc.ohio.gov/>) supports innovative projects and advocacy that promote services and supports for individuals with disabilities, including ASD. The Council is a federally funded planning and advocacy group with the goals of supporting and promoting a coordinated system of services and resources and advancing community inclusion for individuals with developmental disabilities.

Transitions and coordination of services

Early intervention to school

A priority identified through Ohio's Autism Recommendations is the need to create a process to ensure that plans for services are dynamic, flexible, and person centered and that there is programming continuity across settings and/or systems throughout the lifespan. Many state level efforts are underway to address the issue of transition and coordination of services as individuals with disabilities and families move through the service system. These transitions include early intervention to preschool, preschool to school-age services, and school to employment and independent living.

Ohio's service system is complex. Ohio's HHS policy, spending, and administration are split across multiple state and local government jurisdictions. Five state agencies directly administer Medicaid programs and at least 14 administer other health, human services, and education programs. Each of these systems has a local counterpart, most are in 88 counties, and some are regional. The systems are also in smaller units for public health (125 districts) and primary and secondary education (613 districts; <http://healthtransformation.ohio.gov>). The Governor's Office of Health Transformation is taking steps to address this complexity with multiple initiatives to streamline health and human services including creating a cabinet-level Medicaid department, modernizing eligibility determination systems, integrating HHS information capabilities, coordinating programs for children, and sharing services across local jurisdictions. These initiatives will result in systemic improvements and efficiencies to improve continuity as children and families transition across service systems.

School-age to employment

Through Ohio's Employment First Initiative, a strong focus has been placed on the transition from school to competitive employment. Statutory changes in Ohio have been made that will now require that beginning at age 14, appropriate measurable postsecondary goals shall be made part of the youth's IEP, based on age appropriate assessments related to employment in a competitive environment in which workers are integrated regardless of disability. Through the Employment First Advisory Committee, additional work is underway to create a framework to facilitate transition to employment that encompasses multiple agencies and stakeholders. This work will include the identification and prioritization of evidence-based school to employment practice programs for individuals with developmental disabilities, including ASD, and define each agency's role in the implementation.

To further support this work, the Governor's Office of Health Transformation has committed Innovation Funds to be used to launch a training series for stakeholders to further the understanding and implementation of Employment First activity. These training opportunities will allow for a diverse group of professionals and families to understand the importance of the critical years—beginning at age 14—during which adolescents prepare for life beyond high

school. Growing the capacity of trained professionals will result in increased awareness of the necessary components and skills development that will lead to integrated employment. DODD will lead this effort, coordinating with multiple state partners including the Departments of Mental Health, Education, Job and Family Services, and the Ohio Rehabilitation Services Commission. OCALI will take a major role in implementation of this training initiative (Ohio Governor's Office of Health Transformation, 2012).

In addition, the Lifespan Transitions Center at OCALI serves Ohio by offering resources, training, technical assistance, and consultation to support the successful transition of individuals with autism and multiple disabilities throughout their school careers and into their adult lives. Resources address community living and employment.

Training for direct service support workers

A variety of training opportunities are available to direct service providers through Ohio's multiple state and local agencies that assist professionals to obtain/maintain certification or licensure in their fields of practice. OCALI is Ohio's central clearinghouse for autism training and professional development. OCALI offers many modes of training including Internet training modules, Webinars, info-sheets, mini-conferences, and symposia for educators as well as other professional disciplines. OCALI also hosts an annual national conference—OCALICON—drawing families and professionals from across the Nation to share and learn best practice intervention strategies.

A few of Ohio's universities (e.g., Bowling Green State University, Kent State University) are now offering specialized courses of study resulting in an autism credential. Ohio is also home to two University Centers for Excellence in Developmental Disabilities at the Ohio State University Nisonger Center and at the Cincinnati Children's Hospital Medical Center/University of Cincinnati. Both organizations offer autism training, education, and research opportunities for the new generation of professionals entering the field. Both organizations also operate a Leadership in Neurodevelopmental Disabilities Program, supported through the Maternal Child Health Bureau within the Health Resources and Services Administration, U.S. Department of Health and Human Services (http://mchb.hrsa.gov/training/project_info.asp?id=196). These programs provide advanced graduate interdisciplinary leadership training and development.

Another Ohio training resource is Professional Advancement through Training and Education in Human Services (PATHS), which is a multilevel training program for direct support professionals supporting individuals with developmental disabilities. The PATHS curriculum includes specialized training specific to ASD and also offers an opportunity for direct support providers to earn a professional credential.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Several key initiatives are guiding long-term plans for supports and services for Ohioans with ASD and their families. The work of Ohio's IWGA is building relationships and communication

among state leaders, families, and the field to keep the state's autism work relevant, meaningful, and forward-thinking. Core principles keep the group focused on developing policy based on a belief system that ASD impacts the "whole person" and requires an attentive focus on lifespan issues and multisystem solutions (Ohio IWGA, n.d.).

It is expected that the projects supported through the Governor's Office of Health Transformation Innovation Fund (explained earlier in this report) will result in long-term outcomes that improve early identification and intervention for Ohio's youngest with ASD, but also impact the way in which youth and adults are served and integrated into their communities later in life. Additionally, Ohio's work through a State Implementation Grant for Improving Services for Children and Youth with ASD and other Developmental Disabilities funded through the U.S. Department of Health and Human Services is helping to coordinate and expand the state's response to autism.

The launching of the Ohio's first participant-directed waiver for individuals with developmental disabilities including ASD, the SELF Waiver, is also expected to result in positive impact on services and supports. It is envisioned that the waiver will enhance participant direction in Ohio while also helping to address some crucial service needs, particularly functional behavior assessment and clinical therapeutic intervention for individuals with ASD. It will also improve flexibility and creativity for individuals and their families with unique challenges and service needs (Ohio DODD, 2012).

Finally, Ohio's 2012 Autism Recommendations provided the state with a comprehensive blueprint and vision for long-term planning with a focus "across systems and across the lifespan" (OCALI, 2012).

Other relevant programs and services

In addition to the services and programs supported through Ohio's public service system, the state has many resources available to individuals with ASD and their families through the private sector. Ohio now has specialized autism centers in six of its major Children's Hospitals across the state offering diagnostic, medical, and related services. Also, two Centers for Excellence in Autism are housed at University of Toledo and The Rich Center for Autism at Youngstown State University providing service and research. With the inception of the Autism Scholarship Program, the number of private providers offering services for ASD is increasing (Ohio Department of Education, n.d.[a]). The scholarship allows parents of qualified children with autism to use a registered private provider instead of the school district to receive services outlined in the child's individualized education program.

Ohio is also home to two Autism Treatment Network (ATN) sites at Nationwide Children's Hospital and Cincinnati Children's Hospital Medical Center. These sites join the national ATN network of hospitals and physicians dedicated to developing a model of comprehensive medical care for children and adolescents with autism (Autism Speaks, 2013). In addition, the state has two University Centers for Excellence in Developmental Disabilities at the Ohio State University Nisonger Center and at the Cincinnati Children's Hospital Medical Center/University of Cincinnati. Both organizations offer autism training, service, education, and research opportunities.

Locally, some of Ohio's counties are finding creative ways to coordinate across county lines by forming Regional Autism Advisory Councils (RACCs) comprising agencies, professionals, and parents who care for and about individuals with ASD. Ohio's two RACCs are making progress in the way they are addressing the needs of individuals with autism and their families in the southwest and northwest regions of the state (RAAC of Southwest Ohio, 2013).

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OKLAHOMA

Approach

The L&M research team interviewed eight representatives from the state of Oklahoma, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Oklahoma Developmental Disabilities Services Division (DDSD), the Oklahoma Department of Rehabilitative Services, and the Department of Education (SoonerStart).

State background

The state of Oklahoma does not have an active task force on autism at this time. In 2001, the DDSD convened the Autism Working Group to develop a state plan to improve services for individuals with autism. The group met for 2 years and comprised representatives from state agencies, educators, parents, and professionals with an interest in autism. The Oklahoma Autism Network (<http://www.okautism.org/>) was established upon the group's termination to manage and implement "The Individuals with Autism and Their Families Oklahoma Plan" (Easter Seals, 2012). Today, the Oklahoma Autism Network serves as the only statewide organization for individuals with autism, supporting individuals with ASD from diagnosis through adulthood.

State insurance regulations

Oklahoma does not have a specific mandate for coverage of ASD. However, limited coverage became available in November 2010 under SB 2045. The law requires that individual and group health insurance policies that provide medical and surgical benefits provide the same coverage and benefits to children under the age of 18 with autism (Easter Seals, 2012).

A series of health insurance bills were introduced in the 2009 legislative session—SB 1 (also known as "Nick's Law"), HB 1312, HB 1841, SB 36, and SB 46—to require health insurance coverage for the diagnosis and treatment of ASD to individuals 21 years or younger. Covered services would include diagnosis, testing, treatment, therapies, medications, and supplements as prescribed by a licensed physician. Behavioral therapy would be covered up to a maximum of \$75,000 per year for a maximum of 3 years. SB 1, 36, and 46 were referred to the Senate Retirement and Insurance Committee; HB 1841 was referred to the House Economic Development and Financial Services Committee; and HB 1312 died in the House Economic Development and Financial Services Committee in February 2009. No further action has been taken on these bills (Easter Seals, 2012).

In addition, HB 1248 and HB 1624 were introduced in the 2011 legislative session. HB 1248 would create a high-risk insurance pool for people with ASD, and HB 1624 would require health plans to provide insurance to people with ASD. Insurance plans under HB 1624 would not be able to institute dollar limits, deductibles, or co-pays less favorable than provisions that apply to general physical illness. HB 1248 was referred to the Appropriations and Budget committee, and HB 1624 was referred to the Rules Committee. No further action has been taken on these bills (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Oklahoma 1915(c) waivers

Waiver Name	Population Served
OK In-Home Supports Waiver for Children*	Children aged 3–17 with ID
OK Community Waiver*	Individuals aged 3+ with ID
OK In-Home Supports Waiver for Adults*	Individuals aged 18+ with ID
OK My Life; My Choice	Individuals aged 20–64 with physical disabilities
OK Medically Fragile	Individuals aged 19+ who are medically fragile or technology dependent
OK Homeward Bound Waiver	Individuals aged 21+ with ID and certified member of the Plaintiff Class in Homeward Bound et al.
OK Advantage	Individuals aged 65+ or aged 21–64 with physical or other disabilities
OK Sooner Seniors	Individuals aged 65+

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Oklahoma does not have any waivers specific to individuals with ASD at this time.

Other waivers

Three home- and community-based individual support waivers currently serve people with ASD in Oklahoma.

- The *Oklahoma Community* waiver began in 1988 and is designed help individuals aged 3 and older who have intellectual disabilities and would otherwise require the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities. Using a person-centered planning approach, an individual’s team assesses his or her needs and develops a plan to address those needs. The team consists of the individual, his or her legal guardian or advocate, and the DDS case manager. Depending upon the service needs of the individual, the team may include residential and employment staff and professional staff such as a nurse, speech pathologist, psychologist, and physical therapist. The plan for care is reviewed and updated annually for each individual receiving services and the DDS case manager is responsible for providing support and monitoring implementation of the plan. Services are provided through contracted provider agencies throughout Oklahoma and include:
 - Adult day health
 - Agency companion
 - Audiology services
 - Community transition services
 - Daily living supports
 - Dental services
 - Environmental accessibility adaptations and architectural modification
 - Family training and counseling

- Group home
 - Habilitation training specialist services
 - Homemaker
 - Nursing
 - Intensive personal support
 - Nutrition services
 - Occupational, physical, and speech therapy
 - Psychiatric and psychological services
 - Prescribed drugs
 - Prevocational services
 - Respite
 - Remote monitoring
 - Specialized foster care
 - Specialized medical supplies and assistive technology
 - Supported employment
 - Transportation (Oklahoma Health Care Authority, n.d.)
- The *Oklahoma In-Home Supports for Children* waiver was created in 1999 in response to the continually increasing numbers of individuals with developmental disabilities remaining on waiver waiting lists. The capitated waiver allows children and families to select services necessary for individuals to remain in their own home or family home. Individuals are assigned to DDSD case managers to assist them in locating, securing, and coordinating needed services. Eligible children, aged 3–17, may receive needed services including:
 - Adaptive equipment
 - Architectural modifications
 - Family training
 - Environmental accessibility adaptations and architectural modification
 - Occupational and physical therapy
 - Self-directed goods and services
 - Habilitation training specialist services
 - Respite
 - Specialized medical supplies and assistive technology (Oklahoma Health Care Authority, n.d.)
- Similarly, the *Oklahoma In-Home Supports for Adults* waiver allows adults and families to select services necessary for individual to remain in their own home or family home. Individuals are assigned to DDSD case managers to assist them in locating, securing, and coordinating needed services. Eligible adults, 18 years or older, may receive needed services including:
 - Adult day services
 - Audiology services
 - Dental services
 - Environmental accessibility adaptations and architectural modification
 - Family training and counseling
 - Habilitation training specialist services

- Homemaker
- Specialized medical supplies and assistive technology
- Nutrition services
- Occupational, physical, and speech therapy
- Prescribed drugs
- Prevocational services
- Psychiatric and psychological services
- Respite
- Self-directed goods and services
- Supported employment
- Transportation services (Oklahoma Health Care Authority, n.d.)

The In-Home Supports Waivers are provided through agencies contracting with the Oklahoma Health Care Authority. The children's waiver provides less funding than the adult waiver because many services are already available to children through the Medicaid State Plan Early and Periodic Screening, Diagnosis and Treatment Program and the Oklahoma Department of Human Services Disabled Children's Program.

Findings

Services and supports for people with ASD

The Oklahoma DDSD is housed within the Oklahoma Department of Human Services and serves as the lead agency for services to individuals with developmental and intellectual disabilities. In addition to the home- and community-based services, DDSD offers several state-funded services to individuals aged 3 and older and their families (Oklahoma Department of Human Services, 2013).

Early intervention

Oklahoma's early intervention program is called SoonerStart and is designed to meet the needs of infants and toddlers with disabilities and developmental delays by coordinating provider services through the Oklahoma Department of Health. Infants and toddlers aged 0–36 months who have developmental delays or a physical or mental condition are eligible for the SoonerStart program. Services may include:

- Diagnostic and evaluation services
- Case management
- Family training, counseling, and home visits
- Health services
- Nursing services
- Nutrition services
- Occupational, physical, and speech-language therapy
- Special instruction

In 2009, Senate Bill 135 established an early intervention pilot program modeled after Early Foundations, an outreach program that provides early intensive behavioral intervention for children with autism. Early Foundations has four sites, including Oklahoma County, Tulsa County, Canadian County, and Cleveland County, covering 50 percent of the child population in the state. The program serves 23 children across the four sites and receives a federally funded grant through the Institute of Educational Services to study the efficacy of the Early Foundations model (Oklahoma Autism Network, 2012).

School-aged children

The Oklahoma Department of Education oversees special education services in the state. Services are offered in accordance with the Individuals with Disabilities Education Act (IDEA). Oklahoma defines autism as a developmental disability usually manifested before the age of 3 that affects communications and social interactions, which adversely affects a child's educational performance. A diagnosis of autism is not made if the child's educational performance is primarily affected by an emotional disturbance. To be eligible for special education services due to a diagnosis of autism, the student must undergo a comprehensive evaluation to include a student's medical information, communication abilities, and behavioral functioning. Impairments in communication and social interaction are the primary components of an autism evaluation and diagnosis. If eligible, students are entitled to an Individualized Education Program (IEP) and an IEP team that helps to determine which services are necessary for an individual to benefit from special education.

The DDSO offers Family Support Assistance, a cash payment program for families who are caring for children under the age of 18 at home. Families can receive payments of \$250 to \$400 per month depending on the number of children with disabilities in the home. Families who meet the income eligibility may choose this state-funded program in lieu of Medicaid HCBS services. In addition, families caring for children with developmental disabilities at home may be eligible for a voucher respite program through DDSO. The program makes direct payments to respite providers to provide a temporary break, rest, or relief from full-time care of an individual with disabilities.

Adults

The DDSO provides some state-funded support to adults in addition to services offered through the Medicaid HCBS waivers. State-funded services for adults include:

- Group homes—living arrangements for 6 to 12 people who share a home and receive up to 24 hours per day of supervision, support, and training in daily living skills.
- Sheltered workshop—individuals work and receive training in a controlled environment with other people with disabilities. Services include assessment, training, and transitional services leading to community job placement if the individual chooses. Workers are paid in accordance with individual production and the Fair Labor Standards Act.
- Community Integrated Employment—provides placement, job training, and short-term or long-term supports to assist service recipients in achieving and maintaining employment within the community. Services are delivered in integrated settings in the community by contracted providers.

- Assisted living—provided to individuals with intellectual disabilities who do not receive services through a HCBS waiver and require minimal staff supports to live safely in their own home.
- Respite—a voucher respite payment program for caregivers caring full-time for children or adults with developmental disabilities.

The Division of Vocational Rehabilitation (DVR) offers services to adults with a physical, mental, or visual disability that keeps them from working and requires vocational rehabilitation to prepare for, find, keep, or return to employment. DVR services include:

- Employment services, including job search, placement, and followup services;
- Assistive technology, including telecommunications, sensory, and other rehabilitation equipment and devices;
- Training including vocational, postsecondary, on-the-job, personal and vocational adjustment, job search skills development, and job coaching;
- Self-employment programs to help individuals who want to work for themselves to telecommute using computers or operate their own businesses;
- Personal assistance services;
- Transition school-to-work services to help high school students with disabilities prepare for and reach employment goals;
- Supported employment to assist individuals with severe physical, emotional, mental or multiple disabilities with employment in the community;
- Postemployment services to help consumers get, keep, or move ahead in their jobs;
- Specialized programs to assist independent-living consumers who are blind, deaf, hard of hearing, deaf-blind, and individuals with speech impairments, severe disabilities and those who require independent living services; and
- Foreign-language interpreter services for individuals who do not speak English.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals and families can learn about services and supports for ASD through several channels, including referrals from providers and outreach from state agencies. In addition, the Oklahoma Autism Network (OAN) serves as the administrative unit to facilitate planning, financing, and management of the Individuals with Autism and their Families, Oklahoma Plan. OAN is the state's autism information and referral source for families and professionals; it provides both a toll-free number and comprehensive Web site. OAN works closely with the network of parent-led organizations focused on ASD across the state; provides a variety of trainings for state agencies, community organizations, families, and professionals; and organizes and sponsors the annual Statewide Autism Conference.

Transitions and coordination of services

Early intervention to school

Transition from the SoonerStart early intervention program to posttransition settings begins around age 24 months and includes several steps between the child's second and third birthdays.

- An initial transition planning meeting takes place when the child is between 24 months and 30 months of age. SoonerStart staff formally meet with the family to introduce the transition. The goal of this meeting is to discuss all available options at 3 years of age but not to make decisions about placement.
- Between 24 and 33 months of the age, the family is encouraged to visit community programs to get a sense of the environments available to children with disabilities following their transition. These include public preschool, private preschool or childcare, home, Head Start, Even Start, Oklahoma Parents as Teachers, community recreation groups, cooperative play groups, health department play groups, and library story hours.
- Between 30 and 32 months of age, the SoonerStart program is required to complete an evaluation and current assessment of the child's level of functioning. The school district may require additional information to determine eligibility for special education.
- Between 24 and 36 months of age, SoonerStart staff and the family meet to review the Individual Family Service Plan and discuss the evaluation results. The team plans transition activities that should take place prior to the child's third birthday, and the family members decide whether they want to refer their child to IDEA Part B services.
- Between 27 and 33 months of age, a transition conference takes place if the family chooses to refer the child to IDEA Part B special education. SoonerStart convenes a conference between the family, early intervention staff, other current providers, and representatives from the local school district and community programs. The goal is to develop a plan for transition that will be smooth and effective for the child and family.
- The local school district must determine the child's eligibility for special education services by age 3.
- If the child is eligible, an IEP meeting takes place by his/her third birthday, in which the IEP team decides which programs and services are appropriate and necessary for the child. The meeting brings together the family, teachers, administrative personnel, and related service providers to put the plan into writing (Oklahoma State Department of Education and Department of Human Services, 2006).

School-aged to employment

Transition services for individuals begin as required by the Individuals with Disabilities Education Act. The student's needed transition services are part of a long-range plan that coordinates high school (or earlier when appropriate) and the years immediately following high school. The services are focused on improving the academic and functional achievement of the student with a disability to facilitate movement from school to post school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation. The IEP team must indicate the services that will be provided to the student

through implementation of the IEP (e.g., instruction, community experiences, employment and other post school adult living objectives, daily living skills, and/or functional vocational evaluation, if appropriate).

Training for direct service support workers

The Oklahoma Department of Education received funds through Senate Bill 135 to provide specialized training in autism for Oklahoma’s SoonerStart early intervention program direct services providers. Training has been provided in the use of behavioral strategies for young children suspected of having or already having a diagnosis of ASD (Oklahoma Autism Network, 2012).

The Child Study Center at the University of Oklahoma Health Sciences Center received funds to provide primary care evaluation training for physicians to evaluate children with ASD. The program—called SoonerSUCCESS—has provided training to 30 physicians in the Screening Tool for Autism in Toddlers and Young Children, a training designed to teach enhanced diagnostic consultation and screening procedures to pediatric medical providers serving young children. An online collaborative—called the Autism Collaborative—has also been developed for ongoing training and support for physicians in the diagnosis and care of children with ASD (Oklahoma Autism Network, 2012).

A comprehensive autism-training program is offered at the University of Central Oklahoma’s Regional University System. The program provides statewide leadership in training postgraduate and post baccalaureate behavior therapists. The goal of the training is to encourage therapists to specialize in treating and providing services to children with autism.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

SB 135 outlined the need for an applied behavior analysis treatment project through the DDS. This project—called ConnectedKids—is being designed and implemented by the Oklahoma Autism Network at the University of Oklahoma Health Sciences Center. The research project involves parent training in the use of applied behavior analysis with 4–5 hours of intervention provided each week in the home for the parent and child. The project recently completed its pilot phase and began full implementation of the study in March 2012 (Oklahoma Autism Network, 2012).

Other relevant programs and services

- The *Oklahoma Early Access Autism Project* is a project sponsored by the Oklahoma Developmental Disabilities Council. The goal of the project is to provide and promote autism awareness and early detection of ASD. The Early Access Autism Project seeks to reach underserved populations who may not have access to traditional developmental screening services by partnering with local communities throughout the state to offer free autism screening and awareness. The project is family oriented and designed to provide services, resources, and an environment tailored to the needs of each child, family, and community.

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OREGON

Approach

The L&M research team interviewed four representatives from the state of Oregon, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies included the Oregon Office of Developmental Disability Services (ODDS), the Oregon Center for Children and Youth with Special Health Needs (OCCYSHN), the Oregon Council on Developmental Disabilities, and the Oregon Commission on Autism Spectrum Disorder.

State background

The Oregon Commission on Autism Spectrum Disorder began in 2009 through an executive order signed by the Governor. The commission was tasked with developing and monitoring a 10-year strategic plan to help individuals with ASD. The members represent families, educators, health care providers, human services providers, and self-advocates. Currently 13 individuals serve on the commission through several subcommittees: community services for adults; community services for children and families; educator credentials; interagency transition; health care services; redesign of ASD education services; role of health insurance; and screening, identification, and assessment (Oregon Commission on Autism Spectrum Disorder, n.d.).

State insurance regulations

HB 2918 was signed into law in July 2007; it requires coverage for the treatment of pervasive developmental disorders, including autism, for children up to age 18. Coverage includes all medically necessary services, including physical, occupational, and speech therapy. Additionally, Oregon's mental health parity law was enacted in 2005 and requires group health insurance to provide coverage for mental or nervous conditions at the same level as other medical conditions (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Oregon 1915(c) waivers

Waiver Name	Population Served
OR Behavioral (ICF/IDD) Model*	Children aged 0–17 with DD/ID
OR Medically Fragile (Hospital) Model	Children aged 0–17 who are medically fragile
OR Medically Involved Children's Waiver	Children aged 0–18 who require a nursing facility level of care
OR ICF/IDD Support Services*	Individuals of all ages with DD/ID
OR ICF/IDD Comprehensive Waiver*	Individuals aged 18+ with DD/ID
OR Aged and Physically Disabled Waiver	Individuals aged 65+ or aged 21–64 with a physical disability

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

Oregon does not have any waivers specific to individuals with ASD at this time.

Other waivers

In Oregon, three waivers provide services to individuals with developmental and intellectual disabilities; this includes individuals with ASD. ODDS within the Department of Human Services administers all of the waivers.

- The *Oregon Behavioral (ICF/IDD) Model* waiver is available to children with developmental and intellectual disabilities from birth to age 17. The waiver is currently funded below its capacity, and advocates are pushing for a fully funded or comprehensive services waiver for children. Services include:
 - Case management
 - Family training and counseling
 - Special diets
 - Translation (Oregon Department of Human Services, 2011)
- The *Oregon Comprehensive (ICF/IDD)* waiver is available to individuals of all ages with developmental and intellectual disabilities. The waiver offers 24-hour support, which can be provided in or outside of the family home through comprehensive in-home supports, 24-hour residential supports, and employment and community inclusion services. Comprehensive in-home supports help individuals design and manage services necessary to live in their own home or their family's home. Residential supports offer 24-hour support for individuals living outside of the family home in places such as foster care homes, group homes, supported living, and state-operated community programs. Local Community Developmental Disability Programs determine eligibility, and a County Services Coordinator assists the individual and family in developing a service plan. Services include:
 - Case management
 - Alternatives to employment–habilitation
 - Supported employment and prevocational services
 - Occupational and physical therapy
 - Speech, hearing and language services
 - Family training and counseling (Oregon Department of Human Services, 2011)
- The *Oregon ICF/IDD Support Services* waiver is available to individuals aged 18 and older with developmental and intellectual disabilities who are deemed eligible by the local Community Developmental Disability Program. Brokerage support services are available to help individuals remain in their own home or in a family member's home and participate in the community. Individuals first enroll in one of the Support Service Brokerages throughout the state. Through person-centered planning, participants work with a personal agent to design an individual support plan, determine necessary and available services, develop a budget, choose providers, and evaluate services. Brokerage support services are the outcome of a lawsuit against the state of Oregon in 2000, which outlined specific conditions of support services throughout the state (Oregon Department of Human Services, 2011). For individuals with ASD, the waiver usually provides limited funds for employment and other support services. The full list of services includes:
 - Case management
 - Supported employment

- Occupational and physical therapy
- Speech, hearing, and language services
- Community living and inclusion support–habilitation
- Family training and counseling
- Special diets
- Specialized supports
- Support services brokerage operations (organized health care delivery system)

Findings

Services and supports for people with ASD

The ODDS offers services and supports to children and adults across the state (Oregon Department of Human Services, n.d.). Services through ODDS are funded through a combination of state general funds and matching federal Medicaid dollars. The office is broken into 30 Community Developmental Disabilities Programs (CDDPs), which work with families to apply and determine eligibility. If an individual is eligible, CDDP service coordinators help families determine useful services and develop a service plan. The Aging and People with Disabilities division within ODDS offers supports to families and children, such as the Family Support Program, in-home supports, and 24-hour services in foster care or residential placement. The Aging and People with Disabilities division has three program areas, including comprehensive and support services to people with developmental disabilities. Services include:

- Adult in-home services
- Adult residential group homes
- Children’s intensive in-home services
- Children’s residential group homes and proctor homes
- Diversion and crisis services
- Nonrelative foster care for children and adults
- State-operated community programs
- Supported living services
- Vocational services
- Adults support services
- Family support services
- Long-term support for children with developmental disabilities (Department of Human Services, 2010)

The OCCYSHN provides infrastructure-building support to strengthen the availability of services in different communities. OCCYSHN is currently supporting public health nurses across the state who are trained to help families of individuals with ASD to navigate the system. Similarly, they provide support for the Family Navigator Program and operate a family-to-family information center to facilitate the exchange of resources. The Family Navigator Program works

with private practices to identify families in need of help and then coordinates caregivers who have experience navigating multiple child-serving agencies to provide peer support to families of children with behavioral, mental health, or other challenges. Children and families are eligible for these services until transition age, which can vary for each individual.

