Guild
Incorporated

Seeing Strengths. Creating Options. Restoring Health.

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July 17, 2012

David Godfrey, Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

RE: Reform 2020 Comments

Dear Mr. Godfrey:

Thank you for the opportunity to comment briefly on the Reform 2020 Section 1115 Medicaid Waiver request. Thank you, too, for the opportunities the Department of Human Services has provided to the public over the past several months to participate in the process. The goals of the Reform are laudable.

Guild Incorporated, a not-for-profit, community mental health agency, provides an array of evidenced-based community treatment and support services, crisis stabilization, residential treatment, employment services, and supportive housing for adults living with serious mental illness and all its' complexities – seeing strengths, creating options and restoring health.

Services are provided in vivo, where and when needed (e.g., on the street, at one's home, during a doctor's appointment, etc.) Services include intensive case management, assertive community treatment, illness management recovery, integrated dual disorder treatment, supported employment, crisis stabilization, supportive housing, and care coordination. Social determinants of health as well as physical and mental health conditions are addressed simultaneously. Just over 1600 individuals are served over the course of a year.

First, we wish to underscore the importance and value of ensuring that individuals and families have access to on-going, evidence and community-based mental health services as they learn to live with, and successfully manage, chronic health conditions such as schizophrenia, schizoaffective disorder, major depression and other serious mental illnesses. Access to community services is key to the Reform goals of improved health and reduced reliance on institutional care.

We are hopeful that MnCHOICES is being designed such that it is effective in identifying the needs of individuals who have psychiatric disabilities, in addition to other disabilities. Certainly we welcome reductions in administrative complexity and simplification of the system wherever possible, as long as the unique needs of those who have psychiatric disabilities are incorporated into the tools that are used.

We support the policy direction of providing services "earlier in order to prevent or delay the demand for higher cost services." Accordingly, there is value in assuring that quality services are accessible to those who do not meet a level of institutional care.

We support pursuing the 1915(i) option to address gaps in service levels for those living with mental illness of a serious and serious and persistent nature. We need to do anything we can to offer services and supports before people need institutional care. Steps to improve the structure and viability of the current adult mental health rehabilitative services need to be explored - perhaps there is value in incorporating the rehabilitative services into the 1915(i).

To "empower and encourage work", the evidence-based Individual Placement Support model should be expanded and pursued through the 1915(i). Let's align our services to achieve 75% employment among those who have serious mental illness, rather than the current 15-25% employment rate.

We support the inclusion of Housing Stabilization Services in the demonstration projects. Safe, stable housing is at the foundation of health.

At Guild, we know, and have demonstrated, that when people, even those who have most disabling and complex conditions, have access to on-going, high quality, person-centered community mental health services and supports; health can be maintained, homelessness prevented, and disruptive, high-cost health services such as emergency department visits and hospital admissions used only when absolutely necessary.

Thank you for your attention to these brief comments. Please be in contact with us if we can be of assistance in furthering the goals of Reform 2020.

Sincerely,

[redacted]

Grace Tangjerd Schmitt
President

From:	[redacted]
Sent:	Tuesday, July 17, 2012 8:18 PM
To:	*DHS_Reform2020Comments
Subject:	Medical Assistance (MA) proposal; The needs of autistic adults.
Attachments:	White Paper Final Draft.docx

I'm a mother of a teenage boy with an ASD. He's fifteen. For the past three years I've struggled to maintain or get services my son needs so he can become a successful and contributing member of society. His services started to be slowly stripped away from him when he turned 12. My son is on the cusp of adulthood and I worry about what kind of difficulties he'll face once he turns 18. There are little to no services for autistic adults, and I see the needs of adults are not addressed in the waiver request. I feel this is an issue that is being severely overlooked.

I understand the concerns of addressing autism in individuals at a young age. But these same individuals will someday grow up to become adults. Isn't it important that these individuals have the services they need to be successful? We're only setting them up for failure if they don't have anything to help them transition into adulthood and maintain a positive course with positive outcomes.

I feel it's equally imperative that adults already on the autistic spectrum have the services they need. This includes job training and placement, educational and housing opportunities, and social skills development. Autistic adults need these services now. Young autistics will need these services in the future when they become adults. It's important and crucial that the state of Minnesota do something now to ensure the future of people with an ASD.

I'd like to conclude with the fact I'm also a graduate of [redacted] with a Bachelor's of Science in Social Work. Spring quarter of my junior year I wrote a white paper on the needs of services for autistic adults that I sent to Senator Al Franken. I've attached the paper here. I hope you take the time to read it and consider the importance of services for autistic adults, now and those to come.

Thank you for your time.

Sincerely,

[redacted]

AUTISTIC ADULT SOCIAL SERVICES ASSISTANCE

A WHITE PAPER FOR MINNESOTA SENATOR AL FRANKEN
UNITED STATES OF AMERICA SENATE

AUGUST 5, 2011

[redacted]

I. INTRODUCTION

Autism is a developmental disability that affects people of all ages, gender, race, ethnicity, and socioeconomic background. While autism is often thought of as a children's disability, the fact is that the disability does not cease to exist on an 18th birthday. There is currently a significant number of adults who have been diagnosed as autistic, and an ever increasing number of adolescents who are aging into adulthood each day (IAN, 2009). This population is severely overlooked when it comes to providing services that will help them become productive and successful members within our society. While policymakers on every level are working hard to meet the needs of autistic children, little to no effort is being made to meet the needs of autistic adults resulting in an unequal amount of care for a critical group of vulnerable citizens. Most specifically, young autistic adults who age out of high school are in serious need of services that will help them make the transition into adulthood. At this pivotal time in their lives, services that have been proven to help them maintain the skills they developed during their school years, enabling them to maneuver through society as they get older, are not available.

I am writing to you today as a constituent and mother of an autistic teenage boy who will soon begin his transition into adulthood. Like all citizens in the United States, autistic adults have a right to participate in society. They cannot do that, however, without the necessary services to help them achieve this. It is my hope that you will see the importance of this issue and understand the level of urgency needed to modify our service resources.

II. ABSTRACT

For over a decade autism has been viewed as a children's disability and is approached as such despite the fact it knows no age, race, gender, ethnicity, religious affiliation, or socioeconomic status, and that many autistic youth become autistic adults. Focus is placed on a variety of therapies, treatments, and developmental strategies to help autistic children. While this must continue, it is equally important to put this same kind of focus towards autistic adults. Services are not available or are very limited to autistic adults who need care after age 18. Care over the lifespan of an autistic person costs up to $3.2 million dollars (CDC, 2010). "Unless a concerted effort on the part of parents, professionals, employers, and society at large is made to correct these shortcomings, the costs can only be expected to grow in the coming years" (New York Center for Autism, 2009).

III. EXAMINATION

A. CURRENT POLICY SHORTFALLS

Surveys and studies conducted by Think Tanks (New York Center for Autism, 2009), research institutes (SFARI, 2011), and universities alike have found the rates of services for autistic adults of varying ages to be severely lacking. A recent study done at Washington University of St. Louis, Missouri (Feb. 2011) and corresponding article published in the February issue of *Arch Pediatric and Adolescent Medicine* (2011) take a close look at services available to autistic adults during their first few years post high school graduation. The study found a large discrepancy in rates which show 39.1 percent of young autistic adults do not receive the services they need to increase their ability to become productive and successful members of society. Looking at medical diagnostics and care, mental health, case management, and speech therapy as being the services most needed, the below chart reflects the discrepancy between services for high school and post graduation autistic youth.

	Medical	Mental Health	Case Management	Speech Therapy
High School	46.9%	46.2%	63.6%	74.6%
Post Graduation	23.5%	35%	41.9%	9.1%

The sharp contrast in these figures shows a sharp decline in services once young autistic adults leave high school, and highlights that not enough focus is placed on their many important needs (Arch Pediatric Adolescent Medicine, 2011).

Autism is seen as a children's disability with current statistics provided by the Center for Disease Control and Prevention estimating that an average of 1 in 110 children within the United States have an autistic spectrum disorder (CDC, 2011). Most of the focus has been placed on meeting the needs of children such as prevention, early intervention, and locating a cause. Emphasis has also been placed on various forms of therapies to help children develop skills that were affected by the onset of the disability. While these initiatives are critical, this has left the needs of autistic adults severely neglected.

Aside from the need for medical, mental health, case management, and speech therapy services, autistic adults also need services in job training and employment, housing, independent living skills, support and social skills groups, and educational opportunities (New York Center for Autism, 2009). There is a lack of understanding that autistic adults have the potential for employment and can become contributing members of their community when the appropriate support systems are available (New York Center for Autism, 2009).

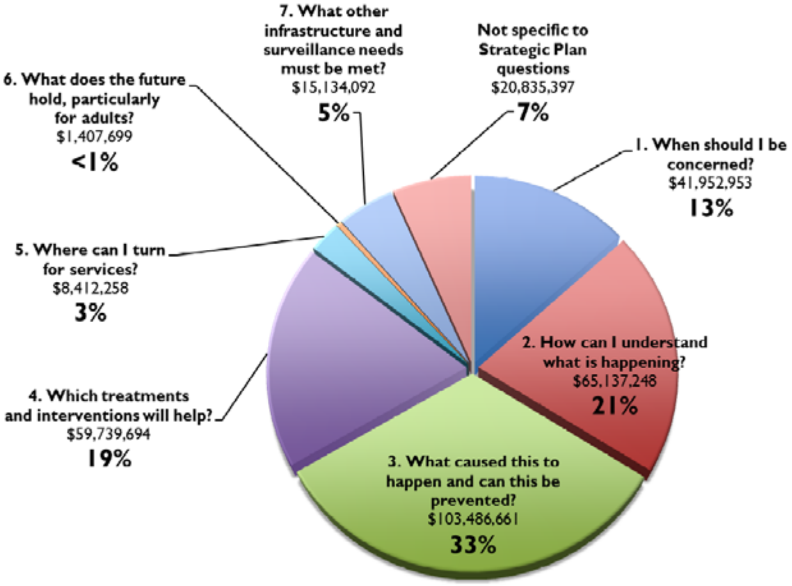
B. MISUNDERSTANDINGS ADDRESSED

Although autism is known on a global level, there is ignorance surrounding the disability. Many people believe that autism has become an epidemic because the numbers of people diagnosed with the disability have increased over the last ten to twelve years from 1 in 10,000 to 1 in 110 (CDC, 2010). "Researchers believe this is due to a greater recognition, with changes in diagnostic practice associated with more trained diagnosticians; broadening of diagnostic criteria to include a spectrum of disorder; a greater willingness by parents and educationalists to accept the label; and better recording systems, among other factors." (Taylor 2006).

There was also a widely held belief that autistic adults did not exist. In recent years, two studies have been conducted in England that refutes this claim. One was done in 2007 by the National Health Services (NHS, 2009, Time, 2009) and another recently in 2011 at the University of Leicester (Arch Gen Psychiatry, 2011, Science Daily, 2011). Both found that autism appears to be just as common amongst adults as it does children. It was discovered that roughly 1 in 100 adults in England are autistic. The findings are consistent with the rates of diagnosed children found in Japan, Canada, and New Jersey, where the prevalence of autism amongst children is the highest, 1 in 94 (Star-Ledger, 2007, Time, 2009). Given these statistics, it is reasonable to believe that the numbers of autistic adults in this country are similar. Furthermore, according to preliminary findings by the Interactive Autism Network (IAN, 2009), a project of the Kenny Krieger Institute, it was discovered that the ages of participants who shared personal information for an online research project and identified themselves as autistic varied from eighteen up to sixty-two (IAN, 2009). As I have stated throughout this document, and as represented in the above data, autistic adults do exist and their numbers will increase as more adolescents grow into adulthood.

C. PROPOSED POLICY REFORMATION

With the passing of the Combating Autism Act (CAA) in 2007, The Interagency Autism Coordinating Committee (IACC), a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder was formed (IACC, 2009). This committee receives funding from both Federal agencies and private organizations. Every year the IACC establishes a Strategic Plan that apportions this funding for autism research to be done in this country. The graph below demonstrates a breakdown of this funding and highlights what can only be described as a clear fundamental bias in a matter of importance in autism research.



Graph provided by *2009 IACC Autism Spectrum Disorder Research Portfolio Analysis Report*

To date, a combined total of seventy-three percent of funding has been put toward gaining understanding, locating the cause, prevention and early interventions, and treatments of autism, with an extremely small amount – only one percent - going towards "what the future holds, particularly for adults" (IACC, 2010). This is outrageous and not acceptable. The allocation of funds needs to be adjusted so more research can be done to identify the needs of autistic adults and provide necessary services, as well as the development of new programs and the sustainment of any current ones for autistic adults of all ages. Funding for the IACC is received from both federal and private sources (IACC, 2011), as such it is essential that this funding continue, but the focus for this money must shift if autistic adults ever hope to find a place within society.

Recently, the Combating Autism Reauthorization Act (CARA) was presented before Congress. On September 7th, 2011, the Senate HELP Committee is scheduled to discuss CARA. It is imperative this Act continue. Without it, the IACC will cease to continue. But most importantly, funding allocated towards autism research will cease as well. I urge you to support the Combating Autism Reauthorization Act so necessary research can continue. I also request that you make a stand for autistic adults and insist that more funding be allocated towards services that will help adults currently on the spectrum and those growing into adulthood become productive and successful members of society.

The number of young autistic adults making their way into adulthood is growing, adding to the already present population. The fact that there are adults of varying ages who are autistic needs to be acknowledged and services need to be available for them to utilize. This is both for young adults to help them transition successfully from high school into adulthood, and for those already on the spectrum. If this is not done now, present autistic adults will continue to find themselves without critical services. Young autistic adults aging into adulthood will experience the same outcome. As a result, both will flounder in a society that failed to provide them with the means to reach their full potential and have a positive future.

There are agencies and organizations at the local and national level that already work to provide the necessary services needed by autistic adults. Two located in the Twin Cities are Fraser Center and Lifeworks Services, Inc. Fraser Center in Minneapolis is considered by many in the Twin Cities to be the premier organization for autism services. Fraser provides autistic adults with “residential living options” (Fraser, 2011), and “home & community supports that assists people with maintaining physical and behavioral health, family well-being, increasing independent living skills and participating in the community” (Fraser, 2011). There is also an organization in St. Paul called Lifeworks Services Inc. that works with autistic and many other disabled individuals to provide career development. As of 2009, approximately 299 businesses throughout the Twin Cities have partnered with Lifeworks. The result is 662 individuals overall have earned $4.1 million in income with the average wage of $8.32 an hour (Lifeworks, 2011).

On the national level, organizations such as Advancing Futures for Adults with Autism (AFAA) are working to bring attention to the need for services for autistic adults. New strategies need to be implemented because “[t]he potential of young adults and adults (14 years of age and older) with autism to become employed and engaged citizens of the U.S. is not so much limited by their disability itself but, rather, by the failures of the system charged with supporting them” (AFAA, 2011). To further stress the urgency of this matter, AFAA hosted a Congressional briefing in Washington, DC on July 15th, 2010. Federal legislators, national policymakers and advocates for [autistic adults] – including [adult autistic self-advocates] – came together to discuss “priorities for action in the public and private sectors that address the increasing and unmet demand for effective services for adolescents and adults with the disorder” (AFAA, 2011).

Organizations like these are vital in guaranteeing the success of autistic adults. It would be imperative that IACC form a collaboration with AFAA to further prevent the economic cost of our country’s systematic failure of its most vulnerable citizens. It would also be beneficial if the IACC studied organizations like Fraser Center and Lifeworks and use them as models to develop additional federally funded programs and services that will help autistic adults of all ages become productive and successful members of society.

D. LONG-TERM RESULTS

Companies such as Best Buy, Cargill, and 3M have autistic adults in their employment and see the benefits of doing so. The Best Buy webteam Vice President, Cindy Hoker, is convinced “that this group is one of the most untapped pools of talent we have.” Autistic adults can be taught the skills needed to succeed in the workplace (East Valley Tribune, 2011). Therefore, it is imperative that services are provided so autistic adults have the chance to participate in these opportunities.

Autistic adults of all ages have a right to “participate in the economic, political, and cultural life of society” (NASW, 2006). They have a right to find their place in the work force, and take advantage of college or vocational training. They have a right to have a place to live, whether it is on their own or in an assisted living facility. Participation in society allows autistic adults the opportunity to live their lives to the fullest. This goes hand in hand with the rights and responsibilities that not only adults with an autism spectrum disorder have to the community, but with what we the community have to these individuals in return. All “[people] have a right and responsibility to participate in society and to work together toward the common good” (NASW, 2006). We can help autistic adults achieve their right to participate in society by guaranteeing services are available for them once they mature into adulthood, and continue to be available to them as they age. It is just as important to guarantee that services are available for already existing autistic adults who have the “fundamental right to things necessary for human decency” (NASW, 2006).

E. CONCLUSION

Autism is not going away. There are autistic adolescents growing into autistic adults. My own son will soon begin the transition into what will be one of the most critical times in his life. He has dreams and goals for himself. I have great concern my son will not be able to meet them due to the lack of services for adults and an even greater lack of funding and research into what the future holds for him and others autistic individuals transitioning into adulthood.

This concern also reaches out to the autistic adults already present in our society. They have a right and responsibility to participate and become productive and successful members. Providing services for these individuals have never been more important or necessary than they are today. It is time the needs of autistic adults stop being overlooked and start being taken into consideration. Today’s autistic children will become tomorrow’s autistic adults. If the needs are not met now, what will happen to future generations when they mature into adulthood and discover the services they need are not there? We cannot afford to fail these individuals, for it will be more costly to them as well as our country if we do not act.

F. APPENDICES

APPENDIX A- AUTHOR(S)

[redacted]

APPENDIX B- REFERENCES CITED

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July 17, 2012

David Godfrey, Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55164

Re: Comments on Autism section of the Reform 2020 Section 1115 Medicaid Waiver Proposal

By email with attached word document and signed pdf to:
Reform2020Comments@state.mn.us

Dear Mr. Godfrey:

I am submitting the following comments as permitted during the public comment period for this proposed waiver. These are my written comments regarding the concerns of the Lovaas Institute Midwest about this proposal.

Background: For the purpose of introducing these comments, I am a licensed psychologist with 25 years of experience as a Licensed Psychologist in Minnesota. I am also a Board Certified Behavior Analyst. I have been employed by a county social services department, a community mental health center, and two universities in Minnesota, as well as serving on three state task forces. I have consulted widely for children and adults with severe disabilities, school districts, and private service agencies across Minnesota. I have incorporated two nonprofits to serve Minnesotans with autism, and I have served as the chairperson of two other statewide nonprofit agencies. I am presently employed as the Executive Director of Clinical Services at the Lovaas Institute Midwest, where we provide intensive early intervention services to children with autism.

My comments will:
1) reinforce the need for a 1915(i) waiver to prevent Minnesota from creating a waiting list that would hamper early intervention,
2) provide support for extending the age of coverage of the 1915(i) waiver to 12 years, and
3) address the extent to which Applied Behavior Analysis can assist in resolving concerns regarding the section on Autism Services in the proposed waiver.

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1) It is critical to fashion an autism services funding stream that will not result in a waiting list for early intervention services.

When the state of Wisconsin transitioned its Katie Beckett coverage of ABA for autism to a 1915(c) waiver, the waiting list increased to over one year. This effectively eliminated the opportunity for early intervention for many children, and particularly those from disadvantages populations, because of the following facts.

In a recent CDC study of factors associated with age of diagnosis of autism, the CDC reports the following:

- The average age of diagnosis of autism is 5.7 years.
- The average age of diagnosis in children with IQs over 70 is 6.6 years.
- The average age of diagnosis in children whose mothers were teenagers at birth is 6.6 years.
- The average age of diagnosis in children whose mothers had less than 12 years of school is 6.3 years.

- 27% of the children with autism had not been diagnosed by the age of 8.

These studies suggest that economically disadvantaged children are unlikely to be diagnosed with autism until after they reach first grade. While studies contradict each other over whether the age of diagnosis of minority children is older than other children, what is consistently found are that less minority children are *ever* diagnosed with autism. This suggests that the age data is severely confounded by the lack of reliable evaluation services for minority children. One study found that rural children are also diagnosed later (at the average age of 8.1 years).

Therefore age-caps are likely to discriminate against disadvantaged children.

Others claim that the older age of diagnosis in general is due to the failure to diagnose young children who are "high-functioning" or have Asperger's disorder, and that this is somehow a trivial problem. However, the ABA studies show that both "low-" and "high-functioning" children are equally likely to recover from intensive early intervention. Further, the cost to society of "high-functioning" adults with autism is estimated at an average of $2 million per person.

Therefore it is imperative that society cover the costs of timely early identification and early intervention for all children, regardless of IQ.

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2) If the evidence in Early Intensive Behavioral Intervention is used as a guide, then the age cap for the 1915(i) autism waiver should be 12 years.

The cost effectiveness of Early Intensive Behavioral Intervention (EIBI) for autism is well documented (I have a full bibliography available on request). Much of the research emphasizes the need to treat the children at as young an age as possible, and this is certainly an important aspect of effective treatment. However, the following list of several hundred references also reports the clinically important impact of Applied Behavior Analysis (ABA) with children who are specifically *above* the age of seven. Several articles of note are highlighted that report the effectiveness of EIBI/ABA that was delivered to children who *started* treatment even up to the age of seven, and then continued treatment for up to five more years, until they were over the age of ten, if still medically necessary.

For a child starting treatment at any age, the average length of intensive ABA treatment would be expected to be 3 years, and the range of medically necessary treatment durations has been shown to be from 18 months to 5 years. Therefore, system-wide, maximum cost effectiveness will be achieved when a competent authorization process involves evaluation of the child's response to treatment and prognosis every six months, as was done in these studies. When applying such standards, the children would not automatically continue treatment indefinitely. Instead the intensity and duration would be tailored to each child's optimum effectiveness, by periodically evaluating each child's individual response to treatment, and thereby dramatically control costs by providing time-limited ABA for only so long as is medically necessary.

The range of age cut-offs in evidence-based EIBI studies were established for the purpose of controlled research, and were based upon a number of factors, such as available funding. They weren't meant to imply that autism was untreatable after those ages. Throughout the EIBI literature, the published range of such age cut-offs, for the purpose of research, was 48 to 84 months for the maximum age to *begin* receiving treatment, and then the subsequent duration of treatment was one to five years.

> **Therefore the age of *completion* of these children's intensive treatment was up to 12 years of age.**

After several groupings of these studies are summarized below, this paper then summarizes the research on the focused treatment of behavior disorders with children who suffer from autism in the ages of five to 21.

The following studies reported age cut-offs *for initiating* intensive treatment up to the age of seven years (84 months).

Eikeseth and colleagues, in 2007, used the following cut-off:

> "All referrals who met the following criteria were admitted to the study: (a) a diagnosis of childhood autism... (b) chronological age between 4 and 7 years at the start of treatment, (c) a deviation IQ of 50 or above... and (d) no medical conditions... that could interfere with treatment." (page 266).
>
> "The largest gain was in IQ; the behavioral treatment group showed an increase of 25 points (from 62 to 87) compared to 7 points (from 65 to 72) in the eclectic treatment group." (page 269).
>
> "in the behavioral treatment group, all correlations among intake age and outcome measures and changes were nonsignificant, with r(12) ranging from –.40 to .46. Thus, age was not reliably associated with outcome or amount of change for this group." (page 273).

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: A comparison controlled study. Behavior Modification, 31, 264-278.

Mudford and colleagues, in 2001, reported the following cut-off:

> "By the age of 4 years, 71% of the sample had started EIBI. At the ages of 5, 6 and 7 years, the corresponding cumulative figures were 91%, 97% and 100%." (page 177).

Mudford, O.C., Martin, N.T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: Some characteristics of UK programs. Research in Developmental Disabilities, 22, 173-182.

These additional studies reported effective treatment of children who *completed* their treatment after the age of five.

Sallows and Graupner, in 2005, reported the following data for children who ranged up to the age of 8.5 years of age at the conclusion of treatment:

> "Following 2 to 4 years of treatment, 11 of 23 children (48%) achieved Full Scale IQs in the average range, with IQ increases from 55 to 104, as well as increases in language and adaptive areas comparable to data from the UCLA project. At age 7, these rapid learners were succeeding in regular first or second grade classes, demonstrated generally average academic abilities, spoke fluently, and had peers with whom they played regularly." (page 433).

Sallows, G.O., & Graupner, T.D. (2005). Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors. American Journal on Mental Retardation, 110, 417-438.

Love, Carr and colleagues, in 2009, reported the following average ages of treatment in a comprehensive survey of nationwide ABA practices:

> "Seventy-four percent (n = 153) of respondents reported that the *average* age of the children they served was between 2 and 5 (33% reported serving children who were 4-years old), and 26% (n = 55) reported an *average* client age of 6 or greater." (page 177).

Love, J.R., Carr, J.E., Almason, S.M., Petursdottir, A.I. (2009). Early and intensive behavioral intervention for autism: A survey of clinical practices. Research in Autism Spectrum Disorders, 3, 421-428.

These additional studies reported meta-analyses of ABA treatment of school-aged children with autism, up to and including the age of 15.

Bellini and colleagues, in 2007, reported the following age ranges of 155 children who benefited from ABA social skills training:

> "21 studies involved preschool-age children, 23 involved elementary age children, and 5 studies involved secondary-age students." (page 158).

Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. Remedial and Special Education, 28, 153-162.

Reichow and Volkmar, in 2010, reported on 31 studies of children, aged four to fifteen, who benefited from ABA social skills training:

> "The school-age category had the highest participant total of the three age categories (N = 291)." (page 156).
>
> "Within the last 8 years, 66 studies with strong or acceptable methodological rigor have been conducted and published. These studies have been conducted using over 500 participants, and have evaluated interventions with different delivery agents, methods, target skills, and settings. Collectively, the results of this synthesis show there is much supporting evidence for the treatment of social deficits in autism." (page 161).

Reichow, B. & Volkmar, F.R. (2010). Social Skills Interventions for Individuals with Autism: Evaluation for Evidence-Based Practices within a Best Evidence Synthesis Framework. Journal of Autism and Developmental Disorders. 40, 149-166.

Brosnan and Healy, in 2011, reported on 18 studies of children aged three to 18, who received effective ABA treatment to reduce or eliminate severe aggressive behavior:

> "All of the studies reported decreases in challenging behavior attributed to the intervention. Of the studies included, seven reported total or near elimination of aggression of at least one individual during intervention in at least one condition." (page 443).
>
> "only four of the studies conducted follow-up assessments. However, each of these studies reported that treatment gains were maintained." (page 443).

Brosnan, J., & Healy, O. (2011). A review of behavioral interventions for the treatment of aggression in individuals with developmental disabilities. Research in Developmental Disabilities. 32, 437–446.

3) I believe that the science of Applied Behavior Analysis and the practice of Behavior Therapy offer solutions for resolving the public concerns regarding the autism services section.

I applaud the DHS intent, which I quote from page 15 here:

> "A new program to deliver early intervention services to support Medicaid eligible children ages 0-7 who have a diagnosis of Autism Spectrum Disorder (ASD). The primary goal of the program is to provide high quality, medically necessary, evidence-based therapeutic and behavior intervention treatments and associated services, such as respite, that are coordinated with other medical – and educational – services. Other goals of the program will be to make a smooth and effective transition into school programs and/or other community services, and demonstrate measurable gains and achievement of identified goals."
>
> "With this waiver request, Minnesota seeks to move the service delivery system to a model that will better integrate medical, behavioral and long-term care services in patient-centered models of care, promote robust primary care, improve care coordination, and better align payment incentives to foster best practices. In addition, Minnesota proposes to modify existing long –term care services and supports to provide additional flexibility to match the right services with participants' needs, at the right time."

ABA and behavior therapy offers objective evaluation methods that can ensure that the cost of early intervention is covered as wisely as possible, regardless of the child's age, diagnosis, or intake functioning level.

State-mandated prior authorization practices should not just be meaningless bureaucracy. ABA practitioners provide therapeutic treatment for children to accomplish important improvements in their behavior and then transition them to independence. We use scientifically established principles to evaluate each child's response to treatment and prescribe the optimum form of behavior therapy for them. We then make customized requests for authorization of whatever further treatment might be necessary.

The intensity that we request is the level that is necessary to do the job. As such, the intensity varies dramatically across children. Some children have simple needs and others have complex needs. Each child's response to treatment is objectively evaluated every six months over the course of an average of three years of treatment. If less clinical supervision and treatment can accomplish the treatment goals, then we identify that level and reduce treatment accordingly.

These accountability practices do increase the amount of clinical supervision that each child receives, but they also result in the effectiveness that is sought by the consumers, and the ability to screen out ineffective treatment in the most timely manner possible.

In the end, the overall cost is reduced because each child reaches their best outcomes in the fastest manner possible, and children who don't benefit are transitioned as quickly as possible.

Is Applied Behavior Analysis (ABA) a cost-effective treatment for autism?

In the past, it was common that affected children would be placed into a state hospital, and their families would be advised to forget them. They were told that their children were incapable of learning language and social attachment. The poor parents of some of those children were further mistreated when they were told that they had caused their children's autism. And all of this was done without any research whatsoever to support these practices.

Yet America is the home of innovation and industry, and at the University of Minnesota, the leading psychologist B.F. Skinner reasoned that the developing science of behavior could be applied to solve human problems. What other purpose for science could there be?

Following his lead, researchers at several hundred universities pursued the science of Applied Behavior Analysis (ABA). Behavior analysts began to venture into the darkest wards of state hospitals and found that they could make profound changes in the behavior of children who suffered from schizophrenia, mental retardation, and autism.

In the 1960's, ABA researchers found that these children could learn and become independent, and their research formed a basis for the deinstitutionalization of state hospitals. Researchers found that they could teach the blind to be independent, the deaf to talk, and the handicapped to recuperate. They found that much of the severe behavior disorders were caused by the very fact that those children were warehoused – 60 children kept in a day room with little care and nothing to do, resorted to rocking and self-injury much like zoo animals. However when the families were empowered to nurture their children in their own homes, they did indeed respond to their families' love and showed more healthy development. These gains strengthened families. The parents formed the Association for Retarded Children and the National Society for Autistic Children, to advocate for family-based ABA treatment of their children, and for local inclusive communities.

However, good intentions and family nurturing were not enough. In the 80's and 90's, most children were still segregated in special education programs and by their teenage years, because of the dangers and severe behavior disruptions, were headed for community group homes. The typical family living with a child with a severe behavior disorder found themselves isolated and preoccupied with their child's daily needs. The disruptive children were not welcomed at church, at school, or even at family Thanksgiving dinners. Further, the children were serious financial burdens on school districts, costing an average of $18,790 per year (according to the GAO) and went onto life-long community group home living, costing an average of $68,908 per year (according to the federal Center for Medicaid Services), overall costing more than $3,200,0o0 per child over their lifetimes (according to a Harvard study).

So did the ABA fail and go away? Certainly not. Now the science was applied to solving these next problems.

ABA Researchers in school special education programs found how to teach the young children to participate meaningfully in regular classes, and how to socialize with their regular peers. They also found how to develop transitional skills to train the adolescents in meaningful work in actual community jobs. Their studies showed the cost effectiveness of these approaches. They also found methods for training the regular schoolteachers to use the behavior analysis procedures.

ABA researchers also began studying how to provide intensive early intervention in the homes of families, to prevent the development of these severe behavior disorders. Once again, they found that the families could be empowered to provide the necessary behavior therapy in their own homes. Under the intensive supervision of these university centers, the parents were able to eliminate severe behavior problems such as sleep disorders, eating disorders, self-injury, destruction, and aggression in 90 percent of the children. Simultaneously the researchers found how to train the parents to foster normal social interactions and language in their children.

With one form of ABA, Early Intensive Behavioral Intervention (EIBI), a good number of the children improved enough in all areas of their lives that, by first grade, they had attained normal IQs, lost their diagnoses, and were able to learn without special education in the regular classrooms. Follow-up studies showed that 90% of these children were able to go on to live productive, independent lives as tax-paying citizens, rather than as tax-spending wards of the state.

Up until the early 90's, the research on EIBI had been conducted in relatively few university centers, with funding from the National Institutes of Mental Health. It was fairly obscure. However it was then that the internet began to foster social networking and Catherine Maurice published a book on the recovery of her children. Her book was substantiated by an independent university study, and families began clamoring for help. Simultaneously, autism began growing from what had been considered a low incidence disorder, into a much more widespread problem.

This was a new and unusual treatment – most professionals still believed that children were born and lived with the same disorder until their deaths, and they preferred to counsel families from the safe distance of their leather couches. So community funding for intensive home-based treatment was hard to find.

And sufficient funding was needed to do the job correctly. This is intensive early intervention, designed to dramatically alter the family's natural lifestyle into a therapeutic lifestyle for three years. As such it is dynamic family therapy, and requires many hours of direct behavior therapy for the child, direct family therapy for the parents, and ongoing behavioral assessment, analysis and clinical supervision of the many individualized treatment changes made along the way. If the critical mass of intensity is not delivered, then the results are neither widespread nor sustained, and the funds are largely wasted. So the natural inclination to parcel out the services is very clearly penny-wise yet pound-foolish.

Therefore the families began going to their school districts for funding. They had a right to IEP funding, but there was little leeway in the school district budgets, especially for the smaller districts, and this treatment went way beyond previous expenditures, and it was home-based, after all. Further, in the vanguard of this treatment, there were very few professionals who understood the therapy and were available to the schools for expertise. In due process hearings, families were able to show the effectiveness of the approach and win the needed funding. However most schools provided only minimal services, which made nowhere near the impact of the intensive programming.

So families turned to health insurance and government Medicaid funds. Pennsylvania, Wisconsin, and California established dedicated EIBI programs. Here in Minnesota, the families succeeded in lobbying for a statewide task force on autism in 1997. The cost-effectiveness data showed that the EIBI was warranted. However, the vested, traditional care providers, the "competition," claimed that the research wasn't yet substantial enough to warrant a programmatic investment in early intervention, and the state did not implement the recommendations, though when individual families pursued Medicaid coverage in hearings, they won.

The ABA research continued to blossom and by 2001, numerous independent panels and state commissions were finding that the results were indeed bona-fide and that the treatment was being accepted as the community standard of care. These bodies included the Surgeon General of the United States, the American Psychological Association, the American Academy of Pediatrics, the American Academy of Child and Adolescent Psychiatry, the National Research Council, the New York Department of Health, and the California Department of Developmental Services, to name a few. ABA and EIBI behavior therapy for autism could no longer be considered investigative, and had clearly reached the mainstream of autism treatment.

There was no alternative. Traditional mental health services were not faring so well. The Minnesota Department of Health 1998 report on children's mental health, the Minnesota Department of Human Services Citizen's League 2001 report on children's mental health, and Blue Cross Blue Shield's 2002 report on Minnesota's mental health system all found services to be in disarray. The Citizen's League reported:

> "More than ten years after its passage, the mission of the Children's Mental Health Act remains utterly unfulfilled. The mental health services a child receives, and the degree to which those services are coordinated and easily obtainable, depends largely on what county the child lives in and the persistence of parents and family members. Education, prevention and early intervention efforts range from limited to virtually nonexistent. No one is held accountable when a child's mental health needs go unmet — and Minnesota's children are suffering the consequences."

All of these reports called for increased access to intensive, family-based services; increased personnel training resources; increased accountability, and increased early intervention. The families were calling for all of these solutions as well.

On the strength of the evidence, the families succeeded in lobbying for a law in 2001 that provided for a dedicated autism program whereby Medicaid would have covered ABA treatment. The law laid out the parameters of effective treatment, and it also included numerous cost controlling mechanisms. The law would have allowed the state to coordinate and manage the services that were directly targeted to autism.

Though the law was not set to be implemented until 2007, families continued to win Medicaid coverage in individual hearings, and the Attorney General forged a settlement with the insurance companies to not automatically deny coverage. ABA providers negotiated agreements for coverage with the state Medicaid program, and also began to be certified by the state CTSS program. Blue Cross Blue Shield took the lead in enabling children to benefit from intensive ABA therapy.

In 2004, Minnesota initiated a new Systems Change Grant to improve service quality in the children's mental health system of care and to improve outcomes for children and families. The state's independent consultant once again found that ABA was an effective treatment:

> "Two treatment families demonstrated Best Support. Intensive Behavioral Treatment was successful in three (3) studies, beating alternative treatments in two (2) of those, and beating a no-treatment control in one (1). Likewise, Intensive Communication Training was also successful in three (3) studies, beating alternative treatments in two (2) of those, and beating a no-treatment control in one (1) study...
>
> "These results are quite promising in terms of effect size, although it should be noted that the outcome variables for these studies mainly involved reductions in the frequency of —autistic behaviors or increases in social communication or other forms of social exchange (e.g., turn taking). None of these studies claimed that children were —autism free following the intervention programs. Nevertheless, these findings represent an extraordinary improvement over the evidence base for interventions for autistic spectrum disorders in the previous Biennial Report...
>
> "The shape of the profile suggests that all successful treatments for autistic spectrum disorders involve teaching communication skills and modeling of appropriate communication or other behaviors. Other strategies include training in non-verbal communication (social skills), teaching parents and teachers to praise desired behaviors, and the setting of goals paired with the intensive rehearsal and reinforcement of behaviors consistent with those goals (i.e., discrete trial training)."
>
> Chorpita, B.F. & Daleiden, E.L. (2007). *2007 Biennial report: Effective psychosocial interventions for youth with behavioral and emotional needs*. Child and Adolescent Mental Health Division, Honolulu: Hawaii Department of Health (pp. 16-19).

However this promise has not yet been fully implemented.

In 2007, the state rescinded the autism law without public notice or hearing. The state also began suspending authorization of coverage for some children, and delaying certification of new providers for others. Some providers responded by curtailing treatment to the level that the state would agree to authorize – others served families who advocated for the full intensity that their children needed. Some providers were certified only on condition that they provide less intensity than others.

In a subsequent hearing sought by families, the state presented the issue as being about which specific components of EIBI were to be covered – the direct child behavior therapy and/or the behavior analysis and clinical supervision. The state claimed that federal rules prevented the coverage of the components. But as evidence, the state provided a letter from the federal government that said something entirely different. The federal letter stated that it required additional information before it could add the autism program to the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) section of Minnesota's state plan as a rehabilitative benefit. The federal government explained the problem this way:

> "autism is a disorder which is developmental in nature and routinely requires treatment similar to that provided to individuals who have mental retardation...
>
> "Habilitation services are typically provided for the purpose of helping persons maintain or acquire new functional abilities while rehabilitative services are provided to restore a lost function."

This opinion was and is unjustified by the evidence that many children with autism have in fact lost their functioning, and that many others never had "mental retardation" and never will. Instead the ABA behavior therapy does in fact restore some children to normal functioning and others to near-normal levels of functioning. There is no credible scientific evidence to the contrary.

In the numerous hearings and mediation meetings since then, we've offered solutions for better management of autism. Yet the state has continued to provide only generic coverage – even when the generic coverage is more costly.

What are the problems that the 1915(i) waiver should correct with Applied Behavior Analysis?

Currently the state manages all treatment as if it were the same, managing specialized, intensive, daily ABA therapy for autism in the same way as weekly psychotherapy for depression. This prevents the state from customizing coverage guidelines for intensive treatment, or for who should be receiving it.

The state has no system for scaling the payment rates to the level of intensity. Instead it is one payment rate no matter how many hours are being delivered.

The state doesn't account for all of the other expenditures being made for the same children. In addition to CTSS, children are also receiving drug therapy, speech therapy, occupational therapy, psychotherapy, social work, foster care, day care, special transportation, in-home care, medical care, nutritional services, special education services, hospitalization, and psychiatric care. The data presented by the state doesn't even include these costs, but a child who accesses these services easily costs over $50,000 per year.

The state doesn't ensure timely access to the most cost-effective early intervention.

The state doesn't cover the increased hourly cost of transitioning the children to less expensive services.

The state's intensive services for rural and disadvantaged families are almost non-existent.

The state doesn't ensure that specialized Board Certified Behavior Analysts are available to deliver these services.

The state removes the incentive for private health insurance companies to cover the same treatment.

Without cost controls, intensive services are offered to children of any age or disability, regardless of the evidence base, and the treatment services are extended in some cases for many years beyond their utility.

Without cost controls, therapy programs that do not have evidence to support them are funded at equal levels with evidence-based programs.

What are the funding solutions for ABA for autism?

There are several mechanisms for establishing a Medicaid fund for ABA therapy. One is to fund it through a 1915(c) waiver, but such programs don't cover the most cost-effective timely early intervention (the current waiting list for habilitative services in Wisconsin is 14 months – delaying the treatment of the average child until they are already in school). The 1915(i) waiver or the EPSDT rehabilitation program ("Medical Assistance") is much more timely and customizable to the child's needs. A dedicated Medicaid autism program would also allow for coordination and management of benefits. The Medicaid program also covers public school-based therapy.

Or, the state's high-risk pool (MCHA) also covers behavior therapy for autism, but requires a six-month wait. The private health insurance policies can also step up share the cost of the behavior therapy.

Without these programs, the family can (and does) pay out of their own pocket.

When these programs don't and the family can't, the cost of the child's behavioral treatment falls to the rest of society. In childhood, most of the costs go to special education, where school district spending for a student with autism is three times the cost of a regular student.

Regardless of the funding source, everyone wants a system of cost-effective management of autism services. But a system of micro-managing the service delivery is not cost-effective. This approach increases bureaucratic costs for both the state and the providers. And all we accomplish then is to produce well-organized files while each child's treatment becomes less effective.

For example, the state spends a great deal on the authorization process – paying professionals to read requests for authorization of coverage for children they have never met. But in fact, they can't realistically afford to take the time to understand the individual needs of thousands of children every six months. So they end up wasting taxpayer money on a sham process, and possibly taking on liability for bad decisions.

Systems of value-based cost management can be much more cost-effective. The use of regulatory resources is most cost-effective when incorporating measures of quality and outcomes, as well as quantity. In the past, traditional psychotherapies haven't produced the kind of objective data that is needed to make these systems work, so the potential has been ignored. But ABA for once gives government and health plans the chance to make money-saving decisions, because it produces objective data.

Instead of micro-managing the process, let's manage the outcomes.

This focus mirrors concepts proposed by the Mayo Clinic and the Minnesota Department of Health's value-based initiative.

Medical necessity should be based upon the evidence and the community standard of care. However, when it comes to evidence, most policy makers have only relied upon one level of evidence. But actually, there are five important levels of evidence-based decision-making that result in the most helpful allocation of resources to all children:

1) Scientific Actuarial Research on Average Costs and Outcomes
   The first level is the obvious one that most policy makers are aware of: the research on evidence-based treatment – children should receive the kind and level of treatment that has been proven to be most effective in meeting clinical needs. This evaluation must be ongoing, as new research indicates innovative approaches.

   At this level, it is necessary to adopt research methods that are logically suited to the specificity of the population. Because the diagnosis of autism is so heterogeneous, the best understanding of potential outcomes is from within-subject designs and registries. Guidance for the optimal time limit for the length of therapy can also be identified.

2) Process Research on Service-Delivery Effectiveness and Accessibility
   But, the second level is to determine the best service-delivery method for each treatment. Some methods of delivery will be much more effective than will others. Some will be much less costly than others. Some will entail much less risk than others. And some will be much more accessible than other. Some methods will enable flexible transitions along the continuum of services and some will prevent transitions. For example, will the system enable or interfere with coordination with the school districts, as the child is transitioned into their services.

   But at this level an important principle, "payment reform," is also investigated. Some models of payment create disincentives for cost-effectiveness. For example, in EIBI, if payment is only made for the direct hours of one-to-one behavior therapy, and not for the behavior assessment, behavior analysis, and clinical supervision, then there is a disincentive to phase out intensity as the child responds. There is also a disincentive to provide low-intensity parent training to less affected children. The reimbursement model may also not accommodate long-distance services in rural areas. Or it may not allow for high-risk services for the dangerous children who become the highest cost children in the future.

   Service delivery research also looks at accessibility in terms of the timeliness of treatment access, the continuity of care and the number of providers available for treatment. Are there enough providers recruited and retained in order to deliver care to those who need it? Does the system enable enough clinical supervision to ensure the necessary consistency of treatment in the face of turnover or other environmental challenges?

3) Value-Based Assessment and Certification of Individual Provider Agencies
   However, the third level of care determination is based upon a frank realization that some provider agencies are better suited to success with certain forms of treatment than others. And

some have frankly abused the system. Therefore this level of care determination is to identify the most cost-effective provider organizations that are delivering each type of treatment.

For this purpose, it is necessary to establish standards for clearly defined providers with appropriate credentials doing clearly defined therapy.

But the service standards are not enough. The primary goal of this form of evidence is to identify the important outcome measures that can be readily evaluated across providers and then used to develop cost-effectiveness comparisons.

4) Prescriptive Assessment of Individual Children at Intake
A fourth level is to identify the optimal form of treatment, intensity, and service delivery for each individual child at intake – to prescribe this optimal treatment based upon individual measures of prognosis, such as parental involvement, age, and complicating conditions.

For this level it is necessary to require a clearly defined treatment population, and require careful documentation of each child's need and evaluation of benefits, within that population.

5) Prescriptive Assessment of Individual Children's Responsiveness to Treatment
But the maximum value is not received until the fifth level in which care-determination is based upon each individual child's responsiveness to treatment.

For this level, each child should be periodically re-assessed and referred to the optimal treatment as they show individualized patterns of response to treatment, just as every other form of medicine does. Each child will not respond the same way, and present technology does not accurately predict treatment outcomes three years hence. In our ongoing research we have found that a dynamic assessment of a child's response to treatment over time is a much better predictor than is a single static assessment at a single point in time. Therefore, in the case of early intensive home-based intervention, we have found that every six months is a cost-effective time frame for re-evaluating responsiveness to treatment and making differential referrals based upon these assessments.

How would this work to improve cost effectiveness?

To use an example, in one of the original long-term outcome studies, 16 children had been placed into state hospitals, with no hope of recovery from their symptoms, and no hope of acquiring basic language and play skills. To everyone's amazement, the children did make clinically significant progress. But what is less well known is that the study was the first of its kind to identify prognostic indicators of response to treatment. Essentially, the researchers were able to identify a matrix of response to treatment. The study compared older and younger children, in interaction with children who had high parental involvement and low parental involvement. The children who responded best were the younger children, who also had high parental involvement. Such children were then the best candidates for home-based treatment with the plain intention of training the parents to be the children's own therapists.

The other children who did not benefit from parent training were not to be "thrown away," as they had already been by society, but instead they were to be referred to other valuable treatment modalities such as center-based treatment, with other services such as medical management, respite, and social groups.

A further matrix took into account that each child could not be predicted to respond based only on the intake measures. Instead, the child's responsiveness to treatment after each six months formed the basis for further service decisions as they progressed. Some children completed treatment in 18 months, and others in three years. Some were referred to center-based care and others to normal school classrooms.

Subsequent research proved the value of that approach, and found more accurate measures of responsiveness to treatment. When replications of the approach were published in 2005, 2006, and 2007, it became clear that we could maximize the value of our limited health care dollars by focusing on real outcome measures and determining the best services for each child.

You hear that the cost can average $100,000 in its most intense year. That is true. But what you don't hear is that the state reports that the average cost of ABA, across both high and low needs, is $35,591 per year. When that is accounted across all children in the state, the cost is $8 per year.

In contrast, the Harvard study estimated the lifetime cost of an untreated child at $3.2 million. ABA reduces these costs in half. But, for the sake of argument, even if ABA only saved 10% of these costs, ABA would still save Minnesota $137.6 million *just for the 430 children being served today*.

Today, the present cost-containment system would incorporate these concepts to determine the best treatment options for each child, and make the best possible referrals, based upon their prognostic indicators. Each child will receive their optimal treatment, and society's resources will be best conserved, if each child can benefit from the earliest possible care determinations. But it is much more than a single decision. What we have learned in this dynamic, 35-year process of treatment development is that there is an ongoing process of behavior assessment, analysis, and clinical decision making that results in the best use of scarce resources.

I and the other ABA providers are eager and willing to consult on the development of detailed outcome measures to be used to implement the above procedures.

Thank you for your attention.

Yours,

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Additional resources may be found at:
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Comments on Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal

Thank you for the opportunity to comment on Minnesota's vision for a more flexible, accountable, and responsive Medicaid program. Courage Center strongly supports the philosophical framework that has guided the formation of these proposals. As Minnesota's largest independent, nonprofit rehabilitation and resource center, we recognize the need for dramatic – and rapid – changes that are needed to better support Minnesotans of all ages with disabilities and complex medical conditions.

Fiscal Analysis Needed

We recognize the complexity involved in determining the budgetary impact of so many (simultaneously) moving parts. However, we hope that significant time and resources can and will be devoted to determining how the proposed changes will impact expenditures between and among support programs as well as the cost-shifting that occurs both within *and* outside services provided by the Department of Human Services. While we do not yet have integrated funding across the health continuum at the individual or even program level for those with disabilities under the age of 65, we do have expenditure and encounter data that allows for this analysis. The Hennepin Health initiative (outlined on p. 20) allows for this analysis on a smaller scale. Said differently:

"It is important to find ways to make a component part of the system more effective and efficient, but it is equally important to understand how that component fits into the larger system and how actions there have consequences elsewhere. A health care reform strategy that saves money in one sector may actually produce a higher cost in another sector."

This citation comes from a key recommendation of the Bridging the Health Continuum working group report to the Health Care Access Commission in November 2007 (http://www.commissions.leg.state.mn.us/lchca/Bridging%20the%20Health%20Care%20Continuum.pdf). All of the principles contained in this report are reflected in the current proposal:

- keep the client and family at the center of the system;
- Integrate and coordinate services under a single, client-centered plan;

- eliminate gaps in services and make it is easy for clients to make smooth transitions between programs, services and providers; and
- do more upstream prevention to prevent problems from developing or getting worse.

But unless we can accurately assess and evaluate the impact of these proposals, (both financial and human) how will we define success or failure?

Alternative Health Delivery and Purchasing Strategies

A number of exciting and creative changes are occurring to achieve both cost savings and improved health outcomes for the most complex and hard to serve enrollees in the Medicaid program. Thank you for consolidating them in one place.

More incentives are needed for disability service providers – particularly community-based providers who are not associated or affiliated with large, integrated health systems – to continue to serve individuals with disabilities. This is especially true for those with multiple chronic conditions and the dually eligible population. How can we better measure and financially reward the successful outcomes achieved by these organizations when savings accrue to other parts of the health system?

Understanding the patient experience within each of these strategies is just as important as the health and financial outcomes. All three prongs of this "triple aim" should be given equal weight in future policy decisions.

Accountable Care Demonstration(s)

Courage Center has provided extensive comments to DHS on the challenges and opportunities presented by provider-based delivery and financing reform, specifically to the Health Care Delivery Systems (HCDS) demonstration now underway (http://www.dhs.state.mn.us/main/idcplg?IdcService=GET_FILE&RevisionSelectionMethod=LatestReleased&Rendition=Primary&allowInterrupt=1&noSaveAs=1&dDocName=dhs16_161402). It will be important to understand how DHS will implement the freedom of choice waiver requested on p. 20, and how it relates to the plan to "encourage the utilization of cost-effective care" in 2014.

Robust consumer protections exist in law and within the managed care contracts held by DHS. While we have limited outcomes data on the individual Medicaid managed care products offered by the health plans, we do have processes and procedures in place to ensure health and safety, access to care, and appeal rights, among other protections. As we expand the menu of provider-based delivery options, the same attention to detail must be considered for these emerging systems of care, especially as we look to a future where providers will be assuming higher levels of financial risk.

We must also ensure that these emerging care systems have the competency and capacity to serve complex populations. While traditional disease management programs address large, high-incidence conditions like asthma, diabetes, and congestive heart failure, there are virtually no evidence-based protocols and defined clinical pathways for the most complex individuals within our health system. To date, DHS has excluded this population from alternatives to fee-for-service – with the Special Needs Basic Care (SNBC) being the notable exception. This must change. We must also foster increased integration of acute-and long-term care services.