Early intervention

The IDEA Part C early intervention and Part B early childhood special education services are housed within the Oregon Department of Education. Early intervention services for children aged 0–3 are provided in the child’s home or other caregiver setting and involve a parent-coaching model. The Early Childhood Special Education (ECSE) program offers services for children from age 3 until kindergarten, including screening, evaluation, specially designed instruction, physical therapy, occupational therapy, and speech/language therapy. These services are provided at community preschools, childcare facilities, and other certified sites (Northwest Regional Education Service District, n.d.).

School-aged children

The ODDS operates the Family Support Program for children aged 0–18 and their families. The program is based on disability rather than economic need and serves to supplement other family and community resources. To be eligible, children must be eligible for developmental disabilities services through their CDDP and live in the family home. Families work with service providers to create a service plan that is tailored to their needs. Before services are appropriated, the service coordinator helps to identify all available resources from family and community sources, including public and private programs, private insurance, and support groups. The service coordinator helps the family to leverage funds to their greatest benefit, and state funds are used for services that are not available from other sources. Within 90 days of entry into the Family Support Program, the service coordinator submits a written plan, which is renewed annually and outlines service costs and sources of funding. Services include:

- Behavior consultation
- Community inclusion
- Environmental accessibility adaptations
- Family caregiver supports
- Family training
- In-home support
- Occupational therapy
- Physical therapy
- Respite care
- Special diets
- Specialized equipment and supplies
- Speech, hearing, and language services
- Transportation (Oregon DHS ODDS, n.d.[d])

The ODDS also offers intensive in-home services for children with significant medical or behavioral needs. Eligibility for the Intensive Behavior Program is determined by the Children's Intensive In-Home Services staff and requires that children meet criteria for developmental disability services through their CDDP. If eligible, children from birth to age 18 can receive flexible support services to help them remain in their home.

The Department of Education offers ASD education services for children from birth to age 21 who are eligible for support from regional programs; Oregon does not require a medical diagnosis for educational services. Regional programs work with local school districts, early intervention services, early childhood special education programs, families, and community agencies to provide specialized services for children with ASD. The state has eight regions, each of which provides evaluation, consultation, resource libraries, teaching support, curriculum adaptations, environmental modifications, communication development, and social skills. Smaller districts also have Educational Service Districts that employ autism specialists (Department of Education, 2013a).

Adults

The ODDS offers services to adults with developmental and intellectual disabilities. The CDDPs help adults establish eligibility, assess needs, and determine the most effective services and supports. Individuals often cannot enter adult services immediately, but the CDDP will give an approximate waiting period. Service coordination is available to any individual not receiving other funded services and is offered to individuals who are waiting to enter support services or who have been denied other services (Oregon DHHS ODDS, n.d.[c]). All of the services offered through the ODDS are based on the idea of self-determination and encourage individuals to work with a service coordinator to choose services and providers. As detailed in the section on waivers above, services available to adults include individual services planning, brokerage support services, comprehensive supports in the home, and 24-hour comprehensive residential supports. ODDS also provides customized employment that is based on the strengths, personal interests, and goals of the individual, while ensuring that the employers' needs are also met. Staff help with job exploration, development, coaching, and support (Oregon DHS ODDS, n.d.[b]).

The Office of Vocational Rehabilitation Services also provides employment assistance to individuals who have physical or mental disabilities that inhibit their ability to maintain employment and require services and support to find and keep a job. Vocational rehabilitation services include assessment, counseling and guidance, independent living services, assistive technology, training services, and job placement (Office of Vocational Rehabilitation Services, n.d.).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Transition from Early Childhood Special Education to the local school district begin 1 year before a child enters kindergarten. At this time, the school district is notified and invited to observe the child to improve transition planning. The school district reviews a copy of the child's Individual Family Service Plan (IFSP), consults with ECSE staff, and then meets with the family to review and establish eligibility. Finally, the child's needs are reviewed at the initial Individualized Education Program (IEP) meeting, and an IEP outlining services and supports is developed to replace the IFSP.

The transition team is made up of the sending program, the receiving program, the parents of the child, and private therapists. The sending program consists of the service coordinator, therapists, specialists, and support staff. The receiving program consists of kindergarten teachers, support staff, an autism specialist, counselor, and special education teachers (Oregon Parent Training and Information Center, n.d.).

School-aged to employment

Individuals with developmental disabilities that have an IEP can continue in special education until age 22. At age 16, the student is invited to all IEP meetings to discuss transition and explain his or her goals, strengths, and preferences regarding post school plans. The school district works with the individual and family to establish goals for adulthood and provide services to ease the student's transition to work and other community inclusion settings. The ODDS also helps with an individual's transition from children to adult services at age 17.

The Oregon Commission on Autism Spectrum Disorders has a subcommittee for interagency transition that is focused on increasing effective cooperation between children's and adults' services. They are in the process of creating standards to build collaboration and measure progress.

Training for direct service support workers

The Healthcare Subcommittee of the Oregon State Autism Commission is currently working on a screening initiative called the Start Project. Project staff visit local communities upon request and provide trainings on developmental disability screening, including autism. They have trained more than 500 health care providers over the past 2 years. They also are working on manuals for physicians to improve treatment for individuals with ASD. Currently, they are developing a toolkit for primary care doctors who care for adults with ASD.

The Department of Education is collaborating with STAR Autism Support to develop a statewide network of Oregon Regional Program Autism Training Sites. The system of training sites provides a proactive approach to individualizing services for children with ASD and helps to build state and local capacity through a systematic training protocol. In addition, the Department of Education offers free training videos, parent training and support, and statewide consultative and resource services to assist regional programs in meeting the needs of students with disabilities (Department of Education, 2013b).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

In 2008, the state of Oregon joined 17 other state developmental disability agencies across the country in creating an Employment First Initiative. Through the initiative, meaningful employment in an integrated setting is seen as a key feature of a full life and must be the first priority in service planning. Phase 1 of the Employment First Initiative took place from April 2010 to April 2012 and focused on promoting policy and building capacity for the implementation. Phase 2 is currently being implemented through 2015 and is based on principles and practices of individual support plans, person-centered planning, wages and benefits, service planning, and employment supports (Office of Developmental Disability Services, n.d.[a]).

The Oregon State Autism Commission is working to coordinate diagnostic evaluations for individuals with ASD through two systems: one is focused on medical identification and the other on educational identification. The Commission elected to use the DSM criteria and is standardizing this across the state.

Additionally, the state would like to increase funding for early intervention services, improve health facilities, and replicate the model of the University of California Davis MIND Institute. The MIND Institute uses telehealth practices to allow families anywhere to go online and receive technical assistance. Colorado and Iowa have created similar models.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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PENNSYLVANIA

Approach

The L&M research team held discussions with three representatives from the Commonwealth of Pennsylvania: the Department of Public Welfare's Bureau of Supports for People with Intellectual Disabilities and the Bureau of Autism Services (BAS). These discussions addressed services and supports for persons with autism spectrum disorders (ASD) for the following areas: developmental disability services, early intervention, special education, public health, mental health, and Medicaid. A representative from the Department of Corrections was also interviewed and addressed services and supports for people with ASD in the corrections system.

State background

In Pennsylvania, ASD services and supports for children and adults are administered through the BAS, Office of Developmental Programs. Pennsylvania does not have a definition for ASD in a written statute. For diagnosis, at the time of interview, Pennsylvania referred to the DSM IV Diagnostic Criteria for Autistic Disorder. Changes to policy or eligibility for services with the release of DSM V have not yet been considered.

State insurance regulations

In 2008, legislation passed in Pennsylvania requiring that coverage for autism be included in all health insurance policies. The PA Autism Insurance Act took effect in July 2009, requiring coverage of up to \$36,000 for ASD diagnosis and treatment. People with ASD requiring treatments that exceed the \$36,000 limit are eligible for state Medicaid reimbursements for the extra expense. The following services are covered under the law:

- Diagnostic assessment;
- Prescription drugs and blood level tests;
- Psychiatric and/or psychological services (direct or consultation);
- Applied behavior analysis; and
- Other rehabilitative care and therapies, such as speech/language pathology, occupational therapy, and physical therapy.

State 1915(c) Home and Community Based Services (HCBS) waivers

As in all states, the waivers available to individuals with ASD also impact the nature of service delivery in the state. Waiver services typically have a waiting list that is triaged by urgency of need. More information about the waivers applicable to the ASD community is given below.

State of Pennsylvania 1915(c) waivers

Waiver Name	Population Served
PA Medicaid Waiver for Infants, Toddlers, and Families*	Children aged 0–2 with ID/DD
PA Consolidated Waiver*	Individuals aged 3+ with ID
PA Person/Family Directed Support*	Individuals aged 3+ with ID
PA OBRA*	Individuals aged 18–59 with DD
PA Attendant Care	Individuals aged 18–59 with PD
PA Independence	Individuals aged 18–60 with PD
PA Adult Autism*	Individuals aged 21+ with autism spectrum disorders
PA AIDS	Individuals aged 21+ with HIV/AIDS
PA COMM CARE	Individuals aged 21+ with brain injury
PA HCBW for Individuals Aged 60 & Over	Individuals aged 65+ or aged 60–64 with PD

*Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- The *Pennsylvania Adult Autism* waiver is designed to serve the unique needs of individuals with ASD over the age of 21 who would otherwise need care in an Intermediate Care Facility for Individuals with Intellectual or Developmental Disabilities (ICF/IID) or an ICF for persons with Other Related Conditions (ICF/ORC). Services include:
 - Day habilitation
 - Residential habilitation
 - Respite
 - Supported employment
 - Support coordination
 - Therapies
 - Assistive technology
 - Behavioral specialist services
 - Community inclusion
 - Community transition
 - Environmental modifications
 - Family counseling
 - Family training
 - Job assessment/finding
 - Nutritional consultation
 - Temporary crisis assistance
 - Transitional work services

Other waivers

- The *Pennsylvania Medicaid Waiver for Infants, Toddlers, and Families* provides habilitation services to children aged 0–2 with an intellectual or developmental disability. A 50 percent delay in one or 33 percent delay in two of the following developmental

areas must be present: cognitive, physical (including vision and hearing), communication, social/emotional, and adaptive. Available habilitation services include:

- Infant/toddler early intervention services
 - Speech and language therapy
 - Physical therapy
 - Occupational therapy
 - Nutrition services
 - Audiology
 - Psychological therapy
 - Social work
- The *Pennsylvania Consolidated Waiver* provides services to individuals aged 3 and older who have an intellectual disability. This waiver emphasizes deinstitutionalization, preventing or minimizing institutionalization, and providing an array of services and supports in community-integrated settings. This waiver provides participant direction opportunities for participants who live in a private home. Participants who live in homes owned, leased/rented, or operated by the agency are excluded from participant direction. Available waiver services include:
 - Education support services
 - Home and community habilitation (unlicensed)
 - Homemaker/chore
 - Licensed day habilitation
 - Prevocational services
 - Residential habilitation
 - Respite
 - Supported employment—job finding and job support
 - Supports coordination
 - Extended nursing
 - Extended therapy services
 - Supports broker services (for participant-direction)
 - Assistive technology
 - Behavioral support
 - Companion
 - Home accessibility adaptations
 - Specialized supplies
 - Transitional work services
 - Transportation
 - Vehicle accessibility adaptations
 - The *Pennsylvania Person/Family Directed Support Waiver* serves the same target and age group as the *Consolidated Waiver* described previously and provides the same range of services, with the exception of residential habilitation. Individuals residing in licensed and unlicensed residential habilitation settings, which include Community Homes for Individuals with Intellectual Disabilities, Family Living Homes, Child Residential Facilities, and Community Residential Rehabilitation Services, are excluded from enrollment in this waiver. Participant-directed opportunities are available.

- The *Pennsylvania OBRA Waiver* provides services to individuals aged 18–59 with developmental disabilities who are Medicaid eligible and require ICF/ORC level of care. The waiver aims to prevent unnecessary institutionalization and to promote living independently by providing services in home- and community-based settings. Participant direction is an available option. Services offered include:
 - Adult daily living
 - Education services
 - Personal assistance
 - Prevocational services
 - Residential habilitation
 - Respite
 - Service coordination
 - Structured day habilitation
 - Supported employment
 - Home health
 - Financial management services
 - Accessibility adaptations/equipment/technology and medical supplies
 - Community integration
 - Community transition
 - Nonmedical transportation
 - Personal Emergency Response System
 - Therapy and counseling

Findings

Services and supports for people with ASD

Early intervention

Pennsylvania has an established network of community evaluation providers available through the Office of Developmental Programs. Anyone concerned that their child may have autism or a developmental delay may use these services for evaluation. The Pennsylvania Bureau of Supports for People with Intellectual Disabilities does community outreach with pediatricians and daycare centers to ensure that the community is aware of the services.

Once identified for service eligibility, early intervention services are provided through the Pennsylvania Department of Education for children from birth to age 5. Early intervention services can include, but are not limited to parent education, support services, developmental therapies, and family-centered child development services. Early intervention services can be provided in many settings, including special education classrooms, the child’s home, play groups, Head Start programs, or daycare. All early intervention programs offered through the Pennsylvania Department of Education are free to the child and the family (Pennsylvania Department of Education, 2013).

School-aged children

School-age children receive services primarily coordinated through the Pennsylvania Department of Education special education programs in accordance with Part B of the Individuals with

Disabilities Education Act statutes. Somewhat unique to Pennsylvania, however, is that children who meet Social Security's definition of disability are considered to be a "family of one" for Medicaid eligibility, and their parents' incomes are not considered. This allows children much easier access to waiver services.

Children can remain in school, and thus in special education programs, until age 21. Individuals with ASD have had some difficulties fitting in smoothly with school services. Many schools in Pennsylvania have zero-tolerance policies for behavioral issues, and as a result, children with ASD can face suspensions or expulsion, creating a gap in services when the child is not in school.

Adults

Adults primarily receive services covered by applicable Medicaid waivers and/or private insurance coverage. Although the waivers and insurance can cover many basic care needs, adults may have difficulty adapting to more independent life after special education services end at age 21 or high school graduation. The BAS is making an effort to help adults with autism assimilate better into community life. These efforts include community education campaigns to help people such as first responders, lawyers, judges, and police understand the needs of autistic adults. Additionally, BAS is working on improving leisure and recreational opportunities for the ASD community by establishing activities that are best suited and most enjoyed by individuals with ASD and tailoring those activities to the ASD community.

Public housing is a challenge for many populations in need, including the mental health, developmental disability, and aging communities. One problem encountered with housing for individuals with ASD is that an individual may be cognitively and verbally proficient yet unable to live independently. Many of these adults remain at home due to lack of housing options, which becomes a problem as parents age or are otherwise no longer able to care for their child.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

Overall, transition from early intervention services to school is smooth; the systems for managing both populations of children are well established and experienced in transitioning. Some difficulty may be encountered, however, as children and families that are familiar with one service and support team must adapt to a new team.

School-aged to employment

When an individual reaches age 21, many supports that had been in place for adults with ASD drop off if the individual does not meet the more stringent criteria for waiver eligibility. Adults still eligible may make use of waiver-based services for employment training or college preparedness. Higher-functioning adults can transition into college or employment, but there may be a lack of services to help them if waivers do not apply.

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Inmates with ASD in the Pennsylvania correctional system are not treated differently or housed separately from the general population unless they experience difficulty integrating into the community or are otherwise being victimized. This separation from the general population would be offered for any inmate suffering these issues: Although it may apply to individuals with ASD, it is not an ASD-specific policy. When an inmate enters the system with an Individualized Education Program from school or an Individualized Family Service Plan, correctional staff and care providers are sometimes aware of an ASD diagnosis; however, many inmates go undiagnosed due to lack of records from childhood and adolescence. Individuals with a diagnosis of ASD who are enrolled in programs to receive secondary diplomas while incarcerated will not receive special services, but the diagnosis will be taken into consideration by the educational staff.

Although staff members do not receive specific ASD training, the correctional officers and staff interacting with individuals with ASD are trained in managing inmates with behavioral and personality disorders. Some “special needs units” excel in these areas.

The Department of Corrections has a close working relationship with the Departments of Public Welfare and Labor and Industry for the purposes of easing reentry into society after incarceration.

Long-term plans to develop new or expanded supports and services (2–5 years)

Although interviewees mentioned hopes for improved services, rates of diagnosis, and training for communities and providers, no specific long-term plans were addressed.

Other relevant programs and services

The *Pennsylvania Network of Care* (<http://pa.networkofcare.org>) is a Web site offered through the Department of Public Welfare to assist the public in finding programs and resources available to meet their needs. The Pennsylvania Network of Care provides tools such as:

- Information and service directories for every county in Pennsylvania;
- A research library;
- Free online trainings available in multiple languages, including American Sign Language;

- Local, state, and national links to government resources and organizations that specialize in mental health;
- Bill tracking to follow current state and federal legislation;
- Social networking; and
- Secure storage of personal folders including health information, reference materials, Wellness and Recovery Action Plans, and Mental Health Advance Directives (Pennsylvania Department of Public Welfare, 2010).

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RHODE ISLAND

Approach

The L&M research team held a discussion with one representative from the Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals to discuss services and supports for persons with autism spectrum disorders (ASD) in the state.

State background

In early 2009, legislation (H.5691, H.5270, S.170, and S.716) was introduced to establish a Joint Commission to Study the Educational Needs of Children with Autism in Rhode Island. H.5691/S.716 was transmitted to the governor on July 7, 2009, and became law on July 16 without his signature. The study focused on diagnosis and assessment, prevalence, impact on family, the role of the family, educational goals, interventions, educational programs, and public policy approaches to personnel training and education. The commission comprised 24 members, including legislative officials, representatives from state agencies, and professionals with an interest in autism. The final report was to be submitted to the General Assembly by January 28, 2010, and was to dissolve by June 15, 2010. However, H.B. 5286 was passed in the 2011 session without the governor's signature, extending the reporting date of the Commission until January 24, 2012, with the commission set to expire on June 28, 2012. No further information is available at this time.

In 2011, the "Welcome to the Rhode Island Resource Guide for Families of Children with Autism Spectrum Disorders (ASDs)" was developed by a committee of experts on ASDs spearheaded by the Rhode Island Department of Health's Office of Special Health Care Needs. Committee members included physicians, members of community service organizations, and families of children with ASD.

State insurance regulations

In 2011, the Rhode Island legislature passed and Governor Lincoln Chafee signed S.B. 107/H.B. 5275, mandating private and state health care plans cover the diagnosis and treatment of ASD. Health plans are required to provide benefits for applied behavior analysis (ABA), speech therapy, occupational therapy, and physical therapy. There is a \$32,000-per-year limit on ABA. Benefits for occupational therapy and physical therapy are to be the same for all other diseases or disorders covered by the health plan.

In the 2012 session, H.B. 7165 amended the scope of coverage for ASD to include psychology, psychiatry, and pharmaceutical services as covered treatment options to the extent that such services are a covered benefit for other diseases and conditions. It also enables licensed psychologists to provide ABA therapy if they have "equivalent experience." S.B. 2559 also passed in the 2012 session, which created a five-member Applied Behavior Analyst Licensing Board within the Department of Health (Easter Seals, 2012).

State Medicaid waivers

Specific ASD waivers

Rhode Island does not have any waivers specific to individuals with ASD at this time.

Other waivers

Rhode Island does not have any home- and community-based services waivers at this time. The Rhode Island Medicaid Reform Act of 2008 directed the state to apply for a “global” demonstration under the authority of Section 1115(a) of Title XIX of the Social Security Act. The Rhode Island Global Consumer Choice Compact 1115 Waiver Demonstration (*Global Waiver*) provides the state with substantially greater flexibility than is available under existing program guidelines. The purpose of the Global Waiver is to redesign the State’s Medicaid program to provide cost-effective services that will ensure beneficiaries receive the appropriate services in the least restrictive and most appropriate setting. The Global Waiver has three major program goals: to rebalance the publicly funded long-term care system, to ensure all Medicaid beneficiaries have access to a medical home, and to implement payment and purchasing strategies that ensure a sustainable, cost-effective program.

Under Rhode Island’s Global Waiver, persons with ASD are eligible for services through RItE Care, Rhode Island’s combination Medicaid and Children’s Health Insurance Program that provides health insurance coverage to low- and moderate-income children, their parents, and pregnant women. Additionally, through its Global Waiver, Rhode Island’s Medicaid program provides comprehensive medical coverage to individuals aged 65 and older and people of all ages with permanent disabilities, including autism.

Findings

Services and supports for people with ASD

The Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals, Division of Developmental Disabilities serves as the lead agency administering a community system of services and supports for persons with developmental and behavioral disabilities, including autism (Rhode Island BHDDH, n.d.). In addition, the Family Resource Counselor (FRC) program is a long-term public-private partnership that serves as an important outreach mechanism for Rhode Island. The FRC serves families statewide at no cost to the child or family. FRCs are specially trained staff members of community health centers, hospitals, and community organizations in Rhode Island who help families find assistance they might be eligible for and assist them in applying for programs.

Early intervention

The Rhode Island Executive Office of Health and Human Services administers the state’s Early Intervention (EI) program. EI is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. EI serves all eligible children (from birth to age 3) and their families, regardless of income or health insurance coverage. EI services are individualized to support and assist families in meeting the goals that they have for their children.

Referrals for a child who has ASD or symptoms of ASD can be made directly to EI programs by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services. When a child is referred to EI, eligibility is determined through an evaluation and assessment performed by the EI program. Some children are eligible based on their diagnoses. This includes children with an

ASD diagnosis. The purpose of the evaluation and assessment process includes not only eligibility determination but also information gathering for planning purposes and answering the family's questions regarding their child's development. After a child is determined eligible for EI, the EI staff and the family design a plan called the Individualized Family Service Plan (IFSP). This plan outlines the child's strengths and needs and documents the family's concerns and priorities. It is developed on the basis of the information gathered from an evaluation or assessment and direct input from the family. The IFSP focuses on the goals or outcomes the team, including the family, identifies for each individual child. The team then talks about the strategies and supports that can be used to meet the desired outcomes or goals in the IFSP. Strategies and supports are transdisciplinary, meaning they involve professionals with various backgrounds working together with the family toward the same outcomes. The plan is developed so that it can be implemented in the child's "natural environment," or where the child spends the majority of his or her day. "Daily routines," like playtime and mealtime, are when most of the strategies take place, making it easier for the family to carry out the plan in between visits from EI. The IFSP is reviewed every 6 months and can be changed at any time.

School-aged children

Schools are the primary service provider for children aged 3–22. Children must have available all educationally necessary services as required by the Individuals with Disabilities Education Act. When a referral is made to the public school system in Rhode Island to determine eligibility for special education and related services, the school system must conduct a meeting within 10 school days to review the referral and request additional information if needed (Rhode Island DOH, 2011). The meeting should include the parent and/or caregiver and qualified professionals to determine whether an initial evaluation is warranted. If further evaluation is determined to be appropriate, the family must sign a consent form and the school system has 10 days from receipt of permission to begin the evaluation process.

Once eligibility is determined for special education services, an individualized education program (IEP) is developed as an agreement between the parents/caregivers of the child and the school system outlining services and roles. The IEP is reevaluated at least annually but the family and educators may hold IEP meetings at any time (Rhode Island DOH, 2011).

Adults

The Rhode Island Department of Behavioral Healthcare, Developmental Disabilities and Hospitals, Division of Developmental Disabilities is responsible for planning, providing, and administering a community system of services and supports for adults with developmental disabilities in Rhode Island. The main goal of these services for adults is to enhance the quality of support/services so that people with disabilities can identify and move toward personal futures of inclusion and participation in community life. In addition, these services and supports are in place in order to safeguard the health and safety of people with disabilities through quality management activities that promote human rights and protect people from abuse and ensure equitable access to and allocation of available resources in order to be responsive to the individual needs of the person.

The division funds a statewide network of community services and support for adults with developmental disabilities by contracting with a variety of community provider agencies. These

services are both privately and publicly operated. Individuals with developmental disabilities are encouraged to direct the funding available to them to meet their need for support. Funding is available in three broad categories: residential services, day/employment services, and family supports.

To be eligible for supports funded through the Division of Developmental Disabilities, individuals must have a severe, chronic disability of a person, which

- Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- Manifested before the person attained age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in three or more of the following areas of major life activity:
 - Personal care
 - Communication
 - Mobility
 - Learning
 - Self-direction
 - Capacity for independent living
 - Economic self-sufficiency
- Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are lifelong or extended duration and are individually planned and coordinated.

In addition, the Rhode Island Community Living and Supports (RICLAS) program has over 25 years of experience in providing a network of supports tailored to individual needs. RICLAS is the only state operated community provider of services to individuals with developmental disabilities living in Rhode Island. RICLAS provides 24-hour residential supports to approximately 285 men and women in 43 residential locations around the state as well as day supports to approximately 175 individuals in various locations. The homes are located throughout the state from Westerly to Woonsocket. Three general types of residential services are provided:

- Special care facilities: three 15-bed facilities that are divided into three 5-person apartments. In addition to direct support staff, these facilities are supplemented with dietary, housekeeping, nursing and program staff.
- HUD apartment programs: 5–7 apartments available for supported individuals in each of 8 HUD apartment complexes in the areas north and east of Providence.
- Group homes: RICLAS operates 31 six-person homes and 1 four-person home in various locations throughout the state

The 3-day support areas are located in Cranston, Hope Valley, and North Kingstown. RICLAS provides the following supports to the individuals in the agency as well as others who may need supports on a temporary basis from home or from other providers:

- Direct support services
- Nursing services
- Psychological services
- Social services
- Nutrition services
- Physical therapy
- Respite care
- Medical services
- Speech therapy
- Occupational therapy
- Transportation services
- Self-advocacy groups

The Vocational Rehabilitation (VR) Program, a subsidiary of the Rhode Island Office of Rehabilitative Services, is the public state and federally funded program that assists individuals with disabilities to choose, prepare for, obtain, and maintain employment. Individuals eligible for vocational rehabilitation services must meet the following qualifications: (1) have a physical or mental impairment which is a substantial barrier to employment, (2) require vocational rehabilitation services to prepare for, secure, retain, or regain employment, and (3) be able to benefit from vocational rehabilitation services in terms of an employment outcome. Individuals with disabilities must first apply for the VR program and be determined eligible before services can be provided. Individuals with significant disabilities are presumed eligible for the program if an application is completed and there is documentation of disability. The eligible individual with a disability and a qualified VR counselor will work together to develop an employment plan called the Individualized Plan for Employment (IPE). The IPE accounts for the individual's unique strengths, resources, priorities, concerns, skills, abilities, preferences, capabilities, interests, and values as well as the barriers to employment.

Systems tracking

As a result of the Rhode Island Evaluation and Treatment Act, the Rhode Island Department of Health is legislatively required to not only evaluate which methodologies would provide an accurate diagnosis of ASD but also develop a system for maintaining records of diagnoses.

Promotion of services and supports for people with ASD

Interviewees told the research team that the Rhode Island Parent Information Network provides materials to families that list all relevant supports and services. In addition, the Rhode Island ASD Support Center promotes services to eligible individual and provides professional

development and technical assistance, best practice guidelines, demonstration classrooms, data systems, and comprehensive planning. The Rhode Island Department of Education (RIDE), Office of Special Populations, through a contract with the Rhode Island Technical Assistance Project, has made available the Autism Support Center to serve as a clearinghouse for information and support for educators and parents of students with ASD (RITAP, 2013). Services available include workshops, training, information, resources, best practices, and other pertinent information that support the educational needs of children with autism.

Transitions and coordination of services

Early intervention to school

When a child in EI turns 28 months old, the family will be asked to sign a release allowing a referral to the local school district. The family's service coordinator will schedule a transition conference meeting with the family and the local educational agency (LEA) to be held around the time the child is 30 months old. At the transition meeting, the team will share information about the child, plan for next steps, and write an individual transition plan. If more information is needed, a plan will be made to delegate that responsibility. Additional evaluations can be scheduled if needed. Children who turn three during the summer months will begin their transition process early so that plans may be finalized before summer break.

Not every child transitioning out of EI will be found eligible for services through the school system, but each of these families should have a transition planning conference. Between age 30 and 35 months, the LEA will convene an eligibility meeting. The evaluation team, including the parent(s)/caregiver(s), will decide whether the child is eligible for special education. If the child is eligible, an Individualized Education Program meeting will be scheduled. If the child is not eligible for special education, the transition team will help the family locate appropriate community resources that may continue to support the child's development as stated in the child's transition plan. All families of children eligible for Medical Assistance should be informed about CEDARR Family Centers at an appropriate time during their experience in EI. A CEDARR Family Center is a place where families can receive help and support for children with special needs. In addition, the CEDARR Family Centers provide an opportunity to connect with other families who have had similar experiences.

With a parent's permission, the EI service coordinator can initiate a referral for the child to CEDARR. A child does not need to be in special education to access CEDARR services. The following services may be available for eligible children and youth with special health care needs serviced through CEDARR Family Centers: home-based therapeutic services, personal assistance services and supports, respite, and Kids Connect (Rhode Island DHS, n.d.). Kids Connect is a program that provides specialized services at licensed childcare centers that can help children with special needs participate, play, and learn along with their typically developing peers; licensed childcare centers and afterschool care programs contract with the state to provide this service.

School-aged to employment

The individual school district (LEA) is responsible for the education of children with special needs aged 3–21. Families are guided through the transition process by their service coordinator and family support staff, who have personally been through this process. It is important to

remember that the family is involved in every step of the transition process. The CEDARR Family Centers help ease transitions from school-aged to employment because they offer a full range of services and treatment options. Further, the Rhode Island Department of Health, Office of Special Health Care Needs' Adolescent Healthcare Transition Program assists youth, families, physicians, schools, and other providers in the transition and transfer of youth with special health care needs from pediatric to adult health care. Rhode Island provides educational materials about the adolescent transition process through its state agencies.

Training for direct service support workers

RIDE Office of Special Populations contracts with the Rhode Island Technical Assistance Project at Rhode Island College to support the Autism Support Center. The Autism Support Center provides workshops regarding professional development and technical assistance, resources, best practice guidelines, demonstration classrooms, data systems, and comprehensive planning (Rhode Island 211, 2012). Workshops are offered through the Autism Support Center. To participate, local school systems can request any of the above workshops, and workshops can be tailored to fit the individual needs of the district. This organization serves the entire state of Rhode Island.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

The Center for Autism and Developmental Disabilities at Bradley Hospital in Rhode Island supports autism research and offers specialized clinical services for children and adolescents between the ages of 2 and 21 who show signs of serious emotional and behavioral problems in addition to a developmental disability, such as autism, Asperger's, or intellectual disability. Available clinical services include inpatient, outpatient, school, residential, and home-based services. The center's model of care emphasizes continuity of care and family involvement (Bradley Hospital, n.d.).

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SOUTH CAROLINA

Approach

The L&M research team interviewed three representatives from the state of South Carolina comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. Overall, these interviews with the Department of Developmental Disabilities and Special Needs (DDSN) sought to provide greater understanding of services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

The South Carolina DDSN develops, coordinates, and funds services for individuals with lifelong disabilities. With regard to ASD, DDSN limits its involvement to those diagnosed with autism, not others on the spectrum such as those with Asperger's syndrome, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett syndrome. Other service providers serving individuals with autism include the school system and vocational rehabilitation.

State insurance regulations

South Carolina has an insurance regulation in place, called Ryan's Law, which applies to children younger than 16 who received a diagnosis of autism before age 8. Under the law, insurance plans must cover treatments prescribed by the child's doctor and cannot refuse other medical care to children because of their autism (American Speech-Language-Hearing Association, 2012). A maximum benefit of \$50,000 is in place for behavioral therapy, including applied behavior analysis (ABA) if it is in a child's treatment plan. Small businesses do not have to offer this coverage (Autism Speaks, n.d.).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of South Carolina 1915(c) waivers

Waiver Name	Population Served
SC Medically Complex Children	Children aged 0–18 who are medically fragile/ technology dependent
SC Pervasive Developmental Disorder*	Children aged 3–10 with autism
SC PRTF Alternative CHANCE Waiver	Children aged 4–19 with serious emotional disturbances
SC Community Supports*	Individuals of all ages with ID
SC ID and Related Disabilities*	Individuals of all ages with ID
SC HIV/AIDS	Individuals of all ages with HIV/AIDS
SC Mechanical Ventilator Dependent	Individuals aged 18+ who are technology dependent
SC Head and Spinal Cord Injury	Individuals aged 65+ or aged 0–64 with a disability
SC Community Choices	Individuals aged 65+ or aged 0–64 with a physical disability

**Note: Of particular importance to ASD population*

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

The *South Carolina Pervasive Developmental Disorder (PDD)* waiver provides habilitative services for Medicaid-eligible children with autism aged 3–10. To qualify, children must have a diagnosis of autism before age 8; they can stay on the waiver for 3 years or until they turn 11. This waiver began in 2007 and currently serves about 650 children, with a waitlist of 850. If a child meets all criteria for this waiver, but is ineligible for Medicaid, the state will pay for all of waiver services. Currently 125 children receive the state-funded version of this waiver. Waiver services include:

- Case management
- Early Intensive Behavioral Intervention (EIBI) assessment
- EIBI plan implementation
- EIBI program development and training
- Lead therapy
- Line therapy
- Self-directed line therapy

Other waivers

Two other waivers in South Carolina also serve the autism population—the *South Carolina Community Supports* and *South Carolina ID and Related Disabilities*. Both waivers require that individuals meet an institutional level of care requirement and are geared more toward individuals with intellectual disabilities or related conditions. Neither waiver has an age limit. The waiting list for services currently numbers about 3,000 individuals.

- The *South Carolina Community Supports* waiver provides the following services:
 - Adult day health care
 - Personal care
 - Respite
 - Adult nursing
 - Transportation
 - Behavior support
 - Career preparation
 - Community services
 - Day activity
 - In-home support
 - Vocational services
 - Psychological services
 - Respite care
 - Environmental/vehicle modifications
 - Specialized medical supplies, equipment, assistive technology
 - Support center services

- The *South Carolina ID and Related Disabilities* waiver provides the following services:
 - Adult day health care
 - Personal care
 - Residential habilitation
 - Respite
 - Adult dental
 - Adult vision
 - Audiology services
 - Prescribed drugs
 - Adult attendant care
 - Adult companion
 - Adult nursing
 - Transportation
 - Behavior support
 - Career preparation
 - Community services
 - Day activity
 - In-home support
 - Vocational services
 - Personal Emergency Response System
 - Psychological services
 - Environmental/vehicle modifications
 - Specialized medical supplies, equipment, assistive technology
 - Support center services

Findings

Services and supports for people with ASD

DDSN is the primary service provider for individuals of all ages with developmental disabilities in South Carolina. The agency contracts with local Disabilities and Special Needs (DSN) boards and other providers to bring an array of services to communities. Availability of services depends on the needs of the individual, funding, and access to service providers. Common services available for people with ASD across the lifespan include:

- Treatment planning and service coordination
- Genetic evaluation, treatment, and counseling services
- Stipends for daycare and transportation
- Audiology services
- Behavioral support
- Environmental and vehicle modifications
- Personal care
- Nursing

- Occupational therapy
- Physical therapy
- Prescribed drugs
- Psychological services
- Respite care
- Specialized medical equipment, supplies, and assistive technology
- Rehabilitation support services

Services for individuals with ASD are funded through waiver programs first, then the state Medicaid plan, and finally through Individual and Family Support Funding. The latter gives support stipends to help families pay for bills and services so they can stay home and care for a disabled child or family member.

The typical point of entry for those with autism, regardless of life stage, is through the DSN boards (despite name similarity they are not branches of DDSN). Each DSN board has a toll-free number, and when families call, they are put through a screening process to determine the appropriate service agency. Families are also given a list of case managers to select from to help them navigate through the system.

Early intervention

BabyNet is the name of South Carolina's early intervention program. BabyNet matches the special needs of infants and toddlers who have developmental delays with the professional resources available within the community. They fund a full array of services according to each child's Individualized Family Service Plan (IFSP), including service coordination, specialized instructions, respite services, and family support stipends for specialized equipment. If the IFSP calls for ABA, children under age 3 are able to receive the service through the early intervention system (South Carolina First Steps, 2006).

School-aged children

School-aged children are primarily served through the school system. Children with disabilities are entitled to all educationally necessary services according to the federal Individuals with Disabilities Education Act (IDEA) legislation. Additionally, aside from waiver services, children may be eligible for case management and other services through DDSN (described above) as well as any medically necessary traditional therapy that is not offered in schools through Medicaid (excluding ABA).

Adults

Although a solid service infrastructure is in place for adults with autism in South Carolina, interviewees noted a lack of accessibility and gaps in service delivery for the adult population. In general, the disproportion of publicly available services between children and adults stems from discrepancies in what Medicaid will cover. In addition to services offered through DDSN across the lifespan (described above), adults may be eligible for specific services such as supported

employment, center-based prevocational services, habilitation/rehabilitation support, mobile work crews, companion services, and dental and vision services (South Carolina DDSN, 2013).

In addition, many adults with autism are eligible for vocational rehabilitation, namely those who “have a documented physical or mental impairment that substantially interferes with their ability to work.” The South Carolina Vocational Rehabilitation Department provides job training and supports, transition services, and assistance getting loans for technology and other supports to promote successful employment (South Carolina VRD, 2013).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Early intervention

South Carolina’s BabyNet program has an employee dedicated to outreach activities whose responsibilities include promoting services to doctor’s offices and conducting public service announcements to ensure that families contact local DSN offices to refer children to early intervention. In addition, the state received a grant 3 years ago from the Centers for Disease Control and Prevention (CDC) to develop materials for children with autism. A major product of this work was a “road map” that helps physicians, families, advocacy groups, and service providers understand how autism services work in the state. A number of autism stakeholders worked together to develop these materials and continue to meet even though the grant has ended.

School-aged children

Interviewees noted that families of children with autism are a cohesive group in South Carolina; the group has an email listserv, which frequently relays the questions and concerns of many families to DDSN. In addition, the South Carolina Autism Society is a nonprofit organization that promotes outreach and awareness to families. They provide information, referrals, and some service coordination, and organize yearly walks and golf tournaments to raise money. Currently, DDSN also has five contracts with various advocacy organizations to help educate families and enroll underserved children in services.

Adults

Outreach for adult services was not addressed in our state interviews.

Transitions and coordination of services

Transition of services in South Carolina is enhanced by its sophisticated tracking system. Beginning with identification in the IDEA Part C program, children with a diagnosis are entered into a statewide database to ensure continuity of services. Additionally, through grant funding from the CDC in 2000, the University of South Carolina, DDSN, and other stakeholders set up the Autism and Developmental Disabilities Monitoring Network. This resource tracks the prevalence of developmental disabilities among children aged 4–8 in the state (Medical University of South Carolina, n.d.).

Early intervention to school

As in other states and mandated by IDEA legislation, children transition at age 3 from early intervention to DDSN and school services. One area of concern in South Carolina is the continuity of ABA therapy. When children transition at age 3, if they are on the waitlist for SC PDD waiver services (which provides ABA therapy), DDSN will allow children to continue receiving ABA until their sixth birthday. However, this applies only to children with an autism diagnosis; therefore, South Carolina state policy places much emphasis on encouraging pediatricians to administer the Modified Checklist for Autism in Toddlers to all children twice between the ages of 18 and 24 months.

School-aged to employment

Planning for formal transition to employment begins between the ages of 14 and 18 and follows a student's Individualized Education Program. During this time, children and families are encouraged to consider academic and personal care courses that children can participate in through the remainder of high school and to meet with a vocational rehabilitation counselor to determine the short-term supports that may be available post graduation (South Carolina Department of Education, 2012).

Training for direct service support workers

All direct care staff members in South Carolina participate in training on a regular basis. These sessions are provided by the Autism Division of DDSN, which is headquartered in Spartanburg and has four satellite offices located throughout the state. The division creates an annual training calendar and makes it available online. Trainings are open to anyone at no cost and typically include attendees from local disability boards, private providers, school districts, and parents.

Corrections

South Carolina DDSN has a Memorandum of Agreement (MOA) with the Department of Corrections to be involved in discharge planning for persons in the correctional system with high functioning developmental and intellectual disabilities. They also have an MOA with the Department of Juvenile Justice (DJJ) to provide a clinician to work with children with developmental disabilities that are in the juvenile justice system. One source noted that discharges from the DJJ could be improved with consistent notification to DDSN when children are released.

Long-term plans to develop new or expanded supports and services (2–5 years)

South Carolina has no major plans to change or expand services at this time. Interviewees indicated that adding the PDD waiver was an important expansion of services, and they are waiting until individuals on the waiver age out of school services before they undergo another expansion project.

Other relevant programs and services

The Developmental Disabilities Council publishes recreational activities offered through DDSN and available in each county. The state provides funding to families so that children can participate in various local programs, such as the YMCA summer baseball leagues and the annual Special Olympics event.

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SOUTH DAKOTA

Approach

The L&M research team interviewed a number of representatives from the state of South Dakota, which included a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the South Dakota Department of Human Services (DHS) Division of Developmental Disabilities (DDD) and Division of Rehabilitation Services (DRS); the South Dakota Department of Education (DOE) Special Education Program and Early Intervention Program; and the University of South Dakota (USD) Center for Disabilities Autism Spectrum Disorder Program.

State background

The State of South Dakota DHS houses the DDD (<http://dhs.sd.gov/dd/>), which serves as the central coordinating agency for individuals with developmental disabilities in the state. The DRS Vocational Rehabilitation Services within DHS also provides services to individuals diagnosed with ASD. Other programs in the state for people with ASD include the DOE Special Education Program and Early Intervention Program and the USD Center for Disabilities Autism Spectrum Disorder Program, which was established by parents of children with ASD. The DDD provides grant funding for the USD Autism Spectrum Disorder Program.

All of the governmental agencies (DDD, DOE, and DRS) examined followed general developmental disability criteria as defined by state statute SDCL 27B-1-18 and the Federal Developmental Disabilities Act. The USD Center for Disabilities defines ASD to include autism, Asperger's syndrome, childhood disintegrative disorder, pervasive developmental disorder not otherwise specified, and Rett syndrome.

In 2000, 262 or 1.56 percent of individuals aged 3–21 who received special education services in South Dakota had ASD. In 2010–2011, 757 or 4.12 percent of individuals with disabilities aged 3–21 who received special education services had ASD (Easter Seals, 2012).

State insurance regulations

South Dakota does not have a specific insurance mandate for ASD. Although South Dakota does have a mental health parity law, the law does not include ASD under its health insurance coverage requirement for the diagnosis and treatment of biologically based mental illness (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

As in all states, the waivers available to individuals with ASD impact the nature of service delivery in the state. The Department of Social Services has administrative authority and responsibility over all of the waivers.

State of South Dakota 1915(c) waivers

Waiver Name	Population Served
SD CHOICES*	Individuals of all ages with DD/ID
SD Family Support *	Individuals of all ages with DD/ID
SD Assistive Daily Living Services	Individuals aged 65+ and aged 18–64 with physical disabilities
SD HCBS for South Dakotans	Individuals aged 65+ and aged 18–64 with disability

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

South Dakota does not have any waivers specific to individuals with ASD at this time.

Other waivers

Currently two 1915(c) waivers in South Dakota provide support to developmentally disabled children and adults, including individuals with ASD.

- The *SD CHOICES* waiver provides comprehensive services to approximately 2,500 participants. To qualify for CHOICES, an individual must be diagnosed with an intellectual and/or developmental disability and must want to receive care in home and community settings. This waiver has no age requirement. Services include:
 - Day habilitation
 - Residential habilitation
 - Service coordination
 - Supported employment
 - Medical equipment and drugs
 - Nursing
 - Speech, hearing, & language services
 - Prevocational services (South Dakota DHS DDD, 2012)
- The *SD Family Support* waiver provides in-home support services to approximately 930 participants with developmental and intellectual disabilities. To qualify for the Family Support 360 program, individuals must have been diagnosed with a developmental disability, require prolonged assistance as determined by the DOE for birth to age 3, and live in the family home. This waiver has no income guidelines. Adults age 18 and older who meet the same criteria are eligible for a local Family Support 360 program. Services include:
 - Personal care
 - Respite
 - Support coordination
 - Supported employment
 - Companion care
 - Environmental accessibility adaptations
 - Nutritional supplements
 - Specialized medical adaptive equipment and supplies
 - Vehicle modifications (South Dakota DHS DDD, n.d.)

Findings

Services and supports for people with ASD

Early intervention

Birth to 3 Connections (<http://www.doe.sd.gov/oess/Birthto3.aspx>) is South Dakota's early intervention program, which provides services for children from birth to age 3 who have a disability or a developmental delay. According to interviewees, if a family or provider suspects that a child has a developmental delay, the family will schedule a screening with Birth to 3 Connections. Next, an early intervention service coordinator or individual service team performs an evaluation and decides whether the child needs an autism evaluation. If ASD is detected, an autism team is brought in from school; however, representatives said that children are typically not diagnosed until at least age 2.

When a child is diagnosed with a developmental delay, the early intervention services available to them include audiology, assistive technology, family training and counseling, home visits, health services, medical services for evaluation, nursing, nutrition, occupational therapy, physical therapy, psychological services, social work services, service coordination, special instruction, speech and language, transportation, and vision.

School-aged children

To identify students with ASD, independent and individual school districts train staff to conduct ASD evaluations. South Dakota school districts will sometimes request onsite consultation services from the USD ASD Program during the initial training process. At the time of the interview, the USD ASD Program offered free training on positive behavioral supports for students with ASD for educators and caregivers of children with ASD and had plans for future training sessions.

Further evaluation of school-aged children is conducted at diagnostic clinics across the state. Diagnostic clinics are available in more heavily populated metropolitan areas of the state, such as the USD ASD Program's clinic in Sioux Falls. The limited number of diagnostic clinical services available in more rural and less populated areas is a problem for families and caregivers who must travel in order to obtain diagnostic tests and followup services.

When children are diagnosed with ASD, they are eligible to participate in special education programs offered by DOE in addition to the SD CHOICES and Family Support 360 programs provided by DDD. The DOE Office of Special Education (<http://doe.sd.gov/oess/sped.aspx>) provides programming and placement options, including early intervention and transition services, to help support the educational progress of students with ASD. The USD ASD program refers families to the Office of Special Education for children 3 years and older.

Adults

DDD is the public provider of services for adults with ASD. Adults with ASD participate in the SD CHOICES and Family Support 360 programs. Interviewees reported that a major challenge for individuals accessing services is the sheer size of South Dakota, which has only a few densely populated areas. If individuals live in a remote area, their access to providers is limited and compounded by the difficulty in attracting providers to serve remote locations. In addition,

DDD works with Native American reservation governments to serve South Dakota residents who live in reservation areas. Many reservation areas are in remote locations with low provider participation, which makes it difficult for those residents to access services.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

School-aged children

Interviewees reported a general dependence on DOE for outreach to help schools identify students with ASD. The USD Center for Disabilities ASD Program incorporates a wide range of outreach through diagnostics, training, and consults across the state. In addition, the program is involved in the CDC's "Learn the Signs. Act Early." campaign, and staff members actively disseminate campaign information and resources through training sessions across the state.

Adults

Outreach to the adult ASD population, their family members, and caregivers occurs during transition to adulthood when DDD, DOE, and DRS come together in partnership to tailor a plan to the needs of the individual.

Transitions and coordination of services

Early intervention to school

The Birth to 3 Connections program starts transition planning at the time the individual family service plan is written. During the 9 months to 90 days before the child turns 3, a meeting is scheduled between the family and school district to familiarize the family with the services that will be provided. This transition planning is supported and facilitated by an interagency agreement between Special Education and Birth to 3 Connections.

For students under the age of 21 who need more support than the school district can provide (e.g., out-of-district placement), DDD works with the school district to develop a plan for transition to another setting. The waiver funds support provided outside of the school district, and the school district matches the funding. This could include services provided through the CHOICES waiver.

School-age to employment

Individuals with ASD who are approaching age 21 are surveyed on an annual basis to prepare for additional supports as they transition to adulthood. DDD, DOE and DRS work together to coordinate a transition plan. A Transition Services Liaison (jointly funded between DOE and DRS) provides technical assistance to schools to connect to services and resources (South Dakota DHS DRS, n.d.). The USD Center for Disabilities ASD Program is also involved in transition, especially when USD providers have had direct contact with the individual.

DRS provides employment development opportunities for 400 students each year through the Project Skills program. According to DRS, 13 percent (52) students in Project Skills have ASD. The program pays wages for individuals to work 250 hours per school year while the student's school provides job training alongside the work experience (University of Montana, n.d.). The Division's Project SEARCH is also available to students in their last year of school (most are aged 21 or 22). In this program, students complete internships in a business setting alongside their classroom experience; interviewees reported that some of the Project SEARCH participants have ASD (East Dakota Educational Cooperative, 2013). In addition, the Department of Labor funds a disability employment initiative to work with youth up to age 24 (United States Department of Labor, 2011).

Training for direct service support workers

The USD Center for Disabilities ASD Program provides training for direct service support workers and to providers who assist individuals with ASD who are transitioning between agencies and into adulthood. In addition, an annual autism conference in Sioux Falls provides training to individuals working with the ASD population (University of South Dakota, 2013).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

During the 2011 legislative session, Governor Dennis Daugaard established the Medicaid Solutions Work Group to develop strategies to contain and control Medicaid costs. The workgroup set up various subcommittees, including the Home and Community Based Services Committee, which developed recommendations for different models of service to meet the needs of individuals who require supports and services in the least restrictive and most appropriate environment. Its other objectives included analysis of future funding opportunities available through the federal government and exploration of patient accountability and reimbursement models. Two recommendations from the workgroup could potentially affect supports and services for individuals with ASD (Office of the Governor of South Dakota, 2011):

- *Recommendation IX: Evaluate Agency Model Domiciliary Care Initiative:* the Domiciliary Care Model is a supervised living arrangement in a home-like environment for adults who are unable to live alone because of age-related impairments or physical, mental, or visual disabilities. This type of program is appropriate for individuals aged 18 and older who are unable to live independently and need assistance with the activities of daily living. The recommendation, if implemented, would provide another viable community living option for adults with ASD who are able to live in a shared environment setting.
- *Recommendation XI: Evaluate Implementation of a Community First Choice 1915(k):* Community First Choice is a new statewide Medicaid 1915(k) plan option for states to leverage a 6-percent increased federal medical assistance rate to provide home- and community-based attendant services for individuals whose income does not exceed 150 percent of the federal poverty level, or higher for those needing an institutional level of

care. The recommendation, if implemented, would provide an increase in federal match funding for services for qualifying individuals with ASD.

Although the recommendations do not mention specific types of disability, individuals with ASD would fall within the general disability definition. The recommendations have not yet been implemented but are being considered for future initiatives to support South Dakotans with ASD in the next 2 to 5 years.

In addition to the 2011 Governor's Medicaid Solutions Work Group recommendations, ASD support agencies and programs in South Dakota are looking at how to develop infrastructure and community capacity to support people with ASD. Specifically, DDD is exploring how to work with DOE to gather data on ASD students in the school system. Using these data, DDD and DOE could project service delivery needs and begin tailoring and/or developing support services specific to the changing needs of individuals with ASD, their families, and caregivers across the lifespan.

Other relevant programs and services

- The *Autism Society of the Black Hills* (<http://www.autismsd.org>) was started in 1997 and is located in Rapid City, South Dakota. The organization offers resources, grant funding to support families of children with ASD, and referrals to general social support programs and services.
- *Autism Speaks in South Dakota* provides families with information, tools, and resources to help them support family members with ASD. Autism Speaks sponsors a Walk Now for Autism annual fundraising and outreach event, and its Web site provides communication about the progress of the national Autism Speaks legislative agenda and advocacy efforts (Autism Speaks, 2013).

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TENNESSEE

Approach

The L&M research team interviewed six representatives from the state of Tennessee, which comprised a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Tennessee Comptroller of the Treasury, the Disability Coalition, the Department of Human Services Division of Vocational Rehabilitation, and the Department of Education (DOE) Office of Special Education.

State background

The government of Tennessee has made many changes in the structure of service delivery for individuals with ASD in the past few years. In 2000, the agencies responsible for individuals with developmental disabilities changed. Around that time, the Division of Mental Retardation was moved into the Department of Finance and Administration and asked to take over services for individuals with developmental disabilities. The Department of Mental Health and Developmental Disabilities is now responsible for more administrative functions, such as system monitoring and evaluation, setting quality standards, and system planning (Tennessee Department of Intellectual and Developmental Disabilities, n.d.[c]). The Department of Intellectual and Developmental Disabilities (DIDD) was a division within the Tennessee Department of Finance and Administration until January 2011. DIDD provides services and supports for individuals with intellectual and developmental disabilities either through their own programs or through contractors. Before the formation of DIDD, there was no true lead agency for individuals with ASD.

State insurance regulations

Tennessee currently has an insurance mandate that any policy that provides coverage for neurological disorders must also cover services for ASD for children under age 12. However, copayments and benefit limits may be applied. Legislators have attempted to mandate coverage past age 12 and to change payment caps for services such as behavioral therapy, but none of these bills have passed (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Tennessee 1915(c) waivers

Waiver Name	Population Served
TN Self-Determination Waiver*	Individuals of all ages with ID and individuals aged 0–5 with DD
TN HCBS Waiver for Persons with MR*	Individuals of all ages with ID
TN HCBS Waiver for MR/DD*	Individuals of all ages with ID and individuals aged 0–5 with DD

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Tennessee does not have any waivers specific to individuals with ASD at this time.

Other waivers

Three waivers in Tennessee provide services to people with ASD. DIDD oversees the daily operations of the waivers and the waiting lists. However, TennCare, the state's Medicaid managed care program, is responsible for the oversight of all Medicaid funded services. The planning process for all three waivers is person-centered, meaning an individual's plan and desires guide the plan of care (Tennessee DIDD, n.d.[a]).