The Governor's Health Reform Task Force, and especially the Care Integration and Payment Reform Work Group, are thoughtfully addressing how we can accelerate the movement away from fee-for-service financing, while avoiding the pitfalls of both cherry-picking and adverse selection (http://mn.gov/health-reform/images/WG-CIPR-2012-7-11-Recommendations%20DRAFT.pdf). It is clear from the content of this proposal that an increasing number of conversations across sections and divisions within DHS are occurring. This must continue as the lines continue to blur between medical and non-medical services in our program design and financing.

We must find meaningful ways for the non-medical support service system that people with disabilities rely on to obtain and maintain their health and independence to be measured and valued by the medical service system – as well as financially compensated for the savings that these long-term services and supports generate for other parts of the health care system. Short of full capitation combining medical and long-term care services, we must continue to seek linkages, either contractual or through statute, that increase the collaboration between the medical and non-medical supports this complex population needs.

Dual Eligibles Initiative

Minnesota has long struggled to effectively finance the care of non-elderly duals within the Medicaid program. The failures of risk adjustment and a legitimate evaluation of the Minnesota Disability Health Options (MnDHO) program are well documented. Minnesota also continues to be challenged by the inadequacies of Medicare financing, which threatens the viability of the current SNBC products for the non-elderly disabled, as well as future attempts to participate in Medicare gain sharing opportunities short of full capitation.

There is currently no forum or working group within DHS for interested stakeholders within and outside DHS to have a meaningful or substantive discussion about the *holistic* needs of this complex population. There are working groups that address acute needs, or continuing care needs, but not both. While information sharing occurs to cross these lines, no forums exist to create integrated solutions that span the continuum of care. This is also true for quality and measurement efforts. While we now have a State Quality Council, it only addresses home and community-based services. There is an evaluation group that was established to look at SNBC plans and products, but it has only met once. Subsequent meetings have all been cancelled.

The modest goals of the current duals demonstration regarding the Financial Alignment Demonstration (FAD) have since been abandoned. While there is certainly a benefit to including CMS and Medicare in the contract arrangements DHS holds with health plans, and better integration of mental health services in both the senior and non-elderly disabled populations is laudable, much more aggressive reforms are being pursued elsewhere. Whether in a health plan context or in a provider-based system assuming some level of risk, we must continue to make progress to address new, integrated financing models to benefit the most complex subpopulation in the Medicaid system – and the providers who serve them. Again, the applicable recommendations coming from the Governor's Health Reform Task Force should be seriously considered

Increased Service and Care Coordination Options

Many individuals in the Medicaid system today have no access to care coordination, case management, or comprehensive care planning due to income or categorical eligibility restrictions. It is exciting to see this as a clear need that is being addressed, especially for those without access to waivered services.

A significant number of services exist today in multiple areas of the Medicaid program to assist individuals with their care planning and management of benefits and services. Many more are proposed as a part of this proposal. Some of these existing services have clear statutory definitions and established criteria regarding who can perform the service. In other cases this is not true.

While we understand the desire to allow for multiple and flexible services coordination options, and experimentation to learn what methods work best for defined populations, we strongly encourage DHS to examine the expanding body of medical literature regarding the common elements of care and service coordination that are proving to be effective. Increasingly, the data is pointing toward *complexity of conditions* (or the number of co-occurring chronic conditions) rather than a single *diagnosis* or disability type to determine what approach works best. We also should consider defining these key elements of service or care coordination regardless of purchasing strategy. We should not have one standard for fee-for-service, another for provider-based ACO-type delivery models, and yet another for health-plan based managed care products. Similarly, clear and easily understood regulations, crafted with stakeholder involvement, should define who is eligible to deliver the services. How we pay for the service(s), and how and why we will pay differently for different coordination options, also needs to be addressed.

Finally, all of these services should be able to be simply explained to the Medicaid enrollees (and/or those who are supporting them in the community) who need to make an informed choice regarding their service coordination options. Who can support me? What services will they coordinate? What information is available to me to help with this decision? How do I know who's good at this and who isn't? All of these questions should be anticipated and answered upon implementation.

Transforming PCA Services to CFSS

We are strongly support the transition from personal care assistance (PCA) to Community First Services and Supports (CFSS) using the 1915k Community First Choice federal authority.

We support the Department's waiver request to use Minnesota's special eligibility rules that apply to our home and community-based waivers for those who meet the level of care of an institution but would remain in the community and receive CFSS services. We strongly support the proposal to use both the 1915k option and 1915i option in order to continue serving people who do not meet Minnesota's institutional level of care criteria. With Minnesota's pending request to change the definition of nursing facility level of care, it is important to make this service available to those who have substantial impairments in functioning which jeopardize their ability to live independently in the community, but may not meet the more stringent criteria in the LOC that is proposed for the CADI and BI waivers.

We support the inclusion of service coordination for CFSS recipients that is currently unavailable for PCA services. This will allow for an assessment of needs and connection with appropriate services that may be able to treat or alleviate the functional impairment or prevent further deterioration of functional ability, reducing a need for services in the long run. It will also help recipients use their flexible dollars wisely. We have seen clients who are currently receiving PCA but with no case manager/service coordinator struggle to access services in our complex systems. At the same time we urge DHS to provide a better definition of the service coordination that will be provided and a plan for how service coordination will take place if an individual is eligible for service coordination under more than one service category, e.g. behavioral health and home care. (See also other comments on case management/care coordination/service coordination.)

We urge that the definition of dependency in Minnesota's PCA program be changed to include persons who need **prompting and cuing** to accomplish activities of daily living and health-related tasks as the program used to permit. Currently, individuals with brain injuries or mental illnesses have great needs but are not served under the current PCA program, or are served inadequately. The nature of their disabilities creates substantial functional impairments that are addressed with frequent and repeated prompting and cuing to accomplish essential tasks to remain independent in their homes. They do not meet the criteria of needing constant cueing and supervision or hands on physical assistance. We believe the current PCA eligibility criteria are discriminatory because the service is not being offered without regard to the type of disability as required by 1915k. With this more inclusive assessment of needs, clients who have extensive needs for cueing and prompting will receive the amount of services they need to remain in their own homes, rather than moving to more institutional or supported settings. The current practice of allotting the minimum 30 minutes per day for clients who do not meet the stricter criteria regarding ADL's are inadequate and simply increasing that to 90 minutes per day does not address needs on an individualized basis.

We are in strong support of the self-directed option under CFSS with an individualized budget. We urge that the budget administrative cost be carefully determined with input of stakeholders so as to provide the maximum amount to the eligible individual for services.

We strongly support the option of CFSS funding assistive technology and home modification in place of human assistance. Currently individuals with these types of needs must go on a waiver to access that funding, even though this is the only need they may have. This would eliminate the unnecessary administrative burden to access the needed funding and realize cost savings with a reduced need for human assistance.
We urge DHS to work with stakeholders to gain a better understanding of how skill acquisition services differ in scope and provider skill level in comparison to hand-on, “doing for” an individual. Assisting someone to gain a skill has a higher level of complexity and staff skill level, with implications for provider standards and training requirements with increased provider costs associated with them.

Supporting Individuals with Mental Illness who are at Risk for Institutionalization Without Access to Integrated Community-Based Systems of Care

Currently, Minnesota Medical Assistance has a psychiatric rehabilitation service, called ARMHS, which has demonstrated effectiveness in reducing the risk hospitalization and institutionalization for individuals with mental illness. However the reimbursement rates for this service are not sustainable to meet the needs of the population. Rates have not been increased since 2008, while costs for providers have increased. Providers have stopped providing the service and other providers have long wait lists due to a reluctance to grow their services with the low reimbursement rates. Courage Center receives some philanthropic support which supplements the service, but does not cover the full cost. Relying on philanthropic support does not ensure a robust system of supports that are needed to further reduce the risks of more costly institutional care.

We thank you for your thoughtful consideration of these comments, and look forward to working with you as we move from the conceptual to operational stage.

John Tschida, vice president, public affairs & research
Cindy Guddal, director, community-based services

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

Thank you for the opportunity to review and provide comments on the *Reform 2020 Pathways to Independence, Section 1115 Waiver proposal* draft document. We applaud the department for the wide-reaching scope of initiatives and cross-departmental efforts that have gone into the proposed reform of Minnesota's Medical Assistance program.

These comments are submitted on behalf of Medica Health Plan State Public Programs department. Through five different programs administered by Medica's State Public Program department, we meet the health care needs of close to 140,000 Minnesotans. It is our mission to make health care affordable, accessible and a means by which our members improve their health.

Medica Health Plan has a long history of partnership with the Department of Human Services (DHS) and is particularly proud to be one of the three health plans DHS partnered with to develop the Minnesota Senior Health Options (MSHO) program. In 1995, MN was the first state to receive approval from the Health Care Financing Administration to demonstrate integration of Medicaid and Medicare in order to better serve dually eligible seniors. Since then, MN has continued to be a pioneer of innovative integration to meet the needs of dual eligibles.

The federal government, along with many state governments, has expressed interest in new service delivery approaches that address not only medical needs, but also social needs, often times through partnership of community agencies with medical providers. Medica takes pride in the fact that our State Public Programs focus very much on social service needs despite the stereotype that health plans function solely though a medical model. It is noteworthy that we partner with 27 counties to provide care coordination through county social service and/or public health departments in addition to contracting with 14 community agencies and 10 care systems to provide care coordination.

One of the reasons Medica has invested in a multi-disciplinary team approach to care coordination is that we are responsible for managing the Elderly Waiver (EW) benefits for our senior programs in addition to health care services creating an integrated system of services and supports for our members. Health Plans' ability to manage these services is a concern held by many states looking to integrate care of dual eligible's and was a sentiment voiced in the July 11th Medicare Payment Advisory Commission's (Medpac) letter regarding CMS's state demonstrations for programs serving dual eligible's[1].

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1 Medpac 2011. Letter to Centers for Medicare and Medicaid Services regarding CMS's demonstrations with states on integrated care programs for dual-eligible beneficiaries (July).

This is not a concern in MN as currently 97% of EW benefits are managed by health plans which historically having been able to manage EW benefits in a more cost-effective manner when compared to EW benefit recipients who receive their services in the fee-for-service system[2].

One of Medica's concerns is that several different pieces of the proposal threaten to fragment our existing MSHO care model, such as case management reform and the implementation of direct provider contracting approach to managing care for dual eligibles. Research supports the need for the integration of Medicare, Medicaid state plan funding and EW services to provide a financial base that allows for care coordination across the continuum[3]. It is the alignment of coordination efforts across primary care, acute care, home and community-based services, and nursing homes, with limited carve-outs that have resulted in MSHO's success.

Medica's involvement in the Preferred Integration Network (PIN) Demonstration is further testament to how Medica is committed to addressing needs above and beyond those identified in a medical model. The PIN is an integrated approach to the delivery of physical and mental health care for adults and children with mental illness or emotional disturbance while assuring coordination with needed social service supports. This demonstration has been successful as it created partnerships between Medica Health Plan, Dakota County Social Service and Medica Behavioral Health to meet the diverse needs of the specific population. We are pleased to know that the success of this demonstration has resulted in the state exploring larger-scale program development based on this model.

We appreciate DHS's ongoing efforts to evolve in the hope of MN continuing to be ranked the #1 state for long-term services and supports [4] in addition to generally being known as a state that is innovative with health care. It is our opinion that the department's partnership with MN's non-for profit health plans is largely responsible for this success.

However, we do have concern of the department compromising some of the success we have had by pursuing initiatives that impact programs that *are* working well. We ask that DHS take careful stock of what is working well and then focus efforts to change what is *not* working well for all stakeholders including recipients.

Below you will find specific comments we have about the *Reform 2020 Pathways to Independence, Section 1115 Waiver proposal* categorized by Medica's concern and specifics of the proposal that we commend the department for pursuing and of which we are clearly in support.

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[2] Sept., 2011 A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers. www.longtermscorecard.org

[3] Malone, Morishita, Paone & Schraeder (2004) Minnesota *Senior Health Options Care Coordination Study.* Final report submitted to the Minnesota Department of Human Services (June).

[4] DHS 2011. Minnesota Department of Human Services. *Elderly Waiver Fact Sheet (DHS-5357), Dec. 2011.*

Medica Health Plan Supports:

- DHS's interest in pursuing the Duals Demonstration. Minnesota has been a national leader in efforts towards seamless delivery of care for dual eligible seniors. Medica supports ongoing efforts towards program development for seniors and dually eligible persons with disabilities

- DHS's interest in improving state efforts towards protection of vulnerable adults and DHS's plan, which includes consolidation of the common entry point system and increased training for community-based professionals that interface with vulnerable adults.

- Future planning towards earlier diagnosis of dementia and development of an integrated health and community service model via an Alzheimer's Health Care Home Demonstration. This is an opportune time to invest in program development to meet the needs of Minnesotans suffering with Alzheimer's disease given our demography and pervasiveness of the disease. This initiative dovetails nicely with initiatives described in the Health and Human Service's National Alzheimer's Project Act released this year.

- Medica Health Plan shares DHS's interest in pursuing evidence-based health promotion as making health care a means by which Medica members improve their health is part of our corporate mission. As a health plan, we have much experience in this area and welcome future opportunities towards collaboration to this end.

- The creation of the Community First Services and Supports (CFSS) Implementation Council. Replacing the existing Personal Care Assistance program with a new program in 17 months is a big undertaking that has the potential to greatly impact many Medica State Public Program Members. We support thoughtful implementation and request the opportunity to be part of this council.

Medica Health Plan Concerns:

- Concern that there is not more focus on further development of the MCO model in the proposal or recognition of the years of innovation that health plan have partnered with DHS to achieve. It is unclear how many of the initiatives listed will impact managed care's role in state public programs.

- The absence of budget/financing information for the proposal is concerning and prevents stakeholders from being able to provide adequate feedback related to fiscal success or caution of failure for proposed changes.

- Concern of DHS requesting a waiver from freedom of choice of providers for future ACO-like developed models. Health plans have been able to demonstrate effective coordination of care while maintaining freedom of choice. Concern of violating program participant's right to choose and DHS moving away from as person-centered delivery system towards a provider-centered delivery system.

- The stratification of populations that will be eligible for the Community First Services and Supports (CFSS), that will be created similar to 1915 (i), 1915(k) and 1915 (j) options is very confusing. A consistent criticism of MN's MA program is the complexity which leads to inequitable and inconsistent services being authorized. It is hard to see how the proposed changes are more simplistic than what we have now. Would it make better sense to transition populations into the new service category instead of overhauling everything at the same time?

- Concern about plan to *"Take case management out of waiver services and creating targeted case management"* as this has implications to health plans managing EW and our Medicare Advantage Special Needs Plan requirements. Since 93% of all EW participants are managed by health plans, we request that DHS collaborate with MCOs on planning for this including having representation at workgroups addressing this topic and consider not including EW in this initiative if pursued.

Again, Medica Health Plan thanks you for this opportunity to provide comments to this important proposal.

Sincerely,

Julie C. Faulhaber
Senior Director, State Public Programs

Comment on DHS Reform 2020

Thank you for the opportunity to comment on this important reform effort.

Lifeworks applauds the Department of Human Services for the work that has done on the Reform 2020 plan, creating a system to promote better outcomes, self direction, and the sustainability of services for people with disabilities and individuals with support needs.

Minnesota has a long history of promoting person-centered services, and it is our hope that the voices of both individuals with disabilities and individuals with support needs are heard as you design and implement the changes proposed in the reform plan.

A key component of the person-centered philosophy is choice. There are several aspects of the reform plan that have the potential to limit choice. Changing from the current FSE model to the FME model is one of the areas of concern. We support this reform limiting providers who can meet certain qualifications. We feel not only quality of services to the individuals are important, but also providers who can follow through on the regulatory policies and procedures of programs. However, on page 39 it states "allow individuals a choice between at least two entities regardless of where they live in the state". Two is not enough to provide choice, if one does not work for the individual, they will then only have one to choose from – one is not a choice. Currently Minnesota has 15 FSEs, many who have developed sophisticated systems for this service and have developed relationships with individuals and families. If current providers are able to meet the new requirements to be a FME they should be allowed to do so. In addition with the RFP process for the FME agencies, previous contractors of the State that would have undue influence on the process should be excluded.

Individuals should also be allowed choice when it comes to support coordinators. Throughout the reform proposal, we support the comments made regarding a need for less complexity and simplified coordination of services which allows individuals to receive efficient and quality services. Although many things are mentioned in a very broad view, we want to voice support over allowing providers to provide a variety of services for individuals, if elected. As a provider, we feel it is important for competition in the market which drives providers to provide innovative and quality services. It forces providers to constantly raise the status quo. We would like to ask the state to not limit choice. For example, currently there is a limitation that a provider cannot provide support planning services and fiscal support services to the same individual. We understand how this can be viewed as a financial conflict; however, it can also be viewed as better quality and coordination of services and does reduce the costs of administrative fees. Previous to this limitation, we provided a level of support planning / coordination as part of our flat fees for fiscal services. Of course, an individual could always elect to keep planning and fiscal services separate, but limiting this choice adds a level of complexity for the individual and increased cost.

To ensure sustainability of services, please design the services so that individuals are able to share services if they chose. For example, if one individual is on CDCS and another is on CFSS, they should have the choice to share staff and split the cost, allowing them to stretch their dollars. This is currently allowed in the PCA program with shared care rates, but other self directed programs are individual services and do not have provisions for shared services. Individuals should be able to share services within the same program and across programs.

With the outcomes that are promoted in the reform plan, there is a need for accessible transportation. For many individuals transportation is the barrier to employment and a meaningful role in the community. Transportation needs to be part of each service.

It is great to see the work on the common service menu as a part of the reform plan. Minnesota has been working on this for many years and it is needed. We have a very complicated system where depending on what funding source the individual has, they may or may not have access to a needed service. Also there are similar services in the different waivers with different provider requirements which adds to the complexity of the system. Often, when you have complexity you have increased costs. Some examples of services that should be streamlined and expanded to other disabilities are:

ILS Therapies – this is currently only a service for the BI waiver. Music therapy is a service that can be purchased with ILS therapies and can be a valuable service for individuals with learning needs, behavioral support needs, and autism. This service should be expanded to the other waivers.

Day Services (DTH, Adult Day, etc.) – currently individuals on the CADI and BI waiver are not able to purchase DTH service and either need to purchase pre-vocational even though they may not be able to work or the provider needs to be licensed as an Adult Day provider. There are many similarities between DTH and Adult Day, an individual should be able to purchase this service regardless of their funding and the service should not add unnecessary complexity for providers.

Personal supports – is currently an option for individuals on the DD waiver only, it should be expanded to the other waivers.

There is also a need for caregiver supports, especially respite. With more individuals living at home the need for respite has increased, especially for families of children with high medical needs or behavioral support needs. Camps and other options for respite need to be available.

Again, thank you for the opportunity to comment on this important and needed reform effort.

Lifeworks Services

July 16, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

RE: Comments on MA Reform 2020 – Section 1115 Waiver Proposal
Housing Stabilization Services

Dear Mr. Godfrey:

Thank you for allowing us the opportunity to offer comments in response to the Department of Human Services Medical Assistance (MA) Reform 2020 proposal, a Section 1115 waiver proposal to amend the State Medical Assistance Plan. Hearth Connection wishes to recognize DHS staff for their hard work in preparing this waiver proposal. Your DHS team members have been excellent in offering ample opportunity for public education and input and have shown a collaborative spirit in drafting this proposal. Hearth Connection wishes to offer its strong support for Section 6.2 on Housing Stabilization Services. Specifically, we wish to recognize the significant steps DHS is taking in the Reform 2020 Waiver Proposal to integrate health care services with community-based supportive housing to achieve positive outcomes in healthy recovery, improved health well-being and housing stability for persons experiencing homelessness.

I write on behalf of Hearth Connection, an innovative, data-driven nonprofit organization dedicated to ending long-term homelessness in Minnesota. As a statewide intermediary, Hearth Connection is the administrator for the Long-Term Homeless Supportive Services Fund in three regional service collaboratives. We support a network of 28 supportive housing programs in 34 Minnesota counties. Annually we serve over 1,300 individuals and distribute over $9 million in funding for intensive support services and rental assistance. Our outcomes include empowering participants to secure housing, stay housed successfully, and improve their health, income and functioning.

Hearth Connection is committed to data collection, analysis, research, and evidence-based programmatic practices. Hearth Connection’s past research, supported by the Robert Wood Johnson Foundation and The Saint Paul Foundation, helped establish supportive housing as a key component of our state’s systemic approach to ending long-term homelessness. Hearth Connection’s research findings documented the impact of supportive housing on housing stability, health and well-being for people with long histories of homelessness, as well as the positive effects of using scarce government resources more wisely. Our research documented and drove best practices among Minnesota nonprofit organizations serving households experiencing long-term homelessness.

General approach and background

Hearth Connection is interested in Medical Assistance for three primary reasons:

1. Under the Affordable Care Act, most homeless persons are Medicaid eligible based solely on their low income status;
2. Many homeless persons have complex physical and behavioral health conditions for which they seek care through frequent utilization of emergency medical care services (emergency rooms) and inpatient hospitalization at a significant cost to public resources; and
3. Capitalizing on Medical Assistance resources will be necessary to deliver adequate levels of supportive services to achieve housing stability and health recovery and to end long-term homelessness in Minnesota.

Supportive Housing (community-based affordable housing coupled with intensive support services) is an evidence-based intervention offering homeless participants access to housing and social services, including individualized goal planning and care coordination as well as enrollment in Medical Assistance and other public programs whenever possible. By combining intensive case management and housing with medical care and a primary care physician, program participants are able to achieve stability in their lives and accomplish goals related to mental, physical and chemical health as well as income and social connectedness.

Under Hearth Connection's service model, intensive case managers work with each participant to build trust and develop an individualized Community-Based Care Plan. Staff members have the professional skills to identify the participant's problems and needs as well as strengths and resources. Goals are determined by each participant. Plans include measurable goals so that participants and staff can assess progress. Care plans are updated a minimum of every six months and include crisis plans when necessary. Many plans begin with meeting immediate food, clothing, medical or shelter needs and progress to include health and wellness recovery goals.

The service model is predicated on community-based recovery; therefore, care plans take into account community-based resources that can support and foster participants' health recovery and social inclusion. Service teams are assembled so that primary providers and other community based supports work together to coordinate participant support.

Our service approach is designed specifically for people who have experienced long-term homelessness. Some essential components of this service approach include intensive case management services, harm reduction approaches, a housing first philosophy, and collaborative, mobile service teams.

Hearth Connection posits that integrating health care services and coordination with supportive housing in community-based settings will benefit Minnesota by enabling the state to better serve persons with disabilities and meet obligations under the Americans with Disabilities Act

(ADA) and the Olmstead decision. Evidence has shown that people served in the community helps to lower Medicaid costs and leads to more positive outcomes for participants.

Hearth Connection has some experience in accessing Medical Assistance resources to offer supportive services to homeless participants. Currently, Hearth Connection accesses MA-Targeted Case Management resources to cover some services delivered to participants residing in supportive housing. Medical Assistance (MA) plays a critical role in financing services and supports for many individuals needing permanent supportive housing (PSH). However, because of the complexity of the MA program, supportive housing providers and local and state government agencies are not always able to access these resources efficiently. Adding to the complexity, recent federal legislation and regulations continue to change the program. Further, Hearth Connection recognizes that even where Medicaid is used to pay for services in supportive housing, it remains just one piece in the patchwork of funding. Services in supportive housing are typically funded through an array of sources such as the State's Long-Term Homeless Supportive Services Fund, HUD's Supportive Housing Program, or local county contracts for behavioral health services. Most supportive housing providers recognize that MA funding only covers a minority fraction of the cost of delivering intensive supportive services to participants.

For the past few years, Hearth Connection and our allies in the supportive housing community have been exploring opportunities to better integrate health care services and health care systems with community-based supportive housing models. Part of this work is strengthening the nexus between MA and services needed in supportive housing. Safe and stable housing is a social determinant of health and health recovery. The research studies mentioned in the Waiver Proposal show improvement in well-being of people who are housed, along with a reduction in the use of expensive crisis emergency care and hospitals.

Hearth Connection's own research mirrors these findings. From 2000 to 2006, The Robert Wood Johnson Foundation funded an extensive study of Hearth Connection's service model, which combined service funding from the State of Minnesota with housing dollars from both federal (HUD) and state programs for people dealing with issues of long-term homelessness. The study specifically examined the impact of the supportive housing program on *participant outcomes and public costs*.

Of the 748 people in the Pilot, researchers looked at data for 518 participants, which included single adults, families and unaccompanied youth from both urban and rural areas of Minnesota. The comparison group consisted of 20,000 other Minnesotans who had indicators of homelessness in their data, 518 of which looked like the Pilot participants in their demographics and use of services. The cost study differed from previous studies in two respects. First, the breadth of services covered is larger than in many other studies. Similar studies have often tracked only a few services, such as emergency room visits and detox stays. In contrast, this study aggregated extensive data on state-funded medical and behavioral health care with criminal justice and child welfare data.

Through the collaborative effort of a third party researcher (National Center for Family Homelessness) and stakeholders at local, county and state levels, the Pilot study was released in March of 2009. Generally, the results suggested a desirable move away from costly, repetitive, and disruptive institutional services and towards necessary routine health care that improves quality of life.

Single Adults

- Use of routine outpatient mental health care and pharmaceuticals increased relative to the comparison group.
- Inpatient mental health care showed a decline, though the difference was not statically significant.
- Use and cost of emergency detox services were lower for Pilot participants.
- Prison costs for the comparison group increased while Pilot participants saw a marked decline in those costs.

Families

- Families saw decreases in use of inpatient medical care.
- Families did not experience the increase in the use of pharmaceuticals that the single adults utilized.
- The cost for outpatient mental health services increased for the Pilot families.

More extensive information on this Pilot study can be found on our website at www.hearthconnection.org.

Given what we know from research, our goal is to better align MA resources to cover a specific benefit set to offer housing stabilization services to persons experiencing homelessness (who are also disabled or experiencing chronic illnesses). Supportive housing providers have been meeting regularly with DHS staff to define these services.

COMMENTS

Hearth Connection's comments are directed to Section 6.2: the Housing Stability Services Demonstration. We appreciate the work DHS has completed in engaging and receiving input from the State's network of supportive housing programs to define this proposal. We look forward to continuing our work with DHS as the Section 1115 Waiver Proposal is refined, adopted and implemented. The following are our specific comments:

1. **Hearth Connection supports the current, modified proposal regarding Housing Stabilization Services.**

It is our understanding that based upon public comments already received by DHS, that Section 6.2 (Housing Stabilization Services) has been amended to include a larger array of supportive services that would be eligible for MA reimbursement. The array of services includes: outreach/in-reach, tenancy supports, service coordination, and community living assistance.

We especially appreciate the inclusion of community living assistance. It has been our experience that case managers for participants in supportive housing spend a considerable amount of time in bolstering independent living skills and assisting participants in health recovery and health care coordination. The average Hearth Connection supportive housing participant has over seven (7) years of continuous homelessness and either a mental health disability or chemical/alcohol addition. While tenancy support and service coordination is a portion of the activities accomplished between case managers and participants, many of participants require a great deal of assistance in improving their independent living skills and navigating interpersonal relationships. Recognizing and planning for services to improve the overall well-being of the individual not only improves our ability to achieve housing stability but leads to better health outcomes as well. Allowing case managers to deliver supportive services that improve individual functioning in a community-based setting not only assists with health recovery but can be accomplished at a lower cost to the State.

2. **Hearth Connection supports the current definition of eligible participants.**

We believe that, in general, the definition of Target Population (p. 61 ff.) is appropriate. The Proposal as originally drafted was only extended to persons receiving Group Residential Housing (Rate II) services. The original proposal did not address the needs of the broader homeless population. Persons experiencing long-term homelessness are often burdened by mental health or chemical/alcohol addiction and have difficulty navigating the Social Security Administration's eligibility process for income support. Many of the homeless participants found in outdoor encampments or emergency shelters are only receiving General Assistance. Limiting the population to those persons receiving GRH services would be too restrictive and miss some of the most vulnerable 'street-dependent' populations.

Since the Waiver Proposal has been out for comment, however, we understand that DHS has considered significant modification to this section. We support the modifications now under consideration to include persons who are homeless, receiving General Assistance and are frequent users of high-cost medical services. This modification puts the Waiver Proposal directly in sync with the purposes of supportive housing.

Also, Hearth Connection believes the inclusion of people now in supportive housing is especially important (these people will return to homelessness without services now being provided).

Hearth Connection's only hesitation is the proposal's restriction of population eligibility to adults (ages 18 and over). Hearth Connection serves all persons experiencing long-term homelessness including unaccompanied homeless youth. Under State law, unaccompanied homeless youth (minors) are eligible to receive MA. Minnesota's homeless youth population is one of the state's fastest growing homeless subpopulations with a minority of youth having histories of long-term homelessness. Homeless youth are particularly vulnerable to physical assault, trauma, and sexual exploitation in street environments and have disproportionate rates of morbidity, mental health disabilities, and chronic illnesses (including HIV) when compared to their housed peers. While we recognize the need to limit the population to contain costs, we would argue that the addition of eligible unaccompanied homeless youth (minors) would not significantly add to the demonstrations cost while it would make significant life-long positive changes for the youth served.

3. **Hearth Connection believes this proposal adequately addresses the State goal of being 'cost neutral.'**

Hearth Connection understands that any waiver proposal to the State's MA Plan must be cost neutral. DHS is aware that permanent supportive housing is a nationally recognized evidence-based model evincing positive outcomes in lowering unnecessary health care utilization and improved health outcomes for participants. Several studies have been conducted in the past two decades, including a multi-year evaluation pilot by Hearth Connection.

Supportive services delivered within community-based housing models have been proven to accomplish housing stability, improve individual functioning and reduce public costs – money now being spent for emergency and inpatient hospital care, jail, prison, shelter, detox and child welfare services. We wish to highlight the research noted on page 65 of the MA Reform 2020 Section 1115 Waiver Proposal in offering evidence of these assertions.

We understand the importance of maintaining cost neutrality in the overall Reform 2020 proposal. And we understand this proposal must either limit the population or the services available. We support the conclusion by DHS to limit the population and not the specific benefit set of services. Supportive Housing providers maintain that flexibility in designing and delivering services to participants will benefit this demonstration pilot in achieving lower costs and better outcomes.

Finally, we recognize that it is necessary to balance the rate structure with the number of households to be served in order to maintain cost neutrality. We strongly favor maintaining a rate structure that will allow providers to provide necessary services, even if it means reducing the number of Minnesotans who can be served under the Waiver. If rates decline to a point where providers cannot provide adequate services, people will not be able to maintain housing and the Waiver will be pointless.

4. **Hearth Connection suggests flexibility in completing functional assessments by trained 'certified screen administrators.**

Under the current proposal, eligibility for housing stabilization services would be determined by a functional assessment administered by a trained certified screen administrator. Hearth Connection understands the importance of having an objective screening tool and mechanism to determine eligibility. However, most disability/functional screening tools are designed to be delivered in a clinical setting (an office or clinic). Many of our participants sleep outside in encampments, in abandoned buildings or sometimes under bridges or in caves. Some homeless persons are distrustful of public systems and will not readily enter a clinic or office building.

Whatever mechanism or tool is developed, it should be flexible enough to be delivered in a variety of environments, including outdoor areas. Additionally, the trained certified screen administrators should include outreach workers and drop-in center case managers whose experience approaching and building trust with homeless persons will be critical to administering the assessment.

Hearth Connection does support the eventual integration of this functional assessment with the MNChoices Comprehensive Assessment tool if this tool can be delivered through hand held devises in a variety of settings by mobile teams.

Finally, we applaud the recognition that eligible service providers of housing stabilization services include “certified peer specialists.” (page 61)

5. **Hearth Connection suggests more opportunities for coordination and involvement with housing stabilization services by accountable care organizations or health plans.**

Given our work in the last few years to integrate health care systems with supportive housing, Hearth Connection has come to an appreciation of the role played by Minnesota’s Health Plans in coordinating services and incubating innovations to reduce costs. It is clear that the current proposal envisions a relationship between DHS and community-based nonprofit organizations offering supportive housing. What is not clear is how this demonstration will interface with accountable care organizations (ACO) or the Health Plans. Hearth Connection recognizes that Health Plans often enter into contractual agreements with community organizations to delivery case management services to persons experiencing mental health disabilities or chemical/alcohol addiction (including persons experiencing homelessness). Given their existing role in providing behavioral health services to homeless Minnesotans, we simply question whether the current proposal envisions the involvement or participant by Health Plans or ACOs.

Thank you again for granting us an opportunity to submit these comments. We remain enthusiastic about the proposal and appreciate the recognition that housing stabilization services are a key to better health outcomes and a potential state resources saver. We look forward to working with DHS to advance the goals of the MA Reform 2020 proposal.

Sincerely,

Richard A. Hooks Wayman

Richard A. Hooks Wayman
Executive Director, Hearth Connection

David Godfrey

Medicaid Director

Minnesota Department of Human Services

PO Box 64998

St. Paul, MN 55164

July 17, 2012

Dear Mr. Godfrey,

On behalf of Community Involvement Programs, I am submitting these comments on the draft of **Reforms 2020: Pathways to Independence**. Our organization has been providing community-based services since 1971. Because we support both people with developmental disabilities and people living with a serious mental illness, we believe we have a unique and broad perspective on Medicaid services in Minnesota. We appreciate the significant effort put forth by the Department in compiling and proposing a wide array of changes and improvements to the supports and services of the Medical Assistance program. We know first-hand that these services provide essential help to many of our most vulnerable citizens so that they can live meaningful and productive lives in their communities. And, while we support many of the proposals in the draft, we do have some serious concerns certain parts of the plan.

Community First Services and Supports (CFSS)

First, with respect to the proposals that will impact people with developmental disabilities, the proposal to reform Personal Care Assistance and CDCS to a new service, Community First Services and Supports (CFSS) is broad and will impact well over 20,000 people in Minnesota with disabilities. We applaud the effort to include persons who will no longer be eligible under the institutional level of care criteria.

While we are not a PCA provider, the proposal includes a plan to combine the current PCA program and the CDCS programs and to replace the FSE agencies under a new model called a Fiscal Management Entity (FME). I would be remiss not to disclose that Community Involvement Programs started as a Fiscal Intermediary - Employer of Record (FIER) and then transitioned to a Fiscal Support Entity (FSE). We currently support about 350 families and individuals as an FSE. We feel we have extensive experience and insight in working with the families and individuals who have participated in the CDCS program.

Included in the Reform 2020 proposal is the plan to take the current 15 FSE’s and hundreds of PCA providers and to administer the program through as few as two to four Fiscal Management Entities. However we question such a need to reduce the number of FME providers. We believe by reducing the number of FME’s to such a small number, access and choice for families and participants will be seriously restricted. The lack of competition would also force costs to rise in the long run. If the state plans to add over 20,000 individuals to the CFSS model, we believe the state and the people with disabilities and their families would be better served by having more FME’s, not fewer.

Behavioral and Mental Health Services

There are a number of initiatives included in the draft of the Reform 2020 that propose to address the services to people who are challenged with a mental illness. With respect to the services that are proposed for persons with a serious mental illness, we have a number of comments.

Access to Medicaid funding for this population is critical in the long run for a sustainable, robust set of services to support people in the community. The recent proposal to change the Level of Care Criteria will force many people with a mental illness out of the current array of Medicaid and Home and Community-based Waiver options. We believe it is imperative that the Department continue to explore options under the 1915(i) that will allow these services to be developed for these individuals.

We also have not seen the most recent version of the MnCHOICES assessment tool. We understand that it is currently being “beta tested” for reliability and validity. We also understand from NAMI that while there have been some improvements when it comes to assessing people with a mental illness, but there is still work to be done to assure that the tool is adequate to determine the needs and services that a person with a mental illness may require. We would urge the Department to open up that development process so that the mental health community can give recommendations on how the tool could be improved and to avoid previous problems of persons with a mental illness being incorrectly screened and assessed.

Housing Stability Services Demonstration

We support your proposal with respect to the Housing Stability Services. Community Involvement Programs has been a leader in providing supportive housing to adults with a mental illness for almost 20 years and have participated in the Housing First and Ending Long-Term Homelessness efforts in Hennepin County. We have found that supportive housing is a cost effective approach to assure that persons with a mental illness can remain in the community and avoid costly hospital stays.

Again, we appreciate the opportunity to comment on some of the proposals that have been put forth by the Department. We know that the staff at DHS has put a tremendous amount of time and resources to put this proposal together. We hope you will consider our feedback based on our years of experience and insight in these areas.

Sincerely,

John T. Everett

Executive Director

Dooley, Lea M (DHS)

From: Cara Benson <carabenson@cfcaccra.org>
Sent: Monday, July 16, 2012 5:11 PM
To: *DHS_Reform2020Comments
Subject: Comments from

To Whom It May Concern:

I am glad to see Minnesota move toward a more consumer directed model of service. There have been many groups that have worked on this type of service for many years. After attending several sessions on the 2020 Reform, I am specifically commenting & asking questions on the CFSS services.

1) Please clarify/expand on the "Agency Option" under CFSS. Does it look like Agency With Choice-as it exists under CDCS now?
2) Define "Self-Directed." Currently some states mandate certain ways of self-directing, which may not be a good fit for all recipients.
3) Minnesota has a history with CDCS that affords recipients the choice of 15 different CDCS providers. It has been proposed the 2-4 agencies will provide the FME services. I urge the Department to consider more than 4. This will give recipients more options based on technology, customer service, and ability to respond to needs/questions. It will offer more consumer choice!!
4) Can the FME also provide the Case Management function?
5) How does Managed Care fit into CFSS? Will MC recipients that have PCA now stay with the MCO and have their services through the FME or Agency, as they choose?
6) If the recipient chooses the "Agency" route, will the Agency have their own Service Authorization to bill off of?
7) Will the FME have the authority to approve the plan (as opposed to the County approving the plan?) If the recipient choose the Agency route, does the Agency have the authority to approve the plan?
8) Are there services outside the FME that the recipient can purchase? If so, what might those be?
9) Can the recipient on CFSS choose to purchase "Waivered" services such as: In-Home Family Support, Respite, Personal Support? Can this be purchased from any agency currently providing that service?
10) It seems like CFSS effects PCA Traditional, PCA Choice, CDCS, and CSG in that these recipients would go to the FME, unless they choose the agency option. Please indicate if that is correct.

Thank you in advance for your attention to this response. I look forward to seeing how Reform 2020 is implemented in the next several months and years.

Cara Benson | Program Director |**Voice:** (952) 935-3515 | **Fax:** (952) 935-7112
1011 1st Street South
Suite 315
Hopkins, MN 55343
www.cfcaccra.org

View your Utilization Report online by logging onto:
http://online.cfcaccra.org/Default.aspx

ACCRA CARE, INC
CONSUMER CHOICE, INC
ACCRA HOME HEALTH, INC
CHOICES FOR CHILDREN, INC
ACCRA HOME CARE, INC

ADDITIONAL LOCATIONS IN:

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910 Main Street #205
Red Wing, MN 55066
P:651-388-1010

Alexandria
1910 Aga Drive PO Box 481
Alexandria, MN 56308
P:320-762-5007

From:	Shelly Elkington <shelly@avenuesforcare.net>
Sent:	Monday, July 16, 2012 4:15 PM
To:	*DHS_Reform2020Comments
Subject:	Comments from
Attachments:	QUESTIONS REGARDING 1115.docx

Attached is questions for public comment regarding the 115 proposal and it's impact on the PCA program.

Thank you for the opportunity to comment and I appreciate being heard.
Please do not hesitate to call with any questions, comments or concerns.

--
Shelly Elkington
Avenues for Care, Inc.
101 So. 1st St. Suite 200
Montevideo, MN 56265
320-269-2929
320-269-2278 fax

QUESTIONS REGARDING 1115 AND THE IMPACT ON PCA AGENCIES:

What happens to recipients currently using PCA Choice and PCA Traditional as far as the transition? Will PCA agencies be informed of the letters being sent out. We are the point of contact for our clients; they will call here if given any information regarding the PCA program.

Who monitors "self-directed" program? Is there supervision still required? Who keeps the supervision documentation? Who is subject to audit for that documentation, the client? Who is responsible for fraud compliance and who pays back any dollars not spent in accordance with the program? We find that the more supervision, the less opportunity for fraud. Chippewa County has one client on CDCS now and neighboring county only has 5 recipients on CDCS. This is not a plan of choice for counties concerned with fraud.

Who does the assessment? PHN's? Since more persons with significant medical issues are going to access the program, and will non medical personnel assess for medical needs?

"Annual review of the budget" is stated in the proposal. Is this is only oversight of dollars and services? What happens when recipients use all of their funds and are left vulnerable or without services for the remainder of the year? This is why flex use was put into place to protect recipients from this.

"Direct and manage". Who determines if someone is capable of that? We will often get persons coming through as PCA Choice with are unfamiliar and unaware of those responsibilities, they often find that too daunting. This would be even more complex as far as management.

Since CDCS was already exempt from the relative rate cut, how does this work now when there will be a good percentage of relatives accessing money from this program? Won't more recipients move to this program and place the same financial burden on it as the PCA program? Wouldn't people who are attempting to commit fraud be eager to use this program as opposed to the current plan that has supervision and accountability?

What happens to PCA providers? Do PCA agencies become CFSS providers, and will there be plenty of time and information to go through that process? If they are eliminated, then who is the contact person for the assessor, and the recipient? Does eliminating most of the PCA agencies and having only a few handle all the PCA/CFSS simply create a very large profit for a few people? The potential for profit increases with volume of clients, this would put a large amount of money in some agencies, and can eliminate the choice for recipients who are happy with their agency and the attention they receive.

Page 38 of the proposal states: "The individual would have the option of handling administrative functions such as financial management of payroll taxes and insurance, or would have the option to choose to arrange for services". How can that work if they choose to try it? This is a complex system at times, and can be cumbersome to manage. Again, where does DHS come to when fraud is committed and they want fund recoupment? What happens if a client with good intentions tries to do financial management and fails to pay payroll taxes and they are subject to fines and liens by the government for non payment of taxes? Do they get a tax ID number? If they choose a financial management entity, who communicates with the client regarding timesheets, and payroll? Does this entity do case management as well? Who manages staffing issues, hiring process, required paperwork, insurance, background checks? Who has the liability for workers comp, bond, liability, and unemployment?

Will this cause a significant increase in workload to county case workers? Will they be doing “case management” and having to micro manage clients? That’s what PCA agencies do now. County case workers seem very short staffed and out of budget for what they currently have. What will the financial benefit be to the state in giving more dollars to counties for this? Currently case workers are given only minimum case management dollars on CDCS, families would have to “budget” for this and most do not.

What is the estimated number of recipients that could be affected by this and the number of PCA’s? What is the overall financial benefit (especially since there is no relative rate cut) given the rates, the potential for fraud, the supervision, increase admin staff to counties, reimbursement to financial support agency?

School social workers, school nurses and guidance counselors managing the cares of disabled children seems like more of a burden being put on already fiscally strapped schools. The proposal says this will require case management by these folks year round and they will coordinate all the community cares outside of the school. This is proposing that guidance counselors with no medical training are able to find resources in a community, determine the needs, and manage them? Isn’t that what a county case worker does? Are not they busy enough? Here, we have two school nurses for 4 schools, she does not spend the day in one building, she does not work the summer, and will the schools have to budget for this significant increase? How much financial responsibility would shift to the schools to do case management and oversee all the services?

Who manages the cares of clients with complex medical needs? This now requires RN supervision for good reason. These clients are medically very vulnerable and a trained person will know when to seek out additional resources.

Goals listed on page 37:

Maintain independence / Direct and manage own cares. The current PCA program currently allows for clients to remain at home much longer than they would without it. They are able to select their own PCA’s, work with the agency in training needs and care plan development. Our RN visits all recipients to assure that these recipients are not being taken advantage of and that the cares are being provided. The flexibility of the PCA program covers health needs, behavioral, and housekeeping. This is often a “one stop shop” for case workers whose clients need a variety of small services. This is a goal currently being met by the PCA program. Our recipients live very busy, complex lives when living with and managing the needs of a disabled person. Asking them to take on more responsibility and take away us as a direct resource will simply overwhelm many of them.

CFCO. Financially what is the savings to the state and is the purpose of revamping the entire program to access federal dollars? With the increase potential for fraud, are those costs being built into the costs?

Power point slide 11. If assessed by a PHN for services as they are currently, will all purchased services need to come from that one assessment? Currently, if they are assessed for 7 hours a day of PCA, they get 7 hours a day, but if they go on a waiver they are cut down to 2 or 3 so the case worker can fit in other services and supplies. Will this be the case now for everyone and if so, will recipients be informed of this beforehand?

I was unsure about the proposals reference to the diagnosis of Autism and being "medically necessary". I'm questioning whether the intent is to not serve anyone diagnosed with Autism. ADA would need to know this as soon as possible so other programs could be put in place for this.

The disabled and elderly always seem to be the experiment group for new programs and it can often come at their expense. Those that are most impacted by this significant change are Minnesota's most vulnerable citizens. Outstate Minnesota has limited resources, but this is one way we are keeping our citizens at home and out in the community by using the most cost efficient program that Minnesota offers. There has been a strong push by DHS to reduce fraud in the PCA program in the last couple of years, and it seems like the proposal does not address these on a significant level. I am urging decision makers to put much more thought into these proposed changes and address the concerns brought forward by agencies, case workers and school districts. A goal date of 2014 seems nearly impractical for revamping one of the largest programs used to keep the elderly and disabled independent and safe.

Shelly Elkington

From: Bessler Daryl <dbessler@co.hubbard.mn.us>
Sent: Monday, July 16, 2012 2:36 PM
To: *DHS_Reform2020Comments
Subject: Comments from

Mr. Godfrey:
Thank you for the opportunity to provide input regarding the Reform 2020, Section 1115 Waiver Proposal. I want to compliment the Department for the substantial effort that you have put forth in creating this proposal. The proposal is extremely expansive/ambitious in nature, possibly too much so, but is clearly attempting to address some of the gaps of current waivers.

Your focus on right service at the right time is spot on. The portion dealing with ASD is also very needed and timely. The idea of integrating or collaborating around the health care and education needs of these children is encouraging. The medical and educational communities need to be plowing the same direction not against one another.

Your proposal in section 9.1 to assist those with complex needs but aren't at risk of institutionalization is totally on track. Sometimes providing a little help on the front end can avoid more expensive solutions longer term.

In general this is a very good proposal and I commend you for the work the Department has put forth. While it is a very comprehensive and thoughtful proposal I'm a bit concerned how the Federal government and even State government can continue to spend more dollars when the Federal government for all intent and purposes, is bankrupt.

Daryl Bessler, Director
Hubbard County Social Services
301 Court Avenue
Park Rapids, Minnesota 56470
Phone: 218-732-2400
Fax: 218-732-3231
dbessler@co.hubbard.mn.us

To: Reform 2020, Pathways to Independence, Section 1115 waiver proposal committee

From: Minnesota State Council on Disability
Joan Willshire Executive Director

Date: June 21, 2012

Re: Comments on Reform 2020, Section 1115 waiver proposal

The Minnesota State Council on Disability (MSCOD) is a state agency statutorily mandated to advise the Governor, state legislature, state agencies and the public regarding disability issues. MSCOD would like to make comment on the Reform 2020, section 1115 waiver proposal.

We realize that sustainability of the Medicaid program has become a major concern and that this opportunity to make State level reforms creates an excellent window for promoting policies that encourage efficiency, effectiveness and inclusiveness. We support the guiding logic behind the waiver proposal that change is necessary and would like to emphasize on the following points.

In a major system overhaul such as this, it is not uncommon for the focus to shift from the intended recipients towards more systematic elements of policy creation/reform. We commend the committee's emphasis on individuals and their choices so far and urge that it continues to be a primary focus throughout this process. We know that this will be a challenge but it is what will make this whole reform a success for everyone.

We are very pleased with the changes in procedural support mechanisms and outcome expectations of the CFSS in comparison to that of the PCA. One of the complaints we hear in the disability community is the issue of PCA hours being reduced. The need for PCA hours will only increase as we all age. We applaud the CFSS's general flexibility and how it is tailored around individual choices/needs. Simplification of this system is long over due and is welcomed. Being able to employ and manage their own direct care is a huge step towards true independence. How this Implementation council works is vital and transparency will be needed for it to succeed. We want to again emphasize that through out this process to keep the person in mind at all times.

We are pleased that the reform policy emphasis on strengthening community support programs in the community. Establishing strong community support systems capable of accommodating the needs/preferences of individuals is a prerequisite to their transition from institutions into the community. We are glad to see that for those individuals that do not meet an institutional level of care will be able to still access those services under another option. Seeking innovative approaches to service coordination with select school districts is a great way to try to do something's differently while working within a current system. Having a single coordinated plan that works across systems, across all disabilities, and to be able to live in the community of your choice, will contribute to better outcomes for the individual with a disability.

Over all we see a plan here that is introducing prevention, elimination of duplication of services, creativity in service development, focuses on employment as a part of ones life's goal, creating housing stabilization is a must, strengthening community supports, which will finally put the person with a disability in the driver seat again to be in control. People will need lots of education and training as this new system unveils.

MSCOD sees the biggest challenge for this waiver proposal will be the communication of the various sections of this waiver. MSCOD has always been a partner with the dept. Human Services and would like to offer to assist in the accessible communication of information regarding the waiver proposal and further developments to the public.

Thank you for the opportunity to pass on our thoughts regarding the Section 1115 waiver proposal. If you have any questions please feel free to contact us with any questions.

Joan Willshire

Dooley, Lea M (DHS)

From: Ratzmann, Eric <Ratzmann@mncounties.org>
Sent: Friday, July 13, 2012 1:44 PM
To: *DHS_Reform2020Comments
Subject: Comments from

To whom it may concern:

Attached are copies of comment from the Minnesota Association of County Social Services Administrators (MACSSA) on the Department of Human Services Reform 2020 proposal. The comment letter is submitted in both Microsoft Word and Adobe PDF. Additionally, the unformatted text of the comment letter has been copied below. Please let me know if the submission requirements have not been met.

July 12, 2012
David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55164

Re: Reform 2020 Public Comment

On behalf of the Minnesota Association of County Social Service Administrators (MACSSA), thank you for the opportunity to comment on the Reform 2020 Section 1115 Waiver Proposal. MACSSA is an organization representing the directors of Minnesota's County Social Service Agencies, which have significant responsibility for administering Medicaid based programs in the state of Minnesota.

MACSSA supports the proposal's stated goal "to provide individuals with the right services, in the right way and at the right time," and "[to] ensure the sustainability of the system through efficiencies achieved." MACSSA agrees that reforms are needed to build a more sustainable system and to simplify administration in order to better manage increasingly complex programs. In general, MACSSA supports the overall policy direction contained in this proposal.

MACSSA understands that at this stage of the proposal there are still many details to work out regarding implementation of the various initiatives and demonstrations. Given that there is still much detail to be developed, it is difficult to speculate with much accuracy what the specific impacts will be on counties and the constituents we serve. As such, MACSSA will respectfully request that the Department of Human Services engage counties extensively and proportionately to our level of responsibility as these initiatives are further developed. As the state's partners and the governmental entities with responsibility for administering many of these programs at the local level, counties have a valuable (and necessary) perspective to provide and interests that are unique from other affected parties.

While MACSSA supports the expansion of services to individuals that the proposal contemplates, we have questions regarding the ability of the state to maintain cost neutrality not just to the state budget but also within the overall *system*. MACSSA is concerned about the potential of increased operational costs for counties that may result from this waiver proposal; however, without a more detailed explanation of how the financing will work and what county roles are contemplated we are unable to fully analyze this issue at this time.