- The *TN Self Determination Waiver* helps individuals with intellectual and developmental disabilities who have moderate service needs and promotes independent living and choices. The Self Determination waiver has a spending cap of \$30,000 per person per year; however, exceptions can be made to the spending cap if a person needs a small number of additional services to be able to stay at home. Services include:
 - Respite
 - Nursing services
 - Nutrition services
 - Occupational therapy
 - Physical therapy
 - Specialized medical equipment, supplies, and assistive technology
 - Speech, language, and hearing services
 - Adult dental services
 - Behavior services
 - Behavioral respite services
 - Day services
 - Emergency assistance
 - Environmental accessibility modifications
 - Individual transportation services
 - Orientation and mobility services for impaired vision
 - Personal assistance
 - Personal Emergency Response System
 - Semi-independent living services (TennCare, n.d.[b])
- The *TN HCBS Waiver for Persons with MR*, also known as the Arlington Waiver Program, serves individuals across the lifespan who meet the level of care for an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) and are class members certified in United States versus the State of Tennessee (TennCare, n.d.). Services include:
 - Residential habilitation
 - Respite
 - Support coordination
 - Nursing services
 - Nutrition services
 - Occupational therapy
 - Physical therapy

- Specialized medical equipment, supplies, and assistive technology
 - Speech, language, and hearing therapy
 - Dental services
 - Behavior services
 - Family model residential support
 - Day services
 - Environmental accessibility modifications
 - Individual transportation services
 - Intensive behavioral residential services
 - Medical residential services
 - Orientation and mobility services for impaired vision
 - Personal assistance
 - Personal Emergency Response System
 - Supported living
 - Transitional case management
 - Vision services (TennCare, n.d.[a])
- The *TN HCBS Waiver for MR/DD*, also known as the Statewide Waiver Program, serves individuals with intellectual disabilities throughout the lifespan and individuals with developmental disabilities from birth until age 5 who meet the ICF/IID level of care. Independent support coordinators help facilitate planning and coordinate activities, help individuals access relevant services in a cost-effective manner, and review and update the plan of care. Services include:
 - Residential habilitation
 - Respite
 - Support coordination
 - Nursing services
 - Nutrition services
 - Occupational therapy
 - Physical therapy
 - Specialized medical equipment, supplies, and assistive technology
 - Speech, language, and hearing services
 - Adult dental services
 - Behavior services
 - Behavioral respite services
 - Family model residential support
 - Day services
 - Environmental accessibility modifications
 - Individual transportation services
 - Intensive behavioral residential services
 - Medical residential services
 - Orientation and mobility services for impaired vision
 - Personal assistance
 - Personal Emergency Response Systems
 - Supported living
 - Transitional case management (TennCare, n.d.[c])

Findings

Services and supports for people with ASD

DIDD has three regional offices that serve as the main points of entry to the department. These regional offices implement the policies and programs developed in the central office but allow the department to have a better understanding of local areas and needs. The regional offices provide some direct services, such as behavioral services and occupation and physical therapy; however, other services, such as residential and day services, are contracted out to local service providers (Tennessee DIDD, n.d.[b]).

The Tennessee Disability Pathfinder (<http://www.kc.vanderbilt.edu/pathfinder/>) is the state clearinghouse of information and is run by the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy University Center for Excellence in Developmental Disabilities. Although the Pathfinder is not exclusively for individuals with ASD, it serves as a helpful resource for this population. Pathfinder staff provides information about services and supports across the state and conducts educational programs and trainings to inform individuals how to best utilize the Pathfinder. They operate a multicultural outreach program to help address barriers to accessing disability services, provide cultural awareness and training, and provide case management to individuals and families with diverse backgrounds.

Early intervention

The Tennessee Early Intervention System (TEIS) is housed in the DOE and is a voluntary education program for children from birth to age 2 who have developmental delays. To be eligible, children must have a 25-percent delay in two developmental areas or a 40-percent delay in one area. Diagnoses of certain disabilities, such as autism, also fulfill eligibility requirements. The state is split into nine regions, each with a separate point of entry (Tennessee DOE, 2009a). Each child in TEIS receives a service coordinator, who helps coordinate the family's experience and service. As the lead agency, DOE helps write the Individualized Family Service Plan and find a service provider.

School-aged children

The Division of Special Education within DOE has different eligibility requirements than the TEIS. Although an autism diagnosis is sufficient to prove eligibility in TEIS, the Division of Special Education requires a separate evaluation to learn more about a child's history and to better understand how ASD affects his or her ability to learn (Tennessee DOE, n.d.[a]). After a child is determined eligible for services, the local educational agency (LEA) will work with the parents and other invested parties to develop an Individualized Education Program (IEP) that identifies goals and the best ways to reach those goals. In 2010–2011, 5,990 or 4.98 percent of children with disabilities aged 3–21 who received special education services had autism (Easter Seals, 2012).

The DOE contracted Vanderbilt Kennedy Center Treatment and Research Institute for Autism Spectrum Disorders (TRIAD) to work with school districts to provide ASD-specific training to teachers and paraprofessionals. TRIAD offers many programs and resources to children with autism and their families; however, only some of those resources are funded by DOE. The program started in 1999 with only teacher training but has expanded to include administrators,

parents, and other individuals who might work with students with ASD. The main training program is a 3-day session that involves interventions with students with ASD, demonstrations, activities, and lectures. Topics of training often include classroom-based assessment strategies, creation of appropriate goals, and teaching strategies to help students get the most out of their lessons. Many training sessions include a followup visit by a TRIAD consultant to further work on skills learned at the workshop. Other training topics include social skills, parent-specific workshops, and para-educator specific workshops (Vanderbilt Kennedy Center TRIAD, 2013a).

The Division of Special Education employs a consultant for Autism and Behavior Programs and Services. The consultant serves children aged 3–21 and all school districts that inquire about consultation services. The consultant frequently participates in IEP meetings, but parents, teachers, and administrators can request individualized consultations. The consultant will visit a child in school, observe and assess behavior, and visit with teachers. The consultant will then develop individualized strategies and interventions to help with the student’s particular hardships. This is an informal assessment process and it usually happens after a formal assessment and diagnosis. The consultant often brings a new perspective to problems, but ongoing help is sometimes necessary. In those cases, help can be provided in the larger TRIAD training sessions and through more localized consultative support programs. Many teachers attend the larger training program at TRIAD to gain more knowledge for future students with ASD (Vanderbilt Kennedy Center TRIAD, 2013b).

The DOE also supports a Positive Behavior Support Initiative with seven project service areas across the state. Each service area is based at a university and works with local school districts to improve education practices through positive behavior support, training and technical support, behavior management strategies, and professional development (Tennessee DOE, n.d.[b]).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

The TEIS service coordinator helps families prepare for transition out of early intervention. The coordinator sets up a transition meeting up to 9 months before a child’s third birthday. Around this time, families usually begin meeting with their LEA to discuss special education services, if necessary. If parents want to apply for special education services, parents must meet with the LEA at least 90 days before the child’s third birthday (Tennessee DOE, 2009b)

School-aged to employment

The Division of Rehabilitation Services runs the Transition School to Work program, which focuses on helping interested disabled individuals move directly from school to work in a seamless transition.

Training for direct service support workers

Vanderbilt Kennedy Center's TRIAD program offers training sessions to all individuals who provide direct service to individuals with ASD in schools as well as other interested parties. This training covers an extensive number of topics with varying levels of intensity.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The Tennessee Disability Coalition received a planning grant in 2009 from the Association of Maternal and Child Health Programs. The Coalition is currently working with the Tennessee Autism Summit Team to develop a comprehensive, coordinated system of health care and related services for children and youth with ASD and related disabilities. The group is hosting “community conversations” to gain input from families, providers, professionals, funders, and policymakers. In addition, the Coalition is conducting a Web-based survey for parents and families to assess existing and needed resources, which will inform development of the state plan (Tennessee Disability Coalition, n.d.).

Although no concrete plans are in place, DOE's contract with the Vanderbilt Kennedy Center's TRIAD has consistently expanded services due to increased need.

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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TEXAS

Approach

The L&M research team interviewed eight representatives from the state of Texas, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included Texas Health and Human Services Commission (HHSC), the state's Medicaid authority; the Texas Department of Family and Protective Services (DFPS); the Texas Department of Assistive and Rehabilitative Services (DARS), the Texas Council for Developmental Disabilities (TCDD); the Texas Department of Aging and Disability Services (DADS); and the Texas Department of State Health Services (DSHS), the state mental health agency.

State background

The Texas Council on Autism and Pervasive Developmental Disorders (TCAPDD) was created in 1987 to make recommendations to the state legislature concerning the needs of those with ASD and pervasive developmental disorders (PDD). This council began their 2010 report with the words, "Eleven of every 1,000 children have an ASD, yet in Texas, no state agency is charged with coordinating ASD services, collecting uniform data, or assessing the needs of the tens of thousands of people with ASD in Texas." The report also mentions deep budget cuts to several programs in Texas that support people with developmental disabilities (TCAPDD, 2012).

Currently, as noted by our state interviewees, eligibility for and availability of services in Texas varies widely across age ranges. Service and promotion agencies include: HHSC, DARS, DADS, TCDD, the Texas Education Agency (TEA), DSHS, and DFPS. In addition, the Texas Autism Research and Resource Center (TARRC), a program of DADS and HHSC, provides a Web resource connecting and describing resources available throughout the state for individuals and families affected by ASD.

State insurance regulations

Texas Insurance Code Chapter 1355 requires that certain health plans (self-funded plans are excluded) provide all "generally recognized" services prescribed by a physician to children from birth to age 9 with ASD. This is comprised of a range of services and therapies including applied behavior analysis (ABA). Deductibles and copays must be consistent with those for other physical disabilities. The law was enacted in 2007 to cover ages 2–6 and expanded in 2009 to children from birth to age 9. The state interviewees noted difficulty with the insurance mandate in that some of the rules are unclear and some insurance companies are not fully providing the required benefits.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Texas 1915(c) waivers

Waiver Name	Population Served
TX Community Living Assistance & Support Services (CLASS)*	Individuals with DD or a related condition of all ages
TX Home and Community-Based Services (HCS) Program*	Individuals with ID/DD of all ages
TX Home Living Program*	Individuals with ID/DD of all ages
TX Medically Dependent Children Program	Medically fragile individuals aged 0–20
TX Youth Empowerment Services	Children aged 3–18 with severe emotional disturbances
TX Community Based Alternatives	Individuals ages 65+ or aged 21–64 with a physical disability
TX Deaf/Blind with Multiple Disabilities	Individuals of all ages who are deaf or blind

*Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

Texas does not have any waivers specific to individuals with ASD at this time.

Other waivers

Individuals with ASD primarily use three community-based services and supports waivers. Interviewees also noted that individuals who think they may be eligible for waivers are encouraged to sign up on the interest (i.e., waiting) list for services (Texas DADS, 2013).

- The *TX Community Living Assistance and Support Services* waiver provides long-term services and supports to individuals with related conditions living in their own homes or with their families and avoid institutional placement. The waiver is intended to supplement existing formal and informal supports. Services include:
 - Adult day health
 - Case management
 - Prevocational services
 - Residential habilitation
 - Respite (in-home and out-of-home)
 - Supported employment
 - Adaptive aids/medical supplies
 - Dental
 - Occupational therapy
 - Physical therapy
 - Prescription medications
 - Skilled nursing
 - Speech/hearing/language
 - Financial management services
 - Support consultation
 - Behavioral support

- Continued family services
- Minor home modifications
- Specialized therapies
 - Hippotherapy
 - Music therapy
 - Aquatic therapy
- Support family services
- Transition assistance

In order to allow consumers more control over the employment of their service providers, consumers may elect the consumer-directed services option. Available supports for consumer direction include financial management services and consultation.

- The *Texas Home Living Program* provides community-based services and supports to individuals with an intellectual and developmental disability living in their own homes or with their families. The waiver is intended to enhance existing informal or formal supports and resources. All services are available through either consumer direction or traditional provider-managed service delivery. Services provided include:
 - Day habilitation
 - Respite
 - Supported employment
 - Prescription medications
 - Financial management services
 - Support consultation
 - Adaptive aids
 - Audiology
 - Behavioral support
 - Community support
 - Dental
 - Dietary services
 - Employment assistance
 - Minor home modifications
 - Occupational therapy
 - Physical therapy
 - Skilled nursing
 - Speech/language therapy
- The *TX Home and Community-based Services* waiver provides community-based services and supports to individuals with intellectual disabilities living in a variety of residential settings including an individual's own home, family home, a foster/companion care setting, or a small group home setting. Individuals may choose to self-direct supported home living and respite services. The annual budget limit for individuals is based on 200 percent of the average institutional cost as well as assessed level of need. Services include:
 - Case management
 - Day habilitation
 - Respite

- Supported employment
- Prescription medications
- Financial management services
- Support consultation
- Adaptive aids
- Dental
- Minor home modifications
- Residential assistance
 - Foster/companion care
 - Supervised living
 - Residential support
- Occupational therapy
- Physical therapy
- Speech/language therapy
- Audiology
- Dietary services
- Behavioral support
- Social work
- Skilled nursing
- Supported home living

Findings

Services and supports for people with ASD

Many services provided by DADS are accessed through local authorities. They provide various services and supports to those with intellectual and developmental disabilities; enroll people in three Medicaid programs including intermediate care facilities (ICFs) and the HCS and Texas Home Living waivers; and assist in permanency planning for those in an ICF. A diagnosis of ASD alone can make a person eligible to receive services from DADS (Texas Council on Autism, 2013).

Early intervention

DARS administers the Early Childhood Intervention (ECI) program in Texas (TARRC, 2011). Children are eligible if they have a medically diagnosed condition, including ASD; auditory or visual impairment; or a developmental delay of at least 25 percent in one or more areas of development. Evaluators use the Batelle Developmental Inventory (BDI-2) to determine developmental impairments (Texas DARS, n.d.).

A number of services, including speech therapy, occupational therapy, nutrition services, case management, and family counseling are provided through local agencies that contract with DARS. Many services are provided in community settings, and Individual Family Service Plans are developed according to the Individuals with Disabilities Education Act (IDEA) statute and regulations.

School-aged children

Texas has 1,247 independent school districts as well as charter schools that are individually responsible for providing educationally necessary services to children under the IDEA legislation. In Texas, school district Preschool Programs for Children with Disabilities (PPCD) provide special education and related services for eligible children with disabilities aged 3–5. PPCD refers to the services provided by the school district, not to the place where they are provided. Eligible children may receive PPCD services in a variety of settings such as prekindergarten, resource rooms, and self-contained classrooms or in community settings such as Head Start and preschool (Texas Education Agency, 2013).

After children leave this program, they are ideally transitioned into a general education classroom with their peers and provided special supports including: speech and occupational therapy, social skills training, teacher aides, assistive devices, curriculum modification, testing accommodations, tutoring, behavior supports, and other special accommodations according to their Individualized Education Program (IEP; TARRC, 2011).

In addition to the local independent school districts, 20 Education Service Centers (ESCs) are located across the state. Each ESC has a staff member who serves as a contact for matters involving ASD. Through the network of 20 regional ESCs around the state and in conjunction with TEA, the Texas Statewide Leadership for Autism Training (<http://www.txautism.net>) at ESC 13 provides a mechanism to access training, technical assistance, support, and resources for educators who serve students with autism. ESC 2 leads the Texas State Conference on Autism.

DARS provides grants for services for children with ASD aged 3–8. Provided through contracted service providers in six different Texas locations, these supports primarily include ABA and other positive behavior support strategies. Although families do not have to live in a specific county to receive services, they must have the means to travel to service areas. During FY 2012, 240 children received services, and 790 were on the waiting list.

Interviewees also indicated that children may receive various traditional therapies, testing, counseling, and medical benefits if they are eligible for Medicaid. This list does not include ABA therapy unless they qualify for HCBS waiver services; however, ABA therapy is also limited in the waiver programs. According to DSHS, mental health services are also available for children aged 3–17 with a functional impairment, including many individuals with ASD. This program includes psychiatric and crisis management services, case management, medication management, and family services. Children typically lose their eligibility for these programs when they turn 18, as adults must have a diagnosis of bipolar, schizophrenia, or major depression to continue these services.

Adults

In addition to waiver services for eligible adults, Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) are an alternate option if individuals meet level of care requirements. DADS manages 13 state-supported living centers, which provide treatment, assessments, 24-hour care, vocational services, and a variety of therapies. Texas also receives funding for a federal “Money Follows the Person” demonstration to support their “Promoting Independence” initiative. This provides opportunity for individuals in long-term care facilities or state-supported homes to return to the community. The demonstration allows DADS to create

community transition teams to coordinate services and supports for those wishing to live in the community (Texas DADS, 2012).

The Vocational Rehabilitation (VR) office, housed within DARS, recently began a VR program specifically for those with ASD. A specific placement team focuses on matching employers who want to employ individuals with ASD with those looking for work (Autism Speaks, 2012). VR also provides traditional therapies, job counseling, rehabilitation and devices, and followup after placement (Texas DARS, 2012).

Additionally, individuals eligible for Medicaid may receive speech therapy and occupational therapy as well as medical services. A Medicaid Buy-In program is available for people on disability who work and exceed the income limits to qualify for Medicaid. Through the program, individuals with disabilities who work and pay a monthly fee can access a variety of low-cost health and community-based services (Texas HHSC, n.d.).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

State interviewees indicated that most people learn about developmental disability services in Texas by word of mouth, local networks, or TARRC. TARRC is administered and financed by DADS, the Texas Health and Human Services Commission, and the Texas Autism Council. This resource includes three components to benefit the ASD community. The first is a Web site in both English and Spanish, which describes services and supports for those with ASD in the state. The second is a yearly conference on autism research, which provides a forum for autism researchers in Texas to come together and present findings. Finally, TARRC sponsors professional trainings that help first responders, including police officers and firefighters, to recognize the signs of someone with ASD and react appropriately.

Early intervention

State interviewees identified the Texas Health Steps program as a source of promotion of early intervention services. This program includes one-hour modules intended to educate health care providers about the steps of a well-child visit, including screening for ASD.

School-aged children

Child Find is a continuous process of public awareness activities, screening, and evaluation designed to “locate, identify, and refer” as early as possible all young children with disabilities and their families who are in need of early intervention program (IDEA Part C) or preschool special education (IDEA Part B/619) services. TEA focuses on individuals aged 3–21, disseminating brochures in 11 languages instructing the community to call the local educational agency (LEA) or ESC if they suspect a child may have a disability.

Additionally, as noted earlier, Texas ESC 2 runs the Texas Autism Conference, which involves promotion of services and awareness both in and out of the ASD community. The yearly conference features presenters and exhibitors from across the state/Nation and caters to parents and others working with individuals on the autism spectrum (ESC 2, 2006). In response to a need

for autism training, ESC 13 has created 15 free online trainings (six of which are in Spanish). The intended audience includes administrators, community members, para-educators, parents, students, support staff, teachers and any others interested in autism.

According to the interviewees, DFPS also helps to identify children with disabilities. For example, DFPS will assist children who are on their caseload and in need of special services with obtaining waiver services and make referrals to DADS for case management and additional services.

Adults

Many adults locate services through the transition process from the school system, which is described below.

Transitions and coordination of services

Early intervention to school

Early intervention to school transitions comply with the rules set out by the IDEA statute and regulations. Transition plans become part of the Individual Family Service Plan when the child is between 27 and 33 months of age, and parents begin to meet with ECI professionals to discuss options available both inside and outside of schools. They meet with school districts and various community service providers and decide what is best for their child. Then ECI makes appropriate referrals (Texas DARS, 2004).

Each LEA will participate in transition planning conferences arranged by the designated local ECI program. In Texas, the transition planning conferences are held 120 days before the child's third birthday (34 CFR §300.132). By the third birthday, an IEP must be developed and implemented for eligible children (Texas DARS, 2004). One interviewee spent time working in the Austin system and mentioned that their ECI worked closely with the area school district, contacted the Child Find office for referrals, and provided records of individual services and accomplishments. The school then does its own assessment and places the child into special education, if eligible.

School-aged to employment

In Texas, transition to employment can begin at age 14 and must begin by age 16, according to IDEA legislation. The process involves reviewing and modifying the IEP and coursework to coincide with educational goals, conducting a vocational evaluation, and making referrals to appropriate government agencies. Vocational rehabilitation typically begins providing services to children as young as age 15 (Texas Project FIRST, n.d.).

Further, ESC 11 acts as the state leadership for transitioning in Texas by maintaining a Web site (<http://www.transitionintexas.org>) and serving as a contact for educators and other professionals when they have questions about the Texas transition process.

Training for direct service support workers

Interviewees indicated that Texas is participating in the national Leadership Education in Neurodevelopmental and Related Disabilities (LEND) campaign. LEND provides a series of trainings ranging from an intense interdisciplinary curriculum to short didactic seminars to

medical students and professionals in a variety of fields as well as the general public. The goal is to improve early identification and diagnosis as well as treatment of and interaction with individuals with ASD. This program is run as a collaborative effort among several Texas universities.

One interviewee mentioned that DARS is teaming up with Texas Tech University to offer training on positive behavior support. Connections for Academic Success and Employment (Project CASE) will help students aged 18–25 with developmental disabilities who are interested in furthering their education beyond high school, to explore careers and pursue meaningful employment. Project CASE is a rural partnership of the Burkhart Center for Autism Education and Research at Texas Tech University; South Plains Community College; the Department of Assistive and Rehabilitative Services; and local business partners (Texas Council for Developmental Disabilities, 2012).

Additionally, the ESC 13 Statewide Leadership for Autism Training program provides free online trainings for members of the education community and others, including parents. Training classes are available periodically at all 20 ESCs as well. Their Web site serves as a support resource for those working with children with ASD (Texas Education Agency, 2012).

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

The TAPDD makes recommendations about changes in services and supports. They have divided their goals into four categories: (1) services to children to age 5, (2) services to individuals aged 5–22, (3) services to individuals aged 23 and older, and (4) research and statewide infrastructure. Their goals primarily focus on increasing services (particularly for adults), improving early diagnosis and treatment, and enhancing coordination of services. Texas has made progress in the fourth area of research and statewide infrastructure with the creation of the TARRC. More recommendations for statewide infrastructure include: establishing an office of autism services, increasing the number of qualified professionals working with people with ASD, and increasing access to services (Texas Council on Autism, 2012).

Interviewees noted “sincere efforts to get early diagnosis in front of the legislators” to improve this aspect of support for the ASD community. One concern, voiced in the 2010 report by the TAPDD, is that IDEA legislation requires only that ECI service providers determine eligibility for the program, not diagnose ASD. In order to mitigate this issue, as part of their 5-year plan, the TAPDD proposes developing a standardized evaluation for ASD, establishing cross-agency procedures for evaluation, and conducting a statewide public awareness campaign (Texas Council on Autism, 2012).

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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UTAH

Approach

The L&M research team interviewed six representatives from the state of Utah, encompassing a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies represented included the Utah State Office of Education (USOE); the Utah Division of Services for People with Disabilities (DSPD); the Utah Division of Rehabilitation Services (DRS); and the Baby Watch early intervention program.

State background

Utah's current spirit of collaboration to meet the needs of individuals with autism began in 2005 with the advent of the Autism Council of Utah (<http://www.autismcouncilofutah.org/>). Parents initiated and still lead this group with the support of the Governor and executive directors in the state. Representatives from many state and nonprofit agencies who serve people with disabilities meet monthly and serve alongside parents to promote supports for people with ASD and their families. In 2008, the creation of an Autism Advisory Board by the governor—the Utah Registry of Autism and Developmental Disabilities—marked the next ASD collaborative in the state. The autism registry is part of the Autism Developmental Disabilities Monitoring grant, given to several states by the Centers for Disease Control (CDC) to study the prevalence of ASD and other developmental disabilities over time. In Utah, the registry is run as a collaborative between the Department of Health (DOH) and the University of Utah (Easter Seals, 2012).

A 2008 report by the CDC found that one in 47 children in Utah met the criteria for an ASD diagnosis compared with a national average of 1 in 88. This study made both local and national news in March of 2012, fueling interest in autism services in the state. Currently, the University of Utah and many state stakeholders are conducting a long-term epidemiological study on the causes of ASD, further generating autism awareness in the state (Sahm & Bemis, 2012).

Although few ASD-specific state services currently exist, the governor signed H.B 272 on March 26, 2012, and established three new autism pilot programs: an autism waiver, funding for public employees' insurance plans to cover autism services, and funding for the state's Autism Treatment Account. These three programs are primarily run through DSPD, which is a subset of the Utah Department of Human Services.

State insurance regulations

Currently, no laws require insurers to cover ASD services in the state of Utah. State advocates have been active in pursuing a mandate and have made some progress. As part of the new three-pilot approach to expanding ASD services, the insurance plan for state and local government employees will begin covering services for employees' children who have ASD. The first round will be limited to 50 children, but interviewees expressed hope that this will increase in the future.

Utah Code Ann. § 31A-22-625 lays out Utah's mental health parity law and requires coverage for some catastrophic mental health conditions, namely those listed in the Diagnostic and Statistical Manual of Mental Disorders. The law specifies that developmental disorders are not

covered when they are the primary reason for treatment (American Speech-Language Hearing Association, 2013).

State 1915(c) Home and Community Based Services (HCBS) waivers

As in all states, Medicaid waivers significantly enhance the ability of Utah to serve their developmentally disabled population. Utah’s Medicaid program falls under the jurisdiction of DOH, and most of the state’s waivers are managed under this branch as well. The new Medicaid Autism Waiver and Community Supports Waiver are run in partnership by DSPD and DOH. Children with disabilities qualify for Medicaid under a rule that states that only children’s assets are considered for financial eligibility. The state provides legal guidance to families to help arrange children’s finances so that they can qualify.

State of Utah 1915(c) waivers

Waiver Name	Population Served
UT Medicaid Autism Waiver*	Children aged 2–6 with ASD
UT Waiver for Technology Dependent, Medically Fragile Individuals	Individuals aged 0–20 who are technology dependent and/or medically fragile
UT Community Supports Waiver for Individuals with ID and/or Related Conditions*	Individuals of all ages with ASD/ID
UT Physical Disabilities	Individuals aged 18–64 with a physical disability
UT Acquired Brain Injury	Individuals aged 18+ with brain injury
UT New Choices	Individuals aged 65+ or aged 21–64 with a disability
UT Waiver for Individuals 65 or older	Individuals aged 65+

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services (CMS), n.d.

Specific ASD waivers

The *Utah Medicaid Autism Waiver* was implemented in January 2013. To be eligible, applicants must be between ages 2 and 6, have a diagnosis of autism, and meet the level of care for an intermediate care facility for individuals with intellectual disabilities. Services to be provided include:

- Financial management services
- Intensive individual support-consultation services
- Respite
- Intensive individual support-direct service

Other waivers

The *Utah Community Supports Waiver* is the other program that is typically accessed by individuals with ASD. The waiver serves individuals of all ages with autism, intellectual disabilities, and developmental disabilities. To qualify, applicants aged 7 years and older must have a functional impairment in at least three of six major areas of life activities. Children under age 7 qualify if they have a diagnosis of intellectual disability. Some of the services offered through the waiver include:

- Day supports

- Homemaker
- Personal care
- Residential habilitation
- Respite care (intensive, group, routine, weekly)
- Supported employment
- Waiver support coordination
- Financial management services
- Behavior consultation
- Chore services
- Companion services
- Environmental adaptations
- Extended living supports
- Family and individual training and preparation services
- Living start-up costs
- Massage therapy
- Personal budget assistance
- Personal Emergency Response System
- Professional medication monitoring
- Specialized medical equipment/supplies/assistive technology
- Supported living
- Nonmedical transportation (CMS, n.d.)