Moreover, MACSSA has questions regarding the role of counties in the various initiatives. For example, the new Community First Services and Supports program contemplates expanded utilization of self-directed care (which counties generally support) without addressing who is responsible for providing education and oversight to clients choosing that option. It is unclear whether this will be a designated role for counties and/or other entities. Without further detail on what county roles are contemplated in this proposal, we are unable to provide more specific comments.

Lastly, we would like to briefly address two specific initiatives contained in the proposal. First, MACSSA would like to thank the Department of Human Services for including housing-related support services. MACSSA agrees that stable housing is a key component to improving health outcomes and reducing health-related expenditures. Second, MACSSA is concerned that there is a proposal being considered to centralize reporting for vulnerable adult maltreatment that has not received county input. Changing the intake/screening process without considering the assessment/investigation function counties provide has the potential to tear apart the safety net for vulnerable adults. Counties will need more information regarding the goals and operational details of this proposal prior to being able to comment.

Thank you again for the opportunity to provide comments on the Reform 2020 Section 115 Waiver Proposal. Counties look forward to engaging with the Department of Human Services to assist in the further development of these reforms.

Sincerely,

John Dinsmore
MACSSA President

Eric Ratzmann
MACSSA Director

Eric M. Ratzmann
Director
MN Association of County Social Service Administrators
125 Charles Avenue
St. Paul, MN 55103

(direct) 651-789-4340
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Website: www.mncounties2.org/macssa/

From: Frost, Stephanie L <Stephanie.L.Frost@HealthPartners.Com>
Sent: Tuesday, July 17, 2012 4:43 PM
To: *DHS_Reform2020Comments
Cc: Clelland, Jennifer J; Devore, Julie; Lasker, Denise P; Sayre, Katie B; Zimmerman, Donna J; Sauer, Robert V
Subject: Reform 2020 Comment letter

Mr. Godfrey,

Both below, in this email, and attached are our overall comment letter and our more detailed comments as an appendix. Thank you for your consideration of our comments.

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

HealthPartners appreciates the opportunity to review and respond to the “*Reform 2020 Pathways to Independence, Section 1115 Waiver Proposal”* draft document. HealthPartners is a longstanding partner with the Department of Human Services in improving the health of public programs enrollees across a range of different programs including Medical Assistance, Minnesota Care, Minnesota SeniorCare Plus and Minnesota Senior Health Options. We are a strong partner with the state both through competitive bidding in the seven county metropolitan area and on a bid basis in greater Minnesota. We are strongly committed patient health, committed to providing an exceptional experience in caring for those we serve, and focused on delivering top quality services with excellence and integrity. We currently serve over 82,700 state public programs enrollees with excellent quality results as demonstrated through our HEDIS scores year after year. We achieve this by being leaders in care innovation and integrated care delivery, by focusing on preventive care and through our interdisciplinary care teams. Our care delivery system was one of the early health care homes certified by the state. Our Triple Aim focus and the excellent results it achieves was just featured in a new Institutes for Healthcare Improvement’s book on care innovations: Pursuing the Triple Aim: Seven Innovators Show the Way to Better Care, Better Health, and Lower Costs.

The Triple Aim calls for accomplishment of three critical objectives at once:

- Improvement of the **health** of the population served;
- Improvement in the **experience** of each individual; and
- Improved **affordability** as measured by total cost of care.

We, therefore, appreciate the focus in the waiver proposal on providing the right care at the right time in the right place. We are committed to the Triple Aim in all we do – it is infused in every aspect of our organization.

The proposals in the waiver draft reach far and deep into a broad range of programs – some of which HealthPartners is currently a significant partner and stakeholder. As such, we believe that we are in a position to be a strong partner in the implementation of the waiver. With these points in mind, we provide the following comments on the Waiver proposal, with additional detailed points presented in the Appendix.

Overall, we support the theme of providing enhanced care coordination services to individuals that is found throughout these waiver proposals. As you are aware, HealthPartners is an experienced provider of care coordination services and has been a key partner with DHS for those services to state public programs enrollees. We also recommend that the waiver request be clearer on the goals of the waivers – the full set of objectives and the timelines envisioned to achieve them. While the draft lays out the proposals, current situations and initiatives, the goals or objectives are not clearly articulated. Neither are the budgets for these proposals. We believe that it is critical that these important features be made explicitly clear in the waiver request. If we do not clearly understand the goals, timing and budget, it will be hard to measure whether the proposals, if implemented, have achieved them. We also suggest that it be made more clear which programs are impacted by which waiver proposals – fee for service, managed care or some other program. Finally, we urge the Department to focus strongly in each proposal on ensuring administrative simplification and streamlining rather than increasing complexity.

One key feature for which we are seeking a clearer understanding is how these proposals interact and intersect with the current PMAP+ Waiver. As a longstanding partner with DHS in serving public programs enrollees, we are seeking to understand **the role of health plans** in the various waiver proposals and how these proposals impact the current programs. There is little mention of managed care plans in the document and no mention of managed care plans' role in the waiver requests. This needs to be made clearer so that we can provide more informed input and suggestions.

Additionally, HealthPartners requests that we be "at the table" in discussions around reform transformation and payment reform as it is envisioned in Integrated Care System Partnerships. This concept occurs not only in the ACO/HCDS arena but also in the Duals discussion in section 2.3. As an Integrated Care Delivery organization, we have a unique perspective to bring to the discussions – be they around the implementation of Triple Aim or around effective design of Total Cost of Care arrangements or the development of quality measurement standards and methodologies for provider partnerships.

In Section 3 of the Waiver proposal – Accountable Care Demonstration, there are proposals for **expanding direct contracting** between the Department and integrated care provider organizations. We believe that it is premature to move quickly down this road when there are, as yet, no results from the HCDS or Hennepin Health experiences. In addition, we believe that maintaining successful operations of ACOs and other integrated care provider options hinges on an active partnership between providers and health plans. There is an important role for managed care organizations "at the table" in ACO discussions and planning.

In Section 4 (PCA) and Section 9 (HCBS), there is a focus on "reforms and improvements" and "redesign" but not a lot of clarity what this would look like. As we have learned over the years, it is particularly important that there be clear definition in both the services offered and those to whom they are offered. We strongly urge DHS to ensure **uniformity in program eligibility criteria** is designing these reforms. Additionally, we note that in both of these programs, DHS is suggesting a change to providing a lower level of service to individuals with lower needs. Has DHS seen evidence that that would be beneficial overall to health outcomes?

Section 5 envisions an expansion of **Consumer Directed Supports**. HealthPartners is strongly in favor of this proposal. We would be interested, within this initiative, to better understand what consumer protections would be put in place. We also emphasize the need to ensure quality and measurable outcomes. In addition, it is important that the program be designed to be flexible enough to allow those who would choose not to receive services in this way to be able to seek other care options.

In Section 9.1.2, there is a new proposal related to services for children with Autism Spectrum Disorder. We are committed to providing services to these children. In fact, two of our pediatricians participate actively on the state's Autism Task Force. We were supportive of the language that passed in the last legislative session requiring the Health Services Advisory Council to review available literature and make recommendations on services to be covered. The focus of this work, as well as all care provided under any of these proposals, should be on evidence-based care. As such, we are troubled that the draft proposal suggests that rather than use evidence or await the results of the HSAC and Task Force work, DHS may "initially propose" benefit and service utilization recommendations. In our experience, it is far harder to scale back a benefit already put into place than it is to proceed in a thoughtful and informed manner. We strongly urge the state not to be rushed by this waiver application to implement benefits without due consideration of the evidence base for benefits and services.

The descriptions of the ACO Title XIX Waiver requests (13.1.1) are straightforward, but we suggest that they need additional rationale to justify why the state would be moving away from such important consumer safeguards as statewideness and freedom of choice or financial accountability standards as actuarial soundness. The state should make clear why these changes are needed and how inequities, lack of choice or financial risk will be managed to the benefit of Minnesotans.

We appreciate the opportunity to comment on this draft. We support the efforts to focus these proposals around the Triple Aim and to provide innovative approaches to those served by our state public programs. We look forward to the opportunity to remain engaged in discussion with DHS as this process moves forward. We want to be involved with these reforms and, given our integrated model, believe that we have much that we can bring to the discussion. Feel free to contact us with any questions or to include us in the development of any of these proposals.

Sincerely,
Stephanie Frost
Senior Policy Manager

Attachment

Reform 2020 Pathways to Independence, Section 1115 Waiver Proposal
HealthPartners Detailed Comments

SECTION 2.0: Long Term Care Realignment

Concerns

- Much of the language references “pre-eligibles” for ECS. Since “pre-eligibles” are those that are not yet on Medicaid with a health plan, we are wondering what supports and services will be in place for those seniors that have 1-3 ADLs.

Questions

- Will the ECS (Essential Community Supports) be in place to support those MSHO/MSC+ seniors with less than 4 ADLs?

SECTION 4.0: PCA/CFSS

Comments

- CFSS appears to be an expansion of the MSHO model
    - Inclusion of waivered services
    - Single care coordinator
    - Annual assessment
    - Criteria/eligibility for institutional vs. non-institutional
    - LTSS (similar to LTCC)
- Clinical care alignment – looking for more guidance
- Appreciate the “start fresh” approach and understand that strategically may position them for best results, but concerned that we may recreate the same situation as before, particularly if fiscal containment and fraud and abuse measures not built in
- The waiver significantly narrows some aspects of PCA and alternately broadens the benefit. It is our hope that there will be adequate transitional time built into this considerable change.
- We would like to see a phased approach – particularly if the entire population that could meet this criteria will need an assessment.

- We support the Services Coordination model demonstration for kids with CFSS.
- We support the narrowing of criteria for individuals to receive "traditional PCA" type services in that this allows for services to be provided to those with the highest needs.

Questions

- Will MSHO model retain its current structure?
- How will CFSS intersect with MSHO and EW?
- Where will the care coordinators for CFSS come from?
- Will the coordination be billable? If so, will a code be created/requested?
- Can family members be the coordinator?
- How will payers reimburse in cases where recipients elect to pay their own providers?

Concerns

- Lack of role for managed care – there is no mention of managed care in the waiver. It is unclear what aspects will be FFS initiatives/demos and which will affect those in managed care.
    - We would like to see language that captures the role of managed care
    - We would like to retain at least some flexibility to manage this benefit in way that makes sense for our organization and our members.
- Concerned there is no mention of measures that build in fraud and abuse monitoring/containment
- Concerned there is no mention of fiscal containment for payers (focus on flexibility for recipients)

SECTION 5.0: Expand Access to Transition Supports

Comments

- We would like to understand how the health plans will intersect with the "pre-eligibles".

SECTION 6.0: Housing Stability Supports Demonstration

Comments

- HealthPartners agrees that there are significant challenges in finding stable housing for individuals in need
- We seek additional information about the funding streams for providing housing services for individuals that are being discharged from hospital settings

SECTION 7: Anoka Metro Regional Treatment Center

Comments

- In our experience, we have not seen impediments when individuals are discharged from Anoka Metro Regional Treatment Center to the community because of their IMD status

- Our experience is that there is continuity of care when individuals are discharged back to the community

- We seek clarification and additional information from DHS around the goals DHS hopes to achieve through these proposed changes

Questions

- We would like more information about the goals surrounding this Waiver initiative

SECTION 9.0: Current and Proposed Initiatives

9.1.2: 1915 (i) for Children with ASD Diagnosis

Comments

- HealthPartners supports evidence-based care and interventions
- We are very interested in the development of the time-limited service set and seek information about how this will be defined
- We seek additional information about and are very interested in the development of agreed upon standards, assessment tools, treatment plans and protocols for objectively measuring progress

Questions

- We understand that DHS may propose benefit and service utilization criteria prior to recommendations from the Minnesota Health Services Advisory Council. Will DHS seek stakeholder input during this process?

Concerns

- As noted in our attached letter, we are concerned that the draft proposal suggests that rather than use evidence or await the results of the HSAC and Task Force work, DHS may "initially propose" benefit and service utilization recommendations

9.1.4: Individuals with mental illness who are at risk for institutionalization without access to integrated community-based systems of care

Comments

- We support the move towards reducing the need to go to a higher level of care before services can be provided
- We also support providing community-based services to members

9.3 Redesign Home and Community Based Services

- We are hoping for a phased-in approach for MNChoices to allow providers the ability to obtain equipment and gain capability with the assessment process and the tool itself.

9.6: Intensive Residential Treatment Services

Comments

- We agree that addressing an individual's medical needs while residing in an IRTS facility has challenges

- We support the Department in developing a proposal for improved integration of medical and behavioral health services for medically complex patients.

9.7: Children Under 21 in an "IMD" Facility
Comments

- We seek to understand as children under 21 in an IMD facility are eligible for Medicaid and can be seen on an out-patient basis now for any medical needs that may arise

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July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

SEIU Healthcare Minnesota appreciates this opportunity to provide comments on the State of Minnesota's Proposed Reform 2020 Section 1115 Demonstration Waiver. Our comments relate to the proposed Accountable Care Demonstration and the proposed Community First Services and Supports program.

SEIU Healthcare Minnesota is pleased to see the proposal for an Accountable Care Demonstration to build on Minnesota's strong track record in care integration, and we too support the stated goals of improving primary care and care coordination in a way that increases provider accountability for the quality and total cost of care.

SEIU Healthcare Minnesota strongly supports the overall vision for the Community First Services and Supports program—especially its focus on expanding self-direction, and the expansion of allowable services to include not only direct assistance but also skills acquisition and cuing, plus assistive technology, environmental modifications, and transition assistance. We also strongly support the state's intention to make these services and supports available to individuals who meet an institutional level of care as well as those who do not. We are pleased also that the proposal includes a commitment to provider training and qualifications (p. 33).

We support the plan's proposal to provide Financial Management Services to participants in the proposed CFSS program who choose to direct their own services and hire and manage their own caregivers, and the proposal to put these Financial Management Services out to bid through a competitive Request for Proposal process (p. 39). We would urge that in the selection process strong preference be given for Financial Management Entities that have a track record of providing similar services in the state of Minnesota.

Finally, we would urge that the Development and Implementation Council (p. 38) should in its recommendations to the legislature take into account not only the value of person-centered planning approaches but also the necessary relationship in self-direction between choice and risk—participants should, in exercising their full freedom of choice to direct their own services, be able to assume certain risks which they understand and choose to assume.

We appreciate the opportunity to provide these comments, and look forward to working with the Department as it continues to develop and implement this proposal.

Thank you for your consideration.

Sincerely,

Julie K. Schnell
President, SEIU Healthcare Minnesota

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey,

I these are my personal comments to the Department of Human Services Reform 2020: Pathways to Independence proposal. I submit them on behalf of myself only as they have not been reviewed or approved by any organization with which I am affiliated.

I Applaud the Department of Human Services for the values of self direction, personal choice, individualized planning, and quality outcomes that have been driving the Medicaid Waiver process, and led to the development of the *Reform 2020* proposal. I agree with the stated *Reform 2020* goals of: better outcomes, the right service at the right time, and ensuring the sustainable future of long term services and supports. I am in agreement with comments previously submitted by the Minnesota Disability Law Center, Lutheran Social Services, and the Minnesota chapter of the National Alliance for the Mentally Ill (NAMIMinnesota).

In addition, I have the following comments and suggestions.

1. Title of Proposal.

I reiterate my concern regarding the inappropriateness of referring to "independence" as the goal of this proposal for Minnesotans with disabilities. No one is truly independent. We all depend upon others for our quality of life. The clothing we wear, the food we eat, the places we live, the roads we drive on in the cars we drive in all our the result of the efforts of many other persons upon which we rely, usually unconsciously, in our daily activities. To implicitly claim that persons with disabilities may obtain quote independence" which is unachievable by persons who are not disabled, is grossly unfair and misleading. Moreover, it furthers the radical individualism which permeates public and political discourse today. I urge the department to revise the title to read "Pathways to Interdependence."

2. DHS will have to grapple with the meaning of "community". Unfortunately, CMS That continues to seek public comment on this issue through its latest NPRM on 1915 (I). This is a critical issue for Olmstead compliance which requires that individuals with this abilities have access to the "most integrated setting" that is appropriate for them.

3. As currently written, the Reform 2020 proposal focuses upon system change rather than the benefits for individuals with disabilities and others covered by Medical Assistance. This focuses understandable But I Agree with L SS that effort should be made to focus upon what individual persons with disabilities have to gain (or lose) from the specific waivers and demonstrations outlined in the proposal. As I indicated during last Friday's group meeting with the Commissioner, each individual with a disability has unique abilities, functional limitations, and needs which they must address. Their individual realities should be the primary focus of any systems change proposal. The Development and Implementation Council is an excellent vehicle for DHS to be reminded of the barriers and problems faced by individuals with disabilities in their daily lives. DHS should establish similar councils comprised of a majority of the affected persons with disabilities for each of its programs and services. Individuals with disabilities who receive DHS or other state services are the real experts and stakeholders, not the advocacy groups, coalitions, and vendors who dominate existing stakeholder advisory groups.

In addition, any individual barrier raised by a consumer of DHS' services should be viewed by DHS as a systemic rather than an individual problem and action should be taken or planned to remove that barrier. As I mentioned last Friday, one of the members of the Olmstead Planning Committee who lives in rural Minnesota mentioned that she had difficulty receiving catheterization services. Apparently the Nurse Practices Act requires catheterization be done by an RN. However, the OPC member said that no RN would drive for one and a half hours to provide her with this 10 minute medical service. It is highly likely that there are more DHS consumers with this problem. DHS staff should fix or make plans to fix all the issues identified by DHS consumers because action at this apparently individual level, on a consistent basis, will result in systemic change as well as greatly improving the lives of Minnesotans with disabilities.
4. Comment 2. Of MDLC

I especially agree with MDLC that there are “serious concerns about the integration of long-term services and supports (LTSS) with health/medical care because of the likely emphasis on the medical model of service provision. …we oppose control over all of one’s LTSS services by a medical care provider without experience in housing, employment, transportation and social relationships in the community. Rather than assigning medical entities or health plans the authority and risk for every project, we recommend seeking proposals where the community support providers are in charge and can subcontract for medical services.”

It seems to me that this is also a serious problem with managed care. Moreover, I am not comfortable with the degree of information available to DHS staff from managed care entities regarding both the scope of medical care actually being provided to managed care consumers as well as the degree to which such entities are sufficiently knowledgeable and desirous of approving long-term services and supports for their members with disabilities.

Olmstead liability may arise against Accountable Care Organizations and managed care entities who fail or refuse to provide needed community-based services and supports to their members with disabilities.

4. MDLC Comment 2.- **Demonstration to Reform Personal Care Assistance (PCA) Services, p. 25**

I strongly agree with MDLC's comments on these issues. I also agree with NAMI Minnesota's comments on the negative impact which will result for adults and children with mental illness if the more stringent Nursing Facilities Level of Care (NFLOC) is granted.

NAMI Minnesota continues to claim that MN Choices does not accurately assess the needs of Minnesotans with mental illness. MDLC agrees with NAMI Minnesota on this point. (See MDLC’s comments regarding 9.3.2). On behalf of the OPC, I will be requesting a copy of all of the MN Choices questions for review in order to better understand NAMI Minnesota's concerns and objections. If the OPC agrees that MN Choices’ questions are inadequate for the assessment of persons with mental illness, we will seek to have DHS make appropriate revisions. Frankly, I do not understand why this controversy continues without resolution. Olmstead liability may arise if DHS uses an assessment tool which discriminates on the basis of mental disability.

5. 4.23. Demonstration of Innovative Approaches to Service Coordination (children with CFSS), p. 41

I strongly agree with comments made by MDL see That and NAMI Minnesota. The last thing that school districts want is additional responsibility for students with disabilities particularly outside school hours.

6. 5.2. Demonstration to Expand Access to Transition Supports, Return to the Community, p. 44 and p. 127

NAMI Minnesota and MDLC both correctly point out that it is not appropriate to limit this programs to persons 65 or older. If it promotes community integration, it should be available to all Minnesotans with disabilities regardless of age.

7. **6.1. Demonstration to Empower and Encourage Independence through Employment Supports, p. 51**

NAMI Minnesota request DHS to use Individual Placement Supports (IPS) also known as evidence-based supported employment instead of the proposed approaches. I have no knowledge regarding IPS or evidence-based supported employment or its effectiveness. However, if NAMI Minnesota is correct about its effectiveness, DHS should adopt NAMI Minnesota's recommendation.

I also agree with MDLC's comments on this section, which also endorses the use of IPS.

8. I join the remainder of MDLC's and NAMI Minnesota's comments.

Respectfully submitted,

Christopher G. Bell

July 17, 2012
UCare Comments on DHS Draft *Reform 2020: Pathways to Independence - Section 1115 Waiver Proposal*

General Comments/Questions:

1. We would like more specificity as to how the proposals will impact managed care and managed care organizations. The draft waiver proposal seems to be written primarily with a Medicaid fee-for-service lens.

2. There is no financial information or budget projections provided as part of this proposal. Please provide information as to how many Medicaid beneficiaries will be impacted and what the costs may be to MCOs, county-based entities, and those establishing/implementing ACOs/ICSPs.

Technical Section 1115 Waiver Comments/Questions:

3. Does the Section 1115 waiver replace the existing PMAP+ waiver, or would these authorities run parallel to each other?

4. If the Section 1115 waiver does not replace the existing PMAP+ waiver, please provide a description of how the new Reform 2020 Sec. 1115 waiver proposal will impact the existing DHS PMAP+ waiver. Specifically, what changes, if any, will be made to the existing PMAP+ waiver if the Reform 2020 Section 1115 waiver is approved?

5. Does DHS authority to deliver services through health plans and county-based purchasing entities come from the existing PMAP+ waiver?

6. Is DHS seeking authority/arrangements with CMS that will limit or prohibit Minnesota from continuing to deliver Minnesota Medicaid services through managed care organizations (HMOs and/or county-based purchasers)?

7. To help stakeholders understand how the new Section 1115 waiver interacts with the existing PMAP+ waiver, please provide a summary comparison of the provisions/elements that are in each of these waivers and a statement about what each element achieves (actual or planned).

8. In general, UCare supports the streamlining of the various waiver pieces (CADI, EW, etc.), but without more detail and role clarity it is difficult to provide specific comments.

Section 2.2 – Long-Term Care Realignment Section 1115 Waiver

9. We are aware of the 2009 legislative changes and are concerned that these modifications to the Nursing Home Certifiable level of care criteria may negatively impact enrollees' eligibility for waivers. This may increase case management time and administrative costs.

10. The Support Alternative Care Program will present a challenge to determine eligibility for services. Will this be administered by a "local agency" such as a managed care organization? This may create more fragmentation over time.

Section 2.3 - Redesigning Integrated Medicare and Medicaid Financing and Delivery for People with Dual Eligibility. *Note: DHS identifies this as "pending with CMS," and features are being discussed with health plans.*

11. At the bottom of page 18, we believe DHS means to refer to "Minnesota Senior Health Options" (MSHO), not "Minnesota *State* Health Options."

12. UCare supports the leadership of the Department in moving to further integrate care for elderly dual eligibles.

13. Please clarify the statement that "DHS will continue to explore with CMS ways in which Medicaid and Medicare can be better integrated for people under age 65 with disabilities without pursuing a fully capitated model."

Section 3 - Accountable Care Demonstration

14. Section 3.2.3, first paragraph: We believe DHS means to refer to "Minnesota Senior Health Options" (MSHO), not "Minnesota *State* Health Options."

    Section 3.2.3 says that "DHS will incorporate purchasing strategies… to stimulate new 'integrated care system partnerships' (ICSPs) between health plans and providers." Specifically, ICSPs are referenced in conjunction with better serving dual eligibles. However, in Sections 3.3.1 and 3.3.2, no mention is made of partnerships with health plans for other forms of accountable care models. Does the Department contemplate a role for health plans only in the care delivery for dual eligibles, but not in other forms of accountable care models?

    Failure to anticipate questions about how ACOs will work within the context of existing managed care programs may slow implementation of ACO initiatives. Please explain the Department's vision for the role of managed care plans in a future of more direct contracting with ACOs. Because several health plan/provider relationships already exist and are operating effectively, we want to assure that the process allows for existing models to continue under this strategy.

15. Looking ahead to 2014 when the Minnesota Health Insurance Exchange is operational, it is important to note that many stakeholders have expressed an interest in ensuring that the same plans offering commercial products in the Exchange also offer a Medicaid product so that an enrollee does not experience a break in continuity of care or a break with a preferred provider if his/her eligibility for a commercial or Medicaid product changes. In the absence of any clear articulation in the waiver proposal of a role for health plans and ACOs, please reconcile the Department's vision for a future of more direct contracting with providers with the fact that many new and renewing enrollees will be choosing a Medicaid plan through the Exchange.

16. If the ACOs and/or ICSPs are to be risk- bearing entities receiving public funding, will DHS require accountable care models to adhere to similar transparency requirements for financial reporting and independent auditing as is required for HMOs? If not, please explain why.

17. Regulation of the financial solvency of risk-bearing provider organizations in ACOs is important to ensure market stability. Bearing financial risk necessarily means that there is a possibility that a provider organization will face financial instability, or even fail -- thus the need for strong financial solvency regulations to ensure that the health care provider market remains stable and that patient care is not disrupted. Does DHS intend to regulate the financial solvency of providers in ACOs and/or ICSPs , and if so, how?

18. How do the July 10, 2012 CMS State Medicaid Director letters (SMD 12-001 and 12-002) regarding "integrated care models" impact this Section 1115 waiver? Will DHS need to amend its proposal due to the release of these two letters?

Quality

19. A number of quality and performance measures have been developed and are currently used to measure delivery of health care services to individuals enrolled in MCOs. Is DHS proposing developing new outcome measures to replace the measures currently in place? If so, to which products/delivery models (HCDS, Hennepin Health, PMAP/MnCare, SNBC, MSC+, MSHO) would the new measures be applied?

Benefits

20. For what benefits will HCDS demonstrations be at risk? Will all HCDS demonstrations have the same risk/gain sharing arrangements? Will the same range of service costs be included across all HCDS demonstration sites?

21. Are the costs of long term care services, including nursing facility and HCBS, included among the services for which HCDS sites will be at risk?

22. Is DHS planning on changing how dental services are provided to MHCP beneficiaries who currently receive dental services through MCOs? If so, how?

23. For dual eligibles, does DHS envision adding any new social and/or county services to the range of services for which managed care organizations (health plans and county-based purchasers) are currently responsible?

HCDS, ICSP

24. Does DHS plan on developing ACO arrangements beyond the nine HCDS sites with which DHS is currently working?

25. How many individuals does DHS anticipate serving through DHS direct contracts with HCDS?

26. If closed networks are implemented, what administrative processes will providers both within, and outside of, the ACO need to follow in order for members to access medically necessary services that are not available from providers within the closed network?

27. Under ICSPs, if closed networks are established, what entity will be responsible for handling appeals? DHS? The provider?

28. Will DHS publish HCDS contracts and payment rates on the DHS website, similar to how managed care contracts and payment rates are currently published?

29. Does DHS expect that over time, ICSP arrangements will become direct contracting/HCDS arrangements?

30. Does Section 3.2.2 correctly state that 10,000 individuals per month will participate in Hennepin Health? July 2012 Hennepin Health enrollment was 5,433 individuals.

31. ICSP arrangements or narrow/closed networks for dual eligibles seem to be at odds with CMS Medicare Advantage requirements for broad provider networks. Does this mean that MSHO will have to depart from the SNP/Medicare Advantage platform to fully implement ICSP?

32. Will ICSPs be allowed to partner with multiple health plans, or just a single health plan? UCare would support ICSPs having the option to contract with multiple health plans and allow for flexibility in the relationships as jointly developed.

33. Is it correct that the ICSP arrangements will only apply to dual eligibles enrolled in MSHO?

<u>RFPs</u>

34. Please confirm that DHS be issuing a RFI preceding the RFP as part of the process toward the creation of the ICSPs.

35. On page 25, first full paragraph, DHS mentions a RFP that will be released in early 2013. It also mentions, we think, that DHS will begin a stakeholder process prior to this 2013 RFP. Please confirm that we are reading this paragraph correctly. [Another way to read this paragraph would be that DHS is releasing two RFPs - one in the summer of 2012 and one in early 2013 – and we want to be sure that this is not what the Department is saying.]

36. However, if there <u>will</u> be two RFPs, please clarify which initiatives begin in what year, and for what activities. Will there be another HCDS RFP, or will be there an ICSP RFP? Will health plans be permitted to participate in the planning process? Are health plans considered providers in this context?)

<u>Shared Savings with Medicare</u>

37. On page 24, the bottom of the first paragraph, the draft proposal talks about sharing savings with Medicare for dual eligibles. Now that Minnesota's Financial Alignment Demonstration (FAD) will not go forward, is DHS still planning on developing a program under which shared savings from dual eligibles experience accrue to CMS?

<u>Enrollment – ACOs</u>

38. What changes in the current enrollment process does DHS envision related to the creation of ACOs? Please refer to Section 3.3.2.

39. Section 3.3.2 notes that: "Medicaid enrollees would directly enroll into these [integrated provider] organizations . . . . " Does DHS expect that health plans will continue to have a role in Medicaid managed care when HCDS is fully implemented, or is health plan involvement in Medicaid managed care expected to decline as HCDS capacity increases?

Data Reporting (top of page 25)

40. Regarding Section 3.3.2: What data reporting requirements does DHS see that will be needed by ACOs? What types of systems does DHS think will be needed to meet the ACO reporting requirements?

Section 4 - Demonstration to Reform Personal Assistance Services

41. Currently, PCA services are available as a State plan service (either through Medicaid managed care or fee-for-service) and, for those eligible, "extended" PCA services are also available through Section 1915(c) HCBS waivers such as TBI, CADI, CAC and EW. If PCA services are delivered as State plan services under the Section 1915(k)(institutional level of care) and 1915(i)(non-institutional level of care) authorities, will extended PCA services still also be covered under the existing Section 1915(c) HCBS waiver programs? Or will they only be covered as State plan services under the new model?

    Or - will PCA services not be delivered via the Section 1915 waivers at all, and only via this proposed Section 1115 waiver? It is unclear, and we are hoping DHS will clarify under what authority PCA services will be part of Minnesota's Medicaid package come 2014.

42. Under the proposed PCA redesign, does DHS anticipate the institutional level of care determination (under the Section 1915(k) authority) to be driven by the level of care criteria outlined on page 17 of the proposal (e.g., a high need for assistance in four or more ADLs; a high need for assistance in one ADL that requires 24-hour staff availability; a need for daily clinical monitoring; significant difficulty with cognition or behavior; or the person lives alone and risk factors are present)? Under the Sections 1915(i)/1915(k) model, what proportion/number of those currently receiving PCA services would no longer be eligible to receive PCA services either under the Section 1915(i) or the Section 1915(k) (or Section 1115) authority?

43. With the PCA redesign, does DHS still expect PCA services to be delivered via managed care organizations (health plans and county-based purchasers)?

44. Page 25, form of PCA services: What features of the current PCA delivery process does DHS consider most complex? What barriers, gaps and redundancies does DHS believe prevent people from accessing the service they need?

45. Page 26, second full paragraph: What groups/categories of individuals does DHS expect to receive the home care service coordination under the CFSS? Will it only be available to those receiving PCA services? Will it be available for both those enrolled in managed care and those who receive Medicaid services via fee-for-service?

46. Page 37: Fourth bullet is unclear – will members participating with a HCBS waiver be able to access CFSS or not?

47. Modification to the current PCA program is clearly needed; however, the proposed language doesn't seem more efficient. For example, members exercising the PCA Choice option often utilize the authorized hours of PCA services before the authorized time period has lapsed, resulting in the health plans needing to authorize additional hours beyond a member's assessed need. Going forward with the option described in the proposed Section 1115 waiver could logically require limits on members' flexing of the benefit and funding of the health plan for care coordination of service. Therefore, UCare suggests that the Department consider limits on use of the PCA Choice benefit.

Section 5 - Demonstration to Expand Access to Transition Supports

48. In general, UCare supports, as it means fewer people spending down to become eligible for Medicaid. However, because Section 5.3 seems intrusive and an unnecessary burden, and also has not been well received in the community, UCare does not support.

Section 6 - Empower and Encourage Housing, Work, Recovery and Independence

49. How will this section impact MCOs? We understand enrollment will be capped at 800 people at any given time.

50. Section 6.2.3, third bullet: Suggest that "and" be deleted and added right before the fourth bullet.

Section 7 - Anoka Metro Regional Treatment Center Demonstration

51. Would MCOs be responsible for paying for Medicaid services in IMDs?

Section 8 - Eligibility for Adults without Children

52. Section 8.1.1 (asset test of $10,000 on adults without children): If Minnesota does not opt to expand Medical Assistance eligibility for adults without children with incomes 75% -133% FPL, as we understand it, there would be no need to seek a waiver of the asset test for these adults with incomes ≤ 75% FPL. That is because (we believe) that the ACA Medicaid requirements otherwise effective 1/1/14 will not apply to states choosing not to expand Medicaid eligibility. Note: CMS may issue clarifications as a result of the June Supreme Court decision that impacts Medicaid eligibility.

    If, on the other hand, Minnesota expands Medicaid eligibility, then this waiver to impose an asset test would be premature (for the MAGI groups) and would presumably violate the ACA's requirement of maintenance of effort in effect through CY '13. In addition, CMS may determine that as of 1/1/14 states that expand Medicaid eligibility cannot have Medicaid eligibility asset tests for the MAGI groups (i.e., the recently promulgated Medicaid eligibility rule applies to states that expand Medicaid eligibility pursuant to the ACA).

    Lastly, UCare opposes an asset test for these adults, as the impact would be to create an additional barrier to some of those on the very low end of the scale – adults without children with incomes ≤ 75% FPL.

53. Section 8.1.2: Pursuant to 2011 legislation, the Department seeks to re-establish a MinnesotaCare 180-day residency requirement for adults without children with income between 75-250% FPL. However, effective 7/1/12, approximately 4200 MinnesotaCare adults without children with

incomes between 200-275% FPL were terminated from MinnesotaCare and offered the opportunity to purchase health care via the Healthy Minnesota Contribution Program. Therefore, we believe the Department would want to revise this proposal and seek a residency waiver for adults without children with incomes between 75-200% FPL.

UCare has several comments:

a. We view the chances of CMS approving this waiver to be highly unlikely, regardless of state law mandating this waiver. In a June 2011 letter to the Department approving the PMAP+ waiver (but not the MinnesotaCare residency waiver), CMS was very clear that it would not approve the residency waiver, as it was contrary to federal law.

b. We oppose this residency requirement, as the impact would be to create an additional barrier to health care for some of our citizens.

Section 9 - Context of Reform: Current and Proposed Initiatives

54. Section 9.1.2: Based on the public concerns raised at the two June 2012 public hearings, we recommend that the Department clarify this proposed Section 1915(i) State plan benefit for children over age seven.

55. Section 9.1.2: Targeting the benefit to children under the age of seven aligns with the research on where intensive treatment models have the most benefit, so we support this definition. As we understand it, the intent on the school IEP driving services for older children is to reduce the number of different assessments currently required to access services. We believe this is a good idea.

56. The Section 9.1.2 language regarding adults is again attempting to move from fragmented funding streams and rules into a coordinated funding for that subset of the most impaired individuals who are in RTCs but who do not need that level of care. We believe this is a good idea.

57. Section 9.3.3: The first full paragraph, first sentence on page 91 uses “demonstrated” rather than “demonstration.” The last sentence in that paragraph seems to be missing the word “of”: “… and data entry lag time <u>of</u> county staff was reduced significantly.”

58. Section 9.3.9: UCare supports this section, which would reduce the substantial variability of vulnerable adult services across the state and potentially enhance effective response to the needs of vulnerable adults.

59. Section 9.4: It is unclear what DHS envisions regarding MCOs in this section. Health plans have extensive experience providing individual and group incentives for preventive care. Health plan representatives participate on the “We Can Prevent Diabetes MN” grant. MCOs welcome all opportunities to come to the table to work on preventive care initiatives.

60. Section 9.5.2 notes that “enrollees who seek care from a high value provider could have their copayments reduced or eliminated. Some people on Medical Assistance are exempt from copayments, so other incentives will have to be identified in order for them to take advantage of this initiative.” However, Section 9.5.3 states that “DHS will identify non-cost-sharing enrollee

incentives," will seek CMS approval to implement those incentives, but will make no specific requests for federal waiver authority at this time.

As written, these sections are confusing. If some enrollees could have their copays reduced or eliminated – while others have differing copays - wouldn't there need to be waivers in place? Yet DHS states that it will not be seeking waivers at this time.

Further, what "non-cost-sharing enrollee incentives" is DHS planning? Will the MCOs be involved in the "consultation with MDH"?

61. Section 9.6: We believe it is a good idea to integrate primary and behavioral treatment within this setting and to establish standards for what would be included.

Section 13- Waiver Authorities Requested

62. In Section 13.1.1, DHS is proposing a waiver of 42 CFR §438.6(c)(5)(iii) (actuarial soundness of payments under risk contracts), but there is no budget/financing information accompanying this proposed waiver, and it is not clear why this waiver is necessary.

63. Section 13.2.2: We think "demonstration populations" could be deleted in the first sentence, or perhaps it should be reworded as follows": "… following expenditures for demonstration populations not covered …."

64. Section 13.3.1: Missing the list of Title XIX waivers sought.

Schels, Johanna T (DHS)

From: [redacted]
Sent: Tuesday, July 17, 2012 4:35 PM
To: *DHS_Reform2020Comments
Cc: [redacted]
Subject: Comments on Changes for Autism Benefits

I was unable to come in person to your meetings. however, I would like to share my comments.

1) Please eliminate artificial age caps (both in early intervention and any medical therapy) - they are more detrimental to long term improvement and a persons ability to live more independently. The more improvement in functioning you can get before the children become adults, the less costly they will be in the long run.

I have a 15 year old son with very severe autism. He needs many services that are not accessible to him and were not accessible to him due to artificial "caps" in age.

For example - he has sensory issues to foods and requires feeding therapy to expand his repertoire of foods that he will eat. We have known this since age 8, yet at the time, providers would not take children over 6. At age 10, the providers changed their service limit to age 8. Now there are no age limits, but since puberty no providers have allowed them to complete therapy due to aggression, although we can show him how to work with him safely.

2) Do not limit access to services to the schools. They have no business getting in the medical decisions of families and physicians. Our son is in a Special and Unique school, which bills medicaid for the cost of a full time aide and "indirect" OT, "indirect" Speech, "indirect" PT, etc. I think it is horrible that they will not provide direct services and we are seeking services outside the school system. Your proposal would limit our sons ability to receive help permanently. The decisions to receive medical interventions should not be the schools to make - some have low quality tenured employees that do not keep up on the latest research and techniques. Medical interventions should be between the physicians and the patients. Also schools bill these services and parents never get to see what they are billing for, whether there children were actually at school on those days etc. The schools lack transparency in this process.

3) Include parents with children at a variety of functioning levels and ages in all future proposed changes to waivers.

Thank you for your time.

[redacted]

From: courtney whitcraft <courtney.whitcraft@gmail.com>
Sent: Tuesday, July 17, 2012 4:27 PM
To: *DHS_Reform2020Comments
Subject: comments regarding Reform 2020: Autism

Hello!

I am Courtney Whitcraft, B.C.a.B.A (Board Certified assistant Behavior Analyst). I have primarily worked with children with Autism ages 1.5-11 years old since 2005. I have been working in the Behavior field since 1998, and achieved my B.C.a.B.A in 2006 (with adults and children with a variety of developmental and genetic disorders)

I encourage you all to consider giving those of us who have expertise in the behavioral field (with the B.C.B.A and B.C.a.B.A.) more responsibility. It's mutually beneficial! We bill at a lower rate (lower than psychologists) and we are specifically trained in all behavior applications, work hard to annually renew our certifications through work and Continuing Education units. Those who are B.C.B.A have to have a masters, those of us who are B.C.a.B.A take extra behavior classes. All of the training and classes allow for education, experience and expertise. Utilize us, please!! I want, need, and crave more responsibility. As I said, it's mutually beneficial, the state will spend less money if you give us more responsibility!
It's more cost effective for the payer and benefits clients and providers because it opens up opportunities for us to provide a wider range of services.

Please think about utilizing us, the behaviorists. Through out all the research we do, we prove that using behavior analysts helps kids, teens, adults, everyone!

Thank you for your consideration!

Courtney Whitcraft, B.A., B.C.a.B.A
8005 147th st W apt 109
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courtney@minnesotaautismtherapy.com

July 16, 2012

The Corporation for Supportive Housing
2801 21st Ave. South, Suite 230
Minneapolis, MN 55407
612-721-3700

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
Saint Paul, MN 55164

RE: Reform 2020 Draft Section 1115 Waiver Proposal

Dear Mr. Godfrey:

I write to you on behalf of the Corporation for Supportive Housing (CSH) with comments regarding the Reform 2020 Draft Section 1115 Waiver Proposal, posted on June 18, 2012. Chief among our concerns is the use of Medicaid for Housing Stability Services, as well as the Community First Services and Supports (CFSS).

CSH is a nonpartisan, nonprofit organization and Community Development Financial Institution (CDFI). We have been working in Minnesota for over 19 years, helping communities throughout the state change systems and leverage resources to create supportive housing. Supportive housing, as CSH defines it, is permanent housing with voluntary support services. This type of housing has been proven as an effective method of reducing Medicaid costs to states. Previous studies have shown an average savings of $5,983 per person per year, of which $3,270 of that is Medicaid savings alone, (Studies summarized in the attachment and available upon request.)

Comments and Recommendations on Demonstration to Reform Personal Assistance Services

Under section 4.2.2, the newly created 1915(i) would allow people with less then an institutional level of need access to Community First Services and Supports (CFSS). While this is an improvement from the currently existing Personal Community Assistance (PCA) services, the new regulation does not provide for all of the people in need of these services. The current requirement only accounts for individuals who need full time help with one or more Activity of Daily Living (ADL), which is only one way to determine if someone is medically in need of a PCA. The Housing Stability Services is planning to use a functional need analysis to determine if someone needs services, which has been a successful method of determining individuals who might some day end up in an instutionalized care. The individuals who would qualify under a

functional analysis, but may not qualify by using an ADL only criteria include those who are long term homeless with functional deficiencies that qualify them for the Housing Stability Services under section 6. This population has historically been underserved by Medicaid. An example of someone who does not have a defined ADL but does have a functional need is
Maggie, a 55 year old woman who experienced 5 years of cycling from psychiatric inpatient care and homelessness for five years before being housed. After she was housed, she struggled to maintain her apartment due to mental illness. Maggie exhibited hoarding behaviors which led to lease violations as her unit was no longer compliant with the local fire code. Maggie was able to receive assistance; with the help of someone coming in to her apartment weekly and talking her through the process of getting rid of items she was able to retain her housing. Unless the CFSS eligibility standards are altered, individuals like Maggie would be ineligible to receive the services they need to stay in their housing and not be institutionalized. To ensure Maggie and others would be able to retain services, CSH strongly advocates extending the CFSS eligibility standards.

The Corporation for Supportive Housing recommends that eligibility for CFSS 1915(i) is broadened to include those who qualify for Housing Stability Services. Allowing most people who receive Housing Stability Services to receive CFSS benefits creates a more comprehensive package of services available to those most in need. If DHS is unwilling or unable to change the eligibility requirement under for CFFS 1915(i), then (DHS) should consider augmenting the services available under the Housing Stability Services to include a similar assistance package.

Comments and Recommendations on Empower and Encourage Housing, Work, Recovery and Independence

6.2 Housing Stability Services

CSH strongly supports including Housing Stability Services in the 2020 Medicaid Reform. Our organization has long known that securing and maintaining housing is crucial for treating our constituents' mental and physical health, and that housing reduces the costs associated with their health plans and health care providers.

CSH proposes adding language that makes clear to CMS that the intent of the Housing Stability Services is not to subsidize rents, but to provide the services needed for clients to find and maintain housing. Additionally, the waiver proposal can specifically state that housing will be available for individuals through state and federally funded housing programs, including GRH, Section 8, Housing Trust Fund, and the private market through earned income.

It is our recommendation that the provider qualifications for outreach workers be expanded. Many individuals who are most knowledgeable and best situated to create relationships with people experiencing homelessness are not academics, but instead are peer support specialists. Formalized training, while helpful, is not always reflective of one's ability to form relationships with those experiencing homelessness. Instead, these relationships are often best fostered by people who have personal experience that allow them to form bonds based on mutual trust and respect. For that reason, the language should be changed to stress that qualified providers are those best at creating meaningful and lasting relationships such as Peer Support Specialists.

Another impediment to ensuring all those in need of services can receive them is the age requirement present in the waiver proposal. Currently, to be eligible, individuals must be at least 18 years old. This requirement should be removed. Recent studies, including the 2009 Wilder Homelessness Survey, have shown that the number of youth experiencing homelessness in Minnesota is rising, and among this number are many youth who have disabilities that allow them to qualify for Medicaid. This demographic must be served; early intervention will help to reduce chronic health problems from presenting, such as those we often see in the long term homeless. Further, those under the age of 18 can qualify to receive Medicaid on their own and meet the other requirements of a disability needed for Housing Stability Services. From that it follows that they should be eligible to receive these services, provided they meet the other requirements.

Providing benefits which lead to housing for those experiencing homelessness costs less than paying for Medicaid. For that reason, limiting the program to 5,000 individuals is unnecessary and should be removed. The waiver can be budget neutral without the cap, as housing has been proven in many states to be a cheaper alternative to providing benefits to those experiencing homelessness. Studies across the United States have regularly shown this to be true; therefore, more individuals can be served by Housing Stability Services while maintaining fiscal neutrality by lowering Medicaid costs significantly.

It is CSH’s position that Housing Stability Services would better assist those in need by enhancing the current service package through adding the CFSS services. These services would help individuals maintain their housing once they have been housed. Many people who have not been housed for long periods of time have a difficult adjustment period once they get their own housing. They need assistance in learning tasks needed to preserve their housing status, including cleaning, managing bills, relationship with neighbors, and making and keeping medical appointments. Adding these services would ensure that those who are housed remain so, and the full economic impact of housing on our Medicaid system is realized.

When the Housing Stability Services billing rate is being determined, CSH recommends a baseline of no lower than $500.00 per individual served. The current rate for Group Residential Housing (GRH) is $459.85 per client per month, which allows for a 15-1 ratio of client to case manager caseload. Hennepin County has put a 15 client cap on their Housing First GRH programs because they have determined this to be the highest number of clients a case manager can effectively serve. This caseload is manageable with the high level of need the average client presents. If the billing rate were to be smaller than our recommendation, the ratio of clients to providers would increase; the level of service would decrease, as would the rate of housing stability.

6.3 Project for Assistance in Transition from Homelessness and Critical Time Intervention Pilot

CSH believes that the use of Critical Time Intervention (CTI) is an effective way to transition individuals receiving services from a high level of service to a lower level. The PATH program can benefit greatly from using CTI to effectively increase the number of people they serve by transferring more clients off their caseloads.

The first-come, first-serve policy the PATH CTI pilot recommends will result in a lack of services for the most vulnerable clients. PATH's goal is serve homeless individuals with mental illnesses; historically those people experiencing homelessness with the highest level of mental health need do not request services due to their mental illness.

CTI is only as effective as the community supports that exist for PATH providers. Currently housing and case management supports can be limited for PATH providers. For CTI to be effective there must be services for PATH clients in place before the demo is implemented. A good fit would be the CFSS services proposed to support once a client is in housing.

Thank you for the providing CSH with the opportunity to comment on these proposals. We look forward to working with the State of Minnesota as the final waiver is created. If you have any follow up questions you can contact me at 612-721-3700. Ext. 108.

Sincerely,

George Stone
CSH Minnesota Director

Summary of Select Permanent Supportive Housing Cost Studies

(August 2009)

			Cost Savings (Increases) Per Person, Per Year									
Community Studied	**# of People in Study**	**Housing**	**Shelter and Homeless Services**	**Emergency Room/ Emergency Medical Services**	**Medicaid/ Health Care**	**Medicaid Alone (included in previous column)**	**Mental/ Behavioral Health**	**Police/Jail/ Corrections**	**Ambulance**	**Detox**	**VA**	**Nursing Home**
Portland Maine (2007)	99	($11,092)	$2,347	$1,297	$4,526		$3,039	$539	$308			
Rural Maine (2009)	163	($5,650)	$4,384	$615	($1,665)		$3,599	$434	$72			
Denver, Colorado	19	($3,956)		$902	$2,975			$685		$4,366		
NY/NY Agreement Cost Study (2001)	4,679		$3,779		$2,901	$1,130	$8,260	$746			$595	
1811 Eastlake in Seattle, WA	95			$3,432	$7,548	$5,880						
Chicago Housing for Health Partnership Study	405	($12,000)		$2,016	$22,799							$8,891
Direct Access to Housing in San Francisco, CA Plaza Apartments	81			$148	$2,799	$2,799		$1,485				$24,460
Average Savings (Costs) for Studies that Included the Cost Category		($8,175)	$3,503	$1,402	$5,983	$3,270	$4,966	$778	$190	$4,366	$595	$16,676
Links to Studies												
Maine	http://www.endhomelessness.org/section/data/interactivemaps/mainecostchart											
Denver	http://www.shnny.org/documents/FinalDHFCCostStudy.pdf											
New York	http://www.csh.org/html/NYNYSummary.pdf											
Notes												
Maine	Notes:1. Rural study numbers are based on information not included in published study but obtained from examiners 2. Rural study includes non-chronically homeless but all had disabilities											
Seattle	Note: Study based on medians set based on interquartile ranges (IQR)											
San Francisco	Notes: All cost numbers are based on Medi-Cal reimbursement											

Summary of Select Permanent Supportive Housing Cost Studies

(August 2009)

Blue Cross and Blue Shield of Minnesota
P.O. Box 64560
St. Paul, MN 55164-0560
651 662-8000
800 382-2000

July 17, 2012
David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

Blue Cross and Blue Shield of Minnesota appreciates the opportunity to provide comments on the draft document, *Reform 2020: Pathways to Independence Section 1115 Waiver Proposal*, which was released to the public on June 18, 2012, by the Minnesota Department of Human Services (DHS).

Blue Cross is the largest not-for-profit health plan in Minnesota, covering 2.3 million members. Blue Plus, a licensed health maintenance organization, has participated in Minnesota Health Care Programs (MHCP) since 1993. Blue Plus currently has more than 134,000 members in the Prepaid Medical Assistance Program (PMAP), MinnesotaCare and Minnesota Senior Health Options (MSHO) and is the largest health plan serving MHCP members in greater Minnesota.

Minnesota introduced managed care for MHCP over two decades ago because the fee-for-service program left too many enrollees without access to consistent, high-quality medical care. Blue Plus and other managed care organizations made their extensive provider networks available to MHCP members, managed financial risk for the state, and offered a wide variety of care management and other services. Over the years, we have also worked with the state to develop and implement innovative programs such MSHO and participated in stakeholder workgroups for initiatives such as development of the assessment tool known as MnCHOICES. These collaborative efforts have contributed to Minnesota's leadership in access and quality for Medicaid enrollees who participate in managed care. To cite just one example, a recent DHS study found that individuals enrolled in MHCP managed care plans were more likely than fee-for-service enrollees to receive a wide range of preventive services. According to the report, "FFS rates are well below rates that are achieved in the managed care delivery system".[1]

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[1] Robert J. Lloyd, *2010 MHCP FFS and Managed Care Performance Measurement Comparison*, Minnesota Department of Human Services Performance Measurement and Quality Improvement Division (December 2011)

In light of our 20-year history of participation in MHCP, Blue Cross notes with concern that the draft waiver proposal rarely mentions managed care. The document makes an effort to link together the programs and services that will be launched or extended through *Reform 2020*, but it does not describe the context in which these reforms will operate. Because more than 600,000 Minnesotans are enrolled in MHCP managed care plans, this context is necessary not only to help reviewers understand the framework of MHCP – but also to clarify which changes will apply to managed care, fee-for-service or both.