Findings

Services and supports for people with ASD

DSPD offers some nonwaiver services although few people are served in this capacity; most individuals receive waiver services through DSPD. According to Utah Title 62A Chapter 5 Section 101, a diagnosis of ASD will not automatically qualify someone to receive services although people with autism qualify if they have a functional limitation in three or more major life activities. The most commonly used services are:

- Community living
- Companion services
- Extended community living
- Respite care
- Supported living
- Supported employment (Utah DOH DSPD, 2009)

Other agencies that provide services to individuals with ASD include the Utah DOH, the USOE, and the Utah DRS.

Early intervention

Baby Watch, Utah's early intervention program, is operated through the DOH. The program contracts with 15 agencies in different regions to provide coordination and services, including

universities, nonprofits, health departments, and school districts. Agencies bill Medicaid for enrolled children but do not have the capacity to bill to private insurance. Services do not vary significantly across agencies because of requirements around Part C of the Individuals with Disabilities Education Act (IDEA); for example, to provide individualized services in the least restrictive environment. However, interviewees noted that private nonprofits often fundraise and sometimes have additional funds for other programs.

Children qualify for early intervention services if they are 1.5 standard deviations below the mean in any area of development. Health departments offer diagnostic services on a sliding scale basis; however, there is a waiting list of 3 to 4 months. One interviewee indicated that children are rarely diagnosed with ASD before the age of 3. Services offered through the Baby Watch program include respite care, traditional therapies, and service coordination (Utah DOH Bureau of Child Development, n.d.). The program does not offer ABA. The state believes ABA is important but is concerned that it may not find providers for the service, particularly those providing to young children. However, stakeholders are excited about the possibility of the trifold legislation expanding the state's capacity to provide ABA and other services. Interviewees indicated that the early intervention program plans to coordinate services with children on the autism waiver; for instance, if a child is getting speech therapy through the waiver, Baby Watch will not duplicate the service.

School-aged children

As in all states, children must be provided services that are deemed educationally necessary according to Part B of IDEA. The state school system partners with the University of Utah and a variety of ASD stakeholders, including the Autism Council, to ensure that staff members are properly trained and children have access to all appropriate, evidence-based treatments. Many school systems have specific autism specialists, and the state office facilitates monthly round-table discussions to exchange ideas. If school-aged children have appropriate eligibility, which is the same as adults, they may also receive DSPD waiver or nonwaiver services (described above).

Adults

Adults with ASD receive waiver or nonwaiver services through DSPD. Additionally, they may be eligible for vocational rehabilitation services through DRS. Interviewees consistently noted that adult services for individuals with ASD are lacking. As one stakeholder said, "Data shows that after kids are out of school, they don't have a lot waiting for them. That's an area of need and a priority for us as a state."

Utah spends roughly \$30 million per year for vocational rehabilitation services. Each of the 10 districts across the state has an office with one district director, three supervisors, and three to four counselors per supervisor, depending on the size of the district. They offer federally mandated vocational rehabilitation services, including supported employment, job coaching, and job placement. Improving access to VR is on the radar of Utah stakeholders as the average client-to-counselor ratio is 230 to 1.

DSPD also runs a state-operated Intermediate Care Facility for Individuals with Intellectual Disabilities called the Utah State Development Center. Currently, approximately 145 adults live in the center and receive a variety of supports depending on the needs of the individual. Professional services include psychology, social work, music, recreation, speech, physical

therapy, and occupational therapy. Individuals are evaluated on a yearly basis to determine whether they desire to and are able to return to their home communities with the support of waiver services (Utah DOH State Developmental Center, 2006).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Stakeholders from various departments mentioned the Utah Parent Center (<http://www.utahparentcenter.org>) as a common source of information for parents of children with special needs. The center is a 501(c)(3) organization founded in 1983 and run primarily by parents of children with disabilities. They are funded through IDEA, federal grants, and money from school districts and provide local volunteers and coaches, workshops, one-on-one consultations, and other outreach services. The Department of Education cited the center's comprehensive Web site and bilingual staff as great tools in the promotion of services to children.

Early intervention

The 15 local agencies that contract with Baby Watch perform outreach activities. They mainly publicize their services through longstanding relationships with physicians; interviewees indicated that many programs have been around for as long as 20 years and are well known in the community. Publicity varies by agency type, but contractors tend to take advantage of their other community relationships for early intervention outreach. For example, two health departments that contract with Baby Watch also run the local Women, Infants, and Children program and ensure that clientele know about early intervention services.

School-aged children

Individual school districts and charter schools use the "Child Find" system and are required to locate and identify students with disabilities. Their approaches vary but typically involve developing relationships with hospitals, doctors, and churches, and advertising in the local newspaper or on local radio channels.

Adults

The Utah Parent Center has a contract with DRS to support outreach to identify children transitioning out of school who may benefit from vocational rehabilitation services. According to one interviewee, aside from this contract, DRS is unable to initiate many outreach activities given a high student-to-counselor ratio and difficulty freeing up staff for the promotion of services.

Transitions and coordination of services

Early intervention to school

Baby Watch and USOE are working together to ensure a smooth transition from early intervention to school. A program called Transition from Early Intervention Data Information System (TEDI) came into its current form in 2011. TEDI is a Web-based interface that allows

USOE and the state to see information about children in the early intervention program when children reach age 27 months and to begin transition planning. This is an automatic referral system, and parents can opt out if they do not want their child referred to special education. School officials emphasize that the system is not perfect and, due to differences in eligibility criteria between IDEA Part B and Part C, it may not identify all children who are eligible for additional school services.

School-aged to employment

Transition has become a major topic in Utah, and stakeholders see a need to improve the process for individuals preparing for adulthood. As mentioned above, services for adults are scarce, and vocational rehabilitation counselors serve many students, limiting their ability to provide individualized support in the transition process. As a result, DRS and USOE have begun collaborating more closely to ensure that vocational rehabilitation and other appropriate agencies are involved in students' transition planning. Since the initiative began, inclusion of outside agencies has gone from participation in 30 to 40 percent of transitions to more than 90 percent.

In addition, the state has a new transition grant that will be awarded to school systems to help them carry out new programs to improve transitions for students with ASD. The focus of the grant is to assess children on an individual basis to see how they can improve their employable skills. USOE recently began accepting applications and will award grants in January 2013.

One interviewee mentioned a particular program of interest—Postsecondary Education, Employment, and Research—which is a partnership of Easter Seals, Utah State University, and USOE to help students' transition into the workforce. The program pairs DRS clients with ASD, typically while they are still in high school, with working peers to give them exposure to a job that interests them. They can volunteer for six weeks and get real work experience with a peer who helps them adjust to the work schedule and learn leadership skills. Often volunteer sites become places of employment.

Training for direct service support workers

Training is required for early intervention and vocational rehabilitation, but interviewees indicated that very little is ASD specific. Vocational rehabilitation provides for video training and modules that address ASD topics as well as an annual presentation conducted by the Utah Medical Center on ASD. The state also has a transition specialist who recently began offering training on ASD.

USOE is quite involved in training staff in various evidence-based practices specific to working with students with ASD. The agency has been committed to offering these trainings for 13 to 14 years. Meetings with district ASD specialists, parents, and school staff along with data from parent surveys help to determine training and service needs. USOE also works with universities, private providers, and the ASD council to organize trainings and workshops. Trainings are generally voluntary, and individual school districts and charter schools determine who attends. Additionally, USOE collaborated with Utah State University to develop an extensive ABA curriculum with access to more than 250 programs, technical assistance, and coaching for school staff. More information on evidence-based autism training can be found on the Utah Personnel Development Center's Web site (<http://www.updc.org>).

Corrections

The Division of Juvenile Justice Services partnered with the Department of Labor and the Department of Education for a workforce development program to help train youth coming out of the corrections system. Part of the focus is on identifying and serving youth with disabilities. The group has regular coordination meetings and is working together to develop a pilot to identify youth in any correctional or alternative high school and get them connected to vocational rehabilitation.

Long-term plans to develop new or expanded supports and services (2–5 years)

State stakeholders indicated that they are focusing on implementing the three pilot programs and otherwise do not have concrete long-term plans. However, they noted that they are continually reviewing data to look for areas in need of improvement and are willing to address those areas as they move forward.

Other relevant programs and services

Utah has an Autism Treatment Account to help families pay for services for children. This was expanded with the recent legislation that provided grants from private and public sources to focus on evaluation and treatment of children aged 2–6 with ASD. With this increase in funding, state stakeholders are trying to identify providers qualified to offer ABA services (Utah DOH Children with Special Health Care Needs, 2013).

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VERMONT

Approach

The L&M research team interviewed three representatives from the state of Vermont, which included a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included Early Intervention, Developmental Disabilities Services of Vermont (DDS), and Vermont Department of Corrections (DOC).

State background

In the past 2 years, Vermont has taken many steps toward improving the availability and scope of autism services and supports available. In 2010, the Vermont Legislature passed Senate Bill 262, an autism reform bill. In May 2012, the Vermont Legislature proposed expansions to previous Autism Insurance Reform Bill provisions with House bill 736 and Senate Bill 223. As of 2012, Senate Bill 223 had been passed, whereas House Bill 736 remained in committee.

State insurance regulations

Senate Bill 262 requires insurance companies to provide coverage of evidence-based, medically necessary ASD therapies, such as applied behavioral therapy. The bill also mandates that insurance companies provide coverage of early intervention for ASD between the ages of 18 months and 6 years and called for a study of ASD reform needs for children over the age of 6 (Autism Speaks, 2010).

Senate Bill 223 follows up on the study of needs for autism reform for individuals over the age of 6. The law requires insurance coverage for screening, diagnosis, testing, and treatment of childhood development disorders, including ASD, from birth to age 21. Additionally, the law requires that the Vermont Agency of Human Services work with insurers and the Autism Speaks organization (autismspeaks.org) to assess whether eligible individuals are receiving evidence-based services, whether and how the services could be improved, and their fiscal impact. This assessment must be completed by January 15, 2014 (Autism Speaks, 2012).

State Medicaid waivers

Specific ASD waivers

Vermont does not have any waivers specific to individuals with ASD at this time.

Other waivers

The state offers home- and community-based services through an 1115 demonstration titled *Global Commitment for Health*. The demonstration provides home- and community-based services for individuals with developmental disabilities, including ASD (Vermont DDAIL, 2013a). These services had previously been provided under a 1915(c) waiver, which was subsumed under the Global Commitment for Health. Services include:

- Housing and home support
- Community supports
- Work supports

- Service planning and coordination
- Respite care
- Crisis supports
- Clinical interventions and transportation

Findings

Services and supports for people with ASD

Early intervention

Children from birth to age 3 who have been diagnosed with ASD receive services under Part C of the Individuals with Disabilities Act (IDEA). IDEA services are managed by the Vermont Department for Children and Families (DCF). Vermont legislation requires the state to have its own eligibility criteria. Vermont's criteria for IDEA Part C services are that children have a measurable or observable delay that is likely to result in a developmental delay. Services covered include:

- Audiology
- Assistive technology
- Counseling/psychological
- Family training, counseling and home visits
- Medical evaluation (for diagnostic purposes only)
- Nursing
- Nutrition
- Occupational therapy
- Physical therapy
- Service coordination
- Social work
- Special instruction
- Speech/language therapy
- Transportation
- Vision

Children with ASD receive IDEA Part C services from a network of early intervention host agencies. Children with ASD also typically receive diagnostic and followup services from one of Vermont's child development clinics. These clinics are operated under the authority of the Children with Special Health Needs division of the Vermont Department of Health. DCF estimates that approximately 3 percent of Vermont's 20,000 children (600 children), birth to age 3, are eligible for IDEA services. Out of approximately 400 children currently being served

under age 3 receiving IDEA Part C services, the number with ASD has varied over the recent past from approximately 30 to 50 children (Vermont Agency for Human Services DCF, 2013).

School-aged children

School-aged children (aged 3 to 22) receive services under Part B of IDEA. Within the school system, a child must have a diagnosis of ASD according to DSM standards given by a physician. Provisional diagnoses will no longer allow children's eligibility to services. Additionally, the diagnosis must show an adverse effect on academic performance. Children under the age of 22 are eligible for case management services through the DDS. Additionally, these children may be eligible to receive a flexible family-funding grant of \$1,000 or less that the family can use to meet children's needs that are otherwise not met. A few children with ASD are eligible to receive home- and community-based services as described above under waivers. Most school-aged children receive services in the schools, but additional help may be supplemented through the mental health community. Services tend to be customized and flexible based on the individual child's needs (Vermont Agency for Human Services DCF, 2013).

Medicaid also provides some services for children with comorbid ASD and mental health conditions. These include inpatient or outpatient care, counseling, and skilled instruction and are provided via fee-for-service or wraparound through the Global Commitment for Health waiver.

Adults

Services for adults are primarily provided through DDS. To be eligible, an individual must have a DSM diagnosis of one of five pervasive developmental disorders, including ASD, and issues with adaptive functioning. DDS provides the following services to eligible individuals:

- Service planning and coordination—assistance for individuals and their families in planning, developing, choosing, accessing, coordinating, and monitoring the provision of needed services for a specific individual.
- Community supports—individualized and goal-oriented services that assist individuals in developing skills and social supports necessary to promote positive growth.
- Employment services—assistance for individuals in establishing and achieving career and work goals; includes employment assessment, employer and job development, job training, and ongoing support to maintain employment.
- Home supports—services, supports, and supervision to individuals in and around their residence up to 24 hours a day. This may include support to persons living in their own home, sharing a home with others (e.g., in an apartment, group home, shared living arrangement), or living with their family.
- Respite services—care provided on a short-term basis (hourly or daily) because of the absence or need for relief of family members, significant others, or other shared living providers normally providing the care to individuals who cannot be left unsupervised.
- Clinical interventions—assessment, therapeutic, medication, or medical services provided by clinical or medical staff.

- Crisis services—time-limited, intensive supports provided for individuals who are currently experiencing, or may be expected to experience, a psychological, behavioral or emotional crisis; includes crisis assessment, support and referral, and crisis beds (Vermont DDAIL, 2013b).

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Promotion of services and supports for persons with ASD was not addressed during discussions with state representatives.

Transitions and coordination of services

Early intervention to school

DCF provides transition planning and support for children transitioning from early intervention services to the school system at age 3. Early intervention provides a support team for the family to assist in the transition process. Transition planning acts as a tracking system; no other formal tracking system is in place. Transitions within the school system, such as elementary to middle school or high school, are fairly smooth as the child is tracked within the school district and continuity of records and interventions are maintained.

School-aged to employment

Transitions from school-aged services to adult life and employment have been a recent area of focus for Vermont. The Department of Education has been providing technical assistance to schools to assist in the creation of quality transition plans.

In 2012, a Web site was launched to assist young adults with ASD and their families with transition to adulthood. The site, VT Transition Guide for Young Adults with Autism & Developmental Disabilities (<http://www.vttransitionguideasd.org>), was created as a response to the need for best practice guidelines and information regarding the transition process, and was funded by a grant to the Vermont Department of Health from the Department of Health and Human Services, Health Resources and Services Administration (HRSA). Although the Web site is primarily aimed at Vermont families, it is designed to be useful, with some limitations, to individuals in any state.

The VT Transition Guide contains a tremendous amount of resources for young adults, their families, and service providers, with separate pages and information targeted to each of these groups. Each page provides links to resources for information, tools, and a “My Story” section that gives transition stories from the perspective of the individual with autism, their families, or service providers. The resource pages offer helpful information, often linked from other external sites, on the following topics regarding transitioning to adulthood:

- Communication and assistive technology
- Cultural diversity

- Employment
- Financial
- Health
- High school
- Housing
- Legal
- Postsecondary education
- Recreation and leisure
- Relationships
- Safety and emergencies
- Self-determination
- Support services
- Transportation

The tools section of the Web site offers the following resources:

- Timelines for transitioning
- Independent living checklist
- Independent living skills chart
- Basic budgeting worksheet

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Within the past 7 years, Vermont has focused on providing better coordination between the DOC and other agencies. On any given day, DOC manages approximately 200 inmates with developmental disabilities, although the number of individuals with ASD is unavailable. All employees undergo extensive training relevant to the Americans with Disabilities Act, including a module on autism-related concerns. Identification of individuals with ASD or other developmental disabilities upon intake is crucial, as presentation of ASD could include anti-social behavior, behavioral noncompliance, or difficulty navigating the correctional system. Without proper identification, these individuals could be inaccurately marked as “problem inmates.”

DOC has a mandate to provide free education to individuals under age 22; the DOC educational program includes special education services for those who require it. In addition to services

available within prisons, DOC has an institutionalized, accredited state hospital for individuals needing more intensive care and supervision than is available in standard inmate settings.

Transition planning out of the correctional system is similar for individuals with ASD as for those without. A transition team addresses plans for housing, employment, and support networks. For individuals with identified developmental disabilities, additional appointments with appropriate agencies will be made.

Long-term plans to develop new or expanded supports and services (2–5 years)

According to the agency representatives that were interviewed, many long-term plans rely heavily on the passage of the bill S. 223, which was signed into law. Act 158 requires both private and Medicaid insurance to cover the diagnosis and medically necessary treatment of early childhood developmental disabilities including ASD for individuals from birth to age 21. The state is currently in the process of implementing the law. Interviewees noted a demonstration program that was initiated in December 2009 to train primary care practices in developmental disability screening. The initial cohort was 40 practices in Vermont. At the time of these interviews, the evaluation of this demonstration was not yet complete. DDS and the Agency of Human Services have a grant from the Health Resources and Services Administration (HRSA) to continue the private practice training through 2013 with the goal of reaching another 40 to 45 practices.

The HRSA grant is also focused on training teams of staff supporting children at early intervention host agencies and in school districts serving children aged 3–5 with ASD. The project involves training and mentoring of teams in evidence-based practices for teaching children with ASD. The grant has also supported Vermont Family Network, a statewide family support organization, to develop a section of their Web site to include information and resources related to ASD. This Web site has a wealth of information related to ASD, training and events, VT services and resources, and so on. In addition, family consultants are available for phone support to families seeking information and support.

The state also has an interagency plan to develop the system of support in education and human services across the lifespan. The state has been implementing this plan for the past 4 years.

Other relevant programs and services

- In addition to the agencies and programs mentioned above, Vermont has two primary organizations that provide outreach and resources to the ASD community:
- *Autism Support Daily* (<http://www.autismsupportdaily.com>) is a Vermont-based 501(c)(3) nonprofit charitable organization, providing guidance, support, informational resources, and family-oriented activities for individuals with ASD. In addition, Autism Support Daily offers financial assistance for medical, educational, or professional services, and treatments or programs for individuals with ASD. Their primary focus is on building a heightened public and professional awareness of the challenges faced, with an emphasis on enabling people with ASD to achieve independent living. Autism Support Daily offers two Online Message Boards—one is exclusively for parents, which enables discussion on a variety of topics via email 24 hours a day, 7 days a week. The second was developed and designed for parents and professionals to provide a friendly and open

forum where polite discussions related to ASD can take place between individuals interacting and working with individuals with ASD—including parents, educators, paraprofessionals, occupational therapists, physical therapists, speech and language pathologists, school staff, caregivers, human service and health care agencies.

- *Vermont Family Network* provides support to families with a wide variety of disabilities and health issues. Interviewees noted that the network is a primary resource for parents of children with ASD. Vermont Family Network provides information, support, and advocacy for families and professionals, with the goal of better health, education, and well-being for all children and families, particularly children and young adults with special needs. In addition to resources and information about developmental disabilities, family consultants are available from 9 a.m. to 5 p.m. on weekdays to help families and individuals find the appropriate resources and agencies to meet their needs. As noted above, an extensive section of the Web site is dedicated to autism resources.

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VIRGINIA

Approach

The L&M research team held an initial discussion with the Director and Community Resource Manager of the Office of Developmental Disability Services to discuss the services and supports for persons with autism spectrum disorders (ASD) in Virginia. Following this interview, L&M received recommendations to discuss this topic further with individuals in a variety of agencies. Through these interviews, the research team sought to gain greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid. The team interviewed a total of eight representatives.

State background

The Department of Behavioral Health and Developmental Services is the lead state agency for developmental disabilities. Within this organization, the Office of Developmental Services focuses on supports and services for individuals with intellectual and developmental disabilities, including autism. Virginia has no definition for ASD in a written statute. For diagnosis, the state refers to the DSM IV¹ Diagnostic Criteria for Autism. A diagnosis of ASD is generally not sufficient in and of itself to qualify for services; rather, eligibility for services is based on need. It is estimated that more than 90,000 individuals in Virginia are on the autism spectrum (Commonwealth Autism Service, 2013).

The 2009 Report of the Joint Legislative Audit and Review Commission to the Governor and the General Assembly of Virginia reviewed the services available in Virginia for ASD. Some of the issues identified in the report included poor coordination of programs, a lack of depth of early intervention services, an inability of the school system to fully address the needs of students with ASD, and limited supports to help adults with ASD achieve independence. The report impacted several agencies and provided impetus to move forward with certain programs and ideas.

State insurance regulations

In 2011, Virginia passed legislation that required state-regulated health plans to provide coverage for the diagnosis and treatment for young children with ASD aged 2–6. In addition, an insurer cannot end coverage or refuse to renew coverage of individuals solely because they have been diagnosed with ASD. The legislation also does not preclude the coverage of treatment and services for children over age 6. The following services are covered under the law:

- Diagnostic assessment
- Behavioral health treatment
- Pharmacy care
- Psychiatric and/or psychological services (direct or consultation)
- Applied behavior analysis

¹ At the time of interview Virginia used the DSM IV. The DSM V has since been released, but implementation for the new criteria has not been established.

- Speech and language pathology
- Occupational therapy
- Physical therapy (Easter Seals, 2012)

State 1915(c) Home and Community Based Services (HCBS) waivers

As in all states, the waivers available to individuals with ASD also impact the nature of service delivery in the state. Virginia has the following 1915(c) waivers in place. More information about the waivers applicable to the ASD community is given below (Centers for Medicare & Medicaid Services [CMS], n.d.).

State of Virginia 1915(c) waivers

Waiver Name	Population Served
VA Children's Mental Health	Children aged 0-21 with serious emotional disturbances
VA Individual & Family Developmental Disabilities Support*	Individuals aged 6+ with DD or related conditions, including autism
VA Day Support HCBW for Persons with MR*	Individuals aged 6+ with ID
VA Technology Assisted	Individuals of all ages who are technology dependent
VA Alzheimer's Assisted Living	Individuals aged 65+ and aged 18–64 with Alzheimer's disease or related dementia
VA Elderly or Disabled with Consumer Direction	Individuals aged 65+ or individuals of all ages with a physical or other disability
VA HIV/AIDS	Individuals of all ages with HIV/AIDS

*Note: Of particular importance to ASD population
Source: CMS, n.d.

Specific ASD waivers

Virginia does not have any waivers specific to individuals with ASD at this time.

Other waivers

- The *Virginia Individual & Family Developmental Disabilities Support* waiver provides individuals aged 6 and older with developmental disabilities or autism with the following services, as needed:
 - Day support
 - In-home residential services
 - Personal care services
 - Prevocational services
 - Respite care services
 - Supported employment (group and individual)
 - Services facilitation
 - Adult companion services
 - Assistive technology
 - Crisis stabilization
 - Crisis supervision
 - Environmental modifications

- Family/caregiver training
 - Personal Emergency Response System
 - Skilled nursing
 - Therapeutic consultation
 - Transition assistance
- The *Virginia Day Support HCBW for Persons with ID* waiver provides individuals with intellectual disabilities aged 6 and older with the following services, as needed:
 - Day support
 - Prevocational services
 - Supported employment
 - Consumer-directed services facilitation

Findings

Services and supports for people with ASD

In general, the assessment phase for a person with ASD serves as the foundation to finding appropriate services and supports. Services vary depending on an individual's need, eligibility, and age as well as the organization providing the services. Services outside waiver programs may be available to individuals with ASD based on age and need.

Early intervention

The Infant and Toddler Connection of Virginia provides early intervention supports and services for eligible infants from birth to age 2 (Infant and Toddler Connection of Virginia, 2012). Virginia has 40 local infant programs (early intervention systems), each of which has a specific catchment area. These programs have a local system manager who is responsible for the operation, functioning, and well-being of the early intervention system. Services are based on the child's Individualized Family Service Plan (IFSP). These primary services can include occupational, speech, and physical therapy as well as educational services. Every family is assigned a service coordinator who is the point of contact between the state and family. The family specifies desired outcomes, which help determine which services are needed.

School-aged children

The Department of Education (DOE) provides services for children aged 3–22 through the school system. Although they are not the sole provider of services to this age group, this agency constitutes a significant source of support for these youth. Services are determined on a child-to-child basis and vary depending on factors such as severity of the disorder, specific needs of the student, and the school the child is in. Academic services can include additional resources in the classroom or a self-contained setting for the child to receive support throughout the day. Additionally, the child may receive speech/language, social, and communicative therapy. For children who require more intensive services than the school can provide, they can also receive waiver support therapy in an outpatient setting as long as there is no duplication of services.

Adults

Adults with disabilities entering the workforce may be eligible for vocational rehabilitation services. These services are based on an individual's need and involve working with a job coach

to obtain employment. Employment is not considered successful until the individual has demonstrated stabilization and held the position for 90 days. Although some of these services are free, most have a cost that varies depending on the individual's financial need.

Systems tracking

In general, agencies have the ability to track services in Virginia; however, most do not track based on diagnosis, so identifying the number of individuals with ASD is difficult. After individuals are identified, agencies often track the services they receive.

Early intervention

The representative for early intervention was unable to answer whether there would be a database to track services. However, the delivery of services identified on a child's IFSP is heavily monitored. Many indicators require 100-percent compliance or the system is considered out of compliance.

School-aged children

The DOE tracks federally required indicators as well as other data points built into the system, such as when transition services take place. The state also conducts a special education child count, which entails a data snapshot of the number of children in special education, their diagnosis location, and whether autism is their primary or secondary classification.

Adults

Although the representative from the Department of Vocational Rehabilitation was unable to speak on the specifics of a tracking system, they recognized that tracking is done for services to determine calculations, such as allocation of funds for long-term support.

Promotion of services and supports for people with ASD

Individuals with ASD and their families may receive information about ASD services and supports through several avenues. A primary source is word of mouth, such as networking, parent support groups, advocacy groups, and community service forums. Many families are able to get information through other involved families.

The Virginia Autism Project is an advocacy organization that was involved in lobbying for autism insurance coverage. This and the Autism Society of America are the two largest autism organizations in Virginia and also serve as important resources for individuals with ASD and their families.

In addition, different agencies share information and make referrals to other agencies' services. For example, a majority of individuals who are referred to adult vocational rehabilitation come from the public school system. State agencies have made efforts to spread information to underserved groups who may not have equal access. For example, the Office of Developmental Services sponsors cultural liaisons and has had workshops for Latinos and African Americans regarding ASD diagnoses.

Early intervention

Promotion of early intervention services is done in part through the ACT Early Summit, which includes a task force focused on getting information to pediatricians and creating diagnosis resources across the state. In addition, providers who go through certification are placed on a listserv that gives updates of autism-related events and provides cross-sector communication across different agencies. There are also billboards, pamphlets, brochures, and posters with information about early intervention services that are targeted to places where parents and physicians go. Finally, the Department of Medical Assistance Services (DMAS) sends a birthday newsletter for all Early Periodic Screening, Diagnosis, and Treatment eligible youth, which includes developmental milestones to promote screening and early identification.

School-aged children

The Department of Education partners with the Department of Behavioral and Developmental Services, DMAS, and the Department of Rehabilitative Services. DOE also works with higher education institutions to promote services in three main ways: (1) providing high school students early exposure to community colleges, (2) a pilot program for students with significant disabilities at 4-year institutions, and (3) linking students accepted to higher education institutes with the school's disability services office to secure services, such as transcribed notes or additional time for tests.

Transitions and coordination of services

Early intervention to school

Although transition from early intervention services is well practiced and typically runs smoothly, some difficulties arise from different eligibility criteria used by early intervention and the schools. Virginia has a statewide early intervention standard, whereas the school systems determine their own criteria for service eligibility and level of need. This can lead to an interruption of an individual's services.

School-aged to employment

The school system works with students and families to consider plans after graduation. Typically post-graduation plans are discussed around age 16 or during the student's junior year. One technique to ease transition to employment is providing students with work experience before they graduate. For example, Project SEARCH places students into internships, especially health-related settings, to gain experience. Many individuals are offered employment by the end of the internship.

After students leave the public school system, it is more difficult to receive services because they go from an "entitlement system" to an "eligibility system." Additionally, different agencies utilize different areas of services that do not necessarily coordinate well. The Department of Education divides the state into eight regions, early intervention has six regions, and the health department has 32 regions.

Training for direct service support workers

Virginia requires different types of training based on the type of service provided and the agency or authority employing the worker. The following training requirements or protocols were identified:

- As of 2009, all early intervention staff must complete online training modules and have the appropriate licensure before working with families and children. The training level and type of training depends on an individual's level and field of work; for example, supervisors must take a module on supervision. The agency can track training for required certifications, but not for unrequired certifications.
- One of the larger training projects has been a professional development training site, where individuals providing direct support can complete educational modules and receive hours toward certification. Individuals may access resources as well as landing pads about best practices on certain topics.
- The Individual and Family Support waiver requires one-to-one training sessions for providers, which can include technical assistance and general training. One recent push was to train law enforcement officers on how to interact in situations involving people with ASD.
- The Virginia school divisions offer their own trainings, and each region has access to a technical assistance center that has an autism specialist. A variety of competencies are offered to teachers.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Virginia is currently developing a more comprehensive waiver system for intellectual and developmental disabilities. The plan may involve combining the Individual & Family Support and Day Support for Persons with ID waivers, as both will be expiring and up for renewal within the next year.

Additionally, early intervention representatives note that strict levels of data standard compliance may result in increased monitoring and adherence to data compliance practices. The standards help ensure smooth delivery of services; however, there has been concern that the attention being given to meeting these measures may take attention away from the quality of service delivery.

Finally, the Department of Education is working on developing three additional guidance documents that focus on parents, development of education plans, and professional development of individuals working with students with ASD. DOE hopes to build local capacity for conducting this training and decrease the need for state oversight.

Other relevant programs and services

- *Project Lifesaver* (<http://www.projectlifesaver.org/>) is a tracking service that utilizes a wristband for anyone who wanders. The band allows for rapid location of the missing person. The Virginia-based program is self-funded and offered on a local basis, nationwide.

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WASHINGTON

Approach

The L&M research team interviewed five representatives from the state of Washington, comprising a range of perspectives related to the delivery of services to individuals with autism spectrum disorders (ASD) in the state. The agencies interviewed included the Division of Developmental Disabilities (DDD), the Office of Superintendent of Public Instruction (OSPI), Early Supports for Infants and Toddlers (ESIT), Children with Special Healthcare Needs (CSHN), and the Washington State Health Care Authority.

State background

The Caring for Washington Individuals with Autism Task Force was created in 2005 and produced two reports that focused on recommendations to improve services for individuals with ASD. The task force eventually published the Washington State Autism Guidebook to highlight important recommendations, create implementation plans for these recommendations, and outline other services and strategies to help families. The task force was disbanded in 2008 (Easter Seals, 2012).

State insurance regulations

Washington does not have a health insurance mandate specific to ASD. Limited coverage is available under a mental health parity law, which makes it illegal to discriminate against individuals with autism or mental illness. Health insurance coverage for mental health conditions is required at the same level as medical conditions (Easter Seals, 2012).

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Washington 1915(c) waivers

Waiver Name	Population Served
WA Children's Intensive In-Home Behavioral Support*	Individuals aged 8–20 with DD
WA Basic Plus Waiver*	Individuals who meet ICF/IID level of care who are at high risk of out-of-home placement
WA Core Waiver*	Individuals who meet ICF/IID level of care who are at immediate risk of out-of-home placement
WA Community Protection Waiver*	Individuals aged 18+ who meet ICF/IID level of care
WA COPEs	Individuals aged 65+ or aged 18–64 with physical disabilities
WA New Freedom	Individuals aged 65+ or aged 18–64 with physical disabilities

**Note: Of particular importance to ASD population
Source: Centers for Medicare & Medicaid Services, n.d.*

Specific ASD waivers

Washington does not have any waivers specific to individuals with ASD at this time. However, the Children's Intensive In-Home Behavioral Support waiver, Core waiver, and Community Protection waiver potentially serve participants with autism. The caveat is that individuals are not eligible based on an ASD diagnosis alone.

Other waivers

In Washington, four waivers are potentially available to children with ASD. However, an individual does not become eligible based on an ASD diagnosis alone for any of these waivers. The waivers are managed by the Aging and Disability Services Administration/DDD within the Department of Social and Health Services.

- The *Washington Children's Intensive In-Home Behavioral Support* waiver is available to children aged 8–20 who have severe behavioral issues that need to be addressed through Positive Behavior Supports and wraparound service delivery. Once a child is enrolled, a family chooses a contracted behavior specialist to develop a positive behavior support plan for their child. Families are actively involved in children's service plan and create a support team including the family, child, natural supports, waiver service providers, school staff, and other involved parties to ensure that services are consistent across home, school, and the community. Every child on the waiver has a case manager who organizes support team meetings every month for the first 3 months and quarterly after that. Services are provided by contracted professionals with an emphasis on in-home support (Division of Developmental Disabilities, 2012). Services offered through this waiver include:
 - Personal care
 - Respite
 - Occupational therapy
 - Physical therapy
 - Speech/language/hearing therapy
 - Assistive technology
 - Behavior management/consultation
 - Environmental accessibility adaptations
 - Nurse delegation
 - Sexual deviancy evaluation
 - Specialized clothing
 - Specialized medical equipment and supplies
 - Specialized nutrition
 - Specialized psychiatric services
 - Staff/family consultation and training
 - Transportation
 - Therapeutic equipment and supplies
 - Vehicle modifications
- The *Washington Basic Plus* waiver provides services to individuals with developmental disabilities that meet the level of care of an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) and are at high risk for out-of-home placement. Services include:

- Personal care
 - Respite
 - Prevocational and supported employment
 - Environmental modifications
 - Skilled nursing
 - Transportation
 - Specialized medical equipment and supplies
 - Adult residential care
 - Adult foster care
 - Physical therapy
 - Occupational therapy
 - Speech/hearing/language therapy
 - Behavior management
 - Specialized psychiatric services
 - Community access
 - Community guide
 - Person to person support
 - Family training
 - Emergency assistance
- The *Washington Core* waiver provides services to individuals with developmental disabilities who require the level of care of an ICF/IID and are at immediate risk for out-of-home placement. Services include:
 - Personal care
 - Respite
 - Residential habilitation
 - Day habilitation
 - Supported employment
 - Environmental modifications
 - Skilled nursing
 - Transportation
 - Specialized medical equipment & supplies
 - Adult residential care
 - Adult foster care
 - Physical therapy
 - Occupational therapy
 - Speech/hearing/language therapy
 - Behavior management
 - Family training
- The *Washington Community Protection* waiver provides services to individuals with developmental disabilities who require the level of care of an ICF/IID and need onsite, 24-hour supervision. Services include:
 - Respite
 - Residential habilitation
 - Day habilitation

- Supported employment
- Environmental modifications
- Skilled nursing
- Transportation
- Specialized medical equipment and supplies
- Physical therapy
- Occupational therapy
- Speech/hearing/language therapy
- Behavior management
- Family training

Findings

Services and supports for people with ASD

In addition to the waiver services mentioned above, the DDD within the Washington State Department of Social and Health Services offers services for individuals with ASD as well as other developmental and intellectual disabilities. Different age criteria determine eligibility depending on disability. An autism diagnosis must be given by a board eligible neurologist, psychiatrist, psychologist, or a board certified developmental and behavioral pediatrician. Children must reapply for services at age 4 and 10. DDD does not have any ASD-specific services, but they focus on positive behavior supports planning and interventions for behavioral challenges. DDD offers many other services, including case resource management to help families and clients identify interests and needs and access services. The full list of services includes:

- Case management
- Adult family homes
- Alternative living situations
- Companion homes
- Dental services
- Employment and day program services
- Group homes
- Nursing
- Occupational, physical, and communication therapy
- Behavior management and counseling
- Medical and psychiatric evaluations
- Residential habilitation services
- Supported living services

In addition, DDD administers the Individual and Family Services Program to support families who are caring for an individual with developmental disabilities. Families can receive services such as:

- Respite
- Therapies
- Architectural and vehicular modifications
- Equipment and supplies
- Specialized nutrition and clothing
- Excess medical costs not covered by another source
- Copays for medical and therapeutic services
- Transportation
- Training
- Counseling
- Behavior management
- Parent/sibling education
- Recreational opportunities

Early intervention

The Department of Early Learning runs the ESIT program, which is the lead agency for the Individuals with Disabilities Education Act, Part C early intervention services across the state. The main goal of ESIT is to find effective services for children from birth to age 3 and to involve families in their child's service plan. ESIT program coordinators work hard to support intensive instruction for infants and toddlers with ASD while promoting a strong parent-child connection. Children diagnosed with ASD are automatically eligible for services, otherwise eligibility is determined by having a 25-percent delay in one developmental area including: cognitive, physical (vision, hearing, fine/gross motor skills), communication, social/emotional, and adaptive functioning.

The ESIT program supports roughly 5,000 children across the state through 35 contracts for early intervention services. Family Resource Coordinators (FRCs) are contracted in each county and serve as points of contact. They help families find and decide on appropriate services and providers. The family, FRC, and other service providers design an Individualized Family Service Plan (IFSP) that outlines goals, priorities, and services to reach those goals. Services offered include:

- Specialized instruction
- Speech therapy
- Occupational therapy
- Physical therapy (Washington State Department of Early Learning, 2010a)

The State Interagency Coordinating Council for Infants and Toddlers with Disabilities and their Families was established to create a coordinated system of early intervention services across the state. Each county has a County Interagency Coordinating Council (CICC) made up of local service providers and family members. The CICCs serve as the advisory body to the local early intervention contracted agency. They promote collaboration with other local agencies, identify gaps in service, and organize local training for interested parties (Washington State Department of Early Learning, 2010b).

School-aged children

Special education services are administered by the OSPI and are available to students aged 3–21. Eligibility is determined through a full individual evaluation and is dependent on having a disability with an adverse educational impact. Special education does not provide ASD-specific services, rather student's needs and supports are outlined in their Individual Education Program (IEP). However, students with ASD often receive specially designed instruction, applied behavior analysis (ABA), and other services.

The CHSN program is based in the Department of Health and serves children under the age of 18 who have emotional, behavioral, or physical problems that require treatment beyond what most children need (Washington State Department of Health, n.d.). CHSN partners with the Office of the Superintendent of Public Instruction, Disability Determination Services, Social Security Administration, Medicaid, Early Support for Infants and Toddlers, and family support groups to coordinate care for students with ASD. To be eligible for CHSN services, children must be at or below 200 percent of the federal poverty level. Eligibility is determined by health need coordinators, who also assist families in finding providers with experience in treating ASD and accessing the services they need. The program does not provide direct services to children with ASD, rather it promotes medical homes for children and supports the infrastructure of neural developmental that provide specialized therapy for children with autism and other developmental disabilities. Although Medicaid or private insurance pay for most direct services, CHSN does offer some general services, such as nutrition supplements, hearing aid batteries, and several types of therapy. The program also supports separate parent organizations that do parent-to-parent matching for peer support and sharing of service information.

The Division of Behavioral Health and Recovery works with local children's mental health coordinators across the state to support the regional network. These programs are determined and approved by the state agency but are created by the local behavioral health community.

Adults

The Division of Vocational Rehabilitation (DVR) determines eligible individuals as those having a disability that is a barrier to employment and requires vocational rehabilitation to gain and maintain a job. Once eligible, participants are assigned a rehabilitation counselor to assess strengths, capabilities, work skills, and interests. The counselor helps to determine how earnings from employment will affect other possible benefits, such as Social Security. DVR also offers independent living services, training and education for employment, and other job-related services (Division of Vocational Rehabilitation, 2013b). In addition, DVR has a Washington State Tribal (Native American) Vocational Rehabilitation Program that specifically helps Native Americans with disabilities find employment.

The Mental Health Program is administered by DDD in collaboration with the Mental Health Division and provides therapeutic services to adult clients who have mental health concerns and may be at risk of psychiatric hospitalization. Services may include:

- Crisis prevention, intervention, and stabilization services
- Crisis diversion bed services
- Psychiatric services
- Funded residential placement (limited).

Systems tracking

The Department of Early Learning began using a new data management system in January 2012. The new system can track diagnoses and services delivered; however, many of the children that they serve have not been diagnosed with ASD yet or have multiple diagnoses. If a child moves to another county, the database can track the services the child received previously. Typically there are no required programs based on the diagnosis listed in the database, rather services are chosen based on the families' priorities and concerns and the individual needs of the child. The department offered training to regional experts in more rural areas of the state to ensure that consultation services are available no matter how far the family lives from the central research center.

The DDD also has a tracking system for services received through their Division or Medicaid. They use a new automated system that can access the previous information system. If the eligibility category is listed as autism, the system can track and sort by that category. If an individual is not listed as having autism, but specific criteria appeared in the assessment, the case manager can identify someone through that assessment.

Promotion of services and supports for people with ASD

Early intervention

The Autism Outreach Project (<http://www.nwesd.org/autism>) is a collaboration between ESIT, the Special Education Office in OSPI, and the Northwest Educational Service District. The project provides information, education, and assistance to individuals aged birth through 21 with ASD and their families; ESIT primarily helps to fund materials, referrals, and training for young children. The Autism Outreach Project offers special events, hosts a lending library with multilingual materials, provides technical assistance to schools and families, and hosts Webinars for families that recently received an ASD diagnosis or suspect their child might have ASD. The project also works to keep medical providers informed of services, because physicians, hospitals, and clinics constitute most referrals to early intervention. One of the key strategies for early intervention awareness is to improve physician training, technical assistance, and awareness around ABA therapy.

The CSHN program works with the "Learn the Signs. Act Early." campaign to promote early screening and identification of children with ASD. The program is based in central Washington and focuses on working with the Hispanic population. CSHN also created a program called Community Asset Matching to promote diagnostic standards and coordination of care across the state. The program looked for dynamic individuals who could pull together community leaders to

work on these issues. The project is ongoing and has led to more structured diagnostic services and better utilizations of local resources in several communities.

School-aged children

The Department of Health offers an online autism guidebook that provides information for families, educators, service providers, health care providers, and other individuals interested in services and supports for individuals with ASD (Caring for Washington Individuals with Autism Task Force, 2010). In addition, the Special Education Office within OSPI offers many written resources to parents of students with ASD, including a document—Educational Aspects of Autism Spectrum Disorders—that outlines information about developing an IEP and IFSP (Office of Superintendent of Public Instruction, 2008). OSPI also offers professional opportunities for those who work with students with ASD and hosts monthly regional district meetings to share information and new resources.

Transitions and coordination of services

Early intervention to school

Once a child turns 3, he or she transitions out of early intervention services. Six to 9 months before the child's third birthday, the Family Resource Coordinator and family begin to develop a transition plan to either preschool special education or other necessary services. At least 3 months prior to the child's third birthday, a transition meeting is held with a representative from the local school district to explain eligibility for special education. If the child is deemed eligible for special education, services are outlined in the IEP that is developed before the child's third birthday (Washington State Department of Early Learning, 2012).

School-age to employment

Every student has a post school plan that includes vocational interests, goals, and abilities; this plan serves as the core service delivery mechanism. The student's transition team consists of the student, parents, school staff, and vocational rehabilitation staff, who work to develop a transition plan while the student is still in high school. Vocational rehabilitation staff help the student gain the relevant skills to achieve employment goals as well as job matching, job placement, and followup consultations for at least 90 days after job placement (Division of Vocational Rehabilitation, 2013a)

Training for direct service support workers

The ESIT program provides certification and licensure but has minimum requirements specific to ASD for service providers. In addition, ESIT offers some general training opportunities that include ASD topics, but are not always ASD-specific.

Corrections

The DDD Community Protection Program is a voluntary program for individuals with developmental disabilities who have been identified as a risk to their community due to crimes they have committed or inappropriate behaviors that require supervision in public. The program is an opportunity for participants to live successfully in the community and continue to remain out of prison or other justice system settings. The program provides intensive 24-hour supervision and environmental and programmatic safeguards to protect neighbors and

community members, to the extent possible, from behaviors that pose a risk to people or property and/or interfere with the rights of others. The structured, specialized environment gives participants the opportunity to make positive choices to resolve or manage the behaviors that require intensive intervention and supervision.

Long-term plans to develop new or expanded supports and services (2–5 years)

Effective January 1, 2013, the Washington State Health Care Authority ABA therapy is covered as a regular benefit for all Apple Health for Kids clients with an ASD diagnosis. Apple Health for Kids is a statewide initiative that streamlines applications and Medicaid service coverage for children of families that live below 300 percent of the federal poverty level (Washington State Health Care Authority, 2012).

Other relevant programs and services

Other relevant programs and services for persons with ASD were not addressed during discussions with state representatives.

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WEST VIRGINIA

Approach

The L&M research team interviewed one representative from the state of West Virginia to gain information about the delivery of services to individuals with autism spectrum disorders (ASD) in the state. Through these interviews, the research team sought to gain greater understanding of the services and supports for persons with ASD in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

The West Virginia Developmental Disabilities Council is a 32-member organization that was established by an Executive Order of the Governor on March 6, 1972. The Council is authorized and funded by the Federal Developmental Disabilities Assistance and Bill of Rights Act (P.L. 106-402). Although the Council is supported administratively by the WV Department of Health and Human Resources, the West Virginia Developmental Disabilities Council is the organization with ultimate responsibility for the delivery of services and supports for individuals with developmental disabilities in the state (West Virginia DDC, 2013). Over 60 percent of the Council is comprised of citizens with developmental disabilities and family members of people with developmental disabilities. These members are appointed by the Governor and serve 4-year terms. The remaining members represent state and private organizations concerned with the provision of services to people with developmental disabilities.

State insurance regulations

On April 1, 2011, Governor Earl Ray Tomblin signed H.B. 2693 (*2011 W. Va. Act, Chap. 13*) into law requiring specified health insurers, including the state's Children's Health Insurance Program, to provide coverage for the diagnosis and treatment of ASD in individuals from age 18 months through 18 years. To be eligible for coverage, the individual must be diagnosed with ASD at age 8 or younger. Coverage includes treatments that are medically necessary and ordered or prescribed by a licensed physician or licensed psychologist, including but not limited to applied behavior analysis (ABA). The maximum annual benefit for ABA is \$30,000 for the first 3 years after diagnosis. After the 3d year, the benefit may not exceed \$2,000 a month until the individual reaches age 18 (Easter Seals, 2012).

In April 2012, Governor Tomblin signed H.B. 4260, which clarified the 2011 autism insurance reform law. H.B. 4260 states that the \$30,000 annual cap on benefits for ABA applies only to ABA, not to all benefits received. This law took effect on June 8, 2012.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of West Virginia 1915(c) waivers

Waiver Name	Population Served
WV MR/DD*	Individuals of all ages with ID/DD
WV Aged & Disabled	Individuals aged 65+ and aged 18–64 with a physical disability
WV Traumatic Brain Injury	Individuals aged 22+ with brain injury

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

West Virginia does not have any waivers specific to individuals with ASD at this time.

Other waivers

The West Virginia Department of Health and Human Services oversees West Virginia's 1915(c) Home and Community Based Services waivers.

- The *West Virginia MR/DD* waiver provides services that instruct, train, support, supervise, and assist individuals who have intellectual disabilities and/or developmental disabilities in achieving the highest level of independence and self-sufficiency throughout their entire lives. This waiver provides services in natural settings, homes and communities where the individual resides. The services provided under this waiver include:
 - Facility-based day habilitation
 - Participant-centered support
 - Respite
 - Service coordination
 - Supported employment
 - Financial management services (for participant direction)
 - Crisis services
 - Dietary therapy
 - Electronic monitoring/surveillance system/onsite response
 - Environmental accessibility adaptations for home and vehicle
 - Participant-directed goods and services
 - Occupational therapy
 - Physical therapy
 - Speech therapy
 - Positive behavioral support
 - Skilled nursing services
 - Therapeutic consultation
 - Transportation

Findings

Services and supports for people with ASD

Early intervention

West Virginia Birth to Three is the statewide early intervention program responsible for overseeing Part C services of the Individuals with Disabilities Education Act (IDEA). A child must be younger than 36 months of age to participate in the West Virginia Birth to Three Program (Virginia DOE OSP, 2011). Children are eligible if they (1) exhibit and have been diagnosed as having a significant delay; (2) have been diagnosed with a physical or mental condition that has a high probability of resulting in developmental delay; and/or (3) are experiencing multiple biological and/or environmental risk factors. Eligible children are assessed through a multidisciplinary evaluation to help identify the needs of the child. With the participation of the family, an Individualized Family Service Plan (IFSP) is developed to help target the services and supports best suited for the child and his or her family. Eight regions offer local points of entry into the West Virginia Birth to Three Program.

School-aged children

West Virginia defines autism as a developmental disability that severely affects communications and social interactions. To qualify for special education, a student with autism must undergo an evaluation before a multidisciplinary team. The potential student must display a minimum of six symptoms from three different categories (Virginia DOE OSP, 2011). The student must show at least two symptoms of extreme difficulties in the social relationships category and at least one symptom of impairment of communications. The student must also display at least one symptom of displaying a preoccupation with objects, sensations, rituals, and routines. Students with autism must have been diagnosed as having autism, show that their condition adversely affects their educational performance, and need special education. The student's educational performance also cannot be primarily affected by an emotional or behavioral disorder.

Adults

In West Virginia, the Developmental Disabilities Council assists with services and supports for adults by providing training and technical assistance to adults and providers to build competent and inclusive communities. In addition, the West Virginia Division of Rehabilitation Services (DRS) helps people with disabilities establish and reach their vocational goals (West Virginia Department of Education and the Arts DRS, 2013). The primary goal for all DRS clients is to become productive working citizens.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals in West Virginia become aware of ASD-related services in the state through a variety of channels. Many agencies have an open referral system in place where anyone can refer individuals to determine whether they are eligible for services. These referrals typically come from parents, physicians, service providers or others who think an individual may need services.

Transitions and coordination of services

Early intervention to school

Transition from early intervention to special education occurs according to the requirements of IDEA. Children leave the West Virginia Birth to Three program when they turn 3. The child's service coordinator and IFSP team are present during the transition process and will assist the family with exploring other needed and available services.

School-aged to employment

Consistent with IDEA, transition planning begins when the student turns 16. Eligible students receive transition services that may include one or more of the following:

- Postsecondary education
- Vocational education
- Integrated employment (including supported employment)
- Continuing and adult education
- Adults services
- Independent living or community participation

Training for direct service support workers

The West Virginia Autism Training Center at Marshall University provides a variety of training, information, and support services to West Virginians with autism, their families, educators, and other persons. Specific training areas are presented below:

- Autism training workshops;
- Family Focus Positive Behavior Support;
- Family coaching by phone; and
- College program.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

- *The West Virginia Autism Training Center*, a state training center on autism was established at Marshall University by law. The center provides training programs, workshops, and resources to educators of students with autism, parents, and others interested in autism. The center provides support services to families and operates the West Virginia Autism Spectrum Disorders Registry. The mission of the Autism Training

Center is to provide education, training, and treatment programs for West Virginians who have autism, pervasive developmental disorder not otherwise specified or Asperger's syndrome and have been formally registered with the center. This is done through appropriate education, training and support for professional personnel, family members or guardians and others important in the life of a person with autism.

- Established by law, the *Autism Trust Funds* establish a tax credit for parents and guardians of children with autism for the creation of trust funds. For a qualifying contribution to a trust fund that benefits the child, the parent or guardian's federally adjusted gross income may be reduced by a maximum of \$2,000 per year for persons who are married and filing jointly or \$1,000 per year for persons who are filing individually or who are married and filing separately. These provisions are effective for taxable years on or after January 1, 2011. Trust funds will only qualify after approval by the West Virginia Children with Autism Trust Board.

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WISCONSIN

Approach

The L&M research team gathered information about services and supports from various online sources in lieu of a discussion with representatives from Wisconsin (see references). Overall the team sought to gain greater understanding of the services and supports for persons with autism spectrum disorders (ASD) in the following areas: developmental disability services, early intervention, vocational rehabilitation, education, special education, and Medicaid.

State background

In February 2005, it was announced that a Council on Autism would advise the Department of Health and Human Services on strategies for implementing statewide supports and services for children with autism and would help direct the department to assist the council with administrative and support services.

The main charge of the Council on Autism was to address some of the important issues identified by an earlier task force on autism, such as:

- Provider staff training issues;
- Provider and parent strategies to recruit and retain line staff;
- Provider outreach efforts to recruit parents to work as line staff; and
- Alternative approaches to the current age restriction policy in the intensive phase.

The Wisconsin Department of Health Services is the primary state agency responsible for the development and implementation of statewide policy, services, and supports for people with developmental disabilities across the lifespan, including persons with ASD.

State insurance regulations

On June 29, 2009, S.B. 3 was signed into law, requiring individual and group health insurance policies and plans, state health care plans, and self-insured plans to provide health insurance coverage for the treatment of ASD. Treatment must be provided by a psychiatrist, a person practicing psychology, a social worker licensed or certified to practice psychotherapy, a paraprofessional working under the supervision of a provider, or a professional working under the supervision of an outpatient mental health clinic. The legislation does not apply to long-term care, Medicare replacement, or supplement policies. It requires a minimum of \$50,000 in coverage annually for intensive services and \$25,000 annually for nonintensive services (Easter Seals, 2012).

State Home and Community Based Services (HCBS) waivers

The Katie Beckett Program is a special eligibility process that allows certain children with long-term disabilities, mental illness, or complex medical needs, living at home with their families, to obtain a Wisconsin ForwardHealth Medicaid card. Those individuals not eligible for other Medicaid programs because the income or assets of their parents are too high, may be eligible for Medicaid through the Katie Beckett Program. Children may be eligible for this source of Medicaid even if they are currently covered under private health insurance policies.

State of Wisconsin 1915(c) waivers

Waiver Name	Population Served
WI Children's Long Term Support DD*	Children aged 0–21 with autism/DD/ID
WI Children's Long Term Support PD	Children aged 0–21 with physical disabilities
WI Children's Long Term Support SED	Children aged 0–21 with serious emotional disturbances
WI Community Options Program	Individuals aged 65+ and aged 18–64 with physical disabilities
WI Family Care MR/DD*	Individuals aged 18+ with DD/ID
WI Self-Directed Support DD*	Individuals aged 18+ with DD/ID
WI Community Integration Program DD*	Individuals aged 18+ with DD/ID
WI Brain Injury	Individuals aged 18+ with brain injury
WI Self-Directed Supports Elderly and PD	Individuals aged 65+ and aged 18–64 with physical disabilities
WI Family Care Aged/Physical Disability	Individuals aged 65+ and aged 18–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services, n.d.