The draft waiver proposal includes a major section on the expansion of the Health Care Delivery System (HCDS) into an Accountable Care Demonstration that encompasses total and partial cost of care arrangements. Minnesota health plans are national leaders in partnering with providers to create innovative payment models, such as Blue Cross' nationally recognized aligned incentive contracts. We believe that successful operation of accountable care models hinges on an active partnership between providers and Minnesota's health plans. Additionally, these efforts should incorporate two important principles that are not clearly reflected in the current draft proposal. The first is simplicity. It is essential to ensure that new models of care delivery and payment result is easier and more affordable access – rather than additional complexity, administrative costs, and discontinuity of care as people move among programs (and between MCHP and exchange coverage after 2014). The second principle is a level playing field. To the extent HCDS/accountable care arrangements take on responsibilities often fulfilled by managed care organizations, they must be held accountable for meeting solvency, coverage and other requirements that apply to MCOs. It is not clear whether the five waivers requested for the Accountable Care Demonstration – especially the two waivers of managed care regulations - would contribute to similar treatment of accountable care organizations and managed care organizations.

The *Reform 2020* proposal also includes important changes that, in some cases, will provide MHCP members with greater flexibility of services and providers. To ensure quality, budget neutrality and enrollee satisfaction, it is important that all parties – MHCP members, providers, health plans and DHS – have a shared understanding of program parameters. The importance of such clarity increases as the program becomes more flexible, and the draft proposal would benefit from revisions to clarify who is and is not eligible for which services. The sections about personal care and transitional services, in particular, currently leave the reader with questions about the services available to people who do or do not meet level of care requirements.

Thank you for the opportunity to provide these comments on the draft waiver proposal. Blue Cross also participated in developing the letter submitted by the Minnesota Council of Health Plans, and we endorse the comments presented in that letter.

Sincerely,

[redacted]

Scott A. Keefer
Vice President
Policy and Legislative Affairs

The Arc
Greater Twin Cities

2446 University Ave. W.
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St. Paul, MN 55114-1740
phone 952-920-0855
fax 952-920-1480

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 644998
St. Paul, MN 55164

Dear Mr. Godfrey:

We are responding to the requests for comments on the **Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal.** Thank you for this opportunity to provide feedback on this important proposal.

For many years, members of The Arc Greater Twin Cities and other members of the disability community have urged the department to transform our service delivery system into a more self-directed and responsive model. We believe that this proposal takes significant steps toward reaching these goals.

There will be challenges in the years ahead in the implementation of these waivers to ensure that these goals remain and do not get lost. We commend the department for embarking upon this path and stand ready to provide as much assistance as we can to fully realize these goals. We urge you to encourage the involvement of individuals and families on the implementation council.

We want to express our full support for the comments that have been submitted by the *Minnesota Disability Law Center* and *The Arc of Minnesota*. There has been a coordinated effort by the *Minnesota Consortium for Citizens with Disabilities (MN CCD)* to present this information to the entire disability community and to gather input.

1.2.2 Demonstration to Reform Personal Assistance Services
We fully support the proposal to adopt the Community First Services and Supports (CFSS) as a Minnesota version of the Community First Choice Option that will expand Personal Care Assistance Services (PCA) and expand self-directed options as previously authorized in the 1915(K) option. However, the redesign of the current PCA services must minimize service interruption to current users.

The definition of dependency should be changed to include persons who need **prompting and cuing** to accomplish ADLs and health-related tasks.

1.2.3 Demonstration of Innovative Approaches to Service Coordination (Children with CFSS).
There has been a goal of better integrating school and home and community-based services for children. However, we are in agreement that the proposal to promote coordination with school services for children who have two or more complex health-related needs, receive mental health services, or exhibit physical aggression will not work well in school districts because of the lack of experience and knowledge base of school staff in serving the individual needs of children outside of the school setting. This was tried in the past with the IIIP process; that system did not work to support students and families.

1.2.5. Demonstration to Empower and Encourage Independence through Employment Supports

We support increased efforts around employment for persons with disabilities. Individuals with disabilities are significantly over-represented among citizens who experience long-term poverty. Without an increase in competitive employment, individuals with disabilities will continue to have limited access to the opportunities, choices and quality of life available to other citizens. We ask that the reform emphasize competitive employment as a desired outcome.

1.2.6. Housing Stability Services Demonstration

We support the proposal to expand housing options for persons with disabilities. Housing services are one of the most critical services for assuring that vulnerable individuals retain the supports necessary to remain in the community. We have worked with the Housing Access Services Program (HASP) and know that providing a full range of supports that begins with lifelong planning is beneficial to the individual and is also cost-effective.

9.12 Services for Children with Autism

As part of the Reform 2020 Medical Assistance (MA), DHS has proposed providing treatments and services to children with autism under a coordinated "Autism Benefit Set." DHS's written proposal purports to provide more streamlined services to children aged 0 through 7, while requiring children over age 7 to receive services through the public school system. This is a reduction of service.

The Arc Greater Twin Cities is very concerned about the lack of detail in the proposal and any age limit on services. Services should be based on need. The plans outlined lack emphasis on service quality and provider standards. It is extremely important that all children who have autism receive MA coverage for medically necessary care. Families of children with autism need affordable access to a range of options for treatments, services and supports.

Thank you for the opportunity to comment. We believe your efforts to welcome and incorporate stakeholder involvement in these reform initiatives will continue to be critical for creating effective and safe services. We look forward to opportunities for continued input through the Implementation Council and other stakeholder work groups and meetings.

Respectfully,

Debbi Harris
Board Chair

Gene Martinez
Senior Public Policy Advocate

From:	Weeks, Stacie <sweeks@mnlsap.org>
Sent:	Tuesday, July 17, 2012 4:13 PM
To:	*DHS_Reform2020Comments
Cc:	Godfrey, David W (DHS)
Subject:	UPDATE to Legal Aid Comments to Reform 2020 Waiver
Importance:	High

Hi,

My sincere apologies! There was a mistake in our first submission of comments to the Reform 2020. Please replace that submission with this submission of comments (See below, and attached for the word version.) Again my apologies for any administrative burdens this may cause. Please don't hesitate to call if you have any questions. If you need a signed version, please let me know.

Thank you!

Stacie

****

Stacie L. Weeks, JD, MPH
Staff Attorney, Legal Services Advocacy Project
651.842.6903 (Office); 612.354.6889 (Cell)

July 17, 2012

VIA EMAIL

David Godfrey, Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164-64998

Re: Comments on Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal

Dear Mr. Godfrey:

The Legal Services Advocacy Project (LSAP) appreciates the opportunity to submit comments on Minnesota's Reform 2020 Section 1115 Waiver Proposal. LSAP is a statewide division of Mid-Minnesota Legal Assistance, which advocates on behalf of all low-income individuals and families in Minnesota.

COMMENTS

I. Section 3: Accountable Care Demonstration

LSAP strongly urges the Department to establish robust consumer protections and accountability measures for the accountable-care demonstration. This includes, but is not limited to, creating requirements for direct notification to patients of their assignment to an ACO, their rights regarding that assignment, any limitations on access to providers and how they can overcome these limitations, and easy and accessible appeal processes to redress future issues or complaints. LSAP also recommends that the Department create guidelines and evaluation procedures to ensure the dissemination of information and delivery of care is conducted in a culturally and linguistically appropriate way.

LSAP has concerns regarding the Department’s request to waive patients’ freedom of choice of provider. Waiving such choices has the potential to result in an adverse impact on access to and continuity of care. This is especially true for underserved or more remote areas of the state, where there are typically a limited number of providers and venues for accessing care.

For this reason, LSAP respectfully requests that the Department build in further consumer protections that specifically look at access issues. This includes, but is not limited to, regular data collection and tracking of health care access, adequate safety-net programs and provider networks, mechanisms to ensure continuity of care, and an easy and accessible appeals process to obtain care outside the accountable-care program to ensure that the patient’s health outcome remains paramount to any short-term savings.

II. Section 8: Eligibility for Adults without Children

a. Asset test for adults without children in Medical Assistance.

LSAP strongly opposes the waiver request to impose an asset test of $10,000 on adults without children who are enrolled in Medical Assistance. Asset-test policies discourage individuals from building the savings and assets they need to become self-sufficient and financially stable. Asset tests also add an unnecessary administrative burden and cost to the system, which conflicts with the state’s current efforts to improve public-program efficiency.

Moreover, the federal Affordable Care Act (ACA) explicitly prohibits states from using asset tests for determining eligibility in the Medicaid Expansion program (adults without children) and applies this prohibition in 2014 to most Medicaid eligibility categories. Therefore, like adults without children, parents will no longer have an asset test—unless they are elderly, medically needy individuals, eligible because of other aid or assistance, or individuals who are eligible for Medicare cost sharing.

LSAP believes that, if the state is to achieve the stated goal of equity in eligibility rules for Medicaid enrollees, Minnesota should be moving away from asset tests, altogether, in accordance with the ACA, instead of reinstating such tests for adults without children.

b. 180-day residency requirement for adults without children in MinnesotaCare.

LSAP strongly opposes the reinstatement of the 180-day durational residency requirement for adults without children in MinnesotaCare. LSAP believes reinstating such a requirement would be not only bad policy, but also unconstitutional under the Fourteenth Amendment of the U.S. Constitution.

In *Saenz v. Roe*, 526 U.S. 489 (1999), the U.S. Supreme Court ruled that states were not free to condition the receipt of financial assistance through the imposition of residency tests that limited benefits for newly arrived residents, based on need. The Court concluded that such provisions violate the third component of the constitutionally protected right to travel by imposing a discriminatory classification on travelers who have elected to become permanent residents of the state in which they are being denied benefits. At this time, LSAP is unaware of any U.S. Supreme Court decisions that have modified or overturned the *Saenz* decision.

c. Fiscal Analysis for Reform 2020 Section 1115 Waiver

> LSAP appreciates the information as provided in this proposal. However, it is difficult to make a full assessment of this waiver without fully understanding its overall fiscal impact. Therefore, LSAP respectfully requests a fiscal analysis of Reform 2020 Section 1115 Waiver. For this reason, LSAP respectfully reserves the right to amend its comments to the waiver once this aspect is provided and reviewed.

CONCLUSION

LSAP appreciates the opportunity to provide comments on the Reform 2020 Section 1115 Waiver Proposal. We also appreciate the Department's efforts to provide public forums for discussion and review of the information in this proposal and look forward to future discussions.

Respectfully submitted,

Stacie L. Weeks, JD, MPH
Staff Attorney

July 17, 2012

Mr. David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN   55164

Dear Mr. Godfrey,

On behalf of nearly 700,000 members in Minnesota, AARP appreciates the opportunity to submit the following comments in response to the Minnesota Department of Human Service’s (DHS) Reform 2020: Pathways to Independence, Section 1115 Waiver, hereinafter referred to as the “Pathway waiver.” We will also provide comments on reform proposals under 1915i, 1915k and other state initiatives.

AARP applauds the Department for taking on such a huge undertaking, and recognizes the enormous challenges our state faces both in terms of an aging population, as well as the budget pressures of how we will pay for this care.

As a result, AARP is supportive of the Department’s efforts to reform the system to be more person-centered in order to achieve better outcomes and efficiencies, improve health, and reduce reliance on institutional care with the goal of creating a system that can most effectively meet the need of an aging population.

We remain concerned, however, that the Medical Assistance (MA) State plan and Essential Community Supports may not be adequate to meet the needs of those terminated from eligibility for the Elderly Waiver because they no longer meet the Nursing Facility Level of Care (NF LOC) as is recommended in the Long Term Care Realignment 1115 Waiver -- submitted previously to the Centers for Medicare & Medicaid Services (CMS).

Thus, we urge the Department to continue exploring ways to mitigate the potential harm to these seniors by exploring how the application of the 1915i state option might be broadened beyond just the recommendations set forth in the Pathway Waiver to address the loss of coverage. As the Department acknowledges, the 1915i state plan option permits states to target populations with specific services packages but it also allows the state to require eligibility criteria that are more stringent for institutional services than the criteria for community services.

On the following pages, are additional comments as they relate to the Pathway Waiver, including the development of new delivery reform models through Accountable Care Organizations (ACOs), Personal Care Assistance (PCA) Services Reform, and the Expansion of Transition Services, along with several other initiatives.

Accountable Care Demonstration – The Need for More Detail on Consumer Protections

AARP supports the development of new care models through Accountable Care Organizations (ACOs) to address barriers and fragmentation of care delivery, and to better align the financial incentives to provide and improve the quality of care. However, AARP believes delivery reform will not succeed without beneficiary acceptance of new care models and active patient engagement in their care. We believe beneficiaries need clear and consistent information before they decide to receive care from a clinician or institution participating in an ACO.

Thus, we urge the Department to provide more specificity around the development of consumer protections in these models and to provide more detail around the risk-sharing mechanisms. In particular we would like to see more detail around the following consumer protections:

- Development of an Independent Complaint and Appeals process for consumers to file complaints or grievances.
- Adequacy of Provider Networks—including geographic proximity of providers.
- Transparency of risk/gain sharing arrangements and mechanisms that avoid either windfall profits or devastating losses.
- Enrollment and Opt-Out Provisions for consumers who choose not to enroll in the ACO.

Demonstration to Reform Personal Care Assistance (PCA) Services

AARP supports efforts to reform PCA Services to enable Minnesota to provide person-centered, consumer-controlled, home- and community-based attendant care services through the application of the 1915k and 1915i state plan options. AARP has a long history of working to ensure people age with choice, independence, and dignity. Community First Services and Supports (CFSS) – which will replace our current PCA benefit under the state plan – can take us a long way toward achieving a person-centered, cost-effective, long-term care system in Minnesota. In addition, it will provide a six percentage point increase in federal matching assistance payment (FMAP). Below are our specific comments related to the new CFSS demonstration:

1. **Use of 1915i in the State Plan Option for individuals who do not meet an institutional level of care -** We are pleased that the Department intends to use the 1915i option which allows our state to provide PCA services to individuals who do not meet an institutional level of care, but choose the PCA self-directed option. Also, we appreciate that the Department will apply the special income eligibility rules used for home and community based waivers to a portion of the population that would receive CFSS, but we would encourage the Department to extend this to all individuals in the demonstration, including those who do not meet the institutional level of care. We believe the special income rules will ensure that all individuals have adequately resources to pay for all of their household expenses in order to live independently in the community.

   As we stated in our opening paragraph, we continue to urge the Department to consider using the 1915i application for seniors who no longer meet the NOLC under the 1115 Long Term Care Waiver. We suggest this because we believe the new ECS program will not be as adequate to meet the needs of many seniors who are currently on the Elderly Waiver program. Additionally, we believe it is consistent with the Department's desire to streamline and simplify the complexities around the myriad of home and community based waiver programs.

2. **Addition of Care Coordination and other services with PCA Services -** AARP supports the provisions in the CFSS option to expand services provided under the PCA self-direction option to include home care targeted case management and service coordination, along with other services such as assistive technology, environmental modifications, skill acquisition and assistance with activities of daily living which includes household chores, shopping and other tasks to maintain independence in the community. However, we believe that PCA services must be restored for those individuals needing prompting and cuing as a dependency. This includes individuals with cognitive limitations, mental illnesses or brain injuries. Finally, we are hopeful that the addition of home care targeted case management for those who choose self-direction may help to address Minnesota's low ranking in home care quality indicators scores.

3. **Criteria for PCA Services which do not align with the Level of Care Criteria -** Under current rules PCA services require meeting criteria that is stricter than the proposed Nursing facility Level of Care. We do not believe that it is consistent for someone to be eligible for an institutional level of care and not be eligible for PCA services. PCA services are actually broader, and therefore anyone who meets institutional level of care should also meet the criteria for PCA services.

Demonstration to Expand Access to Transition Services

AARP strongly supports the proposal to expand access to transition services, including the addition of the long term care consultations and to receive federal matching dollars for these services. With the population rapidly aging in our state, it will be important to offer long term care planning earlier and more often. At AARP, we hear from consumers who tell us that making decisions about long term care planning can be very confusing and that more often than not, families wait to make decisions until a crisis occurs. Thus, there is a real need for more unbiased information for consumers on long-term care planning, along with critical information on financial options.

Long-term care consultation helps consumers understand the costs and choices in available to them, whether that be in a nursing facility, housing with services or at home, where most people prefer to be. In addition, this is projected to save the state millions of dollars, as consumers are expected to stay in their homes longer rather than spend down their assets sooner when they move into more expensive Assisted Living.

Additional Proposals:

Use of 1915i state option for those People with Complex Needs - AARP supports expanding the 1915i state option for those with complex needs, including adults with co-occurring developmental or cognitive impairments and serious mental health conditions.

Lifting the Cap on Medically Complex Seniors who are Vent Dependent - AARP is supportive of this provision which allows individuals who are accessed at this level of need to continue to receive Elderly Waiver Services in their own home or in a housing with services setting, rather than living in an institution to receive this kind of needed care.

MA Eligibility for Adults without Children - We oppose the waiver request to make eligibility more restrictive for Medical Assistance and MinnesotaCare by imposing a residency requirement of 180 days and establishing an asset test of $10,000 for adults without children who have incomes under 75% of the Federal Poverty Level. We believe this will force more people onto the rolls of the uninsured, and thus cost the state more.

Strategies for Integration of Long-Term Services and Supports with Other Initiatives, Health Home Demonstration - We are very supportive of the many proposals to integrate long term services and supports into the state certified health homes; the development of the Alzheimer's Health Care Home Demonstration to implement an integrated primary health and community service model for patients with Alzheimer's disease; and the health home demonstration to integrate behavioral and physical health care for people with mental illness.

In conclusion, AARP believes that the Pathway Waiver -- along with many of the other proposals being undertaken by the Department -- are generally consistent with AARP's goal of ensuring that people have the quality services and supports they need to stay in their homes and communities, instead of more costly institutionalized care. Nevertheless, we remain concerned about the adverse impact the 1115 long term care waiver may have on some seniors who may lose coverage under the EW program and thus would encourage the Department to look at the 1915i state plan option for this population similarly to what the Department is doing with other populations in the Pathway Waiver.

Again, thank you for the opportunity to comment. If you have further questions or need additional information, please do not hesitate to contact me or Mary Jo George, AARP Associate State Director for Advocacy at mgeorge@aarp.org or at 651-271-6586.

Sincerely,

Michele H. Kimball
Director

From: Burandt, Barbara J <Barbara.Burandt@allina.com>
Sent: Tuesday, July 17, 2012 4:05 PM
To: *DHS_Reform2020Comments
Subject: Comments from MNHPC

Palliative Care Services

The Minnesota Network of Hospice and Palliative Care (MNHCP) is an organization whose mission is to promote quality of life in our communities. Our goal is to increase understanding and access to the following vital components of healthcare: advance care planning, palliative care, and hospice services.

MNHCP proposes palliative care services be included as an essential benefit in the Minnesota Health Care Reform 2020. These services are provided to adults, children, and the families of those experiencing a serious and/or life-limiting condition.

Palliative care services offer:

- relief from pain and other uncomfortable symptoms;
- assistance with difficult medical decision making throughout the continuum of care;
- coordination of care services and assistance in navigating the health care system;
- guidance in the development of a plan for quality living based on needs, concerns and goals of care;
- emotional, psychosocial, and spiritual support to patients and their families.

Palliative care, available from birth to adulthood, has the goal of improving the quality of a seriously ill person's life and providing community-based support to patients and families from the time of diagnosis. This differs from hospice care, which focuses on relieving symptoms and supporting patients with a life expectancy of months, not years.

Palliative care, when included in a benefit package, will support robust primary care, facilitate care coordination to reduce fragmentation in the health care delivery system, improve quality of life, and lower the cost of non-beneficial care.

For these reasons, MNHCP strongly believes palliative care services are an example of high quality, cost-effective care and must be included in the Minnesota Health Care Reform 2020.

Links:
https://www.revisor.mn.gov/statutes/?id=256B.021.
http://www.icsi.org/search.aspx?searchFor=palliative+care.
http://www.stratishealth.org/expertise/longterm/palliative.html

Barbara Burandt PHN
MNHPC Chair
Public Policy Committee
Barbara.burandt@allina.com

Southern Prairie Health Purchasing Alliance

Alliance member counties: Chippewa, Cottonwood, Jackson, Kandiyohi, Lincoln, Lyon, Murray, Nobles, Redwood, Rock, Swift and Yellow Medicine

July 17, 2012

Delivered via email to: Reform2020Comments@state.mn.us
David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55163

Re: SPHPA Comments to Waiver Proposal Draft

Dear Mr. Godfrey;

Southern Prairie Health Purchasing Alliance (SPHPA) is pleased to submit comments to the draft *Reform 2020* Section 1115 Medicaid Waiver Request that was released for public review on June 18, 2012.

SPHPA is a developing collaboration in the12 counties in rural southwestern Minnesota that are named above. The Counties have been working together for more than five years to develop a new approach to care delivery for the population that lives and works within our borders. Our developing model features a partnership between the Counties, tribal services, local providers and community services, and is focused on assuring improved care coordination, improved health outcomes and cost savings. The model we envision is much like what has been described on page 21 of the Waiver Request draft regarding Hennepin Health.

We are pleased to read that the State supports the need to better coordinate and integrate these services in order to best support our residents who are enrolled in public programs. While we are ready to respond to the next round of RFPs for Health Care Delivery System Demonstrations, we would encourage the State to consider the following:

- Implementing the proposed Integrated Care Partnerships (ICSPs) for the dually eligible population as an intermediate step toward full risk or partial risk sharing with provider systems, may not be necessary. The continued involvement of health plans may delay achieving the goals outlined in the Waiver Request draft – holding providers accountable for care and outcomes.

- Initiating an additional round of stakeholder input into the major design elements and policy decisions, before releasing the next version of a proposed model and RFP, will likely delay the process for those provider groups who are ready and eager to move forward. While we appreciate the importance of open dialogue, we would welcome the opportunity to begin a demonstration of our model in 2013. We are willing to be a 'blended' demonstration for the State by providing the integration of county health and social services with medical care (as is being tested by Hennepin Health), along with moving forward with a robust reward-sharing Health Care Delivery System demonstration, while also providing many of the health plan 'back office' functions (such as claims payment, enrollment, etc.). We are not a health plan, so taking insurance risk for those participating in our program is not an option at this point. We are more than willing to eliminate the duplicative functions that now occur at the health plan level and provide them at the delivery networks level.

- The Waiver Request draft indicates that counties, tribes, and other community organizations 'can and will be encouraged' to participate in integrated care provider organizations. We suggest that counties must take on leadership roles in developing these organizations in rural areas. Counties are the safety-net for residents who fall through the cracks of the current 'medical' system and for those whose behavioral and mental health issues prevent them from accessing support.

- Data collection and sharing across the team of service providers is critical to the success of these projects. There is a need for both an immediate exchange of key indicators for service delivery purposes and a need for complete data on all services received for population health management and financial accounting. We applaud the State's vision to include in the Waiver Request authority to share data between the state, providers, health care and welfare systems. However, the challenge from our perspective is how to fund the cost of developing data warehousing structures and analytic capabilities. We would encourage the State to think creatively about how it can facilitate financial support for these activities and prevent each accountable network from having to 'recreate the wheel' in this regard.

We appreciate the opportunity to provide our thoughts on the Waiver Request draft and to provide you with a brief description of our vision for the future of health care delivery in rural Minnesota. Please contact me directly, at 507.215-2280 or email jmfischer@starnet.com if you have any questions.

Sincerely,

Mary Fischer
Executive Director

From: [redacted]
Sent: Tuesday, July 17, 2012 3:42 PM
To: *DHS_Reform2020Comments
Subject: [redacted]

My nephew [redacted] has autism. He is unable speak but communicates his needs non-verbally. He attends the [redacted] and it has changed his life. He reads, follows directions and is much calmer since he has been at the [redacted]. [redacted] will not outgrown autism. The need for him to attend the [redacted] is crucial to his family and to [redacted] development.

Kids don't grow out of autism by age 7 so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted] [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

My name is:

[redacted]

[redacted]

Sincerely,
[redacted]
Aunt to the amazing [redacted]

From: Heather Kilgore <Heather.Kilgore@PACER.org>
Sent: Tuesday, July 17, 2012 3:02 PM
To: *DHS_Reform2020Comments
Subject: PACER Center Comments on Reform 2020: Pathways to Independence proposal

David Godfrey, Medicaid Director
Minnesota Department of Human Services

Dear Mr. Godfrey,

Thank you for the opportunity to comment on the draft Section 1115 Waiver Proposal "Reform 2020: Pathways to Independence." As a nonprofit parent center, PACER has worked to ensure inclusion of children and youth with disabilities in their educational, recreational, and other community settings to the greatest extent possible. Minnesota has been a national leader in the quality of service and commitment to supporting individuals with disabilities in achieving their fullest potential in the community. PACER commends the efforts and commitment of the MN Department of Human Services (DHS) and others in seeking to continue this history while reforming services and supports for individuals with disabilities. PACER's comments focus on three proposed demonstration projects: Section 4 - Demonstration to Reform Personal Assistance Services and Demonstration of Innovative Approaches to Service Coordination (Children with CFSS), and Section 9.1.2 – 1915(i) for Children with ASD Diagnosis.

Section 4: Demonstration to Reform Personal Assistance Services

PACER supports the intent to focus the reform of personal care assistance services on consumer direction. Improving personal care assistance services will allow more individuals to live independently, and will have a long term positive effect on individuals with disabilities and their families and communities. The newly renamed program, Community First Services and Supports (CFSS) includes expanded eligibility and increased minimum levels of service. PACER supports these two improvements, and many of the families we serve, who have children and youth with disabilities and/or special health care needs would benefit from these reforms. PACER also supports the efforts to streamline and simplify the access and planning for CFSS. A particularly important reform is the added flexibility of the CFSS program to include skills acquisition and assistive technology. The addition of service coordination for those individuals not already receiving case management will be a critical improvement.

These reforms will require frequent and clear communication with individuals and families, and PACER encourages DHS to include community-based disability organizations as partners in communicating these changes. Through training and individual assistance, PACER assists many families to navigate the current PCA system, and would welcome the opportunity to provide additional services for families. PACER also urges additional efforts at recruitment and retention of qualified staff (including relatives) to provide CFSS because the supply of appropriate, reliable, and skilled PCAs has never fully met the need across the state. Finally, PACER encourages that the training provided to existing and new case managers and those providing the expanded service coordination under the new CFSS program include information on the unique needs of children and youth with disabilities and special health care needs and their families.

PACER has significant concerns with the Demonstration of Innovative Approaches to Service Coordination (Children with CFSS) proposed project. The description of this demonstration raises many questions for PACER as a parent advocacy organization. Though school districts would be chosen based on their willingness to participate, would families have the same ability to opt out? It is critical that families are able to choose whether or not to have school-based service coordination, and still retain access to home care service coordination. Because PACER's primary advocacy services are related to schools and students in special education, we urge close collaboration with school staff and the Minnesota

Department of Education in designing this demonstration. The full support of the school will be critical, particularly for the level of training that a school-based staff member would need to fully coordinate CFSS services for a family.

Section 9.1.2 – 1915(i) for Children with Autism Spectrum Disorder (ASD) Diagnosis

PACER supports the stated intent to deliver coordinated early intervention services for children ages 0-7 with a diagnosis of ASD, including “service coordination, evidence-based behavioral interventions, family psychoeducation, psychological counseling, state plan medical services, and respite.” The need to provide children with ASD and their families with comprehensive services and supports is long overdue. PACER has major concerns with ending this comprehensive approach at age 7 and with the reliance on the Individualized Education Program (IEP) for special education under the Individuals with Disabilities Education Act (IDEA) for services for students with ASD over age 7. The idea of increased integration of Medicaid entitlement programs with the Free Appropriate Public Education (FAPE) mandate under IDEA has complex ramifications for schools and families. PACER has an issue with the lack of detail included in this proposal, as this section raises many questions and offers few answers. PACER urges close collaboration with the Minnesota Department of Education, as well as with parent advocacy organizations specializing in special education if this effort is to move forward.

PACER commends DHS staff for their efforts at reforming Minnesota’s Medicaid programs to better support individuals with disabilities and their families in their communities. Many of the reforms outlined in the Section 1115 Waiver Proposal “Reform 2020: Pathways to Independence” will improve the lives and expand the opportunities for Minnesotans with disabilities. PACER has concerns about the coordination of these reforms with special education under IDEA, the impact on services for children and youth, and with the availability and training of staff and home care service coordinators under the proposed CFSS program. We look forward to participating in further discussions as the process moves forward.

On behalf of PACER Center, thank you for your consideration. We may offer further comments as the process unfolds.

Sincerely,

Paula F. Goldberg, Executive Director
PACER Center
Wendy Ringer, Director
PACER’s Health Information and Advocacy Center

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey,

Lutheran Social Service of Minnesota (LSS) applauds the Department of Human Services for the values of self-direction, personal choice, individualized planning, and quality outcomes that have been driving the Medicaid Waiver process, and led to the development of the *Reform 2020* proposal. I agree with the stated *Reform 2020* goals of better outcomes, the right service at the right time, and ensuring the sustainable future of long term services and supports.

The comments to follow suggest areas where *Reform 2020* can be enhanced to communicate the depth of commitment found in Minnesota to assuring that each individual with a disability is seen as a unique individual, and is understood first for their abilities to design their own life and not have anyone else design it for them. Minnesota will have achieved true reform when each person with a disability is able to achieve optimal quality outcomes and community integration because using the tools afforded by Medicaid supports, they are living their choices and thereby pursuing their life's dreams.

The identifying characteristics that are fundamental to this vision include:

- The system of supports first sees each individual from a standpoint of ability, and asks how supports can be designed to maximize their design for full life in community.
- Service options are easily accessible; the system is navigable so individuals with disabilities and their trusted partners have the tools and information needed to implement their life plans.
- Quality outcomes are set by the individuals and relate intimately to achieving their personal life goals.
- Choice and achievement of personal goals are the driving forces for evaluating plans, and are values that drive licensing functions to focus on personal outcomes and quality of life.
- Individuals with disabilities are knowledgeable of all financial resources available to them and where they have flexibility in spending resources to meet their needs.
- Annual budgets for people with disabilities include accrued savings.
- Minnesotans expect to see and benefit from the full inclusion of their neighbors with disabilities as they creatively engage in all facets of public and private life.
- Full implementation of the Americans with Disabilities Act – with special attention to the standards developed to empower personal choice.
- Simplification of case management that allows for a single case manager, chosen by the individual, who can support full implementation of the individual's life plan. The case

manager should be any person or provider selected by the individual with a disability, and can be hired and fired at will by the individual.

Specific recommendations and edits, numbered one through five below, for *Reform 2020*:

1. System reform can shift the discussion away from the individuals the reforms seek to support. Though there is collective interest in assuring all people with disabilities in Minnesota benefit from *Reform 2020*, the framework of the proposal does not explicitly focus attention on how the proposed benefits will impact individuals. Attached is an edited version of the *Reform 2020* Executive Summary, pages 10-12, changed in tone to reflect the focus on individuals with disabilities in Minnesota.

2. Personal choice as a guiding goal and principle for *Reform 2020* must be accompanied by a robust budgeting tool that affords each individual with a disability the opportunity to fully understand resources they are eligible to utilize. With this full knowledge, people with disabilities and their trusted partners will have true self-direction.

Suggested edit, page 37, add in the first section:

- Build off of the MnCHOICES assessment a complete budget that presents to each person their global individual budget with explanation of how each funding stream applies to them and how it may be utilized to support their life plan (eg. use of funds for Housing, Employment, SNAP and other supports that relate to each person's eligibility). Achievement of this goal would be that the person would be able to decide how to flexibly utilize resources allocated to them in any way they chose (eg. saving on housing and spending more on employment).

3. The Partners Panel has advised throughout the waiver design process that a thoughtful discussion of personal choice and associated risk must be a priority for public deliberation. Achievement of the goals of the proposal require that the understanding of choice and risk and associated system behaviors be updated to reflect the goal of full self-direction and optimal self-determination. There appears to be significant tension between standards aimed at protecting "vulnerable adults" from making choices which may cause them harm and potential tort liability for a provider organization and the ADA which prohibits consideration of risk to self when a person with a disability is otherwise eligible to participate in a program or activity. These issues must be part of the continued stakeholder work, held within the Development and Implementation Council.

Suggested edit, page 38 paragraph three, beginning line three: We will expand participation in the next phase of development and form a separate Development and Implementation Council during the summer of 2012 that will assist the Department in the more detailed planning and protocols, including incorporating the value of person-centered approaches and genuine self-direction with choice and risk into operational structures, that will be necessary when preparing legislation for action by the 2013 Minnesota Legislature, and implementation plans to terminate the PCA program, and establish the Community First Service and Support in its place.

4. Minnesota was early to create opportunity for self-direction and thus has a long track record of effective Fiscal Support Entity (FSE) engagement. New Fiscal Management Entity (FME) contracts established to support exponential growth in self-direction should build off of the proven track record of current FSEs to assure that the quality of service, local knowledge and principled leadership found in the FSE system continues.

Suggested edit, page 39 paragraph three, beginning line three: Candidates will be evaluated based on proven track record of self-directed service within Minnesota, holding appropriate current state credentials, and demonstrating quality of service. FMEs will sustain and enhance current FSE best practice including streamlining services by charging FMEs to complete plan approval and authorize services, and maintaining the high quality, high touch customer service provided to Minnesota today.

5. Demonstrating success must include metrics that reflect the quality of self-direction obtained through implementation of the waiver proposal. Evaluation metrics should include outcomes that speak to quality and rigorous assessment of whether true self-direction has been achieved

Suggested edit, page 108, add to Major Outcomes:

Survey data of CTSS participants to measure personal response on questions of achievement of true self-direction, personal choice, individualized planning, and community integration.

Quality Council cumulative report on Value Of Individual Choices and Experiences (VOICE) reviews conducted with individuals using CTSS. Reportable measures will speak to the VOICE areas of basic assistance, special assistance, relationships, choice, inclusion, economic support, safety and dignity, and coordination.

Lutheran Social Service of Minnesota remains committed to people with disabilities in Minnesota living a “My Life, My Choices” life as soon as possible. I am grateful for the opportunities we have had to contribute to the development of *Reform 2020*. LSS is ready to assist the Department in advocating for the quickest possible turnaround of the proposal at CMS.

Thank you for your commitment to people with disabilities in Minnesota living fully human lives of their own design.

Sincerely,

Jodi Harpstead
CEO

Attachment:
Reform 2020_1 Section One_Executive Summary

The MN Consortium for Citizens with Disabilities
800 Transfer Road, Suite 7A
Saint Paul, MN 55114
Phone: 651-523-0823 ext. 112
Fax: 651-523-0829
www.mnccd.org

To: David Godfrey, MN State Medicaid Director

From: The MN Consortium for Citizens with Disabilities

Re: Public Comments on the Reform 2020 Section 1115 Waiver Proposal

Date: July 17th, 2012

On behalf of the Minnesota Consortium for Citizens with Disabilities (MN-CCD), a state-wide, cross disability public policy coalition, we thank you for the opportunity to submit public comments on the Reform 2020 Section 1115 Waiver Proposal. We agree with the proposal's identified goals of achieving better health outcomes, simplifying programmatic administration and access, ensuring the long term sustainability of the Medicaid program, increasing the flexibility and responsiveness of the LTSS system, and supporting Minnesotans to have a meaningful life at all stages according to their own desires. These proposal goals align well with the three founding principles that guide MN-CCD in our disability policy advocacy work: access to needed services, empowerment and choice, and quality of care.

However, despite the strong alignment between the high level proposal details and MN-CCD's guiding principles, we are all aware of the critical and significant implementation and operational decisions that have yet to be made and that will greatly determine the impact of this proposal on the lives of Minnesotans with disabilities. To that end, below we have outlined specific opportunities that we see for further developing the proposal in such a way that it positively impacts Minnesota's disability community. We have structured our comments around some of the specific initiatives included in the proposal that we feel will most significantly impact Minnesota's disability community. Many of our member organizations (disability advocacy and provider organizations across the state of Minnesota) will also be submitting public comments that will touch on the specific initiatives below as well as other proposal components of interest to the disability community. We are happy to discuss further any of the points below. Again, thank you for the opportunity to provide comments on the proposal.

Section 3: Accountable Care Demonstration

MN-CCD agrees with the overall vision of this section of restructuring provider incentives such that providers are discouraged from providing care in ways that shift costs to other parts of the service system. For Minnesotans with disabilities, a population that can have complex health and long term service needs, this step towards more fully integrating various care needs is positive.

In the "next steps" section of the Accountable Care Demonstration section, an upcoming (Spring 2013) RFP process is described that will allow direct provider contracting with integrated care provider organizations. The proposal describes a stakeholder process that will take place prior to the release of the RFP, and we at MN-CCD encourage the administration to ensure that attention to consumer choice is a formal and explicit agenda item for this stakeholder process. As this proposal describes, Minnesota is currently moving forward with a great number of positive initiatives focused on the provision of healthcare for the disability community. We as a state must make sure that each of these initiatives supports choice for the consumer in how, where and when they access their healthcare and other care needs.

In addition, we continue to have serious concerns about the integration of long-term services and supports (LTSS) with health/medical care because of the likely emphasis on the medical model of service provision. While we certainly support effective coordination of health care and LTSS, we oppose control over all of one's LTSS services by a medical care provider without experience in housing, employment, transportation and social relationships in the community. Rather than assigning medical entities or health plans the authority and risk for every project, we recommend seeking proposals where the community support providers are in charge and can subcontract for medical services. This would be of particular value for persons with high LTSS costs and average to low medical costs or those whose costs are quite stable year to year. We think it is essential to assure that persons who need long-term support services to remain as independent as possible in their communities are able to direct their own services based upon a person-centered plan rather than directed by a medical clinic or hospital. We urge that this proposal include clear safeguards, data reporting, appeal rights and disability-relevant outcome requirements for the provider.

Section 4: Demonstration to Reform Personal Assistance Services

MN-CCD agrees with the overall vision of this section of transforming the current PCA program into a new CFSS program with increased flexibility and overall programmatic simplicity. As has been identified and articulated in multiple studies and reports, the PCA program is a critical service for thousands of Minnesotans with disabilities, so this transition to a new program will be significant. We look forward to working with the administration on the development of the details of this transition, as there is not a great deal of detail in the proposal given how significant this change will be (perhaps understandably as this allows for increased stakeholder input as to the operational details).

We strongly support the proposal to use both the 1915k option and 1915i option in order to continue serving people who do not meet Minnesota's institutional level of care criteria. This is especially important given Minnesota's pending request to make the nursing facility institutional level of care (NFLOC) criteria more stringent, thus eliminating eligibility for important Home and Community-Based Services Waiver programs (EW, CADI, BI) for many people who need assistance to remain in the community. Additionally, we urge inclusion of institutions for mental disease (IMD) as an institution for the level of care requirement in CFSS, as allowed under federal law. We also support the increase in the minimum amount of time for persons who have one dependency in an activity of daily living (ADL) or Level 1 behavior to at least 90 minutes per day.

We urge that the Department of Human Services (DHS) retain the PCA Choice Option by offering three models for CFSS: a fully agency directed support service; an agency service which maintains the beneficial aspects of the PCA Choice Option, such as choosing your staff, training and scheduling; and the new self-directed option with an individual budget. We believe that many people currently using the PCA Choice Option will be reluctant to choose the totally self-directed option, at least initially. These individuals will be hurt by losing the self-directed authority they now have and by a reduction in their PCA staff wages. Clearly the pay for PCAs can be higher in the PCA Choice Option because nurse supervision and other administrative costs are lower for the agency. An abrupt decrease in the hourly wage of many PCAs will threaten the well-being of all current PCA Choice recipients.

We are in strong support of the self-directed option under CFSS with an individualized budget. We urge that the budget administrative cost be carefully determined with input of stakeholders so as to provide the maximum amount to the eligible individual for services.

The 1915k State Plan Amendment Option offers other beneficial aspects, such as skill acquisition, assistance with health tasks and an updated description of instrumental activities of daily living, which includes traveling and participating in the community, as well as communicating by phone or other media, shopping, essential household chores, managing finances, meal planning and other tasks related to maintaining independence in the community.

In addition, the 1915k option requires that assistance and supports be provided in the most integrated settings without regard to the type of disability, age or type of assistance needed to live an independent life. We strongly support these important requirements and believe that a reformed PCA program can offer more flexibility and assistance in tasks needed for persons with disabilities to remain as independent as possible in their communities.

On page 38 of the Reform 2020 proposal, a “Development and Implementation Council” is referenced. It appears that this development and implementation council will be responsible for providing recommendations to the administration on a number of critical issues associated with the transition from PCA to CFSS. We strongly encourage the administration to ensure representation of service recipients (this is already identified as a requirement in proposal) as well as service providers who have expertise in providing PCA services on this implementation council. Specific critical decisions will likely be made by this implementation council, including what will be considered allowable and unallowable expenditures from an individual’s CFSS budget, as well as how the identified service needs will be met through the CFSS program. These types of decisions will greatly impact how this program does or doesn’t work for those who access it, so we strongly urge the administration to seek out the expertise of those who have been accessing and providing PCA services for a number of years here in Minnesota. We, as MN-CCD, would be happy to help connect service recipients and providers with the administration to this end.

Additionally, on page 39 of the proposal, language describes the planned change that will take place in transitioning from Fiscal Support Entities to Fiscal Management Entities. The language indicates that “the final number of entities will be limited, although adequate in number to allow individuals a choice between at least two entities, regardless of where they live in the state.” Given the dramatic reduction this will be from the current number of FSEs here in MN, in moving forward with this specific component of Reform 2020 we would encourage the administration to ensure that individuals will indeed have meaningful choice between at least two high quality providers.

Section 4.23: Demonstration of Innovative Approaches to Service Coordination for children with CFSS
We urge that DHS find another way to assure coordination with school services for children who have two or more complex health-related needs, receive mental health services or exhibit physical aggression to oneself or others or engage in property destruction requiring the immediate intervention of another person. We do not believe funneling intensive service coordination through school districts is a sound idea for a number of reasons. Schools do not now provide services 24 hours a day, 7 days a week. While districts could contract with agencies to do so, this is simply not part of the experience or institutional practice of school districts, and we believe will be inordinately difficult and lead to many gaps and problems for high-need children. Because schools do not provide services all day, 7 days a week, year round, staff are often unaware of the many needs a child has within the community and within their families. Again, it may be possible for a school district to contract with an agency with this expertise, but we do not understand why such a major shift in responsibility would result in positive outcomes for high-need students in a short time frame. Many families do not want all of their medical information to be shared with schools and teachers. It is important to remember that most students have different teachers and support staff every year. In addition, many high-need students have more than one teacher or other staff person during a school year. The spreading of one's private medical information across the school district is simply not warranted or desired by most families.

Additionally, relying on school resources, such as school psychologists, is mentioned as a reason to use the school as a basis for innovative service coordination yet Minnesota ranks low among states in the number of school psychologists across the districts. School psychologists do not have the training required for this level of treatment and service coordination. Our schools are simply not staffed with the professional resources to contribute to this effort. There is some concern that implementation of service coordination would result in cost shifting from special education services to Medicaid. We are concerned because schools have very strong incentives not to identify a student's needs. With authority over Medicaid, we believe the opportunity for cost shifting is increased. We do not think shifting authority to school districts is a sound method to assure children get both the educational and the health care services they need.

Instead, we suggest a demonstration to provide innovative approaches to service coordination for the children described based in our current human services system and relying upon a range of experienced providers to work closely with school districts to assure common approaches to the complex needs of these children in school, within their families and in their communities.

Section 5.2: Demonstration to Expand Access to Transition Supports, Return to the Community
We urge that the "Return to the Community" transition supports for people in nursing homes be clearly described as a service available to persons in nursing homes of any age. The emphasis in the description is on seniors but many persons under 65 could benefit from this effort.

Section 6: Empower and Encourage Housing, Work, Recovery and Independence
Access to housing and employment is a critical issue for Minnesotans with disabilities, and we at MN-CCD support efforts such as this to begin to address this issue. On Page 54 of this proposal, the specific

services that a navigator under this demonstration project will provide are described. It is noted in this description that navigators will have access to DB101 in their work to support individuals in this demonstration. We would encourage the administration to include more explicitly in the list of navigator provided services: “information about employment impacts on housing benefits”. We at MN-CCD have found that one barrier to employment for individuals with disabilities has been unclear information on the impact of employment on housing benefits, particularly when the individual benefits from one of a long list of local and project-specific housing subsidies.

On page 54 of the proposal there is language around the provider qualifications that will have to be met for an organization to be considered as a potential navigation site, and we strongly encourage the administration to maintain those provider standard requirements, particularly the requirement of a demonstrated history of providing employment assistance services to workers with physical or mental health issues. Additionally, the overview of the evaluation and data collection processes that will be used with this particular demonstration project that is described beginning on page 55 is a positive step towards true measurement of this demonstration’s success, and we encourage the administration to seriously consider the findings of the evaluation and use this information to inform programmatic changes.

Additionally, while we support a statewide demonstration program focusing on five target groups of young adults, we are concerned that the requirements to be employed or to have been employed within the year or to have experienced an employment shift within the past year is too onerous for some of the target groups listed. In particular, targeting 18-year-olds and imposing these employment requirements simply misses the mark. We certainly agree that 18-year-olds in the circumstances described in the five groups could well benefit from navigation assistance, but we are concerned these individuals will not be included because they do not have employment experience. We think it is especially important to target young people graduating from high school for employment supports. The longer a person is both out of school and not working the more likely the person will be to seek the total and permanent disability status of Social Security. We urge that the employment eligibility requirements be expanded to include young persons in their first year after high school graduation in the categories listed, regardless of employment experience.

Section 8: Adults without Children Eligibility

We oppose the requested waivers to make eligibility for MinnesotaCare adults without children more restrictive by imposing a durational residency requirement of 180 days and establishing an asset limit of $10,000 for Medicaid eligibility for adults without children who have incomes under 75% of the Federal Poverty Level.

Section 9.1.4: 1915i To Support Individuals with Mental Illness who are at Risk for Institutionalization without access to Integrated Community-Based Systems of Care

We strongly support the development of a 1915i state plan option to provide services which are flexible in terms of type, such as in-home services, employment supports or other therapeutic services and flexible in terms of intensity. The criteria for qualifying for the proposed services, however, are very restrictive. We support broadening a 1915i state plan proposal in order to provide services to persons before they end up in psychiatric hospitals, prisons, jails or nursing facilities.

Section 9.2.1: 1915(i) for Children with Autism Spectrum Disorder Diagnosis
The need to develop unique services for Minnesotans with ASD is something that advocates, providers and the state have all agreed upon, and we are glad to see attention to this issue in the Reform 2020 proposal. On page 80 of the proposal, language describes the vision for Minnesota to develop a 1915 (i) service to deliver early intervention services to support Medicaid eligible children age 0-7 who have a diagnosis of ASD. While there is much language in the proposal about the services that will be offered to this 0-7 age group, there is far less language around services that would be available to individuals with ASD who are over 7 years of age. We would encourage the administration to reconsider this decision given how many individuals with autism are not diagnoses until after age 7, as well as the significant service needs of those with ASD over age 7.

Additionally, we also support the proposal to ask CMS for technical assistance to assure that children from families with income over 150% FPL qualify for Medicaid under TEFRA or HCBS waivers because they meet those criteria for MA eligibility for children with disabilities in families above the required MA poverty levels. However, we urge that this issue be carefully reviewed with stakeholders given the pending changes to the nursing facility level of care (NF-LOC).

Additionally, on page 81 of the proposal it is noted that due to legislation passed during the 2012 legislative session requiring the MN Health Services Advisory Council (HSAC) to review treatments for ASD, it will be these HSAC recommendations, along with stakeholder input, that will guide the program policy on type, frequency, and duration of services to be covered by the 1915 (i). However it is also noted in the proposal that due to timelines, the department may initially propose benefit and service utilization criteria for this service in advance of recommendations by the HSAC, and will then consider amending the submission to CMS if changes are deemed necessary when HSAC completes its work. We would encourage the administration to be more explicit about this potential amendment process, perhaps by including timelines and explicit action steps that will be taken, to ensure that any potential service set implications of HSAC's findings are taken seriously.

Thank you again for the opportunity to comment.

From: Mary Powell <mapowell5@comcast.net>
Sent: Tuesday, July 17, 2012 2:20 PM
To: *DHS_Reform2020Comments
Subject: Reform 2020 comment
Attachments: reform 2020 Autism.docx

Please accept this public comment. Thank you.
Mary Powell, President, Board of Directors
Center for Engaging Autism

Reform 2020 Public Comment July 16, 2012

The Center for Engaging Autism, an organization dedicated to promoting the successful participation of children with autism spectrum disorders and their families in their home, school, or community, is pleased to support the proposed initiative of the Department of Human Services to develop a 1915 (i) waiver to deliver early intervention services to children ages 0 – 7. We share the concern that many young children with ASD have been unable to access appropriate intensive services. Since 1994 research in ASD has provided evidence that young children with ASD show gains in communication, socialization, behavior control, and cognition though intensive intervention by trained therapists. (JADD, 1995) Quality therapeutic services are critical for the development of children with ASD.

The Center for Engaging Autism supports the development of a program of high quality services. These services should be individualized, based on a sound understanding of research in autism spectrum disorders. They should be evidence-based, including the research in the comprehensive behavioral intervention conducted by Sally Rogers (AAP in 2009). We strongly support the intention to coordinate program services with medical and educational services. However, CEA feels that the proposed autism waiver should also include a family centered approach that considers the value of family empowerment to the development of children with ASD.

The Center for Engaging Autism supports of this initiative and offers its participation in the planning and implementation of the proposed waiver. Please contact us at WWW. CEA4autism.org or 612-735-4332.

Center for Engaging Autism Board of Directors
Mary Bergaas
Lesley Heil
Susan Nyvold
Margie Paller
Mary Powell
Tammy Pulver
Joan Shoepke
Beth Synder
Kathy Teegarden
Anne Harrington, Executive Director

From: Troy Fry <frybcba@embarqmail.com>
Sent: Tuesday, July 17, 2012 2:17 PM
To: *DHS_Reform2020Comments
Subject: Reform Feedback

July 17, 2012

David Godfrey, Medicaid Director,
Medicaid Director Minnesota Department of Human Services P.O. Box 64998
St. Paul, Minnesota 55164

To Whom It May Concern,

Topics Included (1) Recognition of Behavior Analysis, (2) Quality assurance for Behavior Analysis, (3) Adoption of a standard of assessments, (4) age and service consideration, (5) school readiness and willingness to collaborate, and (6) focusing on those individual that represent the greatest cost.

I wanted to take provide some feedback on the reform proposal. As a practicing Board Certified Behavior Analyst for the past 25 years in a variety states, I hope the following recommendations will provide some additional insight into future proposals or modifications. First, I would recommend looking to states (Florida, California, Tennessee, etc.) for guidance on the practice of Behavior Analysis. Second, consider looking into the standards and guidelines outlines for practicing Behavior Analyst outlined on the Board Certification site (bacb.com). Despite providing coverage for behavioral services, there is little in the way of adopted standards, program requirements, ongoing program review, etc., which quite concerning as a professional and as a tax payer. The field of Behavior Analysis prides itself in objectivity, transparency, and accountability which I see as asset to both consumers and the state. Perhaps adopting a Behavior Analysis coordinator to oversee the practice, collaborate with relevant agencies and interest groups would provide for effective leadership and ensure quality and effective/efficient practice is occurring across the service delivery spectrum. Bringing together professionals in the field as policy is being forged is critical. Behavior Analysis offers everything the state is seeking....the ability to provide effective and efficient services to all individuals with developmental disabilities with years of evidence-based proof. Behavior Analysis is not a one size fits all, rather treatment is highly specialized to the individual.

I am also concerned about any age caps and assumptions about school readiness. I believe that it is my job to prepare individuals and families for school, which requires different repertoires for different learners, but often there is still a need for schools to modify their systems/supports to ensure the individuals continue to learn and effectively participate in the setting. Unfortunately, even when there is interest on the teacher level to modify and or collaborate, the system often puts up road blocks or simply refuses to team for reasons other than what is best for the child and family. Providers must be accountable to be teaching the right skills, at the right time, in the right way. Assuming a individual will go from intensive 1:1 programming to school without difficulty is not fair by the learner or the school. We need to make sure we are getting kids in groups early, fading structure, fading staff, fading reinforcement, eliminating barriers to learning or using skills, etc. Funding needs to allow for fading within centers by having a billing code for less intensive ratio's making the cost of providing effective treatment significant less. As a Director of a clinic, and someone who wants to be accountable to kids families and funding sources, it was right by the individual and right by the funding source to fade out staffing supports as quickly as possible (i.e., the individual would continue to acquire "targeted" skills). The idea of 1:1 then to school is not likely a successful model for most learners and providers should be encouraged to reinforced for fading supports in more systematic and effective manner. All individuals regardless of age can benefit from Behavior Analysis, the issue is ensuring the right skills are being taught (first things first) in the right way at the right time in the right setting. Clearly, the trajectory is different (age, degree of disability, etc.) but the ability to improve quality of life for individual, family, and systems as well as decrease long-term cost is the same.

I also think that the State would benefit from adopting specific assessments that guide and measure progress for all levels of learners; those following a more typical developmental sequence and those who require a more functional curriculum. Most learners *can achieve "best outcome" if and I think it should be defined as being able to effectively participate in your community without the need for extra supports. Further, I think additional measures are important when determining "outcomes" such as parenting stress, community access, overall individual and family safety, etc. If an individual can become and effective speaker (make his/her wants an needs known, an effective listener (honor the requests of others/community), and limit the number of barriers to accessing the community (family, school, etc.) they and their family can achieve a high quality of life without the need for additional or lifelong "extra" or "significant" supports. Further, the family can stay together as they is less stress, as individual is now able to effectively participate and survive in the "community". If programs and funding only follows those learners who have the best chance to being typical learners, we will have failed greatly as those learners do not represent the "extremely costly" population if effective services are not provided.*

Behavior analysis has a lot to offer individuals and the State. With effective implementation we will not only improve the quality of life of individuals with developmental disabilities and their families but will do so in a way that will result in cost savings to the State allowing for a sustainable system.

Thank you for your continued commitment to individuals with developmental disabilities and their families. Your task is massive, but know there are folks like myself who can and will assist if afforded the opportunity.

Regards,

Troy A. Fry, MS BCBA

From:	Krista Bean <KBean@stdavidscenter.org>
Sent:	Tuesday, July 17, 2012 2:08 PM
To:	*DHS_Reform2020Comments
Subject:	Accommodation request

July 16, 2012

Dear DHS Reform 2020 representatives,

First, I would like to take the opportunity to commend DHS for a creating and releasing a redesign for the PCA program that really shows how innovative and thoughtful we are as a state. The new umbrella of services under Community First Choice Option (CFSS) broadens the scope and menu of services that recipients can use. At times throughout the service it has felt like are trying to put a square through a round hole. The program has morphed into something more than it was originally intended for and is definitely in need of a makeover. Amidst the challenges within the program there are pieces of the structure that are successful and I believe should remain intact.

In the redesign of the program I think it is incredibly important to offer an option similar to the PCA choice option. This service allows for families to have independence in directing the service without having to take on all the administrative duties of self direction. St. David's has a strong traditional program which could be an option for families who are not comfortable self direction, but it would create larger limitations for the recipient to self direct care. The model of the choice program is very unique and does provide a nice support option for families.

Over the past two years the state has put great emphasis on supervision and quality care within the program. This model would allow for more flexibility in the use of the service, which if used appropriately will be very valuable. However, as a state how will we mitigate our risk for fraud/waste/abuse in a larger consumer directed program? Currently, there are supervision requirements in place to assist in monitoring the usage of service, what will this look like under the new program? As an agency we strive to educate our families and operate under a program that protects the integrity of the service. The incorporation of this within the new design of CFSS will be critical for us to evaluate for our organization, as we attempt to calculate our risk.

Again, thank you for your thoughtfulness in the design of this program, the investment that was put into this reform is very apparent.

Sincerely,

Krista Bean

Krista Bean
PCA Program Director, LSW
St. David's Center for Child & Family Development

Building Relationships that nurture the development of every child and family

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From: Deborah Saxhaug <dsaxhaug@macmh.org>
Sent: Monday, July 16, 2012 1:53 PM
To: *DHS_Reform2020Comments
Subject: Accommodation request

4.2.3: Demonstration of Innovative Approaches to Service Coordination (Children with CFSS)
Providing service coordination through a limited number of school districts.

The Minnesota Association for Children's Mental Health does not support schools being the lead agency for this service coordination initiative. We request that the department revise this proposal with direct input of the current school-linked mental health providers and children's mental health advocates.

Among our concerns is the shortage of nurses, counselors and psychologists in many of Minnesota schools. In addition, in most of the schools these individuals are not licensed or qualified mental health professionals. Schools are also most often in session 9 months of the year leaving a potential 3 month gap in services. There are currently two other initiatives in schools that should be at the table in discussing this service coordination model - School Linked Mental Health Grants (DHS) and PBIS (MDE). The existing school based service structure mentioned as a method or vehicle to deliver services does not exist in most schools unless it is related to the School Linked Mental Health Grants.

We would be willing to be part of a conversation that would look at alternatives to having a school function as the lead agency.

Deborah Saxhaug
Executive Director
--
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July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Hand-delivered to DHS

Dear Mr. Godfrey:

We are submitting these comments to the State's Medicaid Section 1115 Waiver Proposal – Reform 2020: Pathways to Independence on behalf of the Employment First Coalition.

The Minnesota Employment First Coalition is a grassroots movement of employment champions from a broad range of disability advocacy organizations, federal, state and local government agencies and educational institutions. Since 2007, the Coalition has hosted employment summits, published summary reports and championed initiatives to support changes in employment policy and practice for Minnesotans with disabilities.

Employment First is the vision of making integrated competitive employment (with or without supports) the first priority and preferred outcome of Minnesotans with disabilities. It is critical to raise expectations about employment through policy and practice, focusing on regular employment with the same wages, standards, responsibilities, expectations and opportunities available to any working-age adult.

Employment is the path out of poverty and into the mainstream of American life. The employment rate of Americans with disabilities is less than one-third that of other citizens, and 65% of individuals trapped in poverty long-term are individuals with disabilities.

Employment of Minnesotans with disabilities is a win-win for all Minnesotans.

- It improves the mental health, physical health, social connections, economic stability and self-sufficiency, and personal growth of Minnesotans with disabilities. It is fundamental to an individual's quality of life and earning the means to exercise freedom and choice as a citizen.
- It increases state revenues and decreases expenditures for public benefit programs, benefiting all Minnesotans with a healthier economy.

Even Minnesotans with significant disabilities can successfully join the workforce providing businesses with valued employees using a strengths-based approach to identify marketable strengths and assets and developing customized job supports to gain and retain employment.

Earlier this year, the Employment First Coalition worked toward including language in the DHS Policy Bill to ensure that certified assessors inform waiver recipients about the benefits of competitive employment, with or without supports. That language included a definition of "competitive employment" used by Vocational Rehabilitation Services, to better align the two departments in their efforts to improve employment outcomes. Throughout the rest of this document we will be using that definition when using the term “competitive employment” which includes integration in the regular workforce and can be with or without ongoing employment supports.

We believe the Reform 2020 proposal falls short in emphasizing competitive employment for Minnesotans with disabilities as a means to achieve the department’s stated goals to:

- Achieve better health outcomes
- Increase enrollee independence
- Increase community integration
- Reduce reliance on institutional level of care
- Simplify administration and access to program
- Create a program that is more financially sustainable

Integrated competitive employment, with or without supports, has been proven to have a positive impact on better health outcomes improving both mental and physical health. It increases independence and, by definition, community integration. It reduces reliance on paid caregivers by building the capacity of businesses to support Minnesotans with disabilities at the workplace.

Individuals living in poverty have less choice in controlling the circumstances of their lives. Reliance on public benefits significantly limits many fundamental choices including where and with whom to live. Competitive employment increases choices with respect to a wide array of personal, occupational, and economic goals available to any citizen. It opens up the different types of work to be considered. It also provides higher earnings than center-based or group community-based employment. Economic power expands opportunities not otherwise available to many individuals with disabilities and those opportunities are directly related to measures increasing quality of life. Through increasing expectations and opportunities with respect to work, Minnesota can multiply the number and diversity of choices available to its citizens with disabilities by expanding participation in both the labor force and community.

The Minnesota Work Incentives Connection has calculated some of the financial impact when Minnesotans with disabilities work. Specifically, the Connection found statistically significant decreases in the following government benefit amounts received at 12-month follow up, as compared to intake:

• Supplemental Security Income (SSI)	-13.0%
• MN Supplemental Aid (MSA):	-14.7%
• Food Support:	-31.9%
• MN Family Investment Program (MFIP):	-30.9%
• Housing Subsidy:	-10.8%

As people with disabilities increase their level of employment, government benefits are reduced. Collectively, benefits received by the 1,559 individuals studied were $83,131 per month lower at

12-month follow up than at intake. Potential savings in government benefits equal $1 million for each year these participants remain employed, or almost $10 million over 10 years.

The group studied by the Connection represents a fraction of Minnesotans with disabilities, and thus only a fraction of benefits program savings that could be realized if more people with disabilities were working. Those who work also pay federal, state and local taxes, and contribute through FICA taxes to the Medicare and Social Security retirement systems, increasing revenues at all levels. They are also better able to support their families and contribute to their communities.

During 2009 and 2010, over 200 individuals participated in listening sessions facilitated by the Minnesota Employment Policy Initiative (MEPI) focused on the question, "What will it take to double employment of Minnesotans with disabilities by 2015?" Groups identified that employment improves the following factors, many of which are consistent with the goals of the Department in their proposal:

- Self-esteem and self-worth
- Identity
- Sense of purpose
- Structure and routine
- Economic stability
- Opportunities to use talents
- Contributions to society
- Physical health
- Mental health & recovery
- Social network
- Impacts society's view about the abilities of individuals with disabilities

Competitive employment is an expectation of citizens without disabilities, but that expectation is absent or "conditional" among many individuals with disabilities, families, educators, the medical community, employment and disability professionals, and employers. The expectation of competitive employment is also not reflected in many public policies.

About 30% of adults without disabilities do not participate in the workforce, and not all citizens with disabilities will work either. If competitive employment is an expected outcome of Minnesotans with disabilities, individuals (and their families where appropriate) could still choose to "opt out" of competitive or other employment, but the expectation of employment would shift the dynamic embedded in the current system which requires individuals and families to "opt into" competitive employment in the face of significant pressure to choose a system of segregated, low paying employment or not to work at all.

Like many states, Minnesota has many individuals with disabilities in segregated, facility-based employment. Recent federal actions through the Department of Justice have challenged the limited access individuals with disabilities have to integrated employment in other states. Minnesota is vulnerable to those types of actions without policies and regulations that are aligned to enhance competitive employment as the preferred outcome for the populations affected by the Department's proposal. To achieve better competitive employment outcomes, the Department, in partnership with other state agencies and community organizations, will need to build the infrastructure through training and technical assistance to support competitive employment in local communities throughout the state. The report card of DTH services should include data on competitive employment outcomes, comparable to the data collected by other state agencies, to monitor progress toward this important goal.

The Department's proposal includes individuals with mental health disabilities as its primary focus in the area of employment in 6.1: Demonstration to Empower and Encourage Independence through Employment Supports. The Employment First Coalition supports the importance of better employment outcomes for this group. However, the Coalition does not fully understand why employment recommendations as proposed in **Reform 2020** do not aggressively advance a well-researched, evidence-based practice in the use of Individual Placement and Supports (IPS). The adoption of IPS policies and methods has been documented to significantly increase job placement and competitive employment outcomes of job seekers with serious mental illnesses (SMI) by a factor of three. In recent years, Minnesota launched its own IPS initiative and already has several highly successful state-funded IPS project demonstrations in operation. The Coalition believes the state agency collaboration established by DHS and DEED provides an excellent framework to expand IPS opportunities throughout Minnesota with the right policy directives and fiscal incentives.

The IPS Supported employment strategy is an evidence-based practice documented by national research studies to increase the job placement and employment success rates of youth and adults living with SMI. A number of studies have shown employment to be a critical ingredient to individual treatment and recovery from SMI because a competitive job helps to shape a life's purpose, daily structures and routines, and increases earned or discretionary income. Competitive employment also promotes higher levels of social interaction with peers in the workforce and community, opportunities to use education and training, increasing contribution of skills and talents to the economy, and increasing self-dependence and self-esteem. One researcher has even identified satisfying competitive employment as important to recovery as the use of medication in managing personal mental illness symptoms.

While the Coalition understands Minnesota's core principle for cost neutrality in implementing the Medicaid reforms, supported employment is also known to be less expensive than other forms of mental illness treatment. In fact, many research studies document a significant reduction in mental illness symptoms, overall cost-savings in healthcare, and less reliance on more expensive forms of medical and mental health treatment for those individuals who choose and engage in competitive work. For these reasons, the omission of IPS within the 1915i provision of the reforms seems to be an opportunity lost and we respectfully suggest you reconsider its inclusion in the 1915i waiver reforms so all Minnesotans with SMI can choose work as a component of their treatment.

The Minnesota Employment First Coalition endorses and supports the State's reform efforts to:

- Deliver technical and navigational support to employed Minnesotans with SMI in the workforce who require assistance to access the services, resources, and expertise they need to stay well and stay working. With this said, however, the engagement of these employment supports and convergence with other mainstream models of employment assistance such as IPS is not well presented. For example, the recommendations do not identify how these services will be integrated within primary healthcare, mental health, and core workforce systems to insure an organized system of care and access to services. Although the Coalition fully supports the idea of keeping employed people working in the labor force, we wonder why the critical needs of "unemployed" Minnesotans with SMI are not included in Phase One of the proposed reforms.

- Engage disability benefits and healthcare planning assistance so job seekers with SMI gain a better understanding of Social Security work incentives and are encouraged to work as appropriate. This reform is absolutely critical to the engagement of effective employment services and obtaining successful employment outcomes. Although Disability Benefits Planning 101 (DB 101) is a highly useful software tool, a majority of people will still need assistance in fully grasping its implications and taking the next steps to go to work. This means there is a significant need to offer technical training in the use and application of the tool throughout Minnesota. Also, it is imperative to engage some individuals with Certified Work Incentive Coordinators (CWICs) to provide a more detailed, clear understanding of how working impacts benefits, healthcare, and other basic living needs. This is an essential hurdle to encouraging more people to work and beginning a cultural shift in the mindset that youth and adults with SMI can work in the right job with the right supports.

- Provide policy support to Minnesota's Medical Assistance for Employed Persons with Disabilities (MA-EPD) to address the healthcare needs and cost barriers of job seekers with high medical expenses. This is also an essential ingredient to competitive employment formula. Access to assistance with healthcare expenses remains a significant and driving factor in the decision of Minnesotans with disabilities to go to work. MA-EPD remains a powerful incentive to work and increases both confidence and encouragement so more people will choose work if MA-EPD is sustained and better communicated to prospective job seekers.

- The proposed demonstration to support the job placement and employment success of youth, ages 18-26, with serious mental illnesses is a very wise addition to the reforms. The Coalition has been working actively with student self-advocates, educators, and families to solicit suggestions on ways to improve policies and practices to remove known barriers to successful transition from school-to-careers. In order to effect sweeping systemic change, it is important to invest in new ideas to support the job placement and competitive employment of youth and young adults. The systems capacities to support the transition of youth into competitive employment with and without support (supported employment) will go a long way in reducing reliance on other forms of mental health treatment and public assistance programs.

The Minnesota Employment First Coalition also believes Minnesota would greatly benefit by the establishment of a cross-functional taskforce or work group specifically organized to study interagency policies, practices, and potential financial models to increase access to IPS and other services leading to competitive employment. SMI is a pervasive illness that impacts thousands of Minnesotans including working-age youth in transition, adults supported by assertive case management teams, adults served in day treatment programs, individual and group therapies, and other community mental health services, adults supported by state-operated services, refugees served by Minnesota Family Investment Programs, disabled veterans returning from foreign wars, and offenders supported by the State and county correctional systems. The complexities of addressing recovery, independence, and sustained productivity in the workforce requires a shared vision and mutually agreed goals by multiple state agencies (MDE, DHS, DEED, MDH, DOC), consumer advocacy organizations, job training and workforce development agencies, and privately and publically-run businesses. The focus of this work group would be to establish a statewide, uniform definition of competitive employment, standardize procedures for state agency data collection and measuring progress, refresh state agency policies to encourage an employment first vision, and promote the use of evidence-based and emerging practices to increase the employability of Minnesotans with mental health disabilities. The work group would measure its success by measurable changes in the competitive employment participation rates of Minnesotans with SMI.

Finally, the co-morbidity and mortality rate for individuals living with SMI is well-documented. Adults with SMI will die 25 years younger than their adult peers. The State of Minnesota's 10 X 10 Wellness Initiative Campaign is designed to address opportunities for public education and promoting holistic healthcare and wellness. Of course, this means better integrating primary healthcare with mental health treatment and engaging community-based services in ways to support the goals of recovery, self-dependency, and enhancing quality of life indices.
The Coalition believes a lifetime of poverty, dependency, and inactivity exacerbates the symptoms of serious mental illness. And frankly, meaningful recovery from mental illnesses is improbable without significant changes in the employment participation and career development rates of Minnesotans with SMI. According to the Substance Abuse and Mental Health Administration (SAMSHA), active participation in satisfying employment is among the "eight dimensions of wellness" in recovery from SMI. Until competitive employment is viewed, accepted, and incorporated as a core, integral component of mental health treatment in Minnesota, the goal of wellness and recovery will continue to be marginalized and beyond the reach of many. The unacceptably low employment participation rates experienced by Minnesotans living with SMI is a testament to the failure of our workforce and mental health systems to engage and move people forward with confidence and success.

Thank you for the opportunity to provide feedback on the proposed Medicaid reforms. The Coalition is available to answer any questions and clarify our comments made in this document. We appreciate the opportunity to comment on such a significant proposal and look forward to working with the Department toward a better employment and economic future for Minnesotans with disabilities.

Sincerely,

Don Lavin
Vice President
Rise, Incorporated
8406 Sunset Road NE
Spring Lake Park, Minnesota 55432
Phone: 763-783-2815

Carol Rydell
Kaposia, inc.
380 E. Lafayette Freeway South
St. Paul, Minnesota 55107
Phone: 651-789-2815

On behalf of the Employment First Coalition

July 16, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey,

The Mental Health Association of Minnesota (MHAM) is Minnesota's first mental health advocacy and education organization. Lay and professional leaders concerned about the horrible conditions in custodial settings founded MHAM in May 1939. For over 70 years, MHAM has worked toward improved lives for people with mental illnesses. Our mission is to enhance mental health, promote individual empowerment, and increase access to treatment and services for persons with mental illnesses.
Mental health treatment is not currently mandated for self-insured plans. Few plans cover the mental health model benefit set that is included under MA and MinnesotaCare. For someone who needs a significant service set because of mental illness, state/federal programs may be their only option. Despite this, these plans have historically not been designed for them, an issue that persists in this outline.

Eligibility for the PCA program was changed to be more restrictive so that many people with a mental illness were no longer eligible or had their hours reduced drastically to roughly half-hour a day. Medicaid Reform must address the loss of eligibility for services. When isolation is a significant barrier to recovery in this population, we need to be very concerned about decreasing access in the name of increasing quality.

The MNChoices program does not adequately assess the needs of children and adults with mental illnesses. This will result in them not being eligible for programs and not having their needs addressed.

The components of the Reform 2020 proposal are, therefore, extremely important since children and adults with mental illnesses are being pushed out of current home and community-based MA programs. We are afraid that Reform 2020 will not create the programs needed to support those who will no longer be eligible for the CADI and PCA programs.

Community First Services and Supports (CFSS)

The MNChoices assessment tool, and eligibility will be based on the new NFLOC. This will result in many people with mental illnesses not being eligible for services under CFSS. When the changes were made to the PCA program by the legislature many of those who no longer qualified for the program or who lost all but 30 minutes of day of service had a mental illness.

We do not think that one ADL or IADL fit the needs of people with mental illnesses well. However the increase to 90 minutes of service a day will help. Our final stance on this facet of the reform will largely depend on the final form the assessment takes. Previous drafts and finalized assessments have historically greatly underweighted the concerns and realities of adults with mental illnesses.

Demonstration to Empower and Encourage Independence through Employment Supports

It is unclear what the future of IPS is in the document. IPS helps people in community mental health service systems to become a part of the competitive labor market. IPS is more effective than other vocational approaches in helping people with mental illnesses to work competitively. IPS is cost-effective when the costs of mental health treatment is considered. MHAM supports continuing IPS as an Evidence Based Practice.

We are not certain that using the Disability Linkage Line is an effective way to engage people with mental illnesses and would recommend some other method be used.

Anoka Metro Regional Treatment Center Demonstration

MHAM supports DHS seeking to waive the IMD exclusion for the Anoka Metro Regional Treatment Center (AMRTC). AMRTC is more like a short-term intensive hospital program in the community than it is an institution. We support being able to receive MA funds for the care and treatment provided.

We understand that a work group will be putting meat on the bone of this proposal, but Community Behavioral Health Hospitals (CBHHs) and their inability to be at capacity needs to be part of the discussion. Without the inclusion of the CBHHs, we are not certain success can be realized.

1915(i) to support individuals with mental illness who are at risk for institutionalization without access to integrated community-based systems of care.

MHAM supports the development of a 1915i with the input of the work group that was discussed. We especially feel that being able to put ARMHS services under 1915i would benefit a great many people and keep the program viable.

The increasing focus on networks, capitated payments, and managed care needs to be balanced with equal attention to the access issues created by this system. Already, SNBC plans have used restricted formularies and limited pharmacy networks to deny access to medication supports needed by people with mental illnesses. Recent developments in anti-psychotic medications mean that many lack generic options or are omitted from formulary coverage due to higher costs. Traditional coverage restrictions, e.g. the requirement that a person try a less expensive option first, do not make sense for these medications. If a person is successfully in recovery with a next-generation medication, the risk to their health presented by a medication change to test a lower cost option may be significant.

Thank you for the opportunity to comment on the Reform 2020 proposal. We wish you all the best in your negotiations with CMS.

Sincerely,

Edward T. Eide
Executive Director

Dooley, Lea M (DHS)

From:	Paul Omodt <pomodt@voamn.org>
Sent:	Tuesday, July 17, 2012 1:43 PM
To:	*DHS_Reform2020Comments
Subject:	Comments from Volunteers of America -- Minnesota

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164
July 17, 2012

RE: Reform 2020 Medicaid Waiver Reform Proposal

Thank you for the opportunity to comment on the proposed Section 1115 Waiver Proposal, Reform 2020: Pathways to Independence. Volunteers of America – Minnesota's mission is to help people gain self-reliance, dignity and hope, and we believe the trend we see from DHS moves in closer alignment to our stated mission. We welcome DHS's efforts to promote greater independence and self-direction for some of Minnesota's most vulnerable individuals. We know that these proposed changes will have a positive impact on persons with disabilities, older adults, caregivers and our communities.

Our primary comments are in three general categories: the availability of mental health services, modification of PCA program, and the availability of affordable housing for changing programmatic models. We believe these three general areas are vital to the eventual success measures we collectively seek.

- **Mental health services are crucial.**

We want to affirm the proposed integration of primary care and mental health services. Since one in five older persons suffers from a diagnosable psychiatric condition, mental health services should not be viewed as an auxiliary to primary care. The number of people age 65 and older with a psychiatric disorder is expected to double over the coming decades according to NAMI. At VOA-MN, we have seen first hand how mental health conditions can negatively affect a person's ability to function on a daily basis. These negative effects can result in unnecessary hospitalizations, poorer health outcomes and increased mortality rates. For example, recent research has shown that older person who suffer from depression have worse outcomes after medical events such as hip fractures, heart attacks or cancer treatment.

We believe mental health parity is crucial and we need to continually guard against those with mental illness getting lost in the 'shuffle'. We need to be mindful of these considerations as we move forward.

- **Modification of the PCA program can be beneficial.**

We have two primary points: We believe in working to unhook the PCA access from the waivers, and we believe working to promote quality assurance is essential. Going beyond generalizations and measuring real-life experiences will be key to informing how the PCA program can be best designed.

- **Lack of availability of affordable housing could capsize the plan.**

We need to be fully conscious of the need to have the affordable housing options available for this model; without adequate housing opportunities, the model will fail for a lack of 'where' to provide the services. We need to be innovative and look at how this plays out in communities all across the state. VOA – MN provides services in both the metro and in greater Minnesota and know that finding affordable housing in which to provide these services is essential to a more community based care model.

VOA-MN looks forward to working with DHS to successfully implement these initiatives. We want to contribute to a state where older adults and persons with disabilities have the best information, access and resources to help support their choices. Thank you for the opportunity to participate in this process.

Sincerely,
Volunteers of America – Minnesota
/s/
Paul G. Omodt
Vice President of External Relations

Paul G. Omodt, ABC, APR, MBC
Vice President of External Relations
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Hennepin

Hennepin County

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July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55164

Dear Mr. Godfrey,

On behalf of Hennepin Health, Hennepin County's integrated healthcare initiative designed to serve the unique needs of a challenging segment of the county's safety net population, we appreciate the opportunity to comment on the Department of Human Services (DHS) **Reform 2020: Pathways to Independence** federal waiver proposal.

We support the DHS proposals to develop innovative and effective Medicaid payment and delivery models and firmly believe by integrating medical, behavioral health, public health human services, and health plans in a patient-centered model of care, the Hennepin Health program can improve health outcomes and lower the total cost of care for our target population (adults without children on Medical Assistance with income at or below 75 percent of the federal poverty level).

To date, a key barrier to communication and streamlined service delivery is the inability to share data among the network participants. We have seen efforts across the nation which may serve as models for us to improve this in Minnesota. The criticality of providers working together across systems for the benefit of those we serve is crucial to gain efficiencies and reduce redundancies. We want to work with DHS to achieve the improved care and cost savings that will result if we can find ways to both facilitate the coordination of care and protect patient/client privacy.

We have given input and support to the response from the Minnesota Association of County Social Service Administrators (MACSSA) and that of Metropolitan Health Plan (MHP). Hennepin Health looks forward to working with DHS on the continued development and implementation of DHS' vision as outlined in the Reform 2020 proposal.

Sincerely,

Jennifer DeCubellis, LPC
Hennepin Health
www.hennepin.us/healthcare

Hennepin
Health
PEOPLE. CARE. RESPECT.

From: Diane Cross <dianec@fraser.org>
Sent: Tuesday, July 17, 2012 12:48 PM
To: *DHS_Reform2020Comments
Subject: Fraser comments on Reform 2020 proposal

June 17, 2012

Mr. David Godfrey
Medicaid Director
Minnesota Department of Human Services
Post Office Box 64998
Saint Paul, Minnesota 55164

Dear Mr. Godfrey:

Thank you for the opportunity to submit these comments in response to the section 1115 Medicaid waiver proposal titled Reform 2020.

Fraser provides healthcare, education, and housing services to thousands of children, adults, and families with special needs. One area that we are noted for is being the oldest, largest, and most comprehensive autism program in Minnesota.

My comments are focused on the “Alternative to the Personal Care Assistance (PCA) program” described in section 4.2 of the proposal, also referred to as Community First Services and Supports (CFSS).

Fraser supports efforts to make the PCA service more flexible and responsive to consumer needs. In particular, we applaud the proposal to raise the minimum service plan in CFSS to at least an average of 90 minutes per day.

As the department considers how to replace PCA with CFSS, please keep in mind that the current PCA service is not financially sustainable for community providers. In addition to low reimbursement rates, the service currently is overburdened with too many regulations and paperwork. Additional financial investment and streamlined regulations will be needed in order to support new client offerings, such as skill acquisition.

On a related note, creating areas of specialty within CFSS will be important to best serving individuals with complex needs. However, achieving this goal will be unlikely without providing a rate differential to support the additional training and oversight needed.

Finally, one suggestion is to integrate the new CFSS provider registry into the existing MNhelp.info platform that already is planned to be rolled into the upcoming MnCHOICES tool.

Again, thank you for considering these comments.

Sincerely,

Diane S. Cross, president and chief executive director
(612) 798-8317
Diane@Fraser.org

Fraser
2400 West 64th Street

Minneapolis, Minnesota 55423

Schels, Johanna T (DHS)

From: [redacted]
Sent: Tuesday, July 17, 2012 12:19 PM
To: *DHS_Reform2020Comments
Subject: Comments re proposed changes to MA for people with autism

Importance: High

I am the parent of a 12 year old son with autism. I am writing regarding the proposed changes to the autism benefit set, particularly, that of limiting therapies (outside of public school) to ages 7 and under. We did not even apply for MA benefits for our son, [redacted] until he was almost 9, as asking for public assistance was not in our nature. It was only after much urging from our county social worker that we realized the benefits that our son would obtain from receiving MA and being on a waiver. The assistance has proved invaluable to his development, as well as to our ability to properly care for him in our home. He has received therapies which have vastly improved his communication and social skills, and we, his parents, have received occasional respite and the will to continue moving forward, being buoyed by his progress.

While public schools <u>may</u> provide some therapies, they do not have the funding, staffing, tools, time, expertise or diversity needed to serve the vast majority of children with autism. Every child requires a unique set of aides depending on the severity of their autism and exact nature. There is a significant difference between Asperger's and autism, as well as differences within these diagnoses (that's why they refer to it as "autism <u>spectrum</u> disorder.") Many public schools are barely able to provide educational services to mainstream children, much less the highly individualized therapies needed by children with autism. The current proposal would put a much heavier burden on our already-struggling public school system, and would leave the needs of the children with autism unaddressed.

I can't even imagine what our situation would be now if our son, [redacted], did not have access to the MA benefits. I know of several other families that have delayed applying for benefits for their children for similar reasons, as well as several who did not even receive a proper diagnosis of autism until after their child was older. The proposal would effectively eliminate many children from receiving <u>any</u> benefits for these reasons.

The proposal to limit benefits to age 7 may seem like it would save money in the short term, but it leaves a huge gap in the child's most formative years, which would mean the difference between them attaining independence and productivity as an adult, and being institutionalized. In the long run, the cost will be much greater than what the short-term savings may appear to be, and not only in financial terms. The cost of a human life – not just a "human life" but the lives of our sons, daughters, siblings, and other loved ones – is what is at stake, and cannot be measured in dollars and cents. There is a saying about being "penny wise and pound foolish." It may be a cliché, but I believe the DHS and State of Minnesota would be well-served to heed that adage. Thank you for your consideration.

[redacted]

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Tuesday, July 17, 2012 12:09 PM
To: *DHS_Reform2020Comments
Subject: Funding

Hello!
Kids don't grow out of autism by age 7 so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.
[redacted] is doing the best he can but he needs our continued help, for the rest of his life. He didn't ask to be autistic, it was was he was dealt in life. Please help his parents do the best they can for him!
If you had to walk in his parents shoes for just a week and help [redacted] thru life you wouldn't have a doubt in your mind what he needs to get thru every day.
Please help him and others like him. He is the sweetest little boy and deserves all the help in life he can get.
Thank you,
[redacted]

MINNESOTA
COUNCIL of
HEALTH
PLANS

COURT INTERNATIONAL BUILDING
2550 UNIVERSITY AVENUE WEST
SUITE 255 SOUTH
ST. PAUL, MINNESOTA 55114
651-645-0099 FAX 651-645-0098

July 17, 2012

Mr. David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

Thank you for the opportunity to review and provide comments on the *Reform 2020 Pathways to Independence, Section 1115 Waiver Proposal* draft document.

The following comments are submitted on behalf of the Minnesota Council of Health Plans (Council). The Council's membership is comprised of Minnesota's seven licensed nonprofit health plans: Blue Cross Blue Shield/Blue Plus of Minnesota, HealthPartners, Medica, Metropolitan Health Plan, PreferredOne, Sanford Health Plan and UCare.

The Council's mission is aligned with the State's: To strengthen Minnesota's position as the nation's healthiest state by leading or supporting efforts with community partners that increase the value of health care services. Specifically, the Council believes in high standards of quality care, broad access to health care coverage and services, affordable health care and a climate that facilitates improvement in quality, access, and affordability.

For over two decades, managed care has been the foundation of Minnesota's Medicaid Program. This model, which is recognized across the country for its excellence and innovation, receives high rankings for quality, access, and enrollee satisfaction. The availability of managed care plan resources – such as broad provider networks, care coordination/case management, and preventive and wellness services – has significantly improved health care access and the quality of care for Medicaid enrollees.

The Role of Medicaid Managed Care Plans in New Accountable Care Models

Discussion of the role of Medicaid managed care plans is virtually absent from the draft proposal. This makes it difficult to understand how managed care fits into the proposal's various components. Council members are especially concerned by the aggressive expansion of direct contracting with provider organizations that is described in Section 3 (Accountable Care Demonstrations).

For example, Section 3.2.3 states that DHS will incorporate purchasing strategies… to stimulate new "integrated care system partnerships (ICSPs) between *health plans and providers*." Specifically, ICSPs are referenced in conjunction with better serving dually eligible people. However, in Sections 3.3.1 and 3.3.2, no mention is made of partnerships with health plans for other forms of accountable care models. Does the Department contemplate a role for health plans only in the care delivery for dual eligibles, but not in other accountable care models?

In fact, Council members maintain that successful operation of ACOs and other models hinges on an active partnership between providers and Minnesota's health plans. The Council's members are committed to working with providers and the State to ensure that individuals receive the care they need, when they need it. Failure to anticipate questions about how ACOs will work within the context of existing managed care programs may slow implementation of ACO initiatives. A sampling of some of the resources and expertise health plans can bring to payment and delivery system transformation include, but are not limited to, the following:

- Facilitating population health management and health risk identification/reduction.
- Providing advanced IT infrastructure for efficiently performing clinical, operational, and administrative functions and performing complex data management and health care analytics.
- Managing networks to ensure individuals can choose among providers that meet high standards. This function includes the performance of credentialing activities, and activities designed to recognize outstanding provider performance.
- Assuming and managing risk to ensure financial stability.

Managed Care Plans and ACOs in the Health Insurance Exchange

As Minnesota moves toward implementation of the insurance exchanges and other provisions of the Affordable Care Act (ACA), it becomes increasingly important to ensure that state reform initiatives are designed in a manner that complements the post-2014 health care environment. This is particularly important in the case of Medicaid. For example, the ACA requires states to develop procedures to apply, renew, and enroll in Medicaid coverage through an internet website, which in turn will allow individuals to obtain information about coverage under Medicaid and Children's Health Insurance Program (CHIP) and compare such coverage to that available through the Exchange.

Program changes that increase the complexity in the health care system, not only in terms of services offered but how an individual accesses the system, will increase problems associated with churning and disruption of care. The following questions pertain to the relationship of ACOs and Medicaid managed care plans in the Health Insurance Exchange environment:

- Does DHS intend to include ACOs as an option from which individuals may choose to enroll in Medicaid through the Exchange?
- If so, will DHS include information on Medicaid ACOs in the required training for navigators and brokers?
- If a county or a non-profit organization provides services under contract with an ACO, is that a conflict of interest that would prohibit that same entity from serving as a navigator?
- Many stakeholders have expressed an interest in ensuring that the same plans that offer commercial products in the Exchange also offer a Medicaid product so that an individual does not experience a break in continuity of care or a break with a preferred provider if his/her eligibility for a commercial or Medicaid product changes. In the absence of any clear articulation of a role for health plans and ACOs, please reconcile the Department's vision for a future of more direct contracting with providers with the fact that many new and renewing individuals will be choosing a Medicaid plan through the Exchange.

Regulation, Reporting, and Financial Transparency of New Accountable Care Models

Council members also recommend that as the State pursues a direct contracting relationship with a provider, it is imperative that a level playing field is established across contracts. Specifically, we believe that provider groups should be required to provide the full range of program benefits and services as currently provided by health plans, meet established financial solvency requirements, and manage risk. The State has a stated value that an individual covered by Medicaid should have access to all needed services through his/her health plan, yet many HCDS entities are not able to provide some of those services (e.g., dental care).

<u>The following questions elaborate on the regulatory requirements for ACOs:</u>

- If the ACOs and/or Integrated Care Provider Organizations are risk- bearing entities receiving public funding, will DHS require accountable care models to meet similar transparency requirements for financial reporting and independent auditing as is now required for managed care organizations? If not, please explain the reason. Minnesota has set high standards for public disclosure and transparency for public programs. We believe that these standards should be maintained regardless of how the state contracts for these services.

- Regulation of the financial solvency of risk-bearing provider organizations in ACOs is important to ensure market stability. Bearing financial risk necessarily means that there is a possibility that a provider organization will face financial instability, or even fail; thus, there is a need for strong financial solvency regulations to ensure that the health care provider market remains stable, and that enrollee care is not disrupted. Does DHS intend to regulate the financial solvency of providers in ACOs and/or Integrated Care Provider Organizations, and if so, how?

In addition to these larger policy concerns, the Council has identified a number of areas in which the proposal needs further clarity. Attached is an addendum that lists specific questions and issues related to various sections of the waiver.

Finally, if the waiver proposal is approved, there will be significant operational issues that will need to be resolved. We are willing to provide any assistance and expertise that the State requests.

Again, Council members thank you for this opportunity to provide comments to this important proposal.

Sincerely

[redacted]

Julie Brunner
Executive Director
Minnesota Council of Health Plans

Attachment

Addendum for *Reform 2020 Pathways to Independence, Section 1115 Waiver Proposal*
MN Council of Health Plans Comments

- *MCOs' roles and how MCOs fit into this Sec. 1115 waiver is not clear.*
    - What impact will the waiver have on MCOs (vs. FFS)?
    - How will the proposed Sec. 1115 waiver intersect with the current PMAP+ Sec. 1115 waiver? With state law (current or to be proposed)?
    - What changes, if any, would be made to the PMAP+ Sec. 1115 waiver if this proposed waiver is approved?
- *Concerns with Sec. 3 (ACOs)*
    - Is DHS seeking authority/arrangements (ICSPs, for example) with CMS that will prohibit the state from continuing to deliver Medicaid (includes MinnesotaCare) through managed care (includes county-based entities)? If no, how might direct contracting impact MCOs (and FFS)?
    - In Sec. 13.1.1, DHS is proposing a waiver of 42 CFR §438.6(c)(5)(iii) (actuarial soundness of payments under risk contracts), but there is no budget/financing information accompanying this proposed waiver, and it is not clear why DHS is pursuing this. Actuarial soundness requirements are necessary to protect states and the entity they contract with for risk contracts. We would not support this type of waiver for managed care organizations or anyone else.
- *MCOs have a long history of collaborating* with the State and community partners on prevention and quality initiatives. MCOs desire to continue to participate in initiatives focused on improving health outcomes.
    - As one example, Sec. 9.4 (promote personal responsibility): *We Can prevent Diabetes grant* aims to reward health outcomes. Health plans have extensive experience providing individual and group incentives for preventive care. Health plan representatives participate on this grant. MCOs welcome <u>all</u> opportunities to come to the table to work on preventive care initiatives.
- *Intersections* with other requirements or groups needs more definition:
    - The Sec. 1115 waiver will require legislation. How might that impact various components?
    - The Minnesota Healthy Contribution program isn't mentioned in Sec. 8.1.2, but should be (i.e., the cap for MinnesotaCare is now at 200% FPL).
    - Eligibility requirements under the Affordable Care Act will have an impact.
    - In Sec. 8.1.1, (asset test of $10,000 on adults without children): If Minnesota does <u>not</u> opt to expand Medical Assistance eligibility for adults without children with incomes 75% -133% FPL, as we understand it, there would be no need to seek a waiver of the asset test for these adults with incomes ≤ 75% FPL. That is because (we believe) that the ACA Medicaid requirements otherwise effective 1/1/14 will not apply to states choosing not to expand Medicaid eligibility. *Note: CMS may issue clarifications as a result of the June Supreme Court decision that impacts Medicaid eligibility.* If, on the other hand, Minnesota expands Medicaid eligibility, then this waiver to impose an asset test would be premature and would presumably violate the ACA's requirement of maintenance of effort in effect through CY '13. In addition, CMS may determine that as of 1/1/14 states that expand Medicaid eligibility cannot have Medicaid eligibility asset tests (i.e., the recently promulgated Medicaid eligibility rule applies to states that expand Medicaid eligibility pursuant to the ACA).

Addendum for Reform *2020 Pathways to Independence, Section 1115 Waiver Proposal*
MN Council of Health Plans Comments (continued)

- *It's often not clear which components are integral to the Sec. 1115 waiver*.
    - Which components of the proposed waiver does the State already have the authority to do?
    - Exactly which activities would require federal waiver approval?
- *More clarity is needed for specific programs as well as for goals and expected outcomes* for programs.
    - It often seems (but is not clear) that DHS' goal is to expand the service but reduce eligibility for that service. See, for example, Sec. 4 (Community First Services and Supports).
    - It appears that DHS is creating a new State plan service for children with autism up to age 7. After age 7, will those services be funded by the school system? If so, what responsibilities will the MCOs have? The current DHS contract states that "Medically Necessary Medical Assistance services that would otherwise be covered by this Contract that are provided by school districts or their contractors and are either: (1) identified in an Enrollee's Individual Education Plan (IEP), or (2) Individual Family Service Plan (IFSP), are not covered."
    - CFSS eligibility criteria are not clear.
- *Timelines* should be clarified for each Section and subsections within.
    - In addition, while it is clear that PCA changes are scheduled for 2014, issues related to workers' training, financial statements etc. have a 17 month development period.

ARRM

July 17, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
Saint Paul, MN 55164

Re: Comments on Proposed Reform 2020 Medicaid Waiver Request

ARRM is an association of 150 providers of long-term care services supporting thousands of people with disabilities through the DD, Brain Injury, CADI, CAC and Elderly waivers, and ICFs/DD and SILS. ARRM is committed to assuring that Minnesota has a viable private provider sector to promote consumer choice, adequate funding, and appropriate regulation. On behalf of our members and the individuals we serve, ARRM is submitting the following comments on the proposed changes in the Reform 2020 Waiver Request.

ARRM strongly supports the goals of the Reform 2020 Proposal for the individuals we serve: improving outcomes for individuals based on their specific needs, providing the right service at the right time, and increasing the efficiency of resources to maintain the long-term care system's sustainability. After reviewing the waiver application, we believe the initiatives included can accomplish those goals. In order to be successful, ARRM believes stakeholder involvement in their development and implementation will be crucial. We look forward to participating.

Now, here are some specific comments on portions of the waiver application:

1. Development of the Community First Services and Supports (CFSS) Option

ARRM believes the current personal care service (PCA) benefit lacks the flexibility in services and payment options to provide the most-effective services for individuals. Replacing the current PCA benefit with a more adaptable set of services will enhance service quality, and allow more individuals to live more independently. Including options like prompting and coaching, not current allowed under the PCA program, will allow providers to meet the needs of more people. However, enhanced flexibility and infrastructure changes in the services delivery system requires a well-trained, highly-skilled, and adequately-compensated workforce to meet demographic challenges, promote stability, and ensure quality. With additional flexibility provided by the federal government under the new 1915 series of waiver options, providing these services also makes sense from a fiscal standpoint. We strongly agree with this proposal.

2. Individualized Budgeting for Services

The movement toward providing individualized service budgets for new and existing long-term care services is also an aspect ARRM supports. In the Reform 2020 Proposal, the department is proposing individuals' budgets for the CFSS and other disability waivered services. We agree that system changes promoting greater individual control in choosing and directing is essential to achieving a greater degree of independence. For this to be most effective, consumers need access to sound and valid information to make informed choices in achieving person-centered outcomes. The types of information and methods of distribution will be important, and should be developed with significant stakeholder input. Finally, the methodology for determining individual budgets needs to be highly transparent and based on a reliable and valid assessment tool.

Also, there needs to be oversight to ensure the proper use of taxpayer resources. The Reform 2020 Proposal references a new financial management structure for self-directed options. We understand the importance of reducing administrative complexity; however, the rationale for replacing the current fiscal support entity (FSE) system is not well-defined. The application specifies fiscal management entities will be chosen by the state (with input from stakeholders) via an RFP process, and limited to allow individuals a choice between at least two entities. It is unclear what advantage is gained by limiting the number of entities, or how one might be chosen over another. In this area as well, ARRM believes stakeholder involvement and transparency will produce the best outcome for the individuals directing their own services.

3. Enhancements for Current Waivered Services

The Reform 2020 Proposal includes new and enhanced services for the existing waivers. We strongly support creating system changes that support people in having meaningful lives at all stages of life; with a primary goal of a simpler system to enhance service access and efficiency. These include more flexible options reimbursing for longer periods. ARRM strongly supports this idea. In the 2012 legislative session, we proposed legislation as part of our *Blueprint for Reform* to create a daily rate for independent living services (ILS). We believe a daily rate for ILS is very similar to this, and will allow more individuals to be moved out of adult foster care so those facilities can serve individuals requiring that level of care.

4. Increasing Access to Housing and Employment

Supporting individuals in community is an important factor to keep them in that setting. However, housing is a huge barrier and requires creative solutions and continued collaboration with all stakeholders and housing partners. In the Reform 2020 Proposal, the demonstration projects to provide new services to maintain housing and employment will advance efforts to maximize community integration. ARRM proposed several initiatives our *Blueprint for Reform* to help individuals secure and maintain their own housing. The additional supports in the waiver application will build on our efforts and we support them. However, more resources and attention must to addressing the housing needs of individuals with complex physical disabilities and health needs is required.

5. Trends in Provider Reimbursement

The new accountable care models have real promise to create a more sustainable and integrated service delivery system. In the Reform 2020 Proposal, these changes only affect traditional health care services. ARRM believes this model will eventually be applied to the services we provide. Our members' knowledge of and experience in managing care delivery will be crucial to developing strategies to reduce costs for long term care services. Consulting providers and soliciting their input in the creation of any new models of payment or service delivery will achieve the best outcomes.

ARRM appreciates the opportunity to provide comments on the Reform 2020 Waiver Proposal. While we support the goals and direction of the reform efforts, stakeholder engagement and involvement developing the details and implementation of the separate initiatives is needed to ensure success and avoid unintended consequences. We look forward to further participation with the department and other stakeholders to preserve and protect Minnesota's most vulnerable residents.

Sincerely,

Darlene Scott President	Bruce Nelson Chief Executive Officer

From: Carol Sime <carol.j.sime@gmail.com>
Sent: Tuesday, July 17, 2012 10:46 AM
To: *DHS_Reform2020Comments
Subject: Disability programs

I haven't had a chance to thoroughly study or discuss the plan, but I can tell you that a lot of people would like assurances that their loved one will not be worse off as a result of these changes. What happens with the money following the people if the money gets cut? What if someone is perfectly happy with their living situation and would be adversely affected by not living with their good friends any longer?

From: Laura Kadwell <laura.kadwell@headinghomeminnesota.org>
Sent: Tuesday, July 17, 2012 9:51 AM
To: *DHS_Reform2020Comments
Cc: Carleen K. Rhodes; Laura Kadwell
Subject: Comments from Heading Home Minnesota
Attachments: Laura Kadwell.vcf

To Whom it May Concern:

The Heading Home Minnesota Community Leaders Council ("the Council") is a public-private partnership of community leaders supporting the work to end homelessness in Minnesota. The Council appreciates the opportunity to comment on Reform 2020: Minnesota's Section 1115 Waiver Proposal to the Centers for Medicare and Medicaid Services.

Background.
The Council, which includes leaders from the philanthropic, business, faith and government sectors, began its work in 2006 with a focus on leveraging resources in support of the State's Business Plan to End Long-Term Homelessness. The Business Plan, which began implementation in 2004, has been successful in creating over 3,500 supportive housing opportunities for individuals, youth and families with children with long histories of homelessness. The Plan has also leveraged significant community resources that are ending homelessness for thousands of Minnesotans.

The primary strategy of the Plan is to create permanent supportive housing – housing with the services needed for people to obtain and maintain housing and to improve their lives. Significantly, these services, so important to improving the lives of Minnesotans, also have potential to reduce public costs – money now being spent for emergency and inpatient hospital care, jail, prison, shelter and detox services. (See Waiver Proposal, p. 65 for supporting research.)

For the past few years, the supportive housing community, including Heading Home Minnesota, has been exploring the nexus between Medicaid and services needed in supportive housing. Housing is the foundation for successful health care. The studies mentioned in the Waiver Proposal, and specifically a study completed by Hearth Connection, Minnesota's Supportive Housing and Managed Care Project, show improvement in well-being of people who are housed, along with a reduction in the use of expensive emergency and hospital-based interventions. The question then has been to define services that could be offered in supportive housing and funded with Medicaid. Supportive housing providers have been meeting regularly with DHS staff (Medicaid, Mental Health, Community Living Supports) to define these services.

Comments
The Heading Home Minnesota Community Leaders Council appreciates the significant steps DHS is taking in the Reform 2020 Waiver Proposal to bring necessary services to some of our most vulnerable Minnesotans – those who are or are at risk of homelessness.

Our comments are directed to Section 6.2: the Housing Stability Services Demonstration. We believe this demo is absolutely headed in the right direction – recognizing the importance of housing in reaching and maintaining successful health outcomes. We appreciate the connections DHS has made with the supportive housing community to define this proposal and expect to continue working with DHS as the Waiver is refined, adopted and implemented.

The Council believes that, in general, the definition of Target Population (p. 61 ff.) is appropriate and believes the inclusion of people now in supportive housing is especially important (these are folks who would be homeless without services currently provided). The Council further applauds the benefits included: outreach/in-reach, tenancy supports, and service coordination. In a perfect world, the service package would be more comprehensive but this is a good starting place.

The Council was concerned when we learned that DHS, in order to maintain cost neutrality, intended to implement Reform 2020 only with households now receiving GRH Rate 2. While a significant subset of the overall homeless population, this group is, nevertheless, a subset. The Proposal as originally drafted did not address the needs of the broader population.

Since the Waiver Proposal has been out for comment, however, we understand that DHS has considered significant modification to this section. We support these modifications now under consideration:

- Expanding the Target Population to include folks who are homeless, receiving General Assistance and are frequent users of high-cost medical services. This modification puts the Waiver Proposal directly in sync with the purposes of supportive housing.
- Including “Community Living Assistance” in the set of services. These services address needs such as assistance and support for basic living and social skills, household management, medication education and assistance, monitoring of overall well-being and problem-solving. We understand this set of services is available to other populations at DHS and believe consistency of services across populations is an important goal, where possible.

The Council understands the importance of maintaining cost neutrality in the overall Reform 2020 proposal. And we understand it is necessary to balance the rate structure with the number of households to be served in order to maintain cost neutrality. We strongly favor maintaining a rate structure that will allow providers to deliver necessary services, even if it means reducing the number of Minnesotans who can be served under the Waiver. If rates decline to a point where providers cannot provide adequate services, people will not be able to maintain housing and the Waiver will be pointless. Conversely, if the State can demonstrate the success of the 1115 proposal with this population, there will be opportunities in future to expand the reach of the Waiver.