Specific ASD waivers

- Wisconsin currently offers services through their *Children's Long Term Support DD* waiver for children up to age 21 with long-term care needs who have a developmental disability, intellectual disability, or autism spectrum disorder and would otherwise require care in an intermediate care facility. Certain functional and support needs criteria must also be met to be eligible. The waiver is intended to keep children within the community and enhance natural supports available to families. Opportunities for participant direction are available. Services provided through the waiver include:
 - Support and service coordination
 - Supportive home care
 - Respite
 - Day services
 - Supported employment
 - Home modifications
 - Housing Counseling
 - Housing start up
 - Mentoring
 - Nursing
 - Specialized transportation
 - Adaptive aids
 - Adult family home
 - Communication aids
 - Community integration services
 - Consultative behavioral intervention services
 - Early intensive behavioral intervention services
 - Specialized medical and therapeutic supplies

- Personal Emergency Response Systems
- Children’s foster care/treatment foster care
- Consumer education and training
- Consumer- and family-directed supports (for participant direction)
- Counseling and therapeutic services
- Daily living skills training
- Financial management services (for participant direction)

Other waivers

- The *WI Family Care MR/DD* waiver provides community-based supports for adults and elderly individuals who have intellectual and developmental disabilities. Services include:
 - Adult day care
 - Case management
 - Daily living skills training
 - Habilitation-day center service
 - Prevocational services
 - Respite
 - Supported employment
 - Skilled nursing services
 - Financial management support (for participant direction)
 - Adaptive aids
 - Adult residential care (1–2 bed adult family homes, 3–4 bed adult family homes, community-based residential facilities, residential apartment complexes)
 - Communication aids
 - Consumer education and training
 - Support broker (for participant direction)
 - Counseling and therapeutic resources
 - Environmental accessibility adaptations
 - Habilitation day services for children
 - Home delivered meals
 - Housing counseling
 - Personal Emergency Response Systems
 - Relocation services
 - Specialized medical equipment and supplies
 - Supportive home care
 - Specialized transportation
 - Vocational futures planning and support
- The *Wisconsin Self-Directed Support DD* waiver provides adults with the opportunity to make decisions about their own care. Under this plan, people with developmental disabilities work together with their families and state agencies to create a support plan unique to the needs of the individual. This waiver encourages people with disabilities to be in charge of their own care. The services include:
 - Adult daycare
 - Daily living skills training

- Live-in caregiver
 - Prevocational supports
 - Respite
 - Supported employment
 - Nursing services
 - Adult family home (1–2 bed; 3–4 bed)
 - Community based residential facilities
 - Adaptive aids
 - Communication aids vendors/interpreter services
 - Consumer education and training
 - Counseling and therapeutic services
 - Customized goods and services
 - Day services
 - Home delivered meals
 - Home modification
 - Housing counseling
 - Personal Emergency Response System
 - Relocation housing start up and related utility costs
 - Residential care apartment complex
 - Specialized medical equipment and supplies
 - Specialized transportation
 - Support broker
 - Supportive home care
 - Vocational and futures planning
- The *Wisconsin Community Integration Program DD* waiver provides community-based supports for adults aged 18 and older who have intellectual and or related developmental disabilities and meet the ICF/IID level of care. Participant direction opportunities are offered. Services are intended to supplement a participant’s natural support system and include:
 - Daily living skills training
 - Live-in caregiver
 - Prevocational services
 - Respite
 - Supported employment
 - Adaptive aids
 - Adult day care
 - Adult family homes (1–2 bed; 3–4 bed)
 - Community-based residential facilities
 - Communication aids
 - Consumer education/training
 - Counseling and therapeutic services
 - Day services for adults
 - Financial management services
 - Home delivered meals
 - Home modifications

- Housing counseling
- Housing start-up
- Nursing services
- Personal Emergency Response Systems
- Self-directed supports
- Specialized medical equipment and supplies
- Specialized transportation
- Support and service coordination
- Supportive home care

Findings

Services and supports for people with ASD

Early intervention

The Wisconsin early intervention program is known as the Wisconsin Birth to 3 Program. It is compliant with Part C of the Individuals with Disabilities Education Act and supports families of children with delays or disabilities under the age of 3.

School-aged children

Eligibility for special education services depends upon a specific criterion for different diagnoses, including autism (Washington DPI, n.d.). These criteria can be found in Wisconsin Administrative Code, Section PI 11.36. The eligibility worksheets are available through the Wisconsin Department of Public Instruction (DPI). DPI program consultants are responsible for the eligibility criteria checklists for each disability areas, including autism. When school districts use the eligibility criteria worksheets, the IEP team documentation of eligibility criteria is more likely to adequately address all of the required elements and results in fewer cases of inappropriate identification.

Adults

Services are also available for adults with disabilities through the Wisconsin Division of Vocational Rehabilitation (DVR). The DVR serves individuals with disabilities that face a substantial barrier to employment (Wisconsin DWD DVR, n.d.). DVR work is done through teams located around the state. These team members are available to assist all customers with their questions and concerns about the services DVR can provide.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Services and supports are promoted through the early intervention program in Wisconsin and other public agencies and providers, including physicians and families.

Transitions and coordination of services

Early intervention to school

At age 3, the Wisconsin Department of Public Instruction (DPI) collaborates with local education agencies to plan for the child's transition. Transition planning conferences are coordinated and are included in the child's Individualized Family Service Plan.

School-aged to employment

The DVR works with high school students who are transitioning from high school to postsecondary education and employment. The DVR partners with the DPI and the Department of Health Services (DHS) and will work with the student and community resources to provide a smooth transition from school to the world of work and community services. Resources for transition include:

- DVR Statewide Transition Action and Resource Team
- Transition Action Guide (TAG) for Post School Planning
- TAG—Short Version
- DPI/DHS/DVR Interagency Agreement
- University of Wisconsin System Coordinators of Services for Students with Disabilities
- Wisconsin Technical College System Key Contact Persons for Students with Disabilities
- DVR's Liaisons to Wisconsin Schools

Training for direct service support workers

The Wisconsin DPI offers a statewide, 2-day, autism training. This basic level training provides an introduction to effective educational programming for students with autism. In addition, an advanced level training focuses on addressing challenging behavior, instructional strategies, social skills, and communication for children ASD.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Long-term plans to develop new or expanded supports and services were not addressed during discussions with state representatives.

Other relevant programs and services

The Wisconsin DHS offers the Family Support Program to provide in-home individual services and supports to families that include an individual younger than aged 21 with severe disabilities, including physical, mental, or emotional disabilities. The program recognizes that meeting the needs of children who have severe disabilities may place hardships on a family's emotional, physical and financial resources. The program offers:

- Information and help in finding services and maximizing community resources;
- Limited funding to buy needed services and goods that cannot be bought through other sources; and
- Help in linking families with other families to strengthen natural supports.

References

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Wisconsin Department of Public Instruction. (n.d.). *Special education eligibility*. Retrieved from http://sped.dpi.wi.gov/sped_eligibility

Wisconsin Department of Workforce Development Division of Vocational Rehabilitation. (n.d.). *Vocational rehabilitation services for job seekers*. Retrieved from <http://dwd.wisconsin.gov/dvr/jobseek.htm>

WYOMING

Approach

The L&M research team interviewed two representatives from the state of Wyoming's Department of Health Behavioral Services Division. The goal for the interviews was to gain greater understanding of the delivery of services to individuals with autism spectrum disorders (ASD) in the state.

State background

The Wyoming Behavioral Health Division was developed in July 2011 by merging the former Developmental Disabilities Division and the Mental Health and Substance Abuse Services Division. The Division oversees two facilities—the Wyoming Life Resource Center located in Lander and the Wyoming State Hospital located in Evanston. The Division, which operates within the Wyoming Department of Health, provides leadership over the design and delivery of services and supports for individuals with developmental disabilities in the state. In addition, the Division oversees the state's Medicaid 1915(c) Home and Community Based Services (HCBS) waivers for people with developmental disabilities, including autism.

State insurance regulations

At this time, the State of Wyoming does not have a specific health insurance mandate for ASD or a mental health parity law.

State 1915(c) Home and Community Based Services (HCBS) waivers

State of Wyoming 1915(c) waivers

Waiver Name	Population Served
WY Children with DD*	Children aged 0–20 with ID/DD
WY Children's Mental Health	Children aged 4–17 with SED and aged 18–20 with mental illness
WY Adult Developmental Disabilities*	Individuals aged 21+ with ID/DD
WY Acquired Brain Injury	Individuals aged 21–64 with brain injury
WY Long Term Care	Individuals aged 65+ and aged 0–64 with physical disabilities
WY Assisted Living Facility HCBS	Individuals aged 65+ and aged 19–64 with physical disabilities

*Note: Of particular importance to ASD population

Source: Centers for Medicare & Medicaid Services (CMS), n.d.

Specific ASD waivers

Wyoming does not have any waivers specific to individuals with ASD at this time.

Other waivers

Three waivers in Wyoming are especially pertinent to individuals with ASD, two for children and one for adults.

- The *Wyoming Children with DD* waiver allows for the provision of services that the regular state Medicaid plan will not cover for eligible children with developmental

disabilities (DD). The Children with DD waiver began in July 2010 and is administered by the Behavioral Health Division. Children aged birth through 20 years are eligible if they have been diagnosed with intellectual and/or developmental disabilities or a related condition and meet the level of care for an Intermediate Care Facility for Persons with Developmental Disabilities. The goal of the waiver is to provide home- and community-based services that enable the child to stay in the local community rather than an institution and relieve pressures on families by helping them meet the needs of their children (Wyoming Department of Health DDD, 2013a). Services offered through the waiver include:

- Case management
 - Community integrated employment
 - Homemaker services
 - Personal care
 - Residential habilitation
 - Respite
 - Special family habilitation home services
 - Agency with choice
 - Independent support broker
 - Child habilitation services
 - Companion services
 - Dietician services
 - Environmental modifications
 - Individually-directed goods and services
 - Residential habilitation training
 - Skilled nursing
 - Specialized equipment
 - Supported living
 - Unpaid caregiver training and education (CMS, n.d.)
- The *Wyoming Adult Developmental Disabilities* waiver is intended to support adults aged 21 and older with developmental disabilities and their families, so that individuals can remain in their home communities and learn skills that will assist them in becoming more independent. To be eligible, a psychologist must confirm a diagnosis of intellectual disability (IQ of 70 or below) or developmental disability due to a related condition. Services offered under the Adult Developmental Disabilities waiver include:
 - Case management
 - Community integrated employment
 - Day habilitation
 - Homemaker services
 - Personal care
 - Residential habilitation
 - Respite
 - Supported living
 - Occupational therapy
 - Physical therapy
 - Speech/language therapy

- Agency with choice
- Independent support broker
- Companion services
- Dietician services
- Environmental modifications
- Individually-directed goods and services
- Skilled nursing
- Specialized equipment
- Unpaid caregiver training and education (CMS, n.d.)

Findings

Services and supports for people with ASD

Early intervention

In Wyoming, Individuals with Disabilities Education Act (IDEA) Part C early intervention services are offered through the Early Intervention Education Unit (EIEU) in the Behavioral Health Division. The EIEU provides assistance and oversight to the regional child development centers across the state that serve young children with disabilities from birth through age 5 and their families (Wyoming Department of Health DDD, 2013b). IDEA Part C services are targeted to meet the developmental needs of infants and toddlers based on an Individualized Family Service Plan (IFSP) and may include:

- Assistive technology/aural rehabilitation
- Developmental therapy/special instruction
- Family training and support
- Speech-language and audiology services
- Occupational, physical, and speech therapy
- Psychological/counseling services
- Service coordination and social work services

School-aged children

The Wyoming Department of Education classifies autism as a developmental disability that significantly affects communication and social interaction. Autism is generally evident before the age of 3 and adversely affects educational performance. To be eligible to receive special education, a child must display impaired communication, impaired cognitive development, and inappropriate relationships. A child must also display abnormal sensory processing and an abnormal range of activities (Wyoming Department of Education, 2013b).

Adults

The Wyoming Department of Workforce Services is tasked with helping people with disabilities establish and reach vocational goals that help them become productive working citizens. During any given year, the Division of Vocational Rehabilitation actively works with more than 4,000 of Wyoming's citizens with disabilities; on average, approximately 700 of those participants

successfully complete a rehabilitation program and enter the workforce (Autism Speaks, 2013). Individuals with ASD age 21 or older may qualify for VR services and mentoring based on the individual's IEP at the time of transition.

Systems tracking

Systems tracking of services and supports for persons with ASD was not addressed during discussions with state representatives.

Promotion of services and supports for people with ASD

Individuals in Wyoming become aware of ASD-related services through several channels. Agencies allow referrals from any source, but referrals typically come from family members, physicians, hospitals, and the school system.

Transitions and coordination of services

Early intervention to school

The EIEU works closely with the Wyoming Department of Education and local school districts to transition children at age 3 if they are eligible for continued services. A transition coordinator works with children who are going on to special education services in the schools. Children who are eligible for special education are entitled to a free appropriate public education (FAPE) in the least restrictive environment (LRE) from the age of 3 through the school year in which the student turns 21. School districts ensure the provision of FAPE in the LRE for each eligible child through the development and implementation of an Individualized Education Program (IEP), which is updated at least annually (Wyoming Department of Education, 2013a).

School-aged to employment

In Wyoming, students are eligible to receive services until their 21st birthday; however, transition out of the school system may happen earlier. At age 18, students may be eligible for life-supported employment as well as certain therapies and equipment when transitioning from school to employment and adult services. Day habilitation does not start until the individual turns 21, as do self-directed services.

Training for direct service support workers

Training for direct service support workers was not addressed during discussions with state representatives.

Corrections

Services and supports for persons with ASD in the corrections system were not addressed during discussions with state representatives.

Long-term plans to develop new or expanded supports and services (2–5 years)

Overall, respondents noted a constraint on resources that has limited any plans to change or expand ASD services. One plan that has been discussed involves more specific licensure requirements.

Other relevant programs and services

ATTAIN: New Horizons in Autism is an annual conference on autism hosted by the Wyoming Institute for Disabilities in the University of Wyoming's College of Health Sciences. Both families of an individual with autism and professionals who provide services benefit from the training conference. The conference links developmental theories of ASD with best practices, including educational modifications and social interventions.

References

- Autism Speaks. (2013). *Wyoming Department of Workforce Services*. Retrieved from <http://www.autismspeaks.org/resource/wyoming-department-workforce-services>
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APPENDIX A: DATA COLLECTION TOOL

State of the States in Services and Supports for Autism Spectrum Disorders (ASD)

Final Data Collection and Verification Tool

Updated February 13, 2012

CMS-0938-1142

Introduction

The Centers for Medicare & Medicaid Services (CMS) has contracted with L&M Policy Research (L&M) and its partners, Thomson Reuters, and the National Association of State Directors of Developmental Disabilities Services (NASDDDS) to address the need among policymakers, key stakeholders as well as families and individuals with Autism Spectrum Disorder (ASD) for information regarding services and supports for people with ASD. The purpose of this tool is to assist the research team in capturing federal and state level information about available supports and services and to communicate through the research team's structured interviews information about additional resources available to people with ASD and the public policy issues that affect people with ASD to key stakeholder audiences. We are interviewing multiple staff at each state, because several state agencies have an impact on supports for people with ASD. For note taking purposes, we are recording this discussion. Do we have your permission to record for this purpose?

PRA Disclosure Statement

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1142. The time required to complete this information collection is estimated to average 1.75 hours per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.

Warm-up

Please tell me a bit about yourself, your job title and your role at [name of State agency/office.]

Qualitative Questions for Agencies that Manage Services or Work Directly with People with ASD²

Identification of Persons with ASD and eligibility for services and supports

- Is there a standard definition established in a rule or written statute that defines ASD for your agency or program? If yes, where could we find that definition? Are you able to explain how ASD is defined?
- Does an ASD diagnosis by itself determine eligibility for services?
 - ___ Yes
 - ___ No [Please describe other diagnoses that are required, such as an intellectual disability].
- Do different services and supports that your agency or program provides have the same eligibility criteria?
 - ___ Yes [Please Describe.]
 - ___ No
- **[FOR ALL EXCEPT CORRECTIONS AND VOCATIONAL REHABILITATION]** How does your agency or program promote early identification and diagnosis of people with ASD?
- How does your agency or program promote identification and diagnosis of people with ASD across the lifespan?
- Are you able to identify or track those individuals with ASD who are receiving services and supports by disability type or diagnosis? If so, how?
 - ___ Yes
 - ___ No

Services and Support for People with ASD

- Does your agency furnish specific programs or services targeted to persons with ASD? **If the interviewee answers no:** Can you tell us more generally then what programs or services a person with ASD might come to receive for the diagnosis (DD/ID etc.) that qualifies him or her?
- Tell us about the specific services and supports your state agency or program provides to people with ASD.
 - **PROBE:** What services and supports does your state agency or program provide to family members or caregivers of people with ASD (leave of absence/respite)?

² These agencies include Medicaid, developmental disabilities services, vocational rehabilitation, education, early intervention, foster care, juvenile justice, and corrections.

- What are the specific behavioral, medical and cognitive interventions that are covered?
- Is there anything else we should know about?
- When people with Autism Spectrum Disorders (ASD) receive services from your program or agency, how do you know whether or not and/or where these individuals received services previously?
 - PROBE: Are data exchanged between state and local service agencies, so that each agency knows the person’s service history, such as what has worked and not worked (subject to privacy requirements)?

Promotion of Services

- How do individuals find out about services and supports that might be available to them? Are there different routes or points of entry that individuals may follow to get information about services and supports available from your agency?
- How does your agency or program attempt to reach populations less likely to be diagnosed with ASD, such as ethnic and racial minorities and low-income individuals?

Coordination of Services and Supports

- Tell us how your state agency or program works with local organizations in their efforts to support people with ASD.
 - IF NEEDED, clarify that we mean for the type of service that is being administered or provided (that is the topic of the discussion). For example special education collaboration at the state level to local agencies/school districts/county level.
 - PROBE: Please give us one or two examples you think should be shared with others?
 - PROBE: How would you improve these types of efforts in your state?

Interagency Transition

- Tell us how transition and/or coordination among services occur for people with ASD for the following situations as well as what types of policies and procedures are in place to ensure each transition occurs for people with ASD:

{In general, ask transition questions below during discussions with DD/Early Intervention/Special Education/Public Health/Mental Health}

- Early intervention to school programs,
- Interventions in school and intervention in the home,

{In general, ask transition questions below during discussions with DD/Early Intervention/Special Education/Public Health/Mental Health, Corrections}

- School to adult services,
- Institution to community,

{In general, ask transition questions below during discussions with DD/Vocational Rehabilitation/Employment/Public Health/Mental Health}

- Day programs to employment,

{In general, ask transition questions during discussions with DD/Early Intervention/Special Education/Public Health/Mental Health}

- Services provided from one agency to services provided by a different agency,
- Privately funded services to publicly funded services?
- For all: What, if anything could be improved for transitioning from one program/set of/type of services and supports to another?

Training

- Does your agency or program require direct support workers working with people with autism to receive specific training for this population?
 - If yes, which entity is responsible for providing such trainings?
 - PROBE: Which personnel are required to take these trainings? What topics are covered? What type(s) of guidelines are provided?
- What other training opportunities are available, if any, to support workers that specifically serve people with ASD?

Leisure/recreation—ASK FOR ALL CONTACTS

- Are leisure and recreational opportunities available to accommodate people with ASD in your state?
 - ___ Yes [Please describe.]
 - ___ No
- Do you track leisure and recreational activities provided at a county or local level within the state?

Future initiatives

- Does your state agency or program have any plans underway to develop new or expanded supports and services in the next two to five years?

Key Contacts for remaining interviews (to ask following discussion with DD staff)

We want to again thank you for taking the time to speak with us today. The information you provided was very helpful and informative. As we mentioned, there are additional people with whom we would like to speak to and are wondering if you could help us identify the appropriate contacts in (your State) for the following areas:

1. Early Intervention
2. Special Education
3. Public Health
4. Mental Health
5. Medicaid

6. Vocational Rehabilitation
7. Corrections
8. Other?

Closing

Before we end, I'd like to give you a chance to share any additional thoughts or comments. Is there anything else you would like to add that you didn't have a chance to say during our discussion today?

Thank you very much for participating in this discussion today. We appreciate your time and willingness to speak with us.

APPENDIX B: METHODOLOGY

Process

To guide the data collection in all 50 states and the District of Columbia, the research team drafted a semistructured interview guide that focused on current services for people with autism spectrum disorders (ASD), policies for people with ASD, and funding and utilization of public supports for people with ASD. The data collection tool may be found in Appendix A. Prior to conducting the qualitative task with state-level offices and departments, however, the team sought approval from the Office of Management and Budget (OMB) for the federally sponsored data collection task as required by the Paperwork Reduction Act (PRA). OMB approved data collection in September 2011. The valid OMB control number for the information collection is 0938-1142.

The team initially reached out to the key contacts identified via consultation with its subcontractors Truven Health (formerly Thomson Reuters) and the National Association of State Directors of Developmental Disabilities Services. The team also consulted as needed with the Centers for Medicare & Medicaid Services (CMS) Contracting Officer's Technical Representative about relevant contacts. Contacts were made to gain feedback on the following areas:

- Corrections
- Developmental disability services
- Early intervention
- Education
- Insurance commissioner
- Medicaid
- Mental health
- Public health
- Employment—vocational rehabilitation

A two-person team conducted the interviews, and all interviewees were asked to take part in a 1-hour interview session. In most states, the research team interviewed multiple staff because several state agencies have an impact on services and supports for people with ASD. We developed a process for reaching out to state developmental disability offices and from there assessed whom across other programs and agencies should be contacted and interviewed to capture the information sought about ASD services and supports across the lifespan. This process is captured in an internal ASD State of the States interview checklist and in the email template developed and approved by CMS requesting interviews. Upon reaching out to key contacts via email, the research team attached three pertinent documents, including a CMS letter of support; project description; and PRA disclosure statement.

The information collected in the interviews was to communicate additional information about services available to people with ASD and the public policy issues that affect people with ASD

to key stakeholder audiences. The information about services and supports for people with ASD is captured in individual state summary profiles using a template approved by CMS project staff. Each summary profile was written on the basis of discussions held with each state. Key interviewees were given the opportunity to review and update their respective state's profile to ensure accurate and timely information. L&M emailed review guidelines to all interviewees, with a timeframe for completing their review. The overall intent of the request was to make updates to content prior to CMS's receipt of the summary profiles.

A glossary of commonly used terms and program references that are captured across many state summary profiles may be found in Appendix C. A summary of insurance mandates and ASD-specific waivers may be found in Appendixes D and E.

APPENDIX C: GLOSSARY OF TERMS

Phrase	Acronym	Definition	Further Information
1915(c) Waiver	—	This Medicaid waiver allows states to provide long-term care services in home- and community-based settings.	http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Home-and-Community-Based-1915-c-Waivers.html
The Act Early campaign (Learn the Signs. Act Early.)	—	A set of guidelines by the CDC to help parents and childcare workers learn the signs of ASD or developmental disabilities and get children into services as early as possible.	http://www.cdc.gov/ncbddd/actearly/index.html
Applied behavior analysis	ABA	A commonly used evidence-based ASD treatment that involves rewarding and encouraging good behaviors.	http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba
Assuring Better Child Health and Development	ABCD	A program funded by the Commonwealth Fund and administered by the National Academy for State Health Policy to improve the delivery of child health services to low-income children and their families.	http://www.nashp.org/abcd-history
Autism and Developmental Disabilities Monitoring Network	ADDM	A group of programs funded by the Centers for Disease Control to estimate the number of children with ASD in various areas of the country.	http://www.cdc.gov/ncbddd/autism/addm.html
Autism spectrum disorders	ASD	A developmental disorder that often includes Autistic disorder, Asperger's syndrome, pervasive developmental disorder not otherwise specified, and Rett syndrome. Characterized by a lack of social engagement, communication, repetitive behaviors, restricted interests, and developmental delays.	http://www.cdc.gov/ncbddd/autism/hcp-dsm.html
Case management	—	See <i>service coordination</i>	
Asperger's syndrome	—	A disorder on the autism spectrum that involves a developmental delay in social skills but no other cognitive area. The DSM-V will eliminate the diagnosis of Asperger's syndrome and include it with ASD.	http://www.cdc.gov/ncbddd/autism/hcp-dsm.html
Child Find	—	A part of the IDEA legislation that requires that all children with disabilities be located, diagnosed, and served appropriately in the school system.	http://idea.ed.gov/explore/view/p/,root,statute,i.b.612,a.3

Phrase	Acronym	Definition	Further Information
Department of Disability Services	DDS	The entity in each state (it may be named somewhat differently) that provides services and supports for individuals with developmental disabilities. It may be a branch of the state's Department of Health, Department of Human Services, or another such entity.	http://www.nasddd.org/index.shtml
Department of Education	DOE	Each state's public office that governs Prekindergarten through Grade 12 education.	http://www.ed.gov/
Developmental disability	DD	A group of conditions due to impairment in physical, learning, language, or behavior areas.	http://www.cdc.gov/ncbddd/developmentaldisabilities/index.html
<i>Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition</i>	DSM-IV	The standard classification of mental disorders used by mental professionals in the United States.	http://www.psychiatry.org/practice/dsm
<i>Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition</i>	DSM-V	A version of the DSM that was published in May 2013. See DSM-IV for more details.	http://www.dsm5.org/Pages/Default.aspx
Early and Periodic Screening, Diagnostic, and Treatment	EPSDT	A benefit that provides comprehensive and preventative health care services for people under age 21 enrolled in Medicaid.	http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Benefits/Early-Periodic-Screening-Diagnosis-and-Treatment.html
Early intervention	EI	Services provided to children from birth to age 3 under Part C of IDEA.	http://idea.ed.gov/part-c/search/new
Easter Seals	—	A nonprofit organization with a large network of branches that provide services, support, and advocacy for children with disabilities.	http://www.easterseals.com/site/PageServer?pagename=ntl_wwa_we_are
Habilitative services	—	This is distinct from rehabilitation because it focuses on developing new skills or functions, as opposed to regaining old function. This is often done through therapies such as speech, occupational, or physical.	http://www.cms.gov/CCIIO/Resources/Files/Downloads/essential_health_benefits_bulletin.pdf
Home and Community-Based Services	HCBS	Services that allow individuals who would otherwise need an institutional level of care to remain in their communities.	http://www.medicaid.gov/Medicaid-CHIPA-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services.html