Once again, the Council appreciates the extent to which DHS has reached out to the housing community in drafting the current proposal and the progress represented here in serving folks who are homeless or at risk of homelessness. We look forward to continuing to work with the Department on this and other proposals to address the well-being of the most vulnerable Minnesotans.

Sincerely,

Laura Kadwell
HHM Community Leaders Council
Statewide Director

On behalf of
Carleen Rhodes, President and CEO
Minnesota Philanthropy Partners
HHM CLC Co-Chair

Laura Kadwell
Heading Home Minnesota
Statewide Director

(612) 721-3700 , x112 Work
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laura.kadwell@headinghomeminnesota.org

Dooley, Lea M (DHS)

From:	MADSA <info@madsa.org>
Sent:	Tuesday, July 17, 2012 8:45 AM
To:	*DHS_Reform2020Comments
Subject:	Reform 2020: Pathways to Independence

July 17, 2012

David Godfrey

Medicaid Director

Minnesota Department of Human Services

P.O. Box 64998

St. Paul, Minnesota 55164

Dear Mr. Godfrey,

MADSA appreciates the opportunity to comment on the Department of Human Services' Federal Section 1115 Waiver Proposal, entitled "Reform 2020: Pathways to Independence."

Sec 2.2 Long-term Care Realignment- MADSA continues to support modifying the nursing facility level of care standards, but we advocate that the state find a way to decouple that standard from the community supports level of care. We note that in **Sec 9.3 Redesign Home and Community-Based Care**, the Department proposes "person-centered choices" with "efforts to reach people earlier to prevent or delay use of public programs and more costly services." Contemporary research indicates that the keys to preventing decline are (1) begin adult day services early enough in the course of an individual's chronic disability and (2) provide continuity and frequency that meet the individual's needs.

We further support the facets of Sec. 2.2 that seek federal matching funds for the Alternative Care and Essential Community Supports Programs. Currently, Adult Day Services clients can make use of the Alternative Care funds. That option has not been extended to those who receive Essential Community Supports. The waiver proposal states that ...in the event that Minnesota is successful in obtaining federal matching funds for the AC and ECS programs, DHS will use at least a portion of the state savings that result to expand the benefits available under the ECS program. MADSA takes the position that consumers should be able to choose whether to spend this benefit on adult day services, even if the total dollars impose natural limits on the extent of services.

We urge the Department of Human Services to continue work to improve the availability and quality of consumer information services, particularly for people faced with what can be sudden changes in their needs and urgent transitions in their care. We note that for individuals who will Return to the Community from nursing facilities and for those who will rely on the Money Follows the Person Program, services available in adult day centers are far more than activities and socialization. Adult day centers can be the place where baths are given, blood pressure checked, and physical therapy provided. This approach saves time, transportation arrangements, and ultimately money. Finally, in the spirit of making complicated systems more consumer-friendly, we are in favor of giving the Maltreatment of Vulnerable Adults Reporting network one centralized call-in number. This not only makes reporting more direct for the general public, it will make our trained staff's reports more efficient and effective because there will no longer be questions about which county to call when the vulnerable adult lives in one county and the center is in another.

If you have any questions or would like additional information, please feel free to contact me at 763.464.2698 or info@madsa.org.

Sincerely,

Lynn Buckley
MADSA President

Schels, Johanna T (DHS)

From:	[redacted]
Sent:	Monday, July 16, 2012 10:47 PM
To:	*DHS_Reform2020Comments
Subject:	comments about DHS proposal on Autism Benefit set

Dear Sir/Madam,

I am writing this email to express my concerns regarding to the DHS proposal on the Autism service. As a mother of a boy with Autism, who has fighting the battle to help my son to reach his highest potential for 4 years, I am deeply worried about the new proposal's age cap. We all know that each child with Autism is different and unique. Some kids might be able to mainstream into the public school education by age 7 after years' early intensive intervention with no or little support. While the other groups of kids, though cognitive normal, still need tons of support in the area of social interaction and communication even at the age 7. Being enrolled my son in the public school's special education program for 1.5 years, I can tell you that the public school cannot take this challenge. Due to the complexity of the Autism, you truly need the experts in the behavior management, social interaction and play, speech and occupational therapy to help this unique and challenging group. Those professionals have years of training specialized for working with these children. You can hardly find such qualification among teachers in the public school systems. Letting the school take over at age 7 regardless if the child is ready will fail those kids and also frustrate the teachers. Teachers are only experts in education. Treating Autism needs more than the educational approach. My own experience of trusting the public school help my Autistic son is a big mistake. That is the period my son made little progress. Because of the detour, my son starts the intensive in-home behavior therapy at 5 y old. So far, we just have a year of therapy. He has already made huge progress in lots of areas in terms of language, self-control, behavior. He just recently starts making progress in social interactions. I expect him continue growing and learning the new social skills. By providing all the medical necessary treatment for him, including speech, ABA, occupational therapy, social skills training, I have no doubt that he will eventually be independent and become a contributor to our community.
Perhaps one day he will work with me: his mother in the field of improving cancer treatment like he always wants now.

So please let all kids with Autism access to the medical necessary treatment regardless their age. The new findings in the neuroscience show the brain plasticity even in the adulthood. Having the age limit of 7 for the autism treatment is not scientific valid anymore. Why not keeping to treat them as long as they make measurable progress.

Thank you so much for your time and kind consideration!

A concerned mom

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Monday, July 16, 2012 9:18 PM
To: *DHS_Reform2020Comments

To who it may concern,

Please do not stop helping my grandson, he is and nonverbal , what will his parents do. No chlid with austsim is cure at any certain age , what are you thinking ? You support people with drug and achololism problems and yet children with a lifetime and have hope you want to stop it . As a long time taxpayer and grandmother, please think of my grandson and all the other children and families struggling everyday to help their child!!!

Thank you,
[redacted]

David Godfrey July 16, 2012
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55164

Subject: Reform 2020 Section 1115 Waiver proposal

Dear Mr. Godfrey,

I'm writing this letter to inform you that I am a Minnesota resident and I firmly believe children of all ages should have access to medically necessary autism intervention treatments. I have a son [redacted] 6 years old) who has a medical diagnosis of autism. [redacted] was diagnosed at the very young age of 16 months old. [redacted] has received numerous treatments during our autism journey, and by far the most effective has been in-home ABA provided by the [redacted]

[redacted] is continuing to learn new skills, and I know as a parent who lives and breathes autism 24 hours a day that he will continue to learn and grow beyond the age of seven. Please do not cap medically necessary treatments at the age of seven.

I can also tell you that every child with autism is very unique. There is no perfect treatment that covers all kids. It's exactly why they call it a spectrum disorder. I also urge you to please continue to allow individually tailored medically necessary treatments.

I want [redacted] to have a chance at the highest level of independence he can achieve. I know this will also help him live a happy life. Please do not make decisions today that will prevent children of all ages reaching their potential. Reducing treatments today will actually cost the state of Minnesota more money in the long run.

I'd like to quickly try to tell a personal long story short. [redacted] and was diagnosed with CLL (chronic lymphocytic leukemia) a few years ago. The disease is starting to have a large impact on my [redacted] including fatigue. Travel to Minnesota for visits is becoming increasingly difficult for [redacted], and I never thought we'd be able to control [redacted] behaviors for a trip to [redacted]. Due to all the recent success of [redacted] ABA therapies, we decided we would try a trip. [redacted] did very well on the trip, and [redacted] was absolutely pleased to have his grand-children visit him for the first time in [redacted]. Attached below is a picture of [redacted] (red shirt) and his younger brother [redacted] on a [redacted]. This will be a treasured moment forever for our family that would have never been possible without [redacted] ABA treatments.

[redacted]

In conclusion, I urge you:

- Please do not create an age cap for treatment and services.
- Please do not take away individually tailored medically necessary treatments
- Please do not make short-term decisions that will ultimately create a larger burden for Minnesotans in the future

Kind Regards,

[redacted]

ausm
autism society of minnesota

July 15, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

Thank you for this opportunity to provide public comment on “Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal.” On behalf of the Autism Society of Minnesota, whose mission is to enhance the lives of individuals with autism spectrum disorders through support, collaboration, and advocacy, we would like to provide specific feedback on section 9.1.2 – 9.1.3, 1915 (i) for Children with ASD.

According to the Center on Disease Control National Center on Birth Defects and Developmental Disabilities, the average age of an autism spectrum disorder (ASD) diagnosis is now 4 years of age. Children of color oftentimes are diagnosed later with some research showing that black children receiving Medicaid were diagnosed nearly 2 years later than white children. Given this data, children are already being diagnosed much later in the Birth-7 year age timeframe in your proposal. We are unclear, given the statement in your proposal as to providing an “intervention service set that tapers off as progress is made, ***or*** that children age out of as they transition to school” and how that relates to the 0-7 age range you are proposing. The Autism Society of Minnesota remains concerned about the lack of clarity in this proposal and recommends that DHS provide interventions that would taper off as the child progresses or extend to at least the age of 21.

As DHS moves toward more clarity in this proposal, we would also like to provide the following recommendations:

- The largest investments we make in children with ASD are healthcare and education. These investments need to be coordinated and collaborative to maximize the return on our investments and to ensure the best possible outcomes for students. Consequently, all agencies that provide services need to be working together along with parents and other advocacy organizations. For example, DHS should work with the Minnesota Department of Education to improve interagency service coordination, especially for children 3 years and older.

- We need to develop an integrated service delivery system between the healthcare and education systems. Currently, both systems continue to operate as separate entities, oftentimes to the detriment of children with ASD and their families.

- A broad range of “high quality, medically necessary, evidence-based therapeutic, *neurodevelopmental* and behavior intervention treatments (in and outside of school) should be covered because every child is different and responds positively to different treatment options. It is unclear if this proposal would cover such interventions as RDI and Floor time, which have also been successful for children with ASD.

- Quality standards and performance measurements for Minnesota Department of Education and DHS service providers need to be in place to ensure high quality therapies and treatments. These standards and performance measurements should be transparent and shared in a format that is as "parent friendly" as possible.

We applaud DHS for considering the establishment of a learning collaborative to improve quality of care in community settings for individuals with ASD. We would like to make the following recommendations to be included as they relate to quality of care:

1. Promotion of Medical Screenings for ASD by 18 months of age. This recommendation is consistent with the American Academy of Pediatrics recommendation that screening be done as early as 18 and 24 months of age for ASD. This will help us identify children with ASD earlier and get them intervention sooner, which will in turn improve outcomes. In order to capture more children with ASD, DHS should partner with the Minnesota Department of Health and physicians to determine strategies to reach parents that may not otherwise utilize regular health checkups for their child.

2. Support for Expansion of Medical Homes for children with ASD. This should include ensuring that providers are rewarded for quality care and outcomes as well as reimbursed at a competitive rate for their services.

3. Promote cultural competency training for professionals serving children with ASD so diverse populations will be diagnosed earlier.

4. Promote ASD certification of case managers so they can better serve the needs of this population across the spectrum.

We also support the two year plan to enhance the integration of Medicaid within the school system. As part of that integration, DHS should work with the Minnesota Department of Education to continue to streamline the billing process through the Medicaid 3rd Party Billing requirement to ensure that schools can do this effectively and efficiently, while providing transparency to parents about services billed back for their child.

Lastly, we would like to thank DHS for bringing this proposal forward. The conceptual framework in the proposal has many key recommendations that will move Minnesota forward in serving children with ASD. Please consider us a partner in this effort and don't hesitate to call upon us for additional information if needed.

Sincerely,

Kim Kang
President

Sherrie Kenny
Executive Director

[redacted]

[redacted]

July 14, 2012

Mr. David Godfrey, Medicaid Director
Minnesota Department of Human Services
P.O. Box 644998
St. Paul, MN 55164

Mr. Godfrey,

Thank you and the Department of Human Service staff for your work to transform the delivery of services to children and adults in Minnesota through the Reform 2020 Proposal.

As a professional serving citizens impacted by developmental disabilities, I welcome the exploration of new models for service coordination and delivery that are “functionally driven according to person-centered plans.” This not only provides access to the lowest cost, highest quality outcomes for people — it is also how the community wants to be served. I applaud your plans for both community and provider input throughout the implementation of these ideas.

As a parent of a 4 year old with Autism, I have particular interest in 1915(i) for Children with Autism Spectrum Disorders (ASD). I appreciate the Department’s effort to create clear access to effective early intervention services. This is a critical need. There are 3 areas about which I’ll specifically comment: the importance of service quality, strategies for transitioning children to school, and a few thoughts about the importance of accessing emerging treatments.

Quality of Service: it’s critical to ensure that services in Minnesota deliver on the promise of Early Intensive Behavioral Intervention (EIBI). Behavior Analysis is a specialized practice, and treating children and adults with Autism is a specialty inside that practice. I urge DHS to bring effective consultants to the table and acknowledge the unique skills required to deliver effective, positive behavioral supports.

While the reform document speaks to developing standards of assessment and treatment as well as measurement, I urge DHS to go further. The practice of Behavior Analysis must go beyond a developmental sequence grid to have a real impact on the lives of children with Autism. A learning cooperative is an important element, and we must require credentialed professionals.

[redacted]

Accessing the therapeutic services recommended by our son’s physicians was complex, but unfortunately our early experiences in that service system have been heartbreaking, both through the school system (ECSE staff discouraged assessing my son for Autism) and in our first private therapy experience (where undisclosed, unnecessary aversive and deprivation procedures were implemented). While our son gained some skills in this ABA program, we saw minimal functional improvement and eventually regression before allegations of abuse surfaced.

The methods that developed without skilled Behavior Analysts on staff in this center should be of great concern to DHS. Supervision of services was provided by a contracted psychologist, who does not list early intervention as a competency with his licensing board. At other times supervision was provided by a Marital and Family Therapist.

Current professional standards have little relationship to the competencies really needed for effective services. An expectation that “Applied Behavioral Analysis” would be *applied* by a *Behavior Analyst* is reasonable.

The design of our Early Intensive Behavioral Intervention (EIBI) programs in Minnesota must match evidence-based practices. Quality services, quality outcomes. Structures and service allocations (e.g. hours/week) should be based on need; how service allocations will be made is unclear at this time, which is also of concern.

In addition to collaborating with the Minnesota Northland Association of Behavior Analysts (MNABA) to make appropriate determinations in this and other areas, I hope that DHS is utilizing the work already completed by the Behavior Analyst Certification Board and other State Associations for Behavioral Analysis

- Behavior Analyst Certification Board - www.bcba.com (conduct guidelines)
- California Association for Behavior Analysis - www.calaba.org (including a task force report on ABA Service Guidelines from 2011: www.calaba.org/sstf/guidelines-abatx.shtm)

Today our son now receives ABA services in a program staffed with skilled professionals: Board Certified Behavioral Analysts, Occupational and Speech therapists, and trained staff. In less than 6 months he has made remarkable progress, far beyond what was accomplished in more than a year in the prior setting.

Progress may seem hard to measure -- but it is obvious. Our son is physically stronger, better coordinated, able to follow direction and is more engaged with others. He is dressing himself (with structural and verbal cues), playing more appropriately (we finally have toys all over the house!) and progressing in his learning (e.g. matching items, making choices).

[redacted]

Most importantly, while he has no verbal language, we are quickly establishing an effective method of communication. The world is opening up for him. We can't help but wonder how far he might have progressed already if our current team had been with us from the start. Every child deserves quality intervention.

School Age Transition: I understand that DHS has clarified an intention to transition to the school system at age 7, not to reduce services. This leaves some open items of concern:

- While the legislature has requested recommendations by age, all other areas of this initiative focus on "people not programs." A benefit set for Autism should follow suit.
  - There must be enough flexibility to meet individual needs. Some children will not have exhausted the opportunity of intensive interventions by age 7, especially those who were diagnosed or began treatment late. Some children may need extended service.
  - Behavior therapy can also be important for gaining and maintaining independence across the lifespan; it is "the right service, at the right time" for many young people and adults with a variety of disabilities, at a variety of ages.
- When we move children from 1:1 therapeutic interventions to traditional, IEP-guided classroom settings, we put at risk the very benefits of early intervention.
  - New models for early intervention must match funding allocations to the professional tiers of service required for effective results (credentials, supervision, parent training).
  - Funding streams should remove barriers to appropriately fading services and staff ratios as children progress. Such a system must be based on need, not age.
- Plans to provide service coordination within the school system also raises concerns. Given the gaps that currently exist in the schools, it's concerning to think that a resource outside of the school system would no longer be available to families. The details of this plan through CFSS services should be outlined for public comment (who, when, where, etc).

We all want our children in regular schools too—but a system that funnels kids into traditional, segregated special education programs won't work—our kids deserve to be tapped, not trapped.

- It seems wise to provide pathways for existing, high quality providers to partner with the schools, rather than limit CTSS services to schools after age 7. We need to discover how to leverage the expertise of the therapeutic community to support both transitions to school and the ongoing success of kids at school and at home.
- As many parents who testified indicated, school districts often refuse behavior-based strategies. Many schools are unprepared to welcome learners on the spectrum. Without a substantial change, the culture of interventions in many schools is unlikely to support kids with ASD to maintain skills, much less continue to build them.

Our story with the schools ended shortly after we received an Autism Diagnosis. Our team recommended we not "waste our time and money" on the assessment. We fortunately knew to act anyway; there was no question my son was regressing.

After his diagnosis, they offered a few mornings of service a week (pending several appointments for an educational diagnosis; one diagnosis is a direction I celebrate). The school system was not then and is not currently structured to offer the evidence-based methods my son needs.

Emerging Treatments: I was hopeful to hear that this benefit set may provide access to a wider variety of treatments, including emerging treatments. Increased access to interventions will improve outcomes, reduce long term service costs and support families for whom many interventions are out of reach. There are many promising medical treatments, including many outside of traditional pharmaceuticals. I urge DHS to consider inclusion of less-traditional biomedical interventions under areas of "coverage with evidence development."

Our son has many allergies, reactive-airway/asthma and significant communication barriers. Exposure to an allergen can lead to extended disruptions in sleep as well as skin and/or digestive health, which become barriers to learning.

We encourage DHS to consider nutritional and biomedical interventions; such careful interventions have made a difference in my son's sleep, digestion, headaches and overall well being. Probiotics alone did wonders to help stabilize his digestion.

[redacted]

Diets have been shown to be effective with seizures in some kids. These and other promising treatments can be expensive, and out of reach for many families.

Thank you:

Autism presents our community—and so many individuals families—with great gifts and many complex challenges. I believe your efforts to welcome and incorporate stakeholder involvement in these reform initiatives will continue to be critical for creating effective and safe services.

Respectfully,

[redacted]

July 16, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dr. Mr Godfrey,

On behalf of Vail Place I am submitting these comments to the Medicaid Section 115 Waiver Proposal: Reform 2020 - Pathways to Independence. Vail Place is a community mental health program which provides case management, supportive housing, employment, and other community supports for adults with serious and persistent mental illness in Hennepin County. Thank you for the opportunity to comment on the Reform 2020 proposal.

Vail Place supports the goals outlined in Reform 2020 to:

- Achieve better health outcomes
- Increase enrollee independence
- Increase community integration
- Reduce reliance on institutional level of care
- Simplify administration and access to program
- Create a program that is more financially sustainable

Vail Place has reviewed the proposal and will provide comment on services for persons with serious mental illness.

4.2.1 & 4.2.2: Community First Services and Supports

Providing for an alternative to the PCA program by providing an array of services and supports to provide assistance with maintenance, enhancement or acquisition of skills to complete activities of daily living, independent activities of daily living and health related tasks to help people live in the community

Vail Place has concerns regarding the Community First Services and Supports (CFSS) for people who need to meet Nursing Facility Level of Care (NFLOC). Over the last year, the NFLOC which has focused on physical symptoms, hands on assistance, daily monitoring, and ADL needs. As a result, many people with a serious mental illness who need a high level of CADI services were determined to be considered “low need”, resulting in lower service funding for individuals. The proposed CFSS services will be using the MNChoices assessment tool, based on the recent revision of the NFLOC, which will further restrict eligibility for people with mental illness.

The proposed program for people who do not need to meet NFLOC will also result in few people with a serious mental illness meeting eligibility as the individual must have a level one behavior or one ADL need. The program will not allow people who have a primary mental illness to meet the criteria as symptoms and interventions are very different from someone who has a developmental disability combined with a mental illness. For example, many people with a primary diagnosis of mental illness have complicating medical issues, but will not meet criteria of having a level one behavior and most people have no ADL concerns. In addition, the cyclical nature of serious mental illness may allow for decrease in symptoms for a period of time only to have high level of symptoms return at a later date, which may affect eligibility.

6.1: Demonstration to Empower and Encourage Independence through Employment Supports

Targeting specific people to provide telephonic navigation, benefits planning and employment support based on the Pathways and Demonstration to Maintain Independence and Employment programs.

Vail Place supports the proposal for Medicaid expansion to people ages 18 – 26 and the emphasis on employment for this group. However, there is concern about the high emphasis on telephonic navigation for these services which is not a good match for young adults with a serious mental illness. For example, a young adult with paranoid schizophrenia is not likely to follow through with telephonic services and will need face to face staff support to be successful. Vail Place is also concerned about the use of the Disability Linkage Line to provide navigation for this program. Young adults with a serious mental illness do not consider themselves disabled and they and their parents usually seek out mental health services as opposed to disability services.

The proposal also outlines using DB101 to manage benefits for people who find employment, however this program does not meet the needs for people who have complicated benefit issues. Also, many young adults may not have a computer or will need to obtain computer access in order to use DB101.

In addition, there is a concern regarding the eligibility criteria that the person must be currently employed, have been employed in the last year or have experience and an employment shift in the last year. The criteria will exclude young adults who want to work but have not been able to find work and may exclude people who have been attending post secondary schools.

6.2 Housing Stability Services

***Provide a new set of benefits to people who have serious functional impairments and housing instability*.**

Vail Place supports the development of additional housing support services for people with functional limitations. The proposal outlines three components: 1) outreach/in-reach, 2) tenancy support services, and 3) service coordination.

We are concerned about using MNChoices for someone who is homeless as the process will not well for someone in a shelter or on the street. People who are homeless require face to face outreach and personal connection in order to provide an accurate assessment. In addition, it is unclear how MNChoices will assess the ADL or IADL needs of a person who is currently homeless, particularly if they have been homeless for a long period of time.

The proposal outlines an array of front end housing services; however, it does not list ongoing support services which are often needed in order for people to maintain their housing. Currently, there is little, if any funding for ongoing housing support and Vail Place recommends the proposal be expanded to include these services.

7. Anoka Metro Regional Treatment Center Demonstration

Waiving the Institutions of Mental Disease (IMD) exclusion to use MA for AMRTC to allow for continuity of care

The proposal requests CMS to waive the IMD exclusion for AMRTC in order to provide continuity of care for people committed to the hospital. Vail Place is in support of the waiver as it will allow people to move from the community, to the hospital and back to the community without having gaps in Medical Assistance which will be a seamless transition for people as they purchase medications and have doctor and therapy appointments.

We are concerned that the proposal links 1915(i) only to a group of people who no longer meet hospital level of care and are unable to move from the state hospital to the community. Vail Place is in support of DHS reviewing a variety of 1915(i) program options that would assist people in the community, not only at AMRTC.

9.1.4 1915(i) to support individuals with mental illness who are at risk for institutionalization without access to integrated community-based systems of care.

Providing a wide range of services to a select group of people with serious mental illnesses who have co-occurring or complex health care needs and no longer need hospital level of care at AMRTC

Over the last year, there has been a lot of discussion in the mental health community regarding the 1915 (i) State Plan waiver to provide additional mental health services for people with serious mental illnesses. Vail Place supports the inclusion of 1915(I) placeholder language in the overall proposal while further details on the program are developed. We support the

We have concerns regarding the eligibility criteria in the proposal for adults with serious mental illness, which will exclude many people. The proposed current eligibility includes people who have a serious and persistent mental illness and difficulty maintaining community-based services as exhibited by extensive hospital stays, AND exhibits two of the following:

- Assaults
- Verbal aggression
- Active chemical dependency
- Past criminal behavior
- Symptoms that do not respond to treatment and require eight hours of supervision per day
- The presence of another illness, condition or disability that makes it difficult to function in the community

These criteria focus on a small group of people at AMRTC which does not include people who are at risk of being committed or hospitalized. In order to meet this goal, we would encourage DHS to explore additional service models and target population.

In addition, we ask DHS staff to revise Adult Rehabilitative Mental Health Services (ARMHS) to review funded services and billing as well as consider new rehabilitative services and billing units not currently funded by the Rehabilitation Option. Also, DHS would need to determine if this would be a good fit for the 1915(i) program.

9.3.2 MnChoices

Providing a singe web-based assessment and planning process tool.

Vail Place recognizes the work DHS staff have made to improve the MNChoices program in order to assess the needs of people with mental illness.
We also feel additional work is needed to improved the assessment for people with serious mental illnesses.

We want to thank you for the work by DHS leadership and staff in developing this proposal which will improve the lives for many people who are elderly and disabled in our state.

Thank you again for the opportunity to provide comment on the proposal.

Sincerely,

Kathie Prieve, CPRP
Director of Community Development
Vail Place

Hennepin County Human Services and Public Health Department

Administration **612-348-4806**
A-2303 Government Center **FAX 612-348-8228**
Minneapolis, MN 55487-0233

July 16, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, Minnesota 55164

Dear Mr. Godfrey:

On behalf of the metro counties, I would like to thank the department for all the hard work that is evident in the Reform 2020: Pathways to Independence, federal waiver proposal. Comprehensive reforms that build on client capabilities, support community integration, and recognize the necessary role of housing are essential to sustain our public programs and better serve our clients into the future.

As the “administrators” in our state supervised/county administered system, we have many questions about how things will actually work. We will not fill this letter with all those questions. We recognize the Reform 2020 waiver request is a high level vision and that is appropriate. We do want to emphasize our willingness and our desire to be part of the work plan as you begin to build toward this vision. We want to contribute to and be part of the successful implementation of these proposals.

In general, our questions are in regard to “what is the role of the county?” As the administrators we have questions about operations, administrative burden and financing that may reduce funding to counties or shift funding responsibility to local property tax. In several areas of the RFP we agree with the vision, but we have concerns that arise from our traditional role as the safety net. In the metro area, health plans and contracted agencies have taken on more direct service and case management responsibilities. County staff are no longer the “eyes” in the community to provide oversight of quality and client safety and we no longer receive the service revenues that were used to fund quality and protection functions.

We support the proposal’s goal of simplified, streamlined administration and increased efficiencies. Counties do not and will not have resources to increase staff. We support early intervention, client directed services, and flexible service packages. We have questions about the county social services infrastructure that must be maintained to assist clients, protect clients, support clients to make good decisions in service packages and continue to serve clients who are connected to county services.

We support the proposal’s initiatives to stabilize housing as an essential intervention in reducing health care costs. . Our clients will benefit from removal of barriers between programs and services so that our staff or community partners can deliver the right service at the right time. The Hennepin Health pilot and the “in-reach” pilots demonstrate the importance of integration and coordination of health care and social services, medical and behavioral health care providers, and access to housing with appropriate services Sufficient options for housing with appropriate services, however, continue to be a challenge for both crisis and stable clients.

We support the proposal’s initiatives to integrate care, develop health care homes with linkages to county social services, and targeted focus on transitions. Counties that work with health care homes, accountable care organizations, and other community integrated care models know that the greatest barrier to communication and streamlined service delivery is the inability to share data. We want to work with The Department of Human Services to achieve the cost savings and improved care that will result if we can find our way to protect client privacy and facilitate pathways through service delivery locations.

The metro counties are ready to participate with the Department to develop and implement the vision of the Reform 2020: Pathways to Independence. We appreciate the opportunity to comment and we look forward to being an integral part of the process to evolve and move forward our health and social services systems.

Sincerely,

Dan Engstrom
Assistant County Administrator
Human Services and Public Health

Cc: 7-County Metro Director Group

Behavioral Dimensions

7010 Hwy 7
St. Louis Park, MN 55426
Office: (952) 814-0207

To: Dr. David Godfrey
Medicaid Director
MN Department of Human Services

From: Nancy Schussler, Ph.D., BCBA-D, Licensed Psychologist
President
Behavioral Dimensions, Inc.

Date: July 14, 2012

Re: DHS Reform 2020 draft proposal

Introduction

Thank you for the opportunity to comment on the DHS draft proposal. In responding to the proposal, I draw on my 35+ years of experience working with persons with autism and other developmental disabilities across the lifespan (see attachment for professional biosketch and description of Behavioral Dimensions). My company, Behavioral Dimensions Inc. (BDI), currently employs 95 staff who serve approximately 100 children spread across the state within the seven county metro area as well as Duluth, St. Cloud, Warroad, and Alexandria. Our clients present with an array of mental health diagnoses, including autism, disruptive behavior disorder, depression, anxiety, and stereotypic movement disorder.

BDI scope of services

Our largest group of clients is served in our in-home intensive Applied Behavior Analysis (ABA) therapy program; currently we are serving approximately 85 children with autism in this program. Behavioral Dimensions also offers other tailored interventions for families whose needs are not met by the ABA therapy program. We treat adolescents and pre-adolescents who come to us in crisis—often with a history of psychiatric hospital stays, day treatment, and police involvement. We provide workshop and in-home consultation to families to increase caregiver capacity to independently problem solve using behavioral principles. We also offer life skills training to address sleep and eating disorders and to teach self-care skills such as toileting, which can have lasting implications for placement and cost of care. We provide consultation services in group homes, schools, and job placements for children and adults with disabilities experiencing severe and persistent aggression and self-injury. Finally, we offer continuing education workshops to licensed psychologists and behavior analysts.

Focus of my feedback

Reflecting on the DHS proposal, I would like to draw on these experiences to address the 'big picture' rather than provide commentary on specifics of the proposal. The scope, content, and mission of the 2020 Reform document is impressive and clearly positions Minnesota as a national leader in providing services to individuals with special needs. As a member of the MNABA task force I have provided input on the MNABA response to the DHS proposal and the Standards for Behavior Analysis document being adopted by MNABA. I believe that these MNABA-sponsored comments provide ample guidance on specific points in the text of the DHS proposal.

Behavioral Dimensions

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Based on previous meetings and interactions with DHS staff charged with the Reform proposal I believe that DHS is taking to heart the stakeholder feedback which will result in well-coordinated, evidence-based services to the citizens of Minnesota and their families struggling with mental health disorders. I am very interested and invested in the translation of these goals into policy, rather than simply editing the document requesting the federal waiver.

My understanding of the proposal's intent is to break down barriers to effective service delivery across diagnostic categories, service categories, and age groups, so I have organized my response as a series of case studies based on my clinical experiences that might serve to illustrate the opportunities and pitfalls that I see coming from the proposal. They are organized to reflect the various needs and types of service delivery that are necessary and the lifespan impact of the proposed changes. I hope that using this format to provide input will illustrate 'real world' impacts of the reform proposal, rather than line by line critiques of what has been written. These case studies are based on actual clients served by BDI and are chosen because they are representative of large numbers of clients in the general population.

In addition, to assist in finalizing the reform proposal, we are mailing hard copies of resources that we use to guide our services. We hope these research articles and books are useful to you.

Types of clients served and impact of current/ proposed service delivery changes

Fully Recovered Autism

Child: JIM – Recovered autism
Age: 10
Diagnoses: Autism
Skill level at intake: Nonverbal, no functional communication skills; screamed unintelligibly for all needs; high rates of stereotypic, nonfunctional toy play; no receptive communication skills; high rates of tantrums and aggression
Chronology of Services:

- At age 2.5: "Recovery-oriented" Intensive ABA services at 40 hours per week for 3 years (continued at 40 hours/wk until discharged); Successfully completed curriculum skills at age 5.5

Current symptoms: None
Current issues: None. Educational placement in regular education setting full time w/o specialized supports; no longer meets ASD diagnostic criteria.
Future needs: None
What reforms are needed:

- To insure that intensive ABA services are available at the very earliest age autism can be diagnosed and provided at the maximum intensity (in this case 40 hours a week, plus parent training).
- Intensive services were required at "full strength" up to discharge; a requirement to taper hours would have delayed or disrupted treatment efficacy.
- How would changes to 9.1.3 "Initiative to advance coordinated care" and language around comprehensive multidisciplinary assessment impact the speed at which JIM could have accessed high

intensity evidence based intervention? Under current practices a referral from a developmental behavioral pediatrician allowed for nearly immediate service provision.

Autism fully mainstreamed, but needs social skills instruction

Child: CAL – Recovered autism; residual issues
Age: 8
Diagnoses: Autism
Skill level at intake: Delayed communication and language, restricted and rigid behavior patterns, problem behavior occurring during tantrums included: hitting, kicking, pushing others, throwing objects, yelling, screaming. Refused to participate in difficult or novel activities.
Chronology of Services:

- At age 2.5: Received Intensive ABA at 40 hours per week for 2.5 years, required 40 hours a week to fully complete treatment plan; discharged at age 5
- Regular education placement with minor case management support
- At age 7: Family contacted BDI due to peer rejection due to rigidity in play and lack of reciprocity. Received social skills training to remediate these deficits 4 - 6 hours per week with a typically developing peer for 10 months

Current symptoms: Can engage in interactive, reciprocal play with peers across several settings. Continued mild social skill deficits; Normal IQ; No aberrant behavior

Current issues: Still has difficulty in social situations with peers when at peer's house; Still served under Individualized Education Plan for case management but remains in a regular education classroom without direct special education services.

What reforms are needed:

- To insure that intensive ABA services are available at earliest age that diagnosis is possible to help remediate symptoms and to promote placement in a mainstream classroom.
- Intensive services were required at "full strength" up to discharge; a requirement to taper hours would have added months to services potentially reducing efficacy or delay school success.
- Regarding Reform 2020 9.1.2 Autism section: how would language in reform around school case management at age 7 effect access to services and interpretation of medical necessity as social requirements of daily environment change with age?
- How would Reform 2020 allow for post discharge consultation to prevent deterioration or development of maladaptive behaviors as child ages? "Booster training" using evidence-based practice should be available for clients and families throughout childhood/adolescence to remediate and not simply accommodate social limitations that can develop over time, by a) systematically targeting and teaching skills like social skills that expand and change with age, and helping clients master important coping skills despite the anxiety that can develop when encountering new and changing social situations rather than avoiding difficult interactions; and b) supporting and enabling parents to managing these changing skills and issues over time. It can be difficult for schools to provide the individualized and intensive focus on social skills issues that specialized service providers are already equipped to deliver.

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Autism not recovered, significant behavior issues

Child: SUE: Autism with dangerous behavioral issues
Age: 8
Diagnoses: Autism
Skill level at intake: Pre-BDI services, at 4 ½ years of age: severe self-injury, aggression, property destruction, elopement, disrobing in public, masturbation using silverware; no functional communication (despite 2+ years of day treatment and speech therapy), Play needed to be continuously monitored for unsafe use of toys/objects.
Chronology of Services:

- Age 3 attended PIE (an outpatient behavioral program), also received some outpatient speech and OT through private providers; Parents requested behavioral support from BDI to provide in home behavioral services in conjunction with PIE's center based parent training to remediate aberrant behavior that was increasing at home.
- Funding mechanism would not pay for two providers; parents decided to forego home-based behavioral services in order to continue to receive center based instruction
- At age 4.5 SUE was referred to BDI again when aberrant behavior had worsened at home. Parents removed SUE from center based services at PIE to receive full time services from BDI. She received 40 hours a week of individual skills training to address skill deficits and to reduce her severe aberrant behavior. Her mother also received 3 – 6 hours of family skills training. BDI trained PCA staff pro bono to ensure consistent interactions across service providers. After approximately a year of service, SUE had made significant progress in reducing aberrant behavior and using an array of functional communication skills. She was also participating in age appropriate play and instructional activities. Her services then had to change because of a serious family event; see next bullet point.
- Following a family tragedy (suicide of father), SUE was placed in a crisis home for 3 months then permanently placed in group home due to her mother's inability to care for her *and* work full time to support her family. In both placements, her mother requested consistent implementation of the effective behavior plan previously used by mother and BDI. Both facilities agreed to this at intake, but then neither followed through, despite repeated meetings to adapt plan to these settings.
- At age 8 SUE's mother is seeking to return her to the family home (see current issues below).

Current symptoms: SUE's headbanging and severe tantrum behavior has not worsened, and in some cases has improved; yet her mother reports that SUE has now pulled out all of her hair—in tantrums or when anxious. When left unsupervised, she continues to engage in dangerous property destruction; often this can occur during the middle of the night when caregivers are sleeping.

Current Issues: In her mother' efforts to bring her home, she is seeking 24 hour a day staffing to care for SUE. This high amount of service is driven by two main factors: 1) SUE cannot remain safely occupied without direct adult supervision at any time of day and 2) she will awaken a number of nights a week and become "quietly" destructive. In order to care for her other daughter, maintain her overall family well-being, and her ability to work, this level of service is being requested by the county. Her mother is also requesting BDI to resume and coordinate behavioral support with both SUE and caregivers—with the ultimate goal of reducing the intensive level of care needed in the future.

What reforms are needed:

- Funding mechanisms must allow for services to occur in all necessary environments. If SUE had received both home-based and center based mental health services at 3 years of age, it is likely she would have made sufficient gains to be able to remain at home with her single-parent mother.
- Reform 2020 must ensure that PCA services are available at levels that would maintain successful home placement like those proposed for elder care and transition from Anoka Co Treatment facility. While 24 hour care seems excessive, it would avoid costly out-of-home placement; in this case, for a 5 year old. For a child like SUE, specific behavioral training in the child's Behavior Plan must occur with all assigned PCA's (as opposed to a specialty-certified PCA) and across all settings; treatment integrity and adherence must be maintained. It is likely that with the addition of evidence-based mental health services directed towards SUE, her need for 24 hour care would reduce over time.
- Mental health services based in applied behavior analysis delivered at home with compulsory implementation by PCA and schools (i.e, beyond sharing ideas and progress updates at a meeting) is necessary to continue to remediate and manage SUE's mental health issues.
- The full definition of "medical necessity" must be applied to children like SUE—specifically services must ultimately be designed "to restore or maintain enrollees health or prevent deterioration of the enrollee's condition" (MN Statute on Medical Necessity). Many individuals with mental health disorders can attain a beneficial level of functioning with adequate supports in their lives. Removal of these supports—for many individuals—will result in deterioration. Service models must account for the long term needs of individuals with chronic mental health issues; this includes many children with autism and other mental health diagnoses.

Unrecovered autism

Child: MAT – Unrecovered autism with 5 year old level language
Age: 10
Diagnoses: Autism
Skill level at intake: Nonverbal; limited play skills; low rates of aberrant behavior
Chronology of Services:

- At age 3: Received Intensive ABA services at 40 hours per week for 3 years, had 40 hours a week until school age; was on track for age appropriate skills development (e.g. had learned "3.5 - 4" year level language)
- At school age: Family wanted therapy to continue, but also wanted MAT to be in school full-time; Because his learning rate continued steadily, we continued his ABA services after school for 3 more years in which he finished the language program bringing his receptive and expressive language to a 5 year level, and completed a significant amount of social skills training.

Current symptoms: Continues to show moderate autism symptoms. Spends majority of school day in special education classroom with 'social inclusion' during nonacademic classes (e.g. gym, art, lunch). No aberrant behavior.

Current issues: None

What reforms are needed:

- To insure that intensive ABA services are available at earliest age diagnosis possible to help remediate symptoms to promote placement in a mainstream classroom.
- Evaluation of need and outcomes for services under Reform 2020 must take into account long term functional skills development that does not result in full recovery. Intensive services were required at "full strength" up to for three years, and continued with decreased hours for 3 years. This treatment developed 5 year old language skills which enable MAT to progress through a special education program without direct paraprofessional support; as an adult, allows gainful employment in setting with minimal or no support from a job coach; may be able to live in semi-independent living.

Toddler with mental health needs and other disabilities

Child: RAE
Age: 8
Diagnoses: Microcephaly; Blind (she sees shadows only); global developmental delay; autosomal recessive condition, very small stature; stereotypic movement disorder with self-injury; severe disruptive behavior disorder
Skill level at intake: High rates of self-injury (head hitting and head banging), severe tantrums, aggression; no functional communication skills; emerging echolalia, limited and stereotypic play skills
Chronology of Services:

- At age 2, Early childhood special education and outpatient speech and OT
- Age 4, Began behavioral services from BDI, 10 - 15 hours of individual skills and 2 – 4 hours of family skills per week. Discharged at 6 years of age when no longer qualified for Severe Emotional Disturbance diagnosis—per MA rules, (despite not completing important skills remaining on treatment plan). Mental health services provided over these two years not only reduced her aberrant behavior to insignificant levels, but also was able to teach her to speak in short sentences to make requests, clarify her requests, ask questions, and engage in fun, teasing, verbal interactions. We also taught her to understand simple language of caregivers. She also learned a wide variety of age appropriate play skills which were modified for her visual disability.

Current symptoms: unknown
Current issues: unknown
What reforms are needed:

- RAE had learned to control her environment and the people in it though displaying an array of serious aberrant behavior. While BDI's treatment of her aberrant behavior was so successful that she no longer qualified as having a severe emotional disturbance, given her current array of disabilities, as well as her 2+ year history of controlling her world through aberrant behavior, it is likely that she will need mental health services again in the future. A mechanism is needed to be able to "keep these kids on our radar" and enable "booster" support to occur more readily and efficiently. How will Reform 2020 create a mechanism to allow preventative consultative services before a child deteriorates to the point of "re-qualifying" for a mental health diagnosis?

- The two years of receiving early childhood and outpatient speech and OT were unsuccessful in addressing her severe aberrant behavior, or increasing functional language use. None of these three disciplines provides an integrated and comprehensive evidence-based treatment package. Because research clearly shows that aberrant behavior can function as a form of communication, speech instruction in the absence of a Functional Behavioral Assessment has been shown to result in neither acquisition of language nor reduction in problem behavior. Programming needs to be developed using the results of a functional behavioral assessment and needs the beginning treatment phases to be carefully tailored to address children's communicative function of their aberrant behavior.
- Reform 2020 endeavors to develop a coordinated care system for children with autism (Section 9.1.3). This endeavor needs to be extended to children like RAE. The multidisciplinary assessment, if it includes a mental health professional, could have identified the serious nature of her aberrant behavior; and hopefully would have also recognized the missing link in previous services. Appropriate mental health services could have begun at age 2.
- Applying a stronger standard across all disciplines to adhere to evidence-based treatment might have prevented the OT from recommending sensory integration techniques to RAE's mother as a means of addressing the aberrant behavior (for which there is no evidence). In many cases, sensory integration actually increases problem behavior. A focus on outcome-based treatment might have led the speech therapist to refer RAE to other interventions, since her treatment plan had not developed functional, intentional language in two years of service, nor did it effect a decrease in aberrant behavior. While this may sound harsh, this is the reality of services that families receive, and families do not have the background to second guess recommendations made by experts. Many families are often first steered to early childhood and outpatient speech and OT, when in fact their child's condition requires the service of mental health professionals.
- The benefits of a well designed team of people to complete a multidisciplinary assessment (again Section 9.1.3.) as close to the first year of life as possible are huge. Reform 2020 must also specify how this will be reviewed and implemented to gain maximum impact from this reform.

Other disorders that result in a deterioration of behavior or functioning

Child: DON
Age: 3
Diagnoses: Smith-Magenis syndrome (a chromosomal disorder) and disruptive behavior disorder
Skill level at intake: typical cognitive functioning, gross and fine motor delays, verbal communication delay (communicated through some signing), sleep disturbance, self-injurious behavior (head hitting and hand biting), aggression, quick to upset/tantrum
Chronology of Services:

- At age 2: Obtained a PCA to assist with care at home; Began Behavioral Services at 11 hours per week, continues to receive OT and speech outpatient services

Current symptoms: Still demonstrating atypically high rates of aberrant behavior (e.g. - self-injury, aggression, property destruction) across many life situations that inhibit quality participation in activities for the child and family. Furthermore, the behavioral symptoms of this child's disorder significantly interferes with DON's potential development and negatively effects family and sibling relationships.

Current issues: This child's treatment plan is focused on developing compliance and cooperation with others and developing independence in functional everyday activities such that aberrant behavior is minimal and easily managed by parents and teachers. Careful teaching and behavioral support is necessary for the child to participate in the simplest everyday tasks, and generalization across people and settings is critical in order to prevent behavioral deterioration and delay the progression of further symptoms.

Future needs: Genetics influence the probability of certain behaviors, but behaviors are still expected to respond to environmental contingencies, so teaching effective communication strategies and appropriate alternative to aggressive or self-injurious behavior is necessary to restore and maintain health. Continued supports through adolescence and access to service are also critical to improve or prevent deterioration of the individual's behavioral condition. A recent study of 21 adults with Smith-Magenis (Udwin et al., 2011) found that without appropriate service none of the adults were able to live independently and were dependent upon caregivers more than would be expected based on their level of intellectual functioning.

What reforms are needed:

- Reform 2020 section 9.1 that discusses the goal to "develop a recovery oriented mental health system" needs to include service categories for children like DON.

Pre-Adolescent with severe mental health needs

Child: KIM

Age: 11

Diagnoses: ADHD, PTSD, PDD

Skill level at intake: Significant aberrant behavior including: leaving home by breaking windows, aggression toward siblings, property destruction (kicking holes in walls), verbally threatening and aggressive to teachers, siblings, parents.

Chronology of Services:

- Repeated in-patient hospitalization for psychiatric disorders and aggressive behavior
- BDI service began with functional behavioral assessment conducted March of 2012. During first two months of service, delivered intensive family skills training to mother and step-father with coaching on responding to upsets and reinforcing positive interactions with siblings and adults and 3 hours per week of individual skills training focused on calmly responding to denials, stopping an activity to complete a task, following instructions. On ongoing basis, is receiving 2 hours of family skills training per week and 6 hours of individual skills training per week.

Current symptoms: Symptoms have lessened, but continues to display verbal disruption, some episodes of property destruction with family, and verbal aggression and noncompliance directed at PCA's.

Current issues: PCA's show high turnover rates and frequent cancellation of shifts without notice. PCA's not trained or willing to implement effective strategies. Inconsistent PCA support significantly contributes to family stress. Significant need for care coordination across providers and with school and county.

Future needs:

- On-going support for all family, caregivers, and teachers to implement effective practices. Current system lacks funding for training and supporting nonfamily members.
- Educational services must be held to the same standards to apply evidence-based practices, and outcome measures. At this child's IEP meeting, teachers said that they did not believe in using reinforcement and felt it was better to discuss problem behavior with child. Parents have little influence with the schools to adopt the same Behavior Plan that has proven effective for their child at home.

What reforms are needed:

- How will schools be held to same standards of evidence-based intervention as mental health providers? (who will mediate disagreements in methods if schools are primary case managers?)
- School personnel are not trained, nor are services configured, to provide psychological or mental health treatment. How will school personnel be trained to provide mental health interventions if needed?

Adolescent with severe mental health needs

Child: TOM

Age: 15

Diagnoses: Bi-polar disorder, autism, post-traumatic stress disorder, anxiety disorder, reactive attachment disorder

Skill level at intake: High use of medications at intake (Lithhobid, neurotonin, seraquol, lamictal, nexium, medaformin, topomax, haldol PRN). Medical issues including sleep disturbances, digestive issues, asthma, and hand tremors. TOM required constant parent interaction and attention. Property destructive to home (walls, doors). TOM attacked siblings with knives and found/made weapons. Self-injury involving slamming head on floor during upsets. Several police calls to home resulting in behavioral health unit hospitalizations and emergency evaluations. Parents frequently needed to physically protect sibling from TOM's attacks.

Chronology of Services:

- PCA services at home, emergency psychiatric care, sensory integration invention through school and home, group therapy through school's CTSS program (that discussed violent video games and activities against mother's wishes)
- Out-of-home placement was recommended by the county and TOM was placed in a day treatment educational program before BDI stepped in and began services. Family was unable to retain PCA's due to aggression and noncompliance leaving family with no respite time or time for other siblings.
- BDI conducted a functional behavioral assessment in June of 2011, began intensive family skills training with parents and created crisis plan in conjunction with County, developed reinforcement system and began practicing waiting for parent attention, responding to stressful situations, behavioral contracts, waiting for requested items, asking for help and asking for breaks, refraining from asking for items that

are not available. Currently receives approx. 7 hours per week of individual skills training. Rates of aberrant behavior significantly reduced within 2 months of service.

- Parent removed TOM from school January 2012 due to school's long-term resistance to meaningful collaboration on behavior plan and concomitant detrimental effects of school-designed intervention on TOM's aberrant and academic behavior.

Current symptoms: Outbursts have significantly reduced in frequency and intensity such that out-of-home placement no longer being considered. Now able to travel on family trips and has begun using a debit card to spend money earned through positive behaviors and household chores. Can separate from mother for periods of 45 minutes to 1 hour which allows his mother to complete work from home and to spend one-on-one time with siblings. Actively and cooperatively participating in home-based school-delivered tutoring, which has now successfully transitioned from home to school site. He is also gardening to sell at farmer's market. Hand tremors ended with removal of psychotropic med and dosage reductions. Mows lawn, sorts laundry, and completes other chores that may lead to meaningful future employment skills.

Current issues: Currently receiving home-bound tutoring by a teacher who was willing to applying BDI's treatment plan—TOM is now showing academic success. Plans are being developed to return TOM to school in order to generalize gains to peer settings. Continue ongoing collaboration with medication management team. Continue in-home programming and extend BDI's treatment plan to new school setting and personnel.

Future needs: Family needs the assurance that supports will occur across all of TOM's treatment settings that maintain and extend the treatment gains he's attained over this last year. Supports must continue to insure that behavioral deterioration does not occur in any setting.

What reforms are needed:

- Allowing access to service at the youngest age possible to help remediate symptoms
- Training for PCA's on current behavior plan to maintained learned skills
- Insurance that schools will implement treatment plan—requires funding for careful implementation and monitoring of success in the school setting
- Funding for family training without child present; the presence of many of these older children in family skills is counterproductive during the "didactic" portion of training
- Funding for functional assessment hours—this is necessary to develop a comprehensive treatment plan

Conclusion

Our intent was to comment on a select number of sections in the Reform 2020 document; namely
4.1/4.2.1 PCA services
4.1 Home and Community Based Care
9.1.2 Autism (particularly medically necessity, evidence-based, intensive behavioral services past 7)
9.1.3 Initiative to advance coordinated care for children with ASD: Birth mandate and utilization of comprehensive, multidimensional assessment to produce service coordination and assign funding responsibility

9.1.4 Mental Illness: develop a recovery-oriented mental health system

I hope the case studies have served to illustrate issues raised in the above sections, and in conjunction with the feedback provided by MNABA and others in the field, will help DHS maximize the impact of the Reform 2020 proposal. Please feel free to contact me with any questions or for any additional materials or documentation as needed. I am interested and available to provide more indepth service to DHS should that be desired. I'm looking forward to seeing the Reform 2020 programs move into implementation. Thank you again for allowing providers to offer feedback.

Respectively Submitted,

Nancy Schussler

Behavioral
Dimensions

7010 Hwy 7
St. Louis Park, MN 55426
Office: (952) 814-0207

Attachment 1: Schussler Biosketch

Clinician/researcher

My educational experience has reflected my commitment to behavior analysis and services to persons with disabilities. I hold a B.A. from St. Cloud State (1975), and M.Ed from Peabody College at Vanderbilt University (1981), and an MA (1989) and PhD (1995) from the University of Kansas. I am a member in the Association for Behavior Analysis International (since 1974). I have work experience across the lifespan in preschool-based, home-based and group home settings, and in state institutions. Both my academic work and my clinical career have emphasized reducing severe aberrant behavior through positive methods such as teaching functional communication skills.