Phrase	Acronym	Definition	Further Information
Individual Plan for Employment	IPE	A plan developed laying out individuals' employment goals and the services that they will need to reach those goals.	http://www.ocfs.state.ny.us/main/cbvh/vocrehab_manual/pdf/SEC06-00%20IPE.pdf
Individual Service Plan	ISP	An example of a type of plan that Lead Education Agencies (LEAs) are required to develop that identifies goals and details the best approach to supporting, educating, and transitioning school-aged children with a disability when they are not in a public school.	http://idea.ed.gov/explore/view/p/.root.dynamic.TopicalBrief,5 .
Individualized Education Plan	IEP	A plan that schools are required to develop per IDEA that identifies goals and details the best approach to supporting, educating, and transitioning each school-aged child with a disability.	http://idea.ed.gov/explore/view/p/.root.regs,300.D,300,52E320 .
Individualized Family Service Plan	IFSP	A plan that details a family's goals for a child, which services the child will receive, and where he or she will receive them. The IFSP emphasizes the family's importance in a child's life.	http://idea.ed.gov
Individuals with Disabilities Education Act	IDEA	Ensures services to children and disabilities. The statute governs how states and public agencies provide early intervention and school services.	http://idea.ed.gov/
Insurance Mental Health Parity laws	—	State laws that require that private insurance cover services for mental illnesses to the same degree as physical illnesses. They may vary by situation or type of plan that falls under the law.	http://www.asha.org/Advocacy/state/States-Mental-Health-Parity-Autism/
Intellectual disability	ID	A disability characterized by significant limitations in intellectual functioning and adaptive behavior with an onset before age 18.	http://aaidd.org/intellectual-disability/definition#.UgKYdBz-scw
Intensive behavioral therapy	IBT	A treatment similar to ABA (also referenced as <i>intensive behavioral services</i> or <i>intensive behavioral intervention</i>).	
Intermediate care facility	ICF	An optional Medicaid benefit that allows states to provide individualized care and rehabilitation for individuals with intellectual and/or developmental disabilities (also referenced as <i>ICF/IID</i>).	http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Intermediate-Care-Facilities-for-Individuals-with-Mental-Retardation-ICFMR.html

Phrase	Acronym	Definition	Further Information
The Katie Beckett provision	—	A statute that allows Medicaid to count only the child's income in establishing financial eligibility for the program if the child would otherwise be eligible for an institutional level of care.	http://www.medicaid.gov/mltss/docs/primer10.pdf
Leadership Education in Neurodevelopmental and Other Related Disabilities	LEND	A series of grants by the Health Resources and Services Administration intended to improve the health of adolescents with neurodevelopmental and related disabilities.	http://www.hrsa.gov/about/news/pressreleases/110825lendawards.html
Least restrictive environment	LRE	The most natural environment for a child. For example, for young children, it might be the home or a day care. For school-aged children, it might be a regular or special education classroom in the school.	http://idea.ed.gov/explore/view/p/,root,statute,l,B,612,a,5
Local educational agency	LEA	The public authority responsible for providing education in a certain area (typically a school district).	http://idea.ed.gov/explore/view/p/,root,statute,l,A,602,19
Medicaid	—	The United States health program for families and individuals with low income and resources.	http://www.medicaid.gov/
Mental Health Parity	—	A requirement that health insurance plans ensure that financial requirements and treatment limitations applicable to mental health disorder benefits are no more restrictive than limitations applied to other medical benefits.	http://www.dol.gov/ebsa/mentalhealthparity/
Mental retardation	MR	Significantly subaverage intellectual functioning along with lack of adaptive behavior with an onset before the age of 18 (see also <i>intellectual disability</i>). Federal law changed the preferred term from <i>mental retardation</i> to <i>intellectual disability</i> ; the newer term retains the same definition (2010 Rose's Law).	http://www.ctc.ca.gov/credentials/creds/federal-disability-definitions.pdf
Modified Checklist for Autism in Toddlers	M-CHAT	Screening for children aged 16 to 30 months to identify those who may need further evaluation to receive a diagnosis for ASD. Parents, guardians, or pediatricians can perform the screening during a well-child checkup.	https://www.m-chat.org/about.php
Part B	—	The section of IDEA that pertains to children aged 3–22. Ensures that children with disabilities have a right to a free and appropriate public education	http://idea.ed.gov/explore/home

Phrase	Acronym	Definition	Further Information
Part C	—	The section of IDEA that pertains to children ages birth to three. It involves providing services to young children in the least restrictive environment, family involvement, and emphasizes transition planning.	http://idea.ed.gov/part-c/search/new
Pervasive developmental disorder not otherwise specified	PDD-NOS	A severe impairment in social interaction that cannot be characterized as ASD or any other disorder.	http://www.cdc.gov/ncbddd/autism/hcp-dsm.html
Play and Language for Autistic Youngsters	P.L.A.Y.	A program developed by Dr. Richard Solomon of the Ann Arbor Center for Developmental and Behavioral Pediatrics. It emphasizes early intervention and playtime with parents as a way to improve language, social skills, and other developmental areas.	http://www.playproject.org/about.php
Related disability	RD	In several Medicaid waivers, it is listed to refer to a disability similar to the one that the waiver covers. For instance, an intellectual or related disability could include ASD, whereas ASD is not an intellectual disability.	http://medicaid.gov/
Respite care	—	Services designed to give a hiatus to the regular caregiver by meeting safety and daily care needs of the youth.	http://www.medicicaid.gov/Medicicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/CBA-Implementation-Status-Report-2009.pdf
Rett syndrome	—	Includes a lack of social engagement, and an abnormally small head circumference. Sometimes considered a part of the autism spectrum.	http://www.cdc.gov/ncbddd/autism/hcp-dsm.html
Service coordination	—	The planning and coordination of multiple services and supports.	http://www.medicicaid.gov/mltss/design/design6.html
Supported employment	—	Ongoing support services to help a person with a disability attain and retain competitive employment.	http://www.ocfs.state.ny.us/main/cbv/vocrehab_manual/10-04_Supported%20Employment.htm
Therapy, occupational	OT	Occupational therapists treat people with disabilities through the therapeutic use of everyday activities.	http://www.aota.org/en/About-Occupational-Therapy.aspx
Therapy, physical	PT	Physical therapy focuses on improving or restoring mobility.	http://www.apta.org/AboutPTs/

Phrase	Acronym	Definition	Further Information
Therapy, speech	ST	The diagnosis and treatment of common speech and swallowing disorders.	http://www.asha.org/careers/professions/slp/
Vocational rehabilitation	VR	A federal grant program that helps those with disabilities receive training for, find, and maintain appropriate employment. The eligibility criteria for VR are broader than for many other state programs.	http://www2.ed.gov/programs/rsabvrs/index.html

APPENDIX D: INSURANCE MANDATES

State	Law ³	Rule ³	Mental Health Parity*
Alabama	AL §27-54-1	Insurance providers must offer plans that cover autism spectrum disorder (ASD) services through age 9. Businesses can opt to provide this coverage, or parents can buy it as a rider. Group health benefit plans must cover treatment and diagnosis of mental illnesses as medical illnesses.	Yes
Alaska	2012 Alaska Sess. Laws, Chap. 63 ⁴	Provides coverage for the diagnosis and treatment of ASD for individuals under age 21 with no maximum benefit.	
Arizona	Ariz. Rev. Stat. Ann. § 20-826.04, § 20-1057.11, § 20-1402.03 and § 20-1404.03	Group health insurers must cover the diagnosis and treatment of ASD. Small businesses and individual policies are exempt. Behavioral therapy is covered at a maximum of \$50,000 per year up to age 9, and \$25,000 per year for ages 9–16.	
Arkansas	AR Act 196	Insurance plans are required to cover the diagnosis and treatment of ASD without limitation. The exception is applied behavior analysis (ABA), which has an annual limit of \$50,000 and is only available to those under 18 years of age.	Yes
California	Cal. Insurance Code § 10144.5	Every health care plan that provides hospital, medical, or surgical coverage must also provide coverage for behavioral health treatment of autism or pervasive developmental disorder (PDD) recommended by a licensed doctor or psychologist and provided by a board-certified behavior analyst. There are no age or dollar limits specified. Plans that do not have mental health or behavioral health services, Medi-Cal, the Healthy Families Program, and the Public Employees Retirement System are all exempt.	Yes
Colorado	Colo. Rev. Stat. § 10-16-104 (1.3)(g), § 10-16-104 (1.4) and § 25.-5-8-107 (a)(IV)	Treatment and coverage for ASD is required for all plans issued after January 2010. ABA therapy is limited to \$34,000 annually for children aged 8 and under, and the limit is \$12,000 annually for children aged 9 through 18. A separate ASD provisions says, “any sickness or accident insurance policy that provides coverage for disabilities due to sickness shall also provide coverage for autism as with any accident or sickness, other than mental illness.”	Yes

³ <http://www.easterseals.com/explore-resources/living-with-autism/state-autism-profiles.html>

⁴ <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>

State	Law ³	Rule ³	Mental Health Parity*
Connecticut	PL 08-132	Individual and group health insurance policies that provide coverage for basic hospital expenses, basic and major medical-surgical expenses, and hospital or medical coverage must also provide coverage for the treatment of ASD, including habilitative services. Several bills have been introduced since this 2009 law to expand coverage to behavioral therapy or expand the types of policies covered, but none have yet been successful.	
Delaware	S.B. 22	Health plans must cover diagnosis, behavioral health treatments, pharmacy, psychiatric, psychological, and habilitative services for individuals under age 21 with ASD. ABA has an annual maximum cap of \$36,000. A separate bill requires insurance plans to cover specialized dental services for children with severe disabilities regardless of their network. ASD is mentioned as a covered diagnosis.	
District of Columbia	DC ST §31-3271 and DC ST §31-3102	Health insurers must cover habilitative services ⁵ for children with a congenital or birth defect—including ASD at a minimum of the same level covered by other conditions. They are not required to cover services offered in schools or early intervention programs. Individuals with ASD may also be eligible for limited coverage under the District's mental health parity law.	Yes
Florida	Fla. Stat. § 627.6686 and § 641.31098	Coverage for well-baby and well-child screening for ASD is required. Individuals with a diagnosis of ASD before the age of 9 will have coverage for the execution of a treatment plan provided by a doctor up to age 18 or until they graduate high school. ABA has an annual limit of \$36,000 or a lifetime limit of \$200,000.	
Georgia	O.C.G.A §33-24-59.10	Group insurers that cover neurological disorders must cover people with an autism diagnosis to the same degree. Since this 2001 legislation passed, several bills expanding ASD coverage have made it to a vote, but none have become law.	
Hawai'i		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in in Hawai'i, but 2012 bills to guarantee coverage have been brought to the state house and senate.	
Idaho		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Idaho.	

⁵ In this document, habilitative services generally include occupational, speech, and physical therapies.

State	Law ³	Rule ³	Mental Health Parity*
Illinois	Public Act 95-1005	Health insurers must cover diagnosis and medically necessary treatment provided by a licensed physician, licensed psychologist, or certified registered nurse practitioner for any medically necessary services. Coverage is subject to an annual limit of \$36,000. A recent update to the law ensures that no one currently diagnosed with ASD will lose his coverage based on the new version of the <i>Diagnostic and Statistical Manual of Mental Disorders</i> (DSM). Illinois also has a mental health parity law that requires insurers to cover serious mental illnesses, including PDDs, at a similar level to other health coverage.	Yes
Indiana	Indiana Code 27-8-14.2	Group health insurance coverage is required for PDDs (including ASD), and individual plans are required to provide an option for ASD coverage. All coverage must be in accordance with a treatment plan prescribed by a health care provider. ASD is defined as a neurological condition in the state, which may also affect insurance coverage.	
Iowa	S.F. 2531	The state employees' health plan must provide all medically necessary services for ASD listed in a service plan prescribed by a licensed physician, licensed psychologist, licensed social worker, or licensed registered nurse practitioner. Possible services provided include pharmacy care, psychiatric care, psychological care, and habilitative services. The maximum annual benefit is \$36,000.	
Kansas	HB 2160	A "pilot bill" signed in 2010 requires coverage for all individuals with ASD under age 19 on the state employees health plan. The law requires coverage of any diagnostic evaluation or treatment, including ABA, that is prescribed by a licensed physician, psychologist, or specialist clinical social worker and "recognized by peer reviewed literature as providing medical benefit to the patient based upon the patient's particular autism spectrum disorder." This began as a pilot due to a Kansas law that requires any insurance reform to first be tested in the state employees' plan. Measures to fully expand ASD coverage failed on a vote in 2012.	
Kentucky	Ky. Rev. Stat. § 319C ⁶	Health insurance companies must cover diagnosis and treatment of ASD, with a maximum annual benefit of \$50,000 for those aged 1–6 and a monthly maximum of \$1,000 for those aged 7–21. Covered services include: coverage of habilitative/rehabilitative care, pharmacy care, psychiatric care, psychological care, and therapeutic care.	

⁶ <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>

State	Law ³	Rule ³	Mental Health Parity*
Louisiana	La. Rev. Stat. Ann. § 22:1050 and 2012 La. Acts, P.A. 208 ⁶	Insurance companies must cover habilitative or rehabilitative care, pharmacy, psychiatric and psychological care, and therapeutic care, including ABA. Coverage extends to all individuals with ASD under the age of 21. The annual maximum is \$36,000, and individual and group plans with 50 employees or less are exempted.	
Maine	LD 1198	Insurers must cover diagnosis and treatment of ASD for individuals aged 5 and younger. ABA is the only service with an annual cap, and that is set at \$36,000.	
Maryland	MD Bus Reg Code §15-835 and MD Bus Reg Code §15-802	Any insurer or HMO that provides hospital, medical, and surgical benefits to individuals or groups will also cover habilitative services for those with a congenital or genetic birth defect. This includes ASD. In addition, a comprehensive mental health parity law requires that mental health benefits be equal to other health benefits.	Yes
Massachusetts	Gen. Laws Ann. ch. IV § 32A-25 and Mass. Gen. Laws Ann. ch. IV § 32A-22 ⁷ and <i>MA Gen. L. ch. 175 §47c</i>	All fully funded health plans governed by the state and the state employee health plan must cover services for individuals with ASD. Plans can opt out of providing ABA if they can prove that doing so over time will increase their premiums by more than 1%. Coverage includes habilitative or rehabilitative, pharmacy, psychiatric, psychological, and therapeutic care, including ABA. Further, coverage is required for medically necessary early intervention services at an annual maximum of \$5,200 per child and a total of \$15,000 for age birth to 3.	
Michigan	2012 Mich. Pub. Acts, Act 100 ⁹	All insurers must cover medically necessary evidence-based treatments prescribed by a licensed physician or psychologist. Covered services may include pharmacy, psychiatric, psychological, ABA, habilitative, or other behavioral services. Combined annual behavioral treatments may be capped at \$50,000.	
Minnesota	MN Stat. §62A.152 and MN Stat. §62A.151	Minnesota has no mandate specifically for ASD services. Its mental health parity law does require that group health policies that provide coverage for mental conditions treated in the hospital must also treat those outside the hospital. Health insurance policies are also required to cover the treatment of children with emotional disabilities—including developmental disabilities—in a residential facility.	Yes
Mississippi		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Mississippi.	

⁷ <http://www.ncsl.org/issues-research/health/autism-and-insurance-coverage-state-laws.aspx>

State	Law ³	Rule ³	Mental Health Parity*
Missouri	Mo. Rev. Stat. § 337.300 et seq. and § 376.1224 ⁹	Insurers must cover evidence-based, medically necessary autism therapies. ABA must be covered up to \$40,000 per year for children through age 18. They also have a mental health parity law under which mental illnesses must have the same coverage as physical or medical illnesses.	Yes
Montana	Mont. Code Ann. § 33-22-515 and Mont. Code Ann. § 33-22-706 ⁹	Health insurers must cover ASD services up to age 18. There is an annual cap of \$50,000 for children aged 8 and under for ABA therapy and \$20,000 for those aged 9–18. There is also a mental health parity law that covers severe mental illnesses including ASD. The mandate includes a list of services provided by licensed professionals that are part of a medically necessary treatment plan.	Yes
Nebraska	NE Rev Stat §44-792 (2007)	The state's mental health parity law specifies that if a plan covers mental illnesses, then it must be covered similarly to other medical conditions. Autism, as defined in the International Classification of Diseases, is included.	Yes
Nevada	Nev. Rev. Stat. § 689A.0435	Group, HMOs, and plans or policies that provide outpatient care must provide health insurance coverage for screening and treatment of ASD. Medically necessary services including habilitative services, pharmaceutical care, psychiatric care, psychological care, and therapeutic care including ABA—if provided by a certified professional—all must be covered. ABA is subject to an annual benefit of \$36,000. The mandate covers children age 18 and under or up to age 21 if still in high school.	
New Hampshire	N.H. Rev. Stat. Ann. § 417-E:2	Treatment of ASD was added to the mental health parity law in 2009. It requires that insurers cover treatment for ASD provided by a licensed physician or psychologist including habilitative/rehabilitative care, pharmacy care, psychiatric care, psychological care, or therapeutic care. A \$36,000 maximum annual benefit is in place for children aged birth to 12 and \$27,000 for those aged 13–21. Insurers may stipulate that services have to be part of a medically necessary treatment plan and consistent with nationally recognized treatment standards.	Yes
New Jersey	New Jersey Statutes L.2009, c.115, s.4. 17B:26-2.1cc	Health coverage is required for medically necessary services for ASD that are prescribed by a physician. Covered treatments include habilitative therapy and evidence-based behavioral interventions.	
New Mexico	N.M. Stat. Ann. § 59A-22-49, § 59A-23-7.9, § 59A-46-50 and § 59A-47-45	Insurers must cover diagnosis and treatment of ASD for individuals aged 19 years and under or 22 and under if still in high school. Only prescribed treatments must be covered, with an annual maximum benefit of \$36,000 and a lifetime benefit of \$200,000. Annual limits will be adjusted for inflation on January 1 of each year, beginning in 2011.	

State	Law ³	Rule ³	Mental Health Parity*
New York	S.5845/A6305A and New York [ISC] §3216	As of November 2012, private insurers must cover screening, diagnosis, and treatment of ASD. If the policy covers prescription drugs and therapeutic care for other conditions, then it must cover both of those for ASD as well. In addition, psychiatric care and psychological care must be covered if provided by a certified or licensed health care provider. The annual cap is \$45,000 for ABA services. A separate provision states that policies may not deny or exclude benefits on the basis of an ASD diagnosis. Insurance policies that would cover hospital, surgical, or medical care should provide similar coverage for ASD.	Yes
North Carolina	H.B. 973	There is no ASD mandate; however, there may be some coverage for those with ASD under the mental health parity law. Insurance plans must provide coverage for mental illnesses—including autism as defined by the DSM—as with physical illnesses. Insurance plans can set their own criteria for medical necessity but must cover a minimum of 30 combined inpatient/outpatient visits per year.	Yes
North Dakota	ND Cent Code §26.1-36-09	According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in North Dakota. However, some coverage may be available for individuals with ASD through the state mental health law, which says that group health insurers must provide the same coverage for the diagnosis and treatment of mental illnesses as other conditions.	Yes
Ohio		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Ohio.	
Oklahoma	S.B. 2045	Individual and group insurance policies that cover medical and surgical benefits must provide the same services to those under age 18 with autism as those without autism.	
Oregon	OR Rev. Stat. 743A.190 and OR Rev. Stat. §743A.168	Health insurers must cover individuals up to age 18 with PDDs, including ASD, and provide medically necessary benefits including habilitative and rehabilitative services. Further, the state's mental health parity law encourages group insurers to cover "mental or nervous conditions at the same level as, and subject to limitations no more restrictive than, those imposed on coverage or reimbursement of expenses arising from treatment for other medical conditions." Autism is included in this law.	Yes
Pennsylvania	S.B. 605 and H.B. 1150	The diagnosis and treatment of autism is mandated for those under age 21, with an annual cap of \$36,000. All medically necessary services are covered.	

State	Law ³	Rule ³	Mental Health Parity*
Puerto Rico		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Puerto Rico.	
Rhode Island	R.I. Gen. Laws § 27-20.11-1 et seq., 2011 R.I. Pub. Laws, Chap. 175, and 2012 R.I. Pub. Laws, Chap. 397	Health plans must cover diagnosis and treatment of ASD, including ABA and habilitative therapies. ABA is subject to an annual \$32,000 limit. Habilitative treatments are to be the same as those for all other diseases and disorders covered by the plan. A later amendment added psychology, psychiatry, and pharmaceutical services and expanded who can provide ABA.	
South Carolina	S.C. Code Ann. § 38-71-280	Group and state health plans must cover ASD services in accordance with a treatment plan prescribed by a medical doctor. Group plans with fewer than 50 employees and individual plans are exempt. Individuals under age 16 who received an ASD diagnosis at age 8 or younger are eligible for coverage. ABA has an annual maximum of \$50,000, and other benefits must be specified in a treatment plan provided by a medical doctor.	
South Dakota		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in South Dakota.	
Tennessee	TN Code §56-7-2367	Insurance companies cannot deny coverage due to an autism diagnosis. Any policy that covers neurological disorders must also cover ASD for children under age 12.	
Texas	Texas Insurance Code Chapter 1355.015	Insurance coverage is mandated for individuals aged 2–18 with autism. All generally recognized services prescribed by the primary care physician in a treatment plan must be covered. ABA is an included benefit.	
Utah	UT Code §31A-22-625	A pilot program provides ASD coverage for 50 employees on the state plan. Some coverage may also be available under the mental health parity law that requires coverage for catastrophic mental health conditions. It does not cover treatment for developmental disorders when that is the primary reason for treatment.	Yes
Vermont	Vt. Stat. Ann. Tit. 8 § 4088i	Health insurance coverage for the diagnosis and treatment of ASD for those up to 21 years of age is required. Coverage for habilitative/rehabilitative, pharmaceutical care, psychiatric care, and psychological care are included.	

State	Law ³	Rule ³	Mental Health Parity*
Virginia	2011 Va. Act, Chap. 876 and 2011 Va. Act, Chap. 878 (H.B. 2467 of 2011, S.B. 1062 of 2011) and VA Code §38.2-3412.1:01	The state employees' health insurance plan in addition to the local choice health program must cover diagnosis and treatment of ASD for children aged 2–6. Other plans are exempt only if costs associated with coverage are more than 1% of premiums charged over the experience period. ABA is covered up to \$35,000 annually; other services may include pharmacy, psychiatric, psychological, and therapeutic care. The state also has a mental health parity law, which says that group plans must cover individuals with biologically based mental illnesses, including autism. Groups of 25 or fewer along with individual and short-term policies are exempt.	Yes
Washington	RCW §48.41.200	According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Washington. Some coverage may be available under the parity law, which requires health insurance coverage and benefits at the same level as medical conditions. It is illegal for plans to discriminate against individuals with autism.	
West Virginia	2011 W. Va. Act, Chap. 13	Certain health insurers, including the Children's Health Insurance Program, must cover ASD services for individuals aged 18 months to 18 years as prescribed by and deemed medically necessary by a licensed physician or psychologist. ABA is subject to a maximum annual benefit of \$30,000 for the first 3 years after diagnosis and \$2,000 per month after that.	
Wisconsin		Requires that individual, group, state, and self-insured plans provide coverage for treatment of ASD. Coverage is subject to an annual cap of \$50,000 for intensive services and \$25,000 for nonintensive services.	
Wyoming		According to the Easter Seals report, no legislation exists regarding insurance coverage for ASD in Wyoming.	

* *Mental Health Parity: The Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA) requires group health plans and health insurance issuers to ensure that financial requirements (such as co-pays, deductibles) and treatment limitations (such as visit limits) applicable to mental health or substance use disorder (MH/SUD) benefits are no more restrictive than the predominant requirements or limitations applied to substantially all medical/surgical benefits. MHPAEA supplements prior provisions under the Mental Health Parity Act of 1996 (MHPA), which required parity with respect to aggregate lifetime and annual dollar limits for mental health benefits. For the State of the State ASD Profiles, denoting mental health parity in the Insurance Regulation table bears in mind the federal law as described above, but more specifically refers to state laws that require certain insurance plans to cover treatment and diagnosis for mental health to the same degree that they would cover a physical or medical illness. These laws are not closely tailored to individuals with ASD and therefore may not cover everyone on the spectrum or every type of evidence-based treatment for ASD.*

APPENDIX E: MEDICAID 1915(C) ASD SPECIFIC WAIVERS

Region	State	Waiver Number	Waiver Name
1	CT	CT.0993	Home and Community Supports Waiver for Persons With Autism
1	MA	MA.40207	Children's Autism Spectrum Disorder (ASD) Waiver
1	ME	ME.0159	Home and Community Based Services (HCBS) for Adults With Intellectual Disabilities or Autistic Disorder
1	ME	ME.0467	Support Services for Adults With Intellectual Disabilities or Autistic Disorder
1	ME	ME.0864	Services for Children With Intellectual Disabilities and/or Pervasive Developmental Disorders
1	NH	NH.0053	BDS Developmental Services
1	NH	NH.0397	In-Home Supports Waiver for Children With Developmental Disabilities
2	NJ	NJ.0031	Renewal Waiver
2	NY	NY.0238	Office for People With Developmental Difficulties (OPWDD) Comprehensive Renewal Waiver
2	NY	NY.0470	Bridges to Health (B2H) for Children With Developmental Disabilities
2	NY	NY.41063	Care at Home (CAH) III
2	NY	NY.40176	NYS OPWDD-CAH IV
2	NY	NY.40200	CAH VI
3	DE	DE.0009	Renewal-DDDS Waiver
3	MD	MD.0339	Waiver for Children With Autism Spectrum Disorder
3	PA	PA.0593	Adult Autism Waiver
3	VA	VA.0358	Individual and Family Developmental Disabilities Support Waiver
4	FL	FL.0294	Family and Supported Living Waiver (Tier 4)
4	FL	FL.0482	Developmental Disabilities Home and Community Based Services Waiver—Tier 2
4	FL	FL.0483	Developmental Home and Community-Based Services Waiver—Tier 3
4	MS	MS.0282	Intellectual Disabilities/Developmental Disabilities (ID/DD)
4	NC	NC.0662	Comprehensive Waiver
4	NC	NC.0663	Supports Waiver
4	SC	SC.0456	Pervasive Developmental Disorder
5	IL	IL.0350	HCBS Waiver for Adults With Developmental Disabilities
5	IL	IL.0464	Support Waiver for Children and Young Adults With Developmental Disabilities
5	IL	IL.0473	Residential Waiver for Children and Young Adults With Developmental Disabilities
5	IN	IN.0378	Community Integration and Habilitation Waiver
5	IN	IN.0387	Family Supports Wavier
5	MI	MI.4119	Children's Waiver Program

Region	State	Waiver Number	Waiver Name
5	OH	OH.0383	Transitions DD Waiver
5	WI	WI.0414	Children's Long Term Support DD Waiver
6	AR	AR.0188	Alternative Community Services Waiver Amendment
6	AR	AR.0936	Autism Waiver
6	LA	LA.0361	Children's Choice Waiver
6	LA	LA.0401	New Opportunities Waiver
6	LA	LA.0453	Supports Waiver
6	LA	LA.0472	Residential Options Waiver
6	NM	NM.0173	Developmental Disabilities Wavier Program
6	NM	NM.0448	Mi Via—Intermediate Care Facilities for Individuals With Intellectual Disabilities Renewal Waiver
7	KS	KS.0224	HCBS-ID/DD Waiver
7	KS	KS.0476	Autism Waiver
7	MO	MO.0698	Autism Waiver
7	MO	MO.0841	Partnership for Hope
7	NE	NE.0394	Day Services Waiver for Adults With DD
7	NE	NE.0396	Comprehensive DD Waiver for Adults
7	NE	NE.40660	Autism Waiver
8	CO	CO.0434	HCBS Children With Autism Waiver
8	MT	MT.0667	Children's Autism Waiver
8	ND	ND.0842	ASD Birth Through Four
8	UT	UT.0158	Community Supports Waiver for Individuals With Intellectual Disabilities and Other Related Conditions
8	UT	UT.1029	Medicaid Autism Waiver
9	CA	CA.0336	HCBS Waiver for Californians With Developmental Disabilities
10	AK	AK.0260	People With Intellectual and Developmental Disabilities
10	AK	AK.0262	Adults With Physical and Developmental Disabilities
10	ID	ID.0076	Developmental Disabilities Waiver
10	ID	ID.0859	Children's Developmental Disabilities Waiver
10	ID	ID.0887	Act Early Waiver