As a licensed psychologist (since 1991) some of my areas of Professional Competency include comprehensive functional skill, behavioral, and communication assessments, program development, monitoring the effects of proactive approaches to learning and behavior problems, and supervision of psychology students and other psychologists. I am also a Board Certified Behavior Analyst (since 2001) and was instrumental in bringing test sites for this national certification to Minnesota. Twenty of our staff members have had formal behavior analysis training and/or are Board Certified in Behavior Analysis.

I am fortunate to have many talented people working with me at Behavioral Dimensions, who all contribute to the high quality of clinical work being done with our clients. Among them, in particular, are:

Tim Moore, Ph.D., BCBA-D, Licensed Psychologist; President of MNABA
John Hoch, Ph.D. Research Director
Erin Cote, Ph.D., Associate Research Director
Jacki Harth, M.A., BCBA, Licensed Psychologist, Clinical Director
Sarah Roberts, M.A., BCBA, Licensed Psychologist; former president of MNABA
Nancy Rueckl-Jones, M.A., BCBA, Licensed Psychologist
Michael Maus, Ph.D., Licensed Psychologist

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MID-MINNESOTA LEGAL AID
MINNESOTA DISABILITY LAW CENTER
Duluth Fertile Grand Rapids Mankato Minneapolis
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July 16, 2012

VIA EMAIL

David Godfrey, Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164-64998

RE: Comments on "Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal"

Dear Mr. Godfrey:

Thank you for the opportunity to comment on Minnesota's nine 1115 Medicaid waiver proposals as well as other reform proposals under 1915i, 1915k, and 1915c and other state initiatives. Our office is Minnesota's designated Protection and Advocacy system which represents children and adults with significant, often lifelong, disabilities, including intellectual and developmental disabilities, mental illnesses, physical disabilities and brain injuries across Minnesota.

1915 Medicaid Waiver Demonstration Proposals

1. Fiscal Analysis

We request the fiscal analysis and background information which has not yet been provided as part of the draft Reform 2020 proposal. We find it difficult to comment on the proposals without clearly understanding the assumed fiscal impact of the various proposals. The following comments are provided without the benefit of the fiscal analysis and may change when we are able to review that information. We do appreciate the complexity of the analyses required and the time pressures involved with such a multifaceted proposal and look forward to reviewing this aspect of the 1115 waiver as soon as it is available.

2. 3. Accountable Care Demonstration, p. 20

Given the requests for waivers of statewideness and freedom of choice under Medicaid, we urge that a description of consumer protections for the accountable care demonstration be added. How will people learn about accountable care demonstrations and how will they be assigned to such demonstrations? Under what circumstances will a person be able to leave an accountable care demonstration? What appeal rights will the person have if disagreements or mistakes occur?

In addition, we continue to have serious concerns about the integration of long-term services and supports (LTSS) with health/medical care because of the likely emphasis on the medical model of service provision. While we certainly support effective coordination of health care and LTSS, we oppose control over all of one's LTSS services by a medical care provider without experience in housing, employment, transportation and social relationships in the community. Rather than assigning medical entities or health plans the authority and risk for every project, we recommend seeking proposals where the community support providers are in charge and can subcontract for medical services. This would be of particular value for persons with high LTSS costs and average to low medical costs or those whose costs are quite stable year to year.

We think it is essential to assure that persons who need long-term support services to remain as independent as possible in their communities are able to direct their own services based upon a person-centered plan rather than directed by a medical clinic or hospital. We urge that this proposal include clear safeguards, data reporting, appeal rights and disability-relevant outcome requirements for the provider.

3. 4. Demonstration to Reform Personal Care Assistance (PCA) Services, p. 25

a. We are in strong support of reforming and modernizing Minnesota's personal care assistance (PCA) services program using the 1915k Community First Choice federal authority, under the title Community First Services and Supports (CFSS).

b. We support the Department's waiver request to use Minnesota's special eligibility rules that apply to our home and community-based waivers for those who meet the level of care of an institution but would remain in the community and receive CFSS services.

c. We strongly support the proposal to use both the 1915k option and 1915i option in order to continue serving people who do not meet Minnesota's institutional level of care criteria. This is especially important given Minnesota's pending request to make the nursing facility institutional level of care (NFLOC) criteria more stringent, thus eliminating eligibility for important Home and Community-Based Services Waiver Program (EW, CADI, BI) for many people who need assistance to remain in the community.

d. Other Comments on the proposal to replace PCA services with CFSS.

i. We urge inclusion of institutions for mental disease (IMD) as an institution for the level of care requirement in CFSS, as allowed under federal law.

ii. We strongly support the increase in the minimum amount of time for persons who have one dependency in an activity of daily living (ADL) or Level 1 behavior to at least 90 minutes per day.

iii. We urge that the definition of dependency in Minnesota's PCA program be changed to include persons who need **prompting and cuing** to accomplish activities of daily living and health-related tasks as the program used to permit. Currently, Minnesota's PCA program is discriminatory in that it does not include the type of help often needed by persons with mental illnesses, cognitive limitations or brain injuries. Many individuals with these conditions need prompting and cuing in order to accomplish essential tasks to remain independent in their homes, but are able to physically accomplish these tasks if provided with such assistance. We believe the current PCA eligibility criteria are discriminatory because the service is not being offered without regard to the type of disability as required by 1915k. Minnesota's current PCA eligibility criteria are limited to persons who need:

(1) **constant cuing and supervision or**

(2) **hands-on physical assistance**.

These dependency criteria do not meet the federal requirements for the scope of 1915k: ". . . as needed, to assist in accomplishing activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related tasks through hands on assistance, supervision or cuing." 42 C.F.R. § 441.500. We understand that there are fiscal constraints and concerns about new participants in a reformed PCA program. We request that DHS consult with external stakeholders on these fiscal matters to assure the broadest consideration of factors affecting future costs and caseloads of a reformed PCA program.

iv. We urge that the Department of Human Services (DHS) retain the PCA Choice Option by offering three models for CFSS:

(1) A fully agency directed support service;

(2) An agency service which maintains the beneficial aspects of the PCA Choice Option, such as choosing your staff, training and scheduling and

(3) The new self-directed option with an individual budget.

We believe that many people currently using the PCA Choice Option will be reluctant to choose the totally self-directed option, at least initially. These individuals will be hurt by losing the self-directed authority they now have and by a reduction in their PCA staff wages. Clearly the pay for PCAs can be higher in the PCA Choice Option because nurse supervision and other administrative costs are lower for the agency. An abrupt decrease in the hourly wage of many PCAs will threaten the well-being of all current PCA Choice recipients.

v. We are in strong support of the self-directed option under CFSS with an individualized budget. We urge that the budget administrative cost be carefully determined with input of stakeholders so as to provide the maximum amount to the eligible individual for services.

vi. The 1915k State Plan Amendment Option offers other beneficial aspects, such as skill acquisition, assistance with health tasks and an updated description of instrumental activities of daily living, which includes traveling and participating in the community, as well as communicating by phone or other media, shopping, essential household chores, managing finances, meal planning and other tasks related to maintaining independence in the community.

vii. In addition, the 1915k option requires that assistance and supports be provided in the most integrated settings without regard to the type of disability, age or type of assistance needed to live an independent life. We strongly support these important requirements and believe that a reformed PCA program can offer more flexibility and assistance in tasks needed for persons with disabilities to remain as independent as possible in their communities.

4. <u>4.23. Demonstration of Innovative Approaches to Service Coordination (children with CFSS), p. 41</u>

We urge that DHS find another way to assure coordination with school services for children who have two or more complex health-related needs, receive mental health services or exhibit physical aggression to oneself or others or engage in property destruction requiring the immediate intervention of another person. We do not believe funneling intensive service coordination through school districts is a sound idea for a number of reasons:

a. Schools do not now provide services 24 hours a day, 7 days a week. While districts could contract with agencies to do so, this is simply not part of the experience or institutional practice of school districts, and we believe will be inordinately difficult and lead to many gaps and problems for high-need children.

b. Because schools do not provide services all day, 7 days a week, year round, staff are often unaware of the many needs a child has within the community and within their families. Again, it may be possible for a school district to contract with an agency with this expertise, but we do not understand why such a major shift in responsibility would result in positive outcomes for high-need students in a short time frame.

c. Many of our clients' families do not want all of their medical information to be shared with schools and teachers. It is important to remember that most students have different teachers and support staff every year. In addition, many high-need students have more than one teacher or other staff person during a school year. The spreading of one's private medical information across the school district is simply not warranted or desired by most families.

d. Relying on school resources, such as school psychologists, is mentioned as a reason to use the school as a basis for innovative service coordination yet Minnesota ranks low among states in the number of school psychologists across the districts. School psychologists do not have the training required for this level of treatment and service coordination. Our schools are simply not staffed with the professional resources to contribute to this effort.

e. There is some concern that implementation of service coordination would result in cost shifting from special education services to Medicaid. We are concerned because schools have very strong incentives not to identify a student's needs. With authority over Medicaid, we believe the opportunity for cost shifting is increased. We do not think shifting authority to school districts is a sound method to assure children get both the educational and the health care services they need.

Instead, we suggest a demonstration to provide innovative approaches to service coordination for the children described based in our current human services system and relying upon a range of experienced providers to work closely with school districts to assure common approaches to the complex needs of these children in school, within their families and in their communities. We urge this proposal be substantially changed prior to submission to CMS.

5. <u>5.2. Demonstration to Expand Access to Transition Supports, Return to the Community, p. 44 and p. 127</u>

We urge that the "Return to the Community" transition supports for people in nursing homes be clearly described as a service available to persons in nursing homes of any age. The emphasis in the description is on seniors but many persons under 65 could benefit from this effort.

6. <u>6.1. Demonstration to Empower and Encourage Independence through Employment Supports, p. 51</u>

a. We are in strong support of efforts to increase employment for persons with disabilities in Minnesota. We support statewide demonstration program focusing on five target groups of young adults. We are concerned, however, that the requirements to be employed or to have been employed within the year or to have experienced an employment shift within the past year is too onerous for some of the target groups listed. In particular, targeting 18-year-olds and imposing these employment requirements simply misses the mark. We certainly agree that 18-year-olds in the circumstances described in the five groups could well benefit from navigation assistance, but we are concerned these individuals will not be included because they do not have employment experience. We think it is especially important to target young people graduating from high school for employment supports. The longer a person is both out of school and not working the more likely the person will be to seek the total and permanent disability status of Social Security. We urge that the employment eligibility requirements be expanded to include young persons in their first year after high school graduation in the categories listed, regardless of employment experience.

b. Recommended changes to disability benefits 101.

While we appreciate the online benefit analysis tool, disability benefits 101 (DB 101), we are aware that the tool itself is not a comprehensive analysis for some people, especially those who benefit from one or another of a long list of local and project-specific housing subsidies. We urge that DB 101 be changed to include information on housing subsidies and the clear recommendation that people with local benefits or other unique types of housing supports be referred to the Work Incentives Connection for a full and individual analysis. It simply is not wise nor fair to attempt a benefit analysis without the full consideration and we understand this may not be possible with an online tool given the variety of unique subsidies available.

c. 1915i for Employment Supports.

We also urge that the Department work with stakeholders to develop a 1915i state plan option for employment supports for all persons with disabilities who meet criteria to be established with stakeholders. The employment supports should, of course, be individually tailored and follow available evidence-based practices such as individual placement support (IPS) for persons with mental health conditions which has been tested at six pilot sites in our state. The recommendation to develop a 1915i proposal for employment supports as well as the Department's proposals on navigation services both point to the challenge of making necessary changes within a very tough fiscal environment. Any employment supports for persons with disabilities which are successful in assisting persons with disabilities to work will produce tax revenue and cost savings. However, some portion of such cost savings would likely come not from Medicaid, but from reduced income supports such as SSI or Social Security Disability benefits, food support, housing subsidies and transportation funding. In order to truly account for the benefits of employment of persons with disabilities, savings in all of these other sectors ought to be able to be part of the fiscal considerations in establishing a broad employment supports program in our state Medicaid plan under 1915i.

d. Transition from Corrections Systems.

We are in very strong support of inclusion of Medical Assistance recipients who are transitioning from the Department of Corrections. This group definitely needs services and supports. If well designed and successful this effort will undoubtedly save corrections funding in the future.

7. **6.2 Housing Stability Services Demonstration, p. 58**

a. We support the demonstration to add housing stabilization and services to our state plan. Again, we strongly support the inclusion of persons leaving correctional facilities, residential chemical dependency treatment and inpatient psychiatric facilities as well as nursing facilities.

b. We support the request to obtain federal Medicaid match for PATH Critical Time Intervention services (p. 66) for those who have not yet been determined eligible for Medical Assistance because they have been homeless and disconnected from services.

8. **7. Anoka Regional Treatment Center Demonstration, p. 72**

We support the proposal to obtain Medicaid match for Anoka’s treatment services so long as these services are intensive, short-term medical services. We also support the exemption from IMD status in order to be able to qualify persons who have received intensive psychiatric services and are ready to return to the community for the Money Follow the Person initiative. We urge more specificity on how the increased funding would be used to both divert persons from Anoka Regional Treatment Center and assist people to return to the community as soon as possible after treatment at Anoka or other psychiatric inpatient settings. We support the request to exempt the state from the IMD exclusion for adults between the ages of 21 and 65 who meet Medicaid eligibility requirements as long as the increased funding is used to divert or assist to return to the community persons with significant mental illnesses.

9. **9.1.4. 1915i To Support Individuals with Mental Illness who are at Risk for Institutionalization without access to Integrated Community-Based Systems of Care, p. 82**

a. We strongly support the development of a 1915i state plan option to provide services which are flexible in terms of type, such as in-home services, employment supports or other therapeutic services and flexible in terms of intensity. The criteria for qualifying for the proposed services, however, is very restrictive. We support broadening a 1915i state plan proposal in order to provide services to persons before they end up in psychiatric hospitals, prisons, jails or nursing facilities.

b. Our specific concerns regarding this proposal include:

   i. The SPMI definition in the Mental Health Act has been viewed in the mental health community as too restrictive for a long time. It does not cover many individuals with severe anxiety related diagnoses who are unable to function without a high level of supports. It does not recognize severe functional inabilities related to a combination of diagnoses or conditions. Use of SPMI criteria will make many "first onset" individuals without extensive hospitalizations ineligible for very beneficial services.

   ii. The targeting of behaviors that are "specifically related to symptoms of the person's mental illness" is confusing and needs to be clarified. (p. 84). For example, if a person has schizophrenia, must the person exhibit symptoms of schizophrenia that are listed in the DSM to qualify? What about maladaptive behaviors that have been learned over a lifetime of living in institutional settings? These are not specifically related to the symptoms of the mental illness, but are likely the reason the person needs more intensive services and supports.

c. Another reform needed to improve Minnesota's services to persons with mental health conditions living in the community is to make changes to adult rehabilitative mental health services (ARMHS). We understand from a number of providers and have seen with some clients that the service limits are too low and inflexible and understand the rates are very low as well. Also, we have seen variable authorization of ARMHS' services so that people do not seem to be treated consistently across the state. Finally, providers are either dropping or having to subsidize ARMHS, which is not a sound trajectory for an important mental health service which has been found effective in stabilizing individuals for successful living in the community.

d. The criterion in "f" (p. 85) of "inability to function in the community or inability to find supportive services in the community" should not be limited to persons who have a mental illness and a co-occurring other illness, condition or disability. This criterion should also be applicable to persons with severe functional limitations due to their mental illness alone, but who may not meet the "eight hours per day of supervision" requirement of 2(e) (p. 84).

e. Will the MNChoices assessment tool be used to determine eligibility for this state plan option? If so, MNChoices needs to be carefully analyzed and amended as needed to make this service accessible and viable for those who need it.

f. We also recommend that DHS work with stakeholders to develop a 1915i for children. Certainly this is needed for those 16 and older, who may be subject to commitment. It can also be a good mechanism to fill gaps in children's mental health services in a cost effective manner.

10. <u>8. Adults without Children Eligibility, p. 76</u>

We oppose the requested waivers to make eligibility for MinnesotaCare adults without children more restrictive by imposing a durational residency requirement of 180 days and establishing an asset limit of $10,000 for Medicaid eligibility for adults without children who have incomes under 75% of the Federal Poverty Level.

11. <u>9.12 Services for Children with Autism, p. 79</u>

a. 1915i state plan service for young children with ASD, p. 80.

   i. We support the proposal to develop a 1915i state plan amendment for a range of intensive services for young children with autism.

   ii. We also support the proposal to ask CMS for technical assistance to assure that children from families with income over 150% FPL qualify for Medicaid under TEFRA or HCBS waivers because they meet those criteria for MA eligibility for children with disabilities in families above the required MA poverty levels. However, we urge that this issue be carefully reviewed with stakeholders given the pending changes to the nursing facility level of care (NF-LOC).

   iii. We urge that a stakeholder group be convened as soon as possible to develop this package of services, eligibility criteria and provider standards.

   iv. To support and augment this proposal, we urge that DHS support a private insurance mandate for coverage of the variety of medically necessary treatments and services for children with autism.

   v. Another related effort, which will support the proposal, is to assure that behavior analysts are recognized as a professional category within our state Medicaid program. Use of the national certification standards should be required and used as the basis for this effort.

b. 9.13 Related Policy Initiative for Care Coordination for Children with ASD, p. 81.

We have serious concerns about several statements in the description of the 9.1.3 related policy initiative. While the title and some statements do indicate this is an undeveloped idea to be worked on over the next two years with stakeholders, there are several other statements which have led many parents to conclude that their child with ASD would not be able to access medical services outside of school after the age of seven. The problematic statements include:

i. “Minnesota will develop a time limited early intervention service set that tapers off as progress is made **or that children age out as they transition to school**.” Page 81, top of page;

ii. “In addition, services for children who are over age seven would generally be included in the child’s IEP and could be informed by HASC’s recommendations in this regard.” Page 81, end of paragraph before bold new section;

iii. “After age seven, it is expected that children would be enrolled in school and receiving any services they are entitled under an IEP, which could include medically-related services in addition to educationally-necessary services.” Page 82, last sentence before bold title for 9.1.4.

The combination of these three statements can be understood to lead to the conclusion that this proposal would mean that after age seven children could no longer be able to access intensive, medically necessary health care services except through the school. Given the dismal school experience of many families of children with ASD due to lack of individual consideration, no choice of treatment approach and, in some instances, use of prone restraint, this prospect has been frightening indeed.

We recommend that this proposal be changed to reflect a general idea to be developed with a stakeholder group over the next two years to assure that children’s rights to a free and appropriate education be assured and that medically necessary services be available depending upon individual need. We certainly agree that school districts have obligations to these children for educational services, but often are ill-equipped and unable to provide those services in the context of intensive behavioral or other services a child needs. Consequently, other ways for school contributions to the child during these intensive treatment periods should be explored and developed.

12. 9.2 1915i for Adults with Co-occurring Developmental Disabilities/Cognitive Impairments/Serious Mental Health Conditions and Diagnosed with a Sexual Disorder and/or Antisocial Personality, p. 85

We support the development of a 1915i service for this population to better design effective services and community supports for this population.

13. 9.3.2 MNCHOICES, p. 88

Since the MNCHOICES' assessment is proposed to be used for a number of new services in this document, in addition to all HCBS waivers, nursing facility, ICF/DD, DD case management and Private Duty Nursing (PDN) services, we urge that special care be taken to assure proper consideration of those who have needs due to mental health conditions. The current assessments do a poor job of assessing the need for services and supports for those with mental health conditions. The ways in which the new MNChoices' assessment will assess the impact of mental health conditions on one's eligibility for services should be clearly communicated and available for all to understand.

14. 9.3.4 Strategies for Integration of Long-Term Services and Supports with Other Initiatives, Health Home Demonstration, p. 93

We strongly support our state seeking funding under the Health Home Demonstration authority to include services for people with mental illness and physical or other complex health care needs.

15. 9.3.6 Enhancements to 1915c Waivers, p. 95

a. We urge the Department to improve the opportunity for self-directed services through the Consumer-Directed Community Supports (CDCS) Option. The current discount of 30 percent over what a person would otherwise use in traditional services defeats many people who would be able to put together a self-directed service plan with more targeted and flexible services. We believe many more individuals would be willing to do this if the discount were reduced to 10 percent.

b. Quality management and a state quality council are discussed on page 97. Minnesota has a very long way to go in developing adequate quality assurance/improvement for our home and community waiver programs. Recent experience in working on the advisory group to change the current aversive and deprivation rule (Rule 40) has revealed that our state does not have data even on emergency use of restraint or 911 calls during which occur during HCBS services. We strongly support a robust effort to collect and analyze outcome data as well as incident reports in order to understand trends and improve services.

16. Service Coordination/Case Management /Care Coordination

There are numerous provisions and descriptions in the 144-page document which refer to service coordination and navigation. We are quite concerned that the proliferation of efforts to coordinate services for individuals will lead to confusion on roles and authorities. We request more details on how people would access these new or reformed types of case management service coordination and what choices they will have in so doing. Today some individuals have more than one case manager/service coordinator which too often results in duplication of effort and conflict. We urge a serious effort across divisions and agencies to thoroughly examine service coordination/care coordination/case management/navigation in order to avoid duplication, confusion and conflict.

17. <u>9.7 Children under 21 in Residential "IMD" Facilities, p. 103</u>

We share the concerns expressed in the description of this issue on pages 103 and 104 and urge the Department, in consultation with stakeholders, to develop some solutions to this issue as soon as possible and certainly in time for the next legislative session should such action be necessary.

In sum, we thank you for the opportunity to comment. We also appreciate the Department's efforts to provide information and inform the public about the many different proposals contained in the Reform 2020 document. We look forward to the fiscal analysis for the 1115 waiver requests and the final submission for CMS.

Sincerely,

Anne L. Henry
Attorney

ALH:nb

Schels, Johanna T (DHS)

From: [redacted]
Sent: Monday, July 16, 2012 3:30 PM
To: *DHS_Reform2020Comments
Subject: Don't cut autism coverage

Dear Mr. Godfrey:

We are writing to express grave concern regarding certain provisions of the new “Autism Benefit Set” proposed by the Department of Human Services. **Limiting access to these benefits to children under 7 would be a terrible blow to older children and their families who *desperately need* these services. Not all children are diagnosed with autism as toddlers; many are diagnosed much later, especially minority children. These children CAN STILL benefit from evidence-based therapeutic treatment delivered in a one-on-one environment. Relegating these services to a child’s school IEP is simply not enough.**

As a whole, the Autism Benefit Set does offer good ideas. However, expecting that these services should be delivered by schools after age 7 is an impossible fantasy. There is simply not the time or the staff required to help these children learn the skills that will ultimately help them live more independent, productive lives.

Intensive, one-on-one treatment such as ABA (applied behavioral analysis) that has been clinically proven to help autistic children function at a more independent level is **impossible in a school setting**. Even in classrooms taught by the best autism specialists, students cannot get the kind of effective, rigorous, evidence-based intervention that ABA provides.

This benefit limit would hit our family in a destructive way. Unfortunately, despite repeated questions from us regarding the possibility of autism, our daughter’s pediatrician resisted the diagnosis, and ultimately delayed our daughter’s diagnosis until she was **5 1/2**. Months of arranging insurance, medical assistance and finally, therapy providers delayed the start of her individual ABA services until she was **nearly six**. Now, our lovely daughter is **7 years old**, and after just one full year of ABA, we can say without any hesitation that our daughter has made progress beyond our wildest dreams.

Under your new provisions, our daughter would not have access to the same services other children who were diagnosed early get.

Once psychologically assessed as “perhaps retarded”, we have seen our daughter’s ability to communicate what she knows absolutely explode. Through painstaking, tireless, consistent and tedious therapy, our daughter’s skills have ballooned. In addition to that, our daughter’s therapists have worked to help us, her parents, learn how to deal with her difficult behaviors.

The difficulty of teaching special needs children such complicated yet basic tasks as dressing oneself may not be obvious to people unfamiliar with disabilities. Our daughter just learned--**at age 7**-- how to put on her own pants. This was a triumph to our family, and would absolutely not have happened without the help of her ABA therapists. Our daughter needed months of one-on-one direction to learn this simple task. We needed the therapists’ help in knowing how we could help her. We see this one simple triumph as a small step towards her living a more independent life.

Our family desperately needs these services to continue. Please don’t derail our daughter from a path that has already delivered such triumphs. **Do not cap at age 7 the Autism Benefit Set. Services should be delivered based on need, not age.**

Thank you for your time.

Sincerely,

[redacted] [redacted]

AXIS HEALTHCARE

where disability care
revolves around
you

July 16, 2012

To: Minnesota Department of Human Services

From: Randall Bachman, Executive Director, AXIS Healthcare

Re: Reform 2020, Input for Public Comment

The Reform 2020 proposal is an ambitious effort to reform Minnesota's Medicaid system that has significant implications for all Medical Assistance beneficiaries, their families, providers, and other stakeholders. It contains many elements of reform that have been proposed by consumers and advocates. It also builds upon the current system of community supports that Minnesota has developed over the years.

While the proposal raises a number of issues and concerns, AXIS Healthcare generally supports the direction and philosophy contained in the proposal. However, as evidenced by feedback in recent public hearings, the proposal raises many questions regarding the details of implementation. We are pleased that an Implementation Council with significant input from consumers and other stakeholders will be established, and hope that this mechanism, as well as other opportunities for feedback, will inform DHS's policy development and practices.

AXIS Healthcare was created over a decade ago as a joint venture of the Sister Kenny Institute of Allina Healthcare, and Courage Center, two well-respected rehabilitation providers in the upper Midwest. The objective was to help working age adults with disabilities or chronic and complex medical conditions maintain their health and live in the community. This is achieved through care coordination and case management by nurses, social workers, and other community support staff with expertise in disability services. Through our work we have demonstrated a reduction in avoidable hospitalizations and re-admissions, successful relocation of persons in facilities back into the community, prevention of recurring conditions that are common to persons with disabilities, and coordination and management of services and supports that help people live healthier lives and allow them to remain at home or in another setting appropriate to their needs.

AXIS Healthcare was the provider of care coordination services with the now defunct Minnesota Disabilities Healthcare Option (MnDHO) program. This program integrated the services of health care coordination and case management under the Medicaid Waivers for persons with disabilities. Unfortunately, for a variety of reasons, including inadequate reimbursement on the Medicare side, the program was terminated at the end of 2010. While the program ended, our Agency has continued on providing care coordination with contracts with health plans under the Special Needs Basic Care program, and through contracts with counties for waiver case management services. We point out this history to underscore our expertise in collaboration with our stakeholder partners, and in disability health care coordination and case management. We hope that DHS takes advantage of our expertise as we have learned a lot about what works and what does not, and pitfalls to avoid.

AXIS Healthcare supports the core values reflected in the proposal: community integration; person-centered services; self-direction and choice; independence and recovery; individual planning; and quality outcomes. Accordingly, we support the direction toward more consumer-directed services, in accord with the My Life My Choices initiative, with the caveat that there needs to be continued strong support for persons who cannot self-direct sufficiently and need assistance. In order to truly achieve these values and direction, however, it will be necessary to focus on effective implementation. This will require a candid assessment of shortcomings and barriers from all parties with the intent of redesigning and streamlining the current infrastructure to make the systems more efficient and effective.

While there are many aspects of the proposal that could impact our agency and the persons we serve, we will limit our feedback to three areas: 1. Service Coordination; 2. PCA changes; and, 3. Infrastructure, including Information Systems.

1. <u>Service Coordination:</u> References to service coordination being the key to effective implementation are numerous throughout the document. As an agency that provides health care coordination and waiver case management services, these references are very germane to our business. The proposal notes that there are people who are eligible but do not get connected with the appropriate service and others who are accessing many services across multiple systems that are not well coordinated. The dilemma of having too many coordinators, yet needing the different areas of expertise that each coordinator or case manager brings to the table, is also described.

   While we support the consolidation of service coordination where it makes sense, we are concerned that it not be assumed that one case manager can handle it all and still be effective. For example, staff who manage waiver services in the community may not necessarily have the expertise or background to provide health care coordination for persons with disabilities or complex medical conditions.

   The proposal would broaden the availability of home care service coordination to persons not enrolled in managed care and not receiving waiver services. Our hope is that there will be a mechanism for persons with disabilities on Medical Assistance who are on fee for service and not on waivers to access health care service coordination from a community-based provider as well.

2. <u>PCA Changes:</u> DHS proposes to transform the current PCA system to Community First Services and Supports (CFSS). We understand that the intention is to make the system more efficient and accountable, and also expand services to those not currently eligible for PCAs.

   While we support the expanded access provided by CFSS, what are the ramifications for an already under funded PCA program? Our hope is that there will be adequate funds to support this expansion.

   Finally, we hope that this reform will eliminate accounting for PCA and skilled nursing in an individual's waiver budget when the waiver does not pay for those services.

3. Infrastructure Changes: We understand that DHS will be planning for necessary IT changes in the spring of 2013. Our hope is that work could start now on upgrading their MMIS system. A start would be to survey stakeholders who have direct experience with the capacities and shortcomings of the system to identify the issues and barriers in preparation for this planning.

   Under Vision for the Future, 3.3.2, the document refers to new integrated provider organizations and the need for accurate and timely information:

   "These new integrated care provider organizations will need the capability to receive data from the state and share data among their members' providers (health care and non-health care) to better manage care for their populations they serve. This includes data analytic capabilities and storage capacity for reporting that potentially use a combination of health care claims, electronic medical records, and social service data to help providers better understand the care their populations are receiving and evaluate outcomes and care model strategies. Organizations must have the capabilities to stratify populations by need and develop appropriate models of care based on those needs."

   Our hope is that DHS with the support of stakeholders will give this objective priority. It is unclear to us whether or not there is funding to make the necessary systems upgrade. However, without modernizing the IT system, the reforms under this proposal will be greatly hindered.

   Regarding other infrastructure changes, the document states on p. 29:

   "The system evolved over a long period of time and now is quite complex and increasingly difficult to manage. Simplification would make it easier and more efficient for participants and providers to navigate and for lead agencies and the state to administer."

   While we certainly support simplification, it is not clear to us what will be simplified and how it will be accomplished. We would like to know more about how this simplification will occur and what mechanism will be used to identify what needs to be simplified.

AXIS Healthcare appreciates the opportunity to provide feedback on the Reform 2020 proposal. Notwithstanding our concerns, we believe that with strong consumer and stakeholder input we can work together with DHS to bring the vision of these reforms into reality. We look forward to participating as a partner in this effort.

WILLIAM MITCHELL
COLLEGE OF LAW

Center for Elder Justice & Policy

July 16, 2012

To: David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, Minnesota 55164

From: Iris C. Freeman
Associate Director, Center for Elder Justice & Policy
William Mitchell College of Law
875 Summit Avenue
St. Paul, Minnesota 55105

Comments to the Department of Human Services on
Section 1115 Waiver Proposal
State of Minnesota
Reform 2020: Pathways to Independence

This statement is submitted on behalf of the Vulnerable Adult Justice Project (VAJP), an elder justice collaborative that has been administratively housed at William Mitchell College of Law since 2007. Participants in the VAJP include professionals from adult protection agencies, public advocacy organizations, elder and disability organizations, health care providers, law enforcement, city and county attorneys, private attorneys, and other government organizations. The group provides a forum for experts who work with and for vulnerable adults to weigh, debate, and ultimately advocate for policies and safeguards that better protect vulnerable Minnesotans.

The Vulnerable Adult Justice Project strongly endorses the Proposal's Section 93.9 to create a statewide, centralized system for Reports of Vulnerable Adult Maltreatment.

The VAJP launched a successful legislative effort in 2009 with two focal areas. One was adding tools for the identification and response to cases of financial exploitation. The other was the centralization of the Common Entry Point for reports of maltreatment. The policy for the latter was enacted that year. No funds have been granted for the purpose since that date.

Minnesota Statutes Section 245A.655
FEDERAL GRANTS TO ESTABLISH AND MAINTAIN A SINGLE COMMON ENTRY POINT FOR REPORTING MALTREATMENT OF A VULNERABLE ADULT.

(a) The commissioner of human services shall seek federal funding to design, implement, maintain, and evaluate the common entry point for reports of suspected maltreatment made under

Minnesota Statutes, section 626.557. The purpose of the federal grant funds is to establish a common entry point with a statewide toll-free telephone number and Web site-based system to report known or suspected abuse, neglect, or exploitation of a vulnerable adult.

(b) A common entry point must be operated in a manner that enables the common entry point staff to:
(1) operate under Minnesota Statutes, section 626.557, subdivision 9, paragraph (b); and subdivision 9a;
(2) when appropriate, refer calls that do not allege the abuse, neglect, or exploitation of a vulnerable adult to other organizations that might better resolve the reporter's concerns; and
(3) immediately identify and locate prior reports of abuse, neglect, or exploitation.

(c) A common entry point must be operated in a manner that enables the commissioner of human services to:
(1) track critical steps in the investigative process to ensure compliance with all requirements for all reports;
(2) maintain data to facilitate the production of aggregate statistical reports for monitoring patterns of abuse, neglect, or exploitation;
(3) serve as a resource for the evaluation, management, and planning of preventative and remedial services for vulnerable adults who have been subject to abuse, neglect, or exploitation;
(4) set standards, priorities, and policies to maximize the efficiency and effectiveness of the common entry point; and
(5) develop a system to manage consumer complaints related to the common entry point.

(d) The commissioner of human services may take the actions necessary to design and implement the common entry point in paragraph (a). Funds awarded by the federal government for the purposes of this section are appropriated to the commissioner of human services.
History: *2009 c 119 s 19*

Our advocacy for the foregoing policy is ample evidence of our commitment to establishing a "statewide toll free hotline with 24/7 response and triage to receive reports of suspected maltreatment of vulnerable adults and determine the need for investigation," as described in the waiver request. We further endorse the "public outreach campaign to raise awareness of vulnerable adult abuse and educate mandated and voluntary reporters on the new reporting system." Streamlining the reporting system is essential to encouraging those who suspect maltreatment to come forward and make a report. Our current patchwork of county-specific daytime and nighttime numbers allows complexity to inhibit reporting. With a centralized entry point and public awareness efforts, Minnesota will strengthen its commitment and effectiveness in responding to the abuse, neglect, and exploitation of vulnerable adults. This is an essential facet of an increasingly localized system of services and supports whose benefits are also marked by the risks of isolation.

Thank you very much for the opportunity to comment. The Vulnerable Adult Justice Project stands ready to serve as an ally in the work to simplify the reporting system and amplify public awareness.

From: Aki Yoshino <ms_yoshino@yahoo.com>
Sent: Sunday, July 15, 2012 3:42 PM
To: *DHS_Reform2020Comments
Subject: Do Not institute an arbitrary age cutoff of autistm therapy benefits

Dear David Godfrey...

Please do not cap autism benefits arbitrarily for children over the age of 7.

Specifically, here's why:

- all children enrolled in Medical Assistance are entitled to coverage for medically necessary treatment prescribed by their treating clinician
- coverage for health care should be based on medical necessity
- if a treatment is evidence-based – such as intensive early intervention behavior therapy or applied behavior analysis, then it should be included in the “Autism benefit set”
- if a treatment is a generally accepted practice, like “social skills therapy” then it should be included in the “Autism benefit set”
- treatments, supports and services should be based NEED, not age
- treatments, supports and services should be based on need, not LABELS
- children who have autism need choices for different treatments, as well as choices for different providers
- don’t limit school-age children to receiving treatment from ONLY schools
- Yes! Please do look at outcome measures – in fact, please look at them NOW — before you make long lasting policy decisions about what types of treatments to cover!
- DHS should provide formal opportunities for members of the autism community to provide input before finalizing policy changes! Specifically, DHS should obtain input from the health care professional who treat individuals who have autism! DHS should also hear from individuals on the spectrum and their friends and family.

best regards,

aki yoshino
2553 brighton ave ne
minneapolis, mn 55418
6122029908

From: [redacted]
Sent: Sunday, July 15, 2012 3:38 PM
To: *DHS_Reform2020Comments
Subject: The MA reform proposal should be rewritten to clarify that there will be NO REDUCTION in MA coverage for children in Minnesota.

Dear David Godfrey...

I am a parent to an autistic child here in Minnesota, active voter and regular tax payer. I'm hoping you'll hear my plea to not arbitrarily cap autism health benefits at age 7.

Specifically, here's why:

- all children enrolled in Medical Assistance are entitled to coverage for medically necessary treatment prescribed by their treating clinician
- coverage for health care should be based on medical necessity
- if a treatment is evidence-based – such as intensive early intervention behavior therapy or applied behavior analysis, then it should be included in the “Autism benefit set”
- if a treatment is a generally accepted practice, like “social skills therapy” then it should be included in the “Autism benefit set”
- treatments, supports and services should be based NEED, not age
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- children who have autism need choices for different treatments, as well as choices for different providers
- don’t limit school-age children to receiving treatment from ONLY schools
- Yes! Please do look at outcome measures – in fact, please look at them NOW — before you make long lasting policy decisions about what types of treatments to cover!
- DHS should provide formal opportunities for members of the autism community to provide input before finalizing policy changes! Specifically, DHS should obtain input from the health care professional who treat individuals who have autism! DHS should also hear from individuals on the spectrum and their friends and family.

best regards,

[redacted]

[redacted]

[redacted]

[redacted]

TO: Minnesota Department of Human Services

DATE: July 14, 2012

RE: Comments to Reform 2020

FROM: [redacted] and [redacted]

Our concerns as a parent of a child with a rare, complex and chronic health condition and as citizens concerned about taking care of the most vulnerable among us are many. Our main concern is that Reform 2020 will operate as a significant cut to current levels of service and leave many kids and families without services or supports during the demonstration project and beyond.

The stated goals of clarifying and streamlining services are laudable goals, but we urge policymakers to prioritize accessibility and availability of all treatment options for persons with autism and related conditions. The proposal should clearly state that the intention is not to cut current services, but to make treatments more accessible, more accountable, and individualized to the needs of the person seeking services through the state health plan.

It is a health plan, so all medically necessary treatments should be covered period. Clearly state there is no age limits on any treatments or therapies, or any other limits except documented medical necessity as determined by a qualified provider and his or her patient.

It is a health plan, so expecting another system to provide medically necessary treatments after a certain age is not reasonable or feasible. The federal government has clearly stated that ABA therapy in particular is medical treatment, not education.

Although officials are quick to point out that the current MA statute does not specifically authorize behavioral therapies such as ABA therapy, practice has been for this therapy to be covered with prior authorization for many years. Our son has benefited from intensive in-home ABA therapy for the last several years and continues to make gains with this therapy. Without therapy, he would likely need a much more restrictive placement than home with his family.

Although ABA has not cured our son of his diagnosis or mitigated all of his symptoms, it has afforded him the opportunity to be integrated into his family, school and community. It has taught him how to learn from the environment and valuable skills of how to ask for help or do what the group is doing or speak to a peer. These all are things we take for granted as they come naturally to many people. For people born with autism or related conditions, these skills are not learned unless the child is taught through intensive ABA or equivalent therapy.

We are very grateful that when [redacted], our insurance company, denied covered for the ABA therapy that our son's doctor recommended, we were able to get Medical Assistance through TEFRA. We were even more grateful that officials considered ABA therapy skills training covered under the current statute and paid for this expensive therapy that has resulted in life changes for our son and our family.

At 7 1/2 , he still has areas of lagging development, especially in the social emotional area. Yet we see gains still and know his development is accelerated by ABA therapy and speech therapy and other therapies that have been recommended for him over the years. He just finished kindergarten in a private school classroom with typical peers, with his one-one behavioral support and an adaptive schedule. Without the therapies that his providers recommended and that we were able to afford because of his MA coverage, the community and learning he experienced this year would not have been possible.

We have learned through experience how over burdened and under funded the public school system is in Minnesota. They were not able to provide the supports our son needed to attend and be successful at school. Although coordination between the education and the health care system is a laudable goal, it is not enough for the health insurance system to simply stop covering services when a child reaches an arbitrary age and expect the school system to start providing medical treatments to these children. The school system is not qualified, funded, or likely to do so effectively.

Children and adults with autism and related conditions deserve access to all reasonable medically necessary treatments for autism and related conditions, just as children and adults with any other chronic medical condition deserve access to treatments to mitigate symptoms and improve functioning and quality of life. There is no age cap on treatment of diabetes or asthma or cancer. There should not be on autism or related conditions either.

Thank you for your consideration. Feel free to contact us if we can provide any additional information.

Sincerely,

[redacted] and [redacted]
St. Paul, MN
Parents of three children, one of whom has Smith-Magenis Syndrome and ASD (and many other diagnoses)

July 12, 2012

Mr. David Godfrey
Medicaid Director
Minnesota Department of Human Services
Elmer L. Andersen Building
540 Cedar Street
PO Box 64998
St. Paul, Minnesota 55164

RE: Reform 2020: Pathways to Independence, Section 1115 Waiver Proposal

Dear David:

On behalf of the Minnesota Governor's Council on Developmental Disabilities, I thank you for the opportunity to provide comments and feedback on the above identified Waiver Proposal. Following are our comments, organized according to specific sections in the Section 1115 Waiver Proposal:

Overall General Comments:

This is a very comprehensive proposal that will allow the State of Minnesota to negotiate with the Centers for Medicare & Medicaid Services (CMS). According to CMS, the key elements of a Section 1115 waiver are to provide for "experimental, pilot, or demonstration projects which are likely to assist in promoting the objectives of the program" while being "budget neutral for the federal government."

The flexibility to work with CMS during such a pilot or demonstration period can be critical in learning more about the effects of reform measures on specific populations of individuals and making the necessary adjustments to assure that the goals envisioned are the goals that can be reasonably achieved. We applaud the Departmetn for undertaking such a broad reform effort.

Overall Comments about New Service Design:

Because of the length and complexity of the proposal, it is difficult to sort out the specifics of the design of each experiment/pilot/demonstration and then also find assurance of budget neutrality. Perhaps during this comment period, the proposal can be strengthened by creating some type of framework to address the following:

1 A process to ensure end user or recipient input, needs, requirements, and expectations was not always apparent in the Section 1115 Waiver Proposal. It may be helpful to emphasize this consumer input in the discussion about each new service/service area.

2 The specific breakthrough or innovation that is being piloted was not always clearly articulated. We suggest clarifying the breakthroughs or innovations in each section since they seem to be pivotal to many of the reform measures presented.

3 The context or information about the market environment, current delivery system, or current capabilities was not always included. Adding this would provide greater understanding about the reform measures being proposed for each service/service area.

4 Include a very specific statement that describes the service or product design point in terms of how to access the service, the particular usability features, operational performance specifications, and cost controls or how budget neutrality will be maintained. These design features are not always evident and would contribute to meeting the key CMS elements for the Section 1115 Waiver Proposal.

5 A description of a test team to validate the specifications of the product or services, operational performance requirements, timelines, the back-up systems, and the testing cycles would seem to be a necessary component. It appears that the Partners Panel may be used to answer some of these questions for one part of the waiver proposal but it’s not clear that the Panel would be assuming this role and responsibilities throughout the waiver proposal. Clarification may be needed.

6 A description of the external review of all design specifications and the method to certify that the service is ready for release is not apparent and a critical component that needs to be added. This step is not obvious.

7 In some instances, projections about the number of users by month, quarter, and year was given or caps were mentioned. Those data were

not included consistently across all parts of the Section 1115 Waiver Proposal and would seem helpful and necessary to add.

8 The business case in terms of costs to design, operate, maintain, and update were not given, and should be established and included if possible.

9 Provider standards are mentioned throughout the proposal but not all aspects are mentioned. A list of suppliers that are capable of delivery under the Section1115 Waiver Proposal should be established and include design specifications, internal quality improvement system, financial viability, and other supplier qualifications. This aspect may come later in the process.

<u>Overall minor editing suggestions and typos</u>:

In reviewing the Section 1115 Wavier Proposal, we came across the following:

Page 43: Last sentence beginning at the bottom of the page, please recheck the language in this sentence, "With federal support, Minnesota could serve more consumers in nursing homes…." Is this a correct statement?

Page 52: Under 6.6.1 First Phase, item 1: Medical Assistance is repeated twice; could this be a typo?

Page 53: Third bullet; should this maybe read, "Have experienced an employment shift?"

Page 56: The last bullet at the top of the page; should this read, “Integrated planning and screening tools…?”

Page 86: Typo in the first paragraph – the word should probably be “effective;” and in the second paragraph, the word should probably be “lessened.”

Page 91: First line in the first paragraph, the word should probably be “demonstration.” Is “First Contact” correct or is this a typo?

Definitions Section:

1 Throughout the proposal, technology and assistive technology terms are used interchangeably. Is this accurate? Should a single term be consistently used throughout? Can a definition be added?

2 Throughout the proposal, person centered planning and person centered plans are mentioned but no definition is provided. Other terms are used throughout the proposal for a variety of plans. Can each plan be specifically identified and can that term then be used consistently throughout the Section 1115 Waiver Proposal?

3 There are language changes throughout the Section 1115 Waiver Proposal for developmental disabilities and intellectual disability, and there's one mention of mental retardation on Page 79. We believe that a single term should be used consistently throughout the Section 1115 Waiver Proposal. Please remove mental retardation from the proposal.

4 **Pages 25 and 26:** There is no definition of "most integrated setting." Since CMS and the Department of Justice are working closely on Olmstead issues, it might be helpful to include a definition.

5 **Page 25:** The use of the terminology personal care attendants, personal assistants, and personal care assistants dates back to 1962 and Ed Roberts. When the terminology is 50 years old, there must be some attention paid to an information campaign to inform Minnesotans about the change in language. People will continue to use PCA to describe the person who is an assistant.

Perhaps CFSS is being proposed only as a means of communicating that type of service with CMS and not a change in the actual terminology within Minnesota. Can this terminology be clarified?

6 In reading across the entire Section 1115 Waiver Proposal, there are several terms mentioned that refer to service coordination and case management, including home care service coordination, service coordination, case management, school service coordination (school employees). Definitions may be necessary

and should be helpful to the reader to understand what specific term is used and what it means in a particular environment.

Regarding the new Community First Services and Supports (CFSS) program:

Page 26: CFSS is described as a less costly option –

Can data be inserted into this page or this section that supports that statement?

Is the cost comparison between the proposed CFSS program and the waivers or with institutional settings? Can this be clarified?

If CFSS is a PCA program that includes training and technology, will the cost savings come from moving people from the waiver to the new CFSS service? Clarification here would also be helpful.

Page 27: There is reference to legislative changes in 2009 that resulted in 170 people losing access to PCA services and that 22,000 people are currently on the PCA program –

Is there any description about those individuals who lost access to PCA services? Did they experience mental health issues?

How many people lost services and were reinstated after appeals?

Are there any additional planned reductions in the future that might not be mentioned here?

Under 4.1.2 What We Want to Change :

Page 29: There is a list of problems presented to support the need for the proposed CFSS program, including not receiving necessary services, not achieving optimal outcomes, and the high cost services that could be avoided. We fully support this description.

As a result of this list of problems, CFSS is proposed as “the right service at the right time, in the right way.” Is it possible to add “at the right cost with the right staff with the right skills?” As you may know, the Department of Defense (DOD) used a very similar phrase to fulfill their GPRA goals, stated as follows:

> "Our security depends on our defense being in the right place at the right time with the right qualities and capacities to protect our national resources"

Minnesota may want to distinguish itself from that DOD approach by adding a few more phrases.

Page 30: The Section 1115 Waiver Proposal states that people who want technology and home modifications would go on the waiver since that is the only way to access those services –

> Can data be inserted here to document this trend?

What types of technology and what types of home modifications are being sought and approved under the waivers?

Page 31: The Section 1115 Waiver Proposal states that 10 percent of people who are currently using PCA services along with a variety of other services will have higher

emergency room visits and hospitalizations along with the associated higher costs when all of those services are not well coordinated –

> Is there any additional information about this subgroup?
>
> Are these individuals experiencing mental health issues? If so, can that be stated?
>
> Did this subgroup help with the redesign of PCA into the CFSS program and, if so, how?

Pages 31 and 32: A long list of problems refer to the waivers and the state plan as being out of alignment and creating "administrative challenges" -

> What part of the Section 1115 Waiver Proposal will bring any or all of the waivers and state plan back into alignment?

Pages 32 and 33: CFSS is described here as PCA + skills + assistive technology (not just technology) + environmental modifications + transitions which will lead to greater self-determination, individualized service budgets, greater fiscal management, greater quality assurance, and greater direction.

These are worthy goals and outcomes that we can definitely support and the Department should be commended for incorporating these into the Section 1115 Waiver Proposal. We suggest that this statement come earlier in the Proposal since it is so well stated and can lead this section.

Page 33: There are several issues presented on these pages that discuss PCA services and additional details may be needed to distinguish between the various PCA options and other related issues.

> First, a lengthy list of issues around providers are mentioned including skill set, certifications, training, provider regulations, and quality assurance, but there are few details about training, oversight, and implementation.
>
> On the previous page, page 32, the PCA Choice program is mentioned along with the fact that there are hundreds of PCA Choice providers but 15 fiscal support entities for people who choose CDCS - a complex system to manage administratively and monitor for quality assurance.
>
> Then, on page 34, one service coordinator is mentioned to plan and support the individual across all services, with CFSS having fewer providers and yet greater capacity for quality assurance. However, everyone in Minnesota should have the choice of at least 2 fiscal entities.
>
> Under the CFSS program, will there be more providers or fewer providers?
>
> If there are fewer providers, how is that reconciled with everyone having a choice of at least two fiscal entities?
>
> Will there be more standards and assurances, or fewer, and how will these be determined?

Pages 34 and 35: There is a long list of initiatives identified on these pages but it’s difficult to track the current status of each, start or launch date, who is affected, and how they will be effectively and efficiently coordinated within the Section 1115 Waiver Proposal. More specifics would be helpful to better understand the connections and give a clearer picture of how individuals who may be receiving services under one of more initiative can navigate a new system.

Page 35: Home Care Case Management (HCCM) is presented as an interim step in the redesign of case management services but a description about this component or program is missing –

Who and/or what is HCCM?

What is the role and relationship to current case management services?

Who will be providing HCCM services, how many HCC managers will be available across the state, and what area(s) will they serve?

What training will be provided?

How will any potential conflict of interest be resolved? It is our understanding that CMS is concerned that service coordination be independent.

Consultation, training, and technical assistance are mentioned and that all services will be coordinated in a single plan. A description about the specific consultation services and technical assistance that will be available, and training that will be offered/provided, would be helpful to add here.

Page 36: The need for a large number of changes occurring at the same time is discussed but the need to phase in changes is also presented. It's difficult to understand how these seemingly contradictory approaches can be reconciled Clarification is needed to better understand how these initiatives will all be implemented without disruptions or gaps in the delivery of services.

The statement that the reasons for applying for a 1915 (i) and 1915 (k) waiver under the Section 1115 Waiver Proposal are to learn, to mitigate risks, and to offer one set of assurances are very laudable goals. However, the desire to build services that align with 1915 (k) because "we are requesting to receive enhanced federal participation," would seem to require a discussion about who would be covered, the potential number of people being considered, and where they currently live.

There are also conflicting references to 1915 (k). In one part of the Section 1115 Waiver Proposal it is discussed for those individuals <u>not</u> meeting an institutional level of care while later in the Waiver Proposal, on page 41, section 1915(i) is discussed for the very same group of individuals. Clarification may be needed.

Waiver definitions are contained at the end of the Section 1115 Waiver Proposal. It may be helpful to move them or also include them here.

Page 37: On this page, the statement is made that the Section 1115 Waiver Proposal will provide participants in home and community based waivers with the option to receive CFSS as part of their waiver. The very next sentence, however, is in direct conflict –

> "To avoid duplication of services, HCBS waiver participants may <u>not</u> receive CFSS" (emphasis added).

At the bottom of the same page, the statement is made –

> "We intend to end our current PCA program and replace it with a more flexible set of services, which we are calling Community First Services and Supports (CFSS).

Are we to understand that CFSS is an option under the waiver, or that CFSS is only offered through the state plan?

If the current PCA <u>program</u> ceases to exist, are PCA <u>services</u> still available but only through the waiver and then only as defined under the state plan versus how they may be defined under CFSS?

CFSS is also discussed as limited to settings of not more than four people; and not in settings owned, leased or controlled by the same provider. We fully support and commend the Department for taking this direction.

Page 38: Budget is based on need, Budget will be set for CFSS and can include "assistive technology" and home modifications. There is no mention of most integrated setting on this page.

Page 39: The term "community support plan" is first used on this page rather than a person centered plan but there is also reference to a "person centered Coordinated Service and Support Plan."

A person centered planning process is mentioned on the previous page, page 38.

> If there is a difference, what is the difference?
>
> Are three different types of plans really intended?

Clarification is needed about setting individual service budgets –

> Is MnCHOICES being proposed for setting the budget?

If so, can more details be provided?

Two service models are presented, a self-direction model and an agency-provider model. If self-direction is selected, a fiscal management entity (FME) is required with an RFP process used to limit the number of FMEs. If an individual must be given a choice of at least two FMEs but the total number of FMEs will be limited, please explain or clarify how this process will work. How will adequate state coverage and choice be assured?

Pages 39 and 40: Budgets and budget protocols are discussed for CFSS and based on the “LT home care rating.” The formula to determine a budget, units of services, and hours seem complicated when, overall, the direction and justification of the Section 1115 Waiver Proposal seem to be on ease of use for individuals needing and using services; and efficiency and effectiveness from an administrative standpoint.
The Waiver Proposal is then proposing five years to analyze, evaluate, and create individual service budgets. Can this item be discussed in greater detail?

Page 40: Under Provider Standards, more information is needed about provider training, including what will be included in the core curriculum and who will be providing the training, number of training hours and delivery methods, ongoing training requirements, how training will be evaluated and how evaluation results will be used to improve future trainings and competencies.

Page 41: Regarding individuals who do not meet an institutional level of care, section 1915 (i) applies; for individuals who do meet an institutional level of care, section 1915 (k) applies. If the data are correct, that 90 percent of individuals currently using PCA services meet an institutional level of care, then only 10 percent of this group of individuals would meet section 1915 (i) criteria or less than an institutional level of care.

If CFSS would be available for all of these individuals, would existing waiver services be available or would these individuals no longer be eligible? See questions and needed clarifications on page 37 above.

<u>School Proposal Section</u>:

Pages 41 and 42: We are concerned about a demonstration project under the Section 1115 Waiver Proposal to test the coordination of school based services for several reasons (We maybe misunderstanding this section because we have been unable to attend the public meetings)-

> The success of a demonstration would require school staff to be available year round and, presumably, that Medical Assistance (MA) eligible students under age 21 would also be receiving extended school year services.
>
> School staff would have to assume care coordination responsibilities in order to bill for the MA services they would be providing, which could be a district contracting issue.
>
> Each school district does not likely have a full complement of related services staff so it would be necessary to consider how itinerant or services shared across school districts would be available in the selected school districts.
>
> Eligible students also have to access CFSS but, because of the waiver/CFSS conflict noted above on page 37, it may be difficult to indentify 1500 students who would meet the criteria from school districts willing to participate
>
> In this part of the Section 1115 Waiver Proposal, cultural competence is not mentioned (especially Somali community).
>
> According to most advocates, most school staff (psychologists, nurses, and social workers) have little or no knowledge of autism or medical conditions and most school staff are unfamiliar with DHS programs and/or how to be a service coordinator.
>
> Additional details may be needed to describe the avoidance of "conflict of interest" issues that CMS has about case managers or service coordinators not being associated with provision of services, as well as how these pieces result in less complexity.

Employment Proposal Section:

Page 52: Pathways to Employment is mentioned as developing policies that focused on employment and consumer directed initiatives. Can this section be expanded to include a discussion on what specific policies were developed, what initiatives grew out of those policies, and what were the results?

Page 53: Add numbers for each of three subgroups identified. Are there data about these groups or information about how these particular groups were selected?

Page 54: The Waiver Proposal states that navigators will be part of the Disability Linkage Line. This seems duplicative of the efforts of the Workforce Centers and Work Incentives Connection.

> What are the differences and what distinguishes the services that would be offered by the Disability Linkage Line?
>
> Are these new navigators trained in person centered planning, the full range of employment issues and employment programs, or life planning?
>
> Are data available about DB101 - who is using this resource, the numbers of people using, evaluation results to date, and Return on Investment?

Page 55: Evaluation questions about employment services are listed here but these questions are not repeated in the evaluation section, pages 105 to 111 at the end of this proposal nor is there any reference back to these questions.

If the Disability Linkage Line is now doing job placements, how will these services complement, supplement, or enhance what Vocational Rehabilitation Services provides?

The data collection items listed here, that are currently being collected by the Disability Linkage Line, don’t match the evaluation questions in this section. Can more information or details be provided to make a direct connection between the evaluation questions and the data collection process?

Page 56: What is the anticipated reduction in use of SSDI, medical services savings, and increased taxes? Are there any projections available and, if so, on what are those projections based?

Has there been any testing of the idea that the Disability Linkage Line is now providing employment and job placement services? Have any data been collected or what data will be collected and how?

Page 57: What is the wraparound option that will be included in a future health insurance exchange?

Page 58: What specific “existing relationships” will be leveraged with DEED, the Department of Education, and Corrections?

What are “medical providers” going to be doing with employment?

What research will they be conducting and what is the purpose of that research?

Under 7. Anoka Metro RTC Demonstration :

Page 73: The footnote states that there are 12 beds for individuals with mental illness and "intellectual" disabilities." Are these the individuals who were transferred from METO/MSHS to Anoka? If so, they come under the Jensen Settlement Agreement and that should be mentioned.

This section discusses the need to redesign the relationship between the Anoka RTC and Medicaid, since individuals residing there are not Medicaid eligible but would be Medicaid eligible if services were available in the community.

Please clarify: Would a demonstration under the Section 1115 Waiver Proposal allow individuals at Anoka RTC to become Medicaid eligible and could they then transition to the community under the Money Follows the Person initiative?

Is this what is keeping them from moving or are there other barriers?

The length of stay is mentioned but are there data on the range of stays?

Page 75: Is there an estimated number of individuals for whom a section 1915 (i) waiver would apply? What is the target for a section 1915(i) waiver here?

The discussion on Page 36 above (Page 8 of our comments) regarding Section 1915 (i) and Section 1915 (k) waivers would suggest that, since these are individuals meeting an institutional level of care, would not a section 1915 (k) waiver apply here?

Under 7.2.1 Evaluation:

Page 76: Are there any specific questions regarding people with developmental disabilities?

Under 9. Context of Reform: Current and Proposed Initiatives:

Page 78: A section 1915 (i) waiver is mentioned for individuals with autism spectrum disorder (ASD), mental illness plus other disabilities plus behavior and committed at Anoka and unable to return to the community; and for people with developmental disabilities and mental health issues and sexual disorders. Would a section 1915 (i) waiver apply to individuals with multiple disabilities and complex conditions?

Section 1915 (i) and Children with ASD:

Page 79: The statement is made that, despite the rise in the incidence of ASD, Minnesota lacks a system of coordinated care. But there is considerable discussion about several agencies and programs that are involved with this issue and are currently providing services.

There seem to be two separate issues and neither is the cause of or leads to the other. A separate discussion about each issue would be helpful.

A section 1915 (i) waiver may give children with ASD better access to a broader range of services that are actually available. A coordinated system of care is another issue. Could these distinctions be made?

Page 80: In the second paragraph, reference is made to children “ages 0-7.” Can this be changed to read birth to age 7.

The goal of developing one program that can provide an integrated set of services for Medicaid eligible children with similar diagnoses and functional needs is quite worthy and ambitious, but it’s not clear how the Section 1115 Waiver Proposal will be able to achieve that end result.

Pages 80 and 81: The services listed in a specific benefit set for children with ASD include service coordination, behavior intervention, counseling, and respite among other (page 80) but page 81 states that the benefit set has yet to be defined. Clarification is needed.

Page 81: Standards, assessment tools, protocols, and learning collaboratives are proposed. How will these activities be connected with a single program, fully integrated benefit set of services, especially when the scope of services is pending?

The statement is made that Minnesota does not currently have any established guidelines for medically necessary, evidence based, early intervention services. The Health Services Advisory Council (HSAC) was assigned by the Legislature to look at efficacy of treatments. Does HSAC have the necessary expertise to make this judgment? What is the specific scope of their work and what is the time frame?

The Department of Human Services will propose benefit and service utilization criteria but will have to meet Legislative deadlines which may not be in sync with HSAC's work. What are the reliability and validity data for the Comprehensive Multi-Dimension Diagnostic Assessment tool? How does this connect to the MnCHOICES assessment tool?

Can this proposal expand on and allow greater opportunities for the input of families, educators, health care professionals, and advocates?

Page 82: Service coordination of special education services (Individual Education Programs), Preschool Special Education (Part B), Infant and Toddler Intervention (Part C), Medical Assistance-IEP benefits, CTSS, and school linked mental health are all mentioned. These are diverse and specialized services. What qualifications will be needed to do this work?

Sex Offenders:

Page 85: The Section 1115 Waiver Proposal states, "There are 134 people with developmental disabilities, and mental health issues, sexual disorders and/or anti-social personality disorders but only four sex offender day treatment providers. Day treatment is not the right service."

This section does not mention the report from the Office of the Legislative Auditor, "Civil Commitment of Sex Offenders," and the specific recommendations about individuals with developmental disabilities and sex offenders who are not benefiting from the Minnesota Sex Offender Program (MSOP).

There is no mention of the MSOP lawsuit or the Jensen Settlement Agreement that affects people at St. Peter.

The term "intellectual disability" is used in this section.

Under 9.3 Redesign Home and Community Based Services:

Page 87: Several initiatives are listed to suggest an emphasis on person centered planning including earlier intervention services; the integration of LTSS, behavioral, and physical health care; enhancements to 1915 (c) waivers; case management reforms; crisis intervention and protection protocols; and health care reforms. The list, however, does not necessarily connect to person centered planning principles.

Page 92: The proposed Home and Community Based Services Report Card is an exciting initiative. Several services are listed here that have not been mentioned previously including day training and habilitation, assisted living, and corporate foster care. What level of effort will be needed to collect, and analyze data, and create report cards across the service system?

Page 95: People first language should be used in all waiver descriptions.

Page 96: Anticipated waiver changes are mentioned including a new menu of services for all five home and community based waivers, more options for home of your own, changes to “provider standards,” a “universal worker,” and “technology to support the person in lieu of staffing.” Can each of these be clarified and more details provided?

The term “technology” is used. Should this read “assistive technology?” If technology includes assistive technology, that should be specifically stated. How will current definitions be updated and what changes are being proposed? It is not clear that technology as used here includes devices as well as services.

The redesign of a new financial management structure is presented in connection with a section 1915 (j) option but details are needed. What specifically prompted a redesign? What has been learned from the current financial management structure that will be included in the redesign and what were the sources of that learning?

Page 97: Assisted Living is mentioned but it’s not clear who would be moving into assisted living. Can that information be added?

Regarding the statement that “[t]he state has established a consistent quality management structure across all waivers," what specifically is this referencing?

Page 98: Under Provider Standards, it is mentioned that recommendations will be provided to the 2013 State Legislature regarding “a new licensing and quality outcome system for home and community based services.” What specific recommendations are being considered?

Rule 40 committee work is mentioned briefly but there’s no mention of positive behavioral supports. Can more information about the Rule 40 Advisory Committee be included here?

A long list of problems and solutions about case management are identified. Is there any information about priorities or data that will be used to prioritize the reforms?

Page 99: Under Crisis Intervention and Protection of Vulnerable Adults, a long list of solutions for crises are identified, including positive behavior training, person centered approaches, technical assistance, mobile crisis intervention, and increased crisis capacity; along with indicators to avoid use of emergency room, civil commitment, and law enforcement. Information is missing about numbers, costs, what is actually being planned, and how these solutions will intersect with the Jensen Settlement Agreement. Can these additions be made to this section?

A statewide, centralized vulnerable adult reporting system is proposed. Can more information be added here -

> When will the system be implemented?
>
> What will be the reporting process and what kind of reports will be available?
>
> What training will be provided and who will provide?
>
> How will the system be staffed?
>
> How will data collected and reports produced be used to prevent problems?
>
> What analysis will be done to identify patterns so that abuse can be prevented?

Re: Money Follows the Person (MFP): In Minnesota, a total of $187.4 million in MFP grant funds will be received across five years, and $13.4 million in the first year -

> Where is this money being spent and how?
>
> What are the results to date?
>
> Is there a strategic plan in place?
>
> What information has been communicated about this effort to date and how?

Under 9.4 Promote Personal Responsibility and Reward Health Outcomes:

Page 100: How will the diabetes prevention program intersect with people with disabilities?

What is the Community Living Mini-Assessment that will be conducted by Dr. Greg Arling? How is this connected to MnCHOICES?

Under 10. Evaluation:

Pages 105-118: The evaluation design section could be strengthened if there are individual designs for each part of the Section 1115 Waiver Proposal but with an overall design offered. For example, providing an outline of sample numbers, targets and comparisons, and how samples will be drawn would contribute to the collection of data and outcome measures that are more closely matched with the envisioned reforms for each of the initiatives.

Page 108: Increased community integration is mentioned in connection with the CFSS and Service Coordination Demonstration. The concept of community integration seems to run through much of this proposal and should be a primary indicator in the overall evaluation design

What are the data sources for personal level outcomes?

We appreciate the time and effort invested by the Department in the preparation of this Section 1115 Waiver Proposal. Thank you again for the opportunity to be involved in this review and comment process.

Cordially,

Colleen Wieck, Ph.D.
Executive Director

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Schels, Johanna T (DHS)

From: [redacted]
Sent: Saturday, July 14, 2012 10:47 PM
To: *DHS_Reform2020Comments
Subject: ABA Services for Children with Autism

Our daughter is 7 years old and has been receiving ABA therapy since she was 4 1/2. Prior to enrolling her in the ABA program, she spent a school year in the public school special ed classroom. She was lost in the background in that classroom and made no progress in that year.

In March this year we enrolled in public school again and again it was a disaster. The schools do not have the capability to provide these children the resources necessary to give them the individual programming necessary for them to be able to learn and have a chance to be successful in the community. We are back in an ABA program and feel that it is imparative that she is able to get these services if she is to have any chance to learn, make progress and succeed.

[redacted]

From: [redacted]
Sent: Saturday, July 14, 2012 5:38 PM
To: *DHS_Reform2020Comments
Subject: MEDICAID REFORM 2020 RESPONSE

RE: Medicaid Reform2020 Response

Hello:

Saw your website today & felt I must reply. Medicaid has been a "sore spot" with me. I am an older disabled person dealing with major health issues.

And am apparently not qualified for Medicaid. My income is strictly disability from 3 sources. Well below what I use to earn. My long-term disability insurance will end at retirement age (quite awhile from now), so a big drop in income in future.

But right now, I have to pay all my transportation myself, (MetroMobility) about $300/month more or less. Have mandatory medical treatment sessions several times a week (to keep alive), and between that, clinical visits. I take alot of medications (can't get social security help with that) and since I'm not quite retirement age, and unable to work, have no transportation help from family/ friends, I find this a burden.

Why do Medicaid people get their transportation paid for? When I seem to have more health expense than they do? Medicaid seems to go by income, rather than actual expenses vs. income. WHY? Had to sell my old car 8 yrs. ago couldn't afford gas/repairs.

I'm not rich by any means. I pay rising market rate rent for my tiny studio apartment I've lived in for 20+ yrs. And food, etc. is constantly rising. Isn't there any help for people like me? I don't qualify for things like food stamps, yet I'm on a special diet with more food expense. I don't have kids for welfare help. It's a shame that people who never paid into the system seem to get alot of help, while we who have paid taxes for years can't get a grant or something to help with burdensome health-related costs.

THANKS FOR CONSIDERING MY INPUT! [redacted]

Anyhow, I hope this helps your Medicaid Reform2020 initiative. I probably won't be around to see the final product, but want you to know there are others like me out there that aren't getting help.

From: [redacted]
Sent: Saturday, July 14, 2012 8:52 AM
To: *DHS_Reform2020Comments

To Whom It May Concern:

I have a grandson who is on the autism spectrum. He receives assistance in school and outside of school. As he has gotten older and more demands are made upon him, he needs the assistance in and out of school for his continued functioning and adaptation. Services provided now will pay off in the long term as his functioning and meeting the demands that society requires of him. Please do not cut out the out of school services which my grandson needs.

Sincerely,
[redacted]

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Autism Spectrum and Neurodevelopmental Disorders Clinic

Clinic Location:
717 Delaware Street SE
Suite 340
Minneapolis, MN 55414

Main: 612-625-3617
Fax: 612-625-3261

July 11, 2012

Dear Deputy Assistant Commissioner Wagner and additional Members of the Department of Human Services Waiver Proposal “Reform 2020” Committee,

We in the Autism Spectrum and Neurodevelopmental Disorder Clinic at the University of Minnesota are pleased with many aspects of your proposed Reform 2020 waiver. The proposed waiver will help many young children with autism spectrum disorder (ASD) more easily access evidence-based, medically-necessary treatment, behavioral intervention and family supports.

We do have concerns about uniformly requiring transition into the school system at age 7. While the majority of children we see are transitioned into school by age 7, there are without a doubt children and families who greatly benefit from short term, family centered behavioral intervention and in some cases more intensive behavioral services after that age. Addressing significant problem behaviors that occur in the home clearly is beyond the purview of school systems. We believe that by developing outcome criteria that can objectively assess response to intervention at any age, an age cap would not be necessary; children of any age who are showing measurable benefit addressing their needs related to ASD and their ability to function more adaptively in the community should continue to receive evidence-based and medically-necessary intervention services. Similarly, for those children at any age who are not demonstrating measurable gains, other evidence-based intervention approaches and/ or educational services should be tried.

As you state in your proposal, “The Department will work with providers, medical experts and clinicians to develop agreed upon standards, assessment tools and protocols for objectively measuring progress.” We are in a unique position to assist with the development of agreed upon standards, as we are not providers of intervention services, yet we routinely and objectively assess core symptoms of ASD and co-occurring conditions, monitor response to intervention, and make medically necessary treatment and educational recommendations. We would welcome the opportunity to work with you on these matters.

Thank you for your continued efforts to serve children with autism and their families.

Sincerely,

Robin K. Rumsey, Ph.D., L.P.
Pediatric Neuropsychologist
rumse002@umn.edu

Amy Esler, Ph.D., L.P.
Psychologist
esle0007@umn.edu

Michael Reiff, MD
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reiff001@umn.edu

Desirae Rambeck, MA
Care Coordinator
drambeck@umphysicians.umn.edu

From: [redacted]
Sent: Friday, July 13, 2012 9:53 AM
To: *DHS_Reform2020Comments
Subject: Regarding the "autism benefit set"....

I am a grandmother of a boy with autism. I am also a retired educator who has worked with children ages 10 to 18 with this disorder. My love for my grandson and my experience with students compels me to write and challenge the notion that services/funding could be cut after the age of six. Ridiculous!
Parents and school districts alike are ill-equiped to face the challenges presented by autism without the financial support offered by MA coverage.

Please reconsider your stance on this critically important issue for families, children, and community.

Sincerely,

[redacted]

Please keep me informed of any continued discussions or decisions.

From: [redacted]
Sent: Friday, July 13, 2012 8:52 AM
To: *DHS_Reform2020Comments
Cc: [redacted]
Subject: Proposed MA "Autism Benefit Set" Concerns

Good afternoon,
I am writing in response to the Department of Human Services' proposed changes to MA coverage for people with Autism Spectrum Disorder via an "Autism Benefit Set."

As a parent of a child with ASD, the DHS proposal is most striking to me because the "Autism Benefit Set" would only extend through age 6 and my son just turned 7 last month.
It is incorrect to assume that MA, and other services which can be obtained with it, are no longer needed after age 6.\
While early intervention is critical, most children on the Autism Spectrum are not diagnosed before the age of **two**, and their needs often increase as they get older. This is what I have found with my son. As he starts to navigate the world on his own, he simply requires more support and services.

It would be a devastating blow to pull the rug out from under so many families when their children with ASD reach the age of 7, as well as cripple the school districts that are already struggling with reduced budgets.

Please reconsider this change. I found out about the public hearings after the fact, but hope that there will be other opportunities to voice my opinion. My contact information is below if you would like to discuss this over the phone.

Sincerely,

[redacted] | [redacted]

The Long-Term Care IMPERATIVE
A Minnesota Collaboration for Changes in Older Adult Services

Comments on the Reform 2020: Pathways to Independence: Section 1115 Waiver Proposal

Date: July 12, 2012

To: David Godfrey
Medicaid Director
Minnesota Department of Human Services
P.O. Box 64998
St. Paul, MN 55164

From: Patti Cullen, CAE
President/CEO
Care Providers of Minnesota
(952) 854-2844
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Gayle Kvenvold
President/CEO
Aging Services of Minnesota
(651) 645-4545
gkvenvold@agingservicesmn.org

Re: Comments on *Reform 2020* Section 1115 Medicaid Waiver

The Long-Term Care Imperative is a legislative collaboration between Care Providers of Minnesota and Aging Services of Minnesota, the state's two long-term care trade associations. The Long-Term Care Imperative is pleased to have the opportunity to offer the following comments on the *"Reform 2020: Pathways to Independence*" Section 1115 Waiver Proposal.

General Comments:

Intent

We are pleased to see the statement for the next step which infers significant changes to the current segregated approach to health care and long term care:
"The next step for Minnesota's service delivery system is expanded full and partial risk sharing at the provider level, using prospective, global or population-based payment structures that include the costs of providing traditional health care and other Medicaid covered services in addition to costs outside of the traditional health care system that impact a Medicaid enrollees' health and outcomes (e.g., social services and public health services). This will provide an incentive not to shift the cost of services on to other parts of the health care and long-term care system, as well as other county and social service systems, while also allowing providers flexibility in managing upfront resources and making needed infrastructure investments under a prospective payment."

That is a laudable goal that we hope the Department of Human Services (DHS) can continue to focus on, moving ahead to a fully integrated system. Having said that, it appears that the waiver request is a collection of programs, concepts, and initiatives to move the state forward without a specific action plan for each of the items. It is difficult to comment specifically in areas where there is no action plan, or data to support the specific initiative. We do appreciate the forward thinking of the state, and we are looking forward to continued discussions in the areas identified in the proposal.

However, before moving too far down the path, we do want to highlight some general areas of concern for each of the categories below.

Waiver Requests

We support two of the three waiver requests. First, the specific request to waive statewideness is appropriate, and we support that particular request. We urge the state to consider the specific needs of rural communities when developing sites for their demonstrations, where access to certain services is difficult due to distance and/or operational challenges with fewer numbers of enrollees. We also support the request to facilitate data-sharing. Our experiences with care transitions in particular support the need for data sharing across the "lines" of services to avoid duplication, negative consequences, and fragmentation of care and services. We do have concerns, however, about the third waiver request: the waiver of freedom of choice of provider as a blanket waiver request. Consumer protection, especially for the frail elderly and persons with disabilities, needs to be a built-in feature yet the proposal was virtually silent on consumer rights. Currently it appears the only consumer protection is the ability to "walk"—to leave one program/provider and move to another. By removing choice of vendor, consumers, especially in rural communities where options may already be limited, are particularly vulnerable.

Section 2.2: Long-Term Care Realignment Waiver

As we have stated in the past when the state agency submitted the long-term care realignment waiver, we continue to have concerns about individuals who will be displaced when this is implemented. Since this waiver request is referenced as a related reform initiative, we must remind the state agency about our overriding concern. We would summarize our concerns as being critical of the proposed policy for what we believe will result when the state begins to implement the new level of care criteria. We anticipate extraordinary challenges and costs for providers and others who must deal with those who become or are newly deemed ineligible despite clear need for assistance and lack of income or savings to purchase help. We also anticipate conflict between those assessed for eligibility and government agents; conflict between providers shifting responsibility for such seniors; and conflict between seniors and their family members. A further concern we have relates to the responsibility for transition for those newly ineligible for Medicaid or Elderly Waiver services. The lack of infrastructure and services in many rural areas of the state will make this transition very problematic.

Federal Matching Funds for Alternative Care Program and Essential Community Supports Program

We would like to offer our strong support to one aspect of the waiver application- the request for federal financial participation on Alternative Care (AC) and the new Essential Community Supports (ECS) program. Federal support for these programs seems like an appropriate use of federal funding to assist the state in serving people in community settings. We strongly suggest that the state increase the ECS benefit amount and the services eligible under ECS, in order to address the gaps that are going to occur as the result of the level of care policy.

Section 2.3: Duals Demonstration

We also submitted a response to the duals demonstration proposal, concerned that expanding the current health plan-centric model does not allow for true integration of acute and long term care services and supports. We believe that overall there is likely enough total money in the current system, assuming you consider acute, post-acute, ancillary, end of life and long-term care services, to effectively serve the dual eligible population, but current funding is poorly distributed and divided up between providers based on a "silo mentality" that does not focus on how to use resources to achieve the best outcomes. The duals demonstration has the potential to make great improvements in care but only if the financing is designed with incentives to provide the most appropriate and least costly option for each recipient.

Section 3: Accountable Care Demonstration

We are generally supportive of the proposed accountable care demonstration, particularly to the extent that it focuses on a fully-integrated model that is similar to Program of All-Inclusive Care for the Elderly (PACE), where all payment streams are combined and the incentive is to provide the most appropriate care for the least cost, with rewards to providers who are able to do that. As with many of the concepts in the reform proposal, there are not enough details at this point to know for sure whether an accountable care demonstration can achieve these goals and be workable for providers and consumers, but we view it as a positive step that is worth investigating.

Section 4. Community First Services and Supports (CFSS)

While we understand that CFSS is intended to replace all/part of the current Personal Care Assistance Services (PCA) the proposal is lacking the data to determine the full impact of the proposal. It is unclear since the PCA services do not align with the level of care criteria who will be eligible to receive CFSS and who will not. It is also unclear if the proposal will increase or decrease the numbers of participants in the future. Additionally, it appears that CFSS will cover the services an individual may need but will not pay for their housing needs, so how is the CFSS program going to intersect with the housing demonstrations to ensure that affordable housing is targeted to those individuals qualifying for CFSS without a "family home"?

Section 5: Demonstration to Expand Access to Transition Services

The premise of this demonstration is that transitioning individuals to their own home is always in their best interest, and we believe that is not always the case. The concept of "right service-right place-right time" is important especially if the state is seeking to follow the health reform "triple aim". There are circumstances where living in a single family dwelling with all of the necessary home care services is not only the most expensive option, but it may also have a diminishing quality of life impact given the research about isolation and depression with seniors in certain circumstances. We strongly encourage the state to take a few additional steps before expanding transitional supports and level of care criteria further:

1. Evaluate the per person cost benefit of current transition initiatives;
2. Utilize latest research on effective transitions for persons with Alzheimer's disease and their caregivers;
3. Using surveys and focus groups, analyze the current population in both nursing facilities and assisted living setting both on what their needs are but also why they chose to move to those settings; and
4. Identify the total costs for transitions over time to include acute care costs, social service costs, long term care services and supports.

Section 6.2: Housing Stability Services Demonstration

We have been experiencing over the past few years an increase in the numbers of younger individuals with serious and persistent mental illness and/or chemical dependency with a health condition being admitted into nursing facilities and assisted living establishments. We hope that this demonstration can include a special focus on this population because we acknowledge that the current setting for services is not the most appropriate setting. Often times the placement is made because there are no other options in the community; or because the options for housing focus only on their mental health needs without addressing health conditions such as skin wounds, untreated diabetes, etc.

Section 9.3.2: MnCHOICES

We applaud the process the Department of Human Services has been using to develop and test this comprehensive tool, which will be a key mechanism in the future to ensure that individuals receive the long term care services and supports they need. What is not included in the discussion to date, however, are the details about financing. Currently the long term care consultation is financed through nursing facility rates and we believe there needs to be a transition away from that mechanism. There are also other vehicles that fund current screenings. We are also unsure about the use of MnCHOICES in primary care/health care home settings and urge further discussions about how the integration into those settings will be funded.

In addition, we ask DHS for more detail on the transition to MnCHOICES from the current LTC Consultation assessment tools and the Customized Living tool. We assume that modifications will be needed to the Customized Living tool, and hope that these modifications will improve the ability of case managers to identify the need for interventions for behaviors, redirection, coaching, and general oversight/supervision. We also hope that any revisions to the CL tool will result in more realistic identification of time necessary to complete needed tasks. Currently, many case managers are authorizing inadequate amounts of time for various EW services.

We also support the statewide assessor training and certification in hopes that it will bring greater consistency in treatment of waiver clients. Currently there is great variation among lead agency staff in the way they gather information—with some refusing to communicate with the clients' current providers who know their needs best. In addition, we have found that some lead agencies, especially certain counties, have set policies regarding what services they will and will not authorize--sometimes in contradiction to DHS policies. For example, some counties refuse to authorize EW Customized Living for housekeeping and laundry services when a client has a need for that service, even though those services are clearly eligible under the EW CL waiver program.

We also hope that having the assessment and other date in electronic format—allowing the audit function to be standardized and automated—will also improve the consistency of assessments and authorized services and will result in a more fair system to waiver clients.

Section 9.3.3: Home and Community Based Services Report Card

We acknowledge the need to provide consumers with information to help them make informed purchasing decisions and we encourage the state to move ahead cautiously in that endeavor. Unlike the development of the nursing home report card, where the services delivered are very homogenous, the home and community based services delivery system is varied and flexible to meet consumer needs. Even within a subsection of services—housing with services—there are significant variations with sizes, settings, and services available. Minnesota has established a unique model of separating the housing from the services, which has ensured maximum flexibility to meet consumer needs and interests. Because of that variation, the establishment of a uniform report card that is both consumer friendly and objectively based will be very challenging. We encourage the state to establish a process for input, testing, and discussion and an extended timeframe to accomplish their goals.

One major concern is that there is little uniform data available for assisted living programs or housing with services establishments. The little data DHS currently has is only for MA waiver clients, who compose a small proportion of the residents being served in these settings. Collecting additional data needed to provide a comprehensive picture of these settings will be a costly and challenging task for both the state and for providers. Similar data challenges exist for other HCBS that may be the subject of future report cards.

We also do not believe the project, as stated, is actually measuring outcomes per see, but is focusing on provider descriptives. Because of this, we wonder how this "report card" that simply describes the services and costs will be an improvement over the Uniform Consumer Information Guide (UCIG) that Housing With Services (HWS) providers must now make available to prospective HWS residents. There has been no evaluation to see if this 7-page document is even useful to consumers, and it is unclear how another document that "educates consumers about differences" among HWS would help consumers in their decision-making process. Moreover, given the decentralized nature of HCBS and the associated pricing and service models, we doubt that DHS will be able to collect meaningful and universal data on the descriptives identified. Even now the UCIG only presents a general picture of services and costs. In order for a prospective HWS resident to fully understand what services may be available to meet his/her needs and what the cost will be is to have the on-site RN complete an assessment and develop a proposed **individualized service plan**. A generic report card will not provide that detailed information that a prospective resident may need when making decisions about housing and service options.

Section 9.3.4 Alzheimers Health Care Home Demonstration

Consider the addition of the following parameters to the existing parameter which states *"build on the physician's algorithm for early identification of dementia to implement a fully integrated primary health and community service model for patients with Alzheimer's disease and their caregivers*":

- Comply with Health Care Home certification standards regarding dementia and documented care approaches that use dementia as an organizing principle of care;
- Establish and document referral paths to and partnerships with community based services organizations that provide some or all of the supportive services identified in the Practice Algorithm (e.g., cognitive and physical function, caregiver support, emotional and social supports, safety, planning, etc.); and
- Implement care management and care transitions support that evidence establishes are effective in dementia populations.
- Establish and implement policies that incorporate specifically trained primary caregivers in the care of persons with Alzheimer's and related dementias

In addition, we recommend that this demonstration effort should coordinate with the work being done by the various working groups that are part of the Preparing Minnesota for Alzheimer's 2020. These groups are doing work on early identification of Alzheimer's/dementia, curriculum for medical professionals, etc.

Section 9.3.5: Critical access study for home and community based services

As part of the critical access study for HCBS, we urge DHS to consider both current and **future** workforce issues, particularly in rural areas. While maintaining waiver clients in homes scattered throughout their communities may be a laudable goal, "windshield time" due to long distances and decreasing numbers of available workers may have a significant impact on the ability to provide HCBS to persons in rural areas.

Section 9.3.5: Redirect Residential and Nursing Facility Services

We are concerned that the proposal includes an expected outcome of planning and analysis before conducting the studies, especially when it comes to critical access study of core services. We have experienced what happens when portions of the infrastructure for a given population are reduced and/or removed, as is evidenced by the increasing number of younger individuals with mental illness and health needs entering nursing facilities. Until core infrastructure needs-- such as affordable housing, crisis response services, health care in supportive housing settings--are

addressed, there will be populations that are disenfranchised and that won't be served due to increased level of care criteria. It is important for the state to first implement and evaluate the implications of the first level of care changes before increasing the service eligibility threshold again. Not only do we need better data to measure the impact of these changes; we also need to involve social services, public health and others in the discussion to be certain communities are ready and able to respond with services to fill in the gaps created by these redirections.

Section 9.3.6 New In-home Support and Technology

While we agree that using technology to assist people living throughout the community can be useful—particularly if they have a family caregiver who can help fill in some of the gaps—we recommend that DHS consider how to make better use of technology also for those waiver clients who live in housing with services. For private pay residents, especially those with dementia, monitoring technology has been proven to improve outcomes by identifying problems (e.g., UTI) before they become severe enough to require hospitalization. As DHS re-visits the current waiver requirements, we hope you will make changes to make it easier for providers and their clients to access funding for various types of technology to improve clients' outcomes.

Section 9.3.6: New Budget Methodology to Serve Medically Complex Seniors

We are pleased the state acknowledges the fact that the rate setting methodology for the Elderly Waiver program is insufficient to meet the needs of certain individuals. We have two recommendations for this initiative: First, that they look beyond the limitations of “ventilator dependent” and focus instead on the clinical needs of individuals who need the higher threshold of nursing and therapy services. Secondly, we encourage the state to calculate total costs when determining which setting is the lesser cost for comparison purposes.

In order to achieve long-term cost savings, we would also recommend that DHS reconsider some of its policies related to Customized Living/24-hour Customized Living. These waiver packages do not pay for any licensed nursing time other than medication set-ups. By allowing some flexibility to pay providers for some licensed nurse visits—for example when an EW Customized Living client has returned from the hospital or when the client has the flu—this could potentially eliminate some transportation/clinic costs, or even avoid unnecessary hospitalization. While some health plans are now have Nurse Practitioners or even physicians on-site in some HWS settings, another way to avoid more expensive services would be to allow RNs and LPNs that know their residents/clients well to take a more active role in providing early interventions to avoid more expensive care later.

Section 9.3.6: Threshold for Accessing Residential Services.

As waiver clients are required to meet increasing thresholds for residential services (e.g., HWS), we urge DHS to consider how to assist private pay residents who may have lived in the residential settings for a long-time prior to becoming eligible for waiver services. While the Level of Care criteria do include some considerations—such as whether the individual will have certain risk factors and will be living alone—if a resident has lived in a HWS setting of their choice for several years, made friends and had their health stabilized as a result of the meal plan, socialization, etc., significant amounts of assistance may be necessary if they can no longer receive needed services if they continue living in that setting.

Section 9.3.7: Rate Methodologies

We want to state on the record that the Customized Living (CL) tool may have made some improvements in rate setting, it has not resulted in "fair" and "consistent pricing across the state." Counties and other lead agencies are still administering the tool inconsistently; for example, with some lead agencies refusing to authorize CL for housekeeping and laundry, which are clearly eligible services under DHS' policies and the waiver. In addition, the tool has not resulted in services individualized to a particular client's needs. We know that case managers are using standardized approaches—such as using a flat five minutes for each medication administration task no matter whether the client has 2 or 12 medications. In addition, rather than try to be creative in terms of bringing in volunteers or other agencies to meet all of a client's assessed needs, case managers often simply reduce the time allowed for the CL provider for all services in order to stay within a client's service rate limit, while still expecting the CL provider to provide all services in full without appropriate reimbursement. As DHS develops the rate methodology for disability services, we hope there will be adequate testing and evaluation of the methodologies and that that information will inform changes needed to the EW CL tool.

Section 9.3.8: Redesign Case Management

We agree that it will be an improvement to separate the administrative functions that have been assigned to case managers from the services of case management, and hope that this frees up case managers to spend more time in responding to changes in client's needs and in revising service plans as needed. As DHS looks to improve case management functions, we urge DHS to consider the important case management function played by providers' nurses and other health care professionals who work directly with waiver clients. In Customized Living services, the on-site RN plays the primary day-to-day role of case management in contacting the physician about changes in condition, side effects of medications, etc., yet there is no reimbursement for this valuable service. We hope as the case management system is redesigned, that this important function that providers fulfill will be recognized by lead agencies with resulting improvements in outcomes for clients.

Section 9.3.9: Statewide, centralized system for Reports of Vulnerable Adult Maltreatment

Minnesota plans to establish a statewide toll free hotline with 24/7 response and triage to receive reports of suspected maltreatment of vulnerable adults and determine the need for investigation. While we are supportive of a more streamlined approach, during the past two years, a collaborative initiative known as the Vulnerable Adults Justice Project (VAJP) has been discussing similar concepts, along with the need for simplified reporting. If the state moves ahead with this change, we encourage you to build off of the work that is already underway with VAJP. In addition, if there is a major initiative that changes the current reporting system, we encourage the state to look ~~and~~ at training, resources, and expectations to local officials to address the growing challenge of financial exploitation of the elderly.

Section 10: Data, System and Evaluation Criticisms

In general, it is disappointing that much of the evaluation proposal focuses on process without addressing how care and the associated healthcare outcomes for a specific client are to be measured. The work on the duals project assumes that care will be virtually organized, but doesn't specify how providers will do so. The CFSS, Redirect Residential and Nursing Facility Services, New Budget Methodology to Serve Medically Complex Seniors, Demonstration to Expand Access to Transition Services, and other areas speak to how DHS will manage the new system, but are silent on how providers will improve the health outcomes under these new constructs. For example, the fact that medication listings and reconciliation, which is a key problem area for successful transition, is not mentioned, leads one to think this is not focused on the consumer, and on consumer outcomes.

Furthermore, this appears to be a theoretical construct at this point. No evidence is provided that by aligning payments, needs, and services that better health-related outcomes will be achieved. On this, it is disappointing that none of the waivers and programs discuss how eHealth technology and the sharing of data will be incorporated and used to improve and measure health outcomes.

Finally, in general, the evaluation laid out seems to rely on old ways of measurement, not newer and more client-related. Are we avoiding hospital stays? Are people managing their specific diseases or conditions better? What are the expectations for providers and care coordinators to communicate and coordinate? How often are care coordinators and case managers meeting with their clients?

Schels, Johanna T (DHS)

From: [redacted]
Sent: Thursday, July 12, 2012 1:05 PM
To: *DHS_Reform2020Comments
Subject: Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

Dear Dr, Godfrey,

Kids don't grow out of autism by age 7, so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

It is frightening to me that these kids would stop getting much needed help at Age 7. I have a very good friend whose son is in the public school system with autism, and they don't have the resources to help him. This is wrong!

Please do not take away the basic right of proper care for these children. Please do the right thing and DO NOT pass this waiver.

Kindest Regards,

[redacted]

[redacted]

July 11, 2012

David Godfrey
Medicaid Director
Minnesota Department of Human Services
PO Box 64998
St. Paul, MN 55164

Dear Mr. Godfrey:

On behalf of the National Alliance on Mental Illness of Minnesota (NAMI Minnesota) I am submitting these comments to the State's Medicaid Section 1115 Waiver Proposal – Reform 2020: Pathways to Independence. NAMI Minnesota is a statewide grassroots organization dedicated to improving the lives of children and adults with mental illnesses and their families. Nearly 100% of our board and staff either live with a mental illness or have a family member with a mental illness. We appreciate the opportunity to comment on such a far reaching proposal.

NAMI Minnesota supports the purpose of the Medicaid reforms to:

- Achieve better health outcomes
- Increase enrollee independence
- Increase community integration
- Reduce reliance on institutional level of care
- Simplify administration and access to program
- Create a program that is more financially sustainable

Medicaid, or as it is called in Minnesota, Medical Assistance (MA), is an invaluable program for children and adults with mental illnesses and their families. For many, it is the **only** way to obtain access to treatment and supports. We believe it is important to remind the department that the health care system for children and adults with mental illnesses continues to this day to discriminate against people needing mental health treatment and supports to achieve wellness and recovery.

Mental health treatment is not currently mandated for self-insured plans. Over 40% of Minnesotans are under self-insured plans. Companies that self-insure can legally not cover mental health and substance abuse treatment. Individual policies, under Minnesota law, can exclude coverage for mental health treatment. Nearly 8% of Minnesotans have coverage under individual policies. Thus, nearly 50% of Minnesotans that are insured may not have access to mental health treatment.

If mental health treatment is covered under private insurance, what is covered is variable. Few private plans cover the model mental health benefit set which is included under MA and MinnesotaCare. Final federal parity regulations have not yet been adopted and so it is not clear how major components of the law to ensure equity and parity will be implemented. People continue to struggle with obtaining insurance coverage, particularly with non-quantitative treatment limits and medical necessity.

Even under MA, discrimination exists. The TEFRA program (Katie Beckett Waiver) is different for children with mental illnesses than for children with developmental disabilities. These children have to meet a higher standard – hospital level of care – resulting in far fewer families being able to access the TEFRA program for the services that their children need to remain in their home.

This background information is important. When people cannot access treatment and supports that are needed for their mental illness they often turn to publicly funded programs – like MA. The coverage and eligibility criteria for mental health treatment and supports, becomes hugely important since there is no where else to turn for help.

Great progress was made in 2006 and 2007 in expanding coverage for effective treatment and supports (model mental health benefit set) and in expanding access by increasing rates for mental health providers. During the past two years, NAMI has seen these specific programs held largely harmless, but have witnessed the legislature and department make drastic changes to other MA programs that have significantly negatively impacted people with mental illnesses and thus greatly reduced people's ability to access needed supports to live well in the community.

The most detrimental changes are ones made to the Nursing Facility Level of Care (NFLOC), the PCA program, and the CADI program. Changes to these programs will or have resulted in countless people with mental illnesses being tossed out of programs that provide the in-home supports they need to live at home in their communities.

The NFLOC proposed changes: 1) require hands-on assistance thus eliminating eligibility for people who may need cueing to meet their daily needs; 2)require daily monitoring thus eliminating eligibility for people who need only weekly injectable medications or medication checks; 3) no longer mention disorientation which could have included someone experiencing delusional thoughts or psychosis; 4) no longer include safety which in the past could have included people who were suicidal or had self-injurious behaviors; 5) refocuses on physical symptoms and no longer includes aggression, recent hospitalizations, cutting or otherwise hurting oneself, or even self-neglect. The reason it is important to remind the department about the NFLOC changes is that it will result in far fewer people with mental illnesses being able to qualify for the CADI program. Of people currently on the CADI program, 34.1% have a serious mental illness and 25.8% have a serious and persistent mental illness. The NFLOC changes will result in thousands of people with a mental illness no longer being eligible for this waiver. Medicaid Reform must address the loss of eligibility for services.

Eligibility for the PCA program was changed to be more restrictive so that many people with a mental illness, particularly children, were no longer eligible or had their hours reduced drastically to roughly half-hour a day. These cuts especially impacted children from communities of color. Medicaid Reform must address the loss of eligibility for services.

The CADI program was changed last year by reducing funding for people with "low needs." Many of those people were people with a mental illness since the assessment tool did not adequately assess needs related to mental illnesses. It is easy to understand that someone who cannot bring a fork to their mouth needs assistance. It's harder to understand that someone's symptoms may make it difficult to leave the house to purchase groceries and cook may need assistance. But either way, without assistance, neither will eat. Yet, the latter person would be deemed “low needs.” Thus many mental health providers lost 10% of the funding and some people were faced with losing services.

The MNChoices program, which is a universal assessment tool, still does not adequately assess the needs of children and adults with mental illnesses. This will result in them not being eligible for programs and not having their needs addressed.

Even before these changes, we have seen the poor outcomes for children and adults with mental illnesses– 70% of youth in the juvenile justice system have one or more mental health diagnoses, over 25% of our prisons and 60% of our jails are filled with people with mental illnesses, more than half of those who are homeless have a mental illness or chemical dependency, and over 500 people die every year in Minnesota due to suicide. The current Medicaid program isn’t totally working for people with mental illnesses and it will only get worse. The only time NAMI has witnessed significant positive changes to the mental health system was in 2006 and 2007 with the passage of the Mental Health Initiative, where we used MA funding for specific services that had evidence to prove their effectiveness and that were designed to explicitly meet the needs of people with mental illnesses.

The components of the Reform 2020 proposal are, therefore, extremely important since children and adults with mental illnesses are being pushed out of current home and community-based MA programs and if the NFLOC changes are approved, even more will lose their supports. NAMI Minnesota is very concerned that the Reform 2020 will not create the programs needed to support those who will no longer be eligible for the CADI and PCA programs.

NAMI Minnesota unequivocally supports the development of a waiver specific to the needs of children and adults with mental illnesses and that does not tie eligibility to facility level of care or multiple hospitalizations.

In reviewing the proposal NAMI specifically looked at changes that would worsen the situation for people with mental illnesses and identified lost opportunities for actually improving the lives of children and adults with mental illnesses.

3.2.2: Accountable Care Demonstration Project

Establishing Hennepin Health, providing an integrated health delivery network for people under MA expansion.

NAMI supports the department’s request for waiving state-wideness for the Hennepin Health project. Hennepin Health builds on the Preferred Integrated Network project in Dakota County and has the potential to provide better coordination of treatment and supports. Starting in one county and learning how to do this effectively before going statewide makes sense.

4.2.1 & 4.2.2: Community First Services and Supports

Providing for an alternative to the PCA program by providing an array of services and supports to provide assistance with maintenance, enhancement or acquisition of skills to

complete activities of daily living, independent activities of daily living and health related tasks to help people live in the community.
The main problem that NAMI has with the current PCA program is the limited half-hour per day (two units) of services and the lack of appropriate training of PCA providers. The proposal does include provider standards which may help address the current problem related to lack of training on mental illnesses. This new program will use the MNChoices assessment tool, which we believe is still flawed, and eligibility will be based on the new NFLOC. This will result in many people with mental illnesses not being eligible for services under CFSS. When the changes were made to the PCA program by the legislature many of those who no longer qualified for the program or who lost all but 30 minutes of day of service had a mental illness, were children and were African American or from other culturally specific communities.

There is a second program for people who do not meet the NFLOC but who have one ADL or a level one behavior. Due to the definition of a level one behavior, we do not believe we will see people with mental illnesses who were cut from the program be able to come back on to it. Exhibiting a behavior once a week is not really relevant to people with mental illnesses who may go for several weeks without a serious symptom and then have several difficult days or weeks in a row. The proposal will increase the number of units per day to 90 minutes, which is certainly much better than 30 minutes.

NAMI hopes that the some of the service options under this program will aide with coordination. The ability to include CFSS services as part of a waiver could certainly help with this aspect.

4.2.3: Demonstration of Innovative Approaches to Service Coordination (Children with CFSS)

Providing service coordination through a limited number of school districts.
Children with mental illnesses clearly need more supports than are currently provided under MA. This has been noted in the Intensive Needs Report which showed that roughly 10% of the children used over 50% of the inpatient bed days and were receiving community-based services - but at the same intensity as other children. Due the recent passage of a law governing the use of seclusion and restraints in the schools, we now understand that the use of prone restraints on children is intrinsically tied to lack of access to intensive mental health services. In fact, the 2012 Legislature is requiring the MN Department of Education to convene a group to study how to reduce the use of all seclusion and restraints by looking at a number of factors, including access to mental health services. Thus, NAMI strongly supports a better and more intensive care coordination model.

There are, however, several problems with this specific proposal. The first is that you have chosen schools to be the agency providing care coordination. Many schools do not operate year round. Many of the personnel in schools that the application refers to – school psychologists, social workers, school counselors – are not licensed mental health professionals and are not clinicians. Few districts are true CTSS providers, providing the full range of services, including day treatment. They largely provide skill building. Most importantly, the proposal makes no mention of how this new service will interact with what has become an extremely effective program – school-linked mental health services.

One of the reasons that the Mental Health Action Group (MHAG) chose mental health providers to be the recipients of the school-linked mental health grants is that they have licensed mental health professionals, operate year round and are able to bill all insurance providers. Additionally, when a child changes schools (voluntarily or expulsion) the provider can continue to provide services to the child – their care is not interrupted.

For many children with a serious mental illness, they are neither on the TEFRA program nor on a CADI waiver. For those that are, they often also have private insurance. Schools are required to bill their private insurance first since MA is the payer of last resort. When services are provided by the schools, parents can deny permission to bill their private insurance for these services due to FAPE. You will be making the situation more difficult than it needs to be by placing this service with the schools.

NAMI Minnesota does not support the schools being the lead agency for this new service and urges the department to revise this proposal with direct input of the current school-linked mental health providers and children's mental health advocates.

6.1: Demonstration to Empower and Encourage Independence through Employment Supports

Targeting specific people to provide telephonic navigation, benefits planning and employment support based on the Pathways and Demonstration to Maintain Independence and Employment programs.

People with a serious mental illness have the lowest employment rate of any disability group. Less than 15% are employed. And yet, employment is an evidence-based practice – it actually helps people get better. Theoretically, NAMI Minnesota supports efforts to include employment programs under MA. However, we are perplexed as to why IPS, an approach based on research and proven to be effective in helping people with serious mental illnesses obtain and retain employment, was not included in this proposal.

IPS, also known as evidence-based supported employment, helps people in community mental health service systems to become a part of the competitive labor market. IPS is nearly three times more effective than other vocational approaches in helping people with mental illnesses to work competitively. IPS is cost-effective when the costs of mental health treatment are considered. Several studies have found a reduction in community mental health treatment costs for supported employment clients, while other studies have found a reduction in psychiatric hospitalization days and emergency room usage after enrollment in supported employment. Service agencies that have replaced their day treatment programs with IPS have reduced service costs by 29%.

People who obtain competitive employment through IPS have increased income, improved self-esteem, improved quality of life, and reduced symptoms. Approximately half of the people who enroll in IPS become steady workers and remain competitively employed a decade later.

DHS is proposing a program targeted largely at young adults with a serious mental illness who are in MA expansion, MA-EPD, or MFIP, or young adults exiting foster care or people transferring from the Department of Corrections. And yet, the department is not proposing to use an evidence-based practice for people with mental illnesses. Instead the department is proposing to carry out activities that have absolutely no evidence behind them.

The proposal is to conduct outreach, provide navigators, use the Disability Linkage Line and utilize DB101.

While we have not done extensive research, nor contacted the department directly due to time constraints, we have not been able to find data demonstrating that the approach used under Pathways was successful in reaching young people with mental illnesses. The last report we could find was from the first quarter of 2011 and it did not contain outcomes or data.

In looking at the Minnesota Demonstration to Maintain Independence and Employment (DMIE) Report published in February 2010 there is data, but it should be analyzed more closely before using this approach. First, is the low response rate of 16% and the fact that only half of them were approved, leaving just 8% of the total mailing. Granted, this is higher than most market research efforts; however, in terms of reaching people to prevent them from going on to a variety of disability programs, we believe it is low. Outreach to enroll people under the new proposal includes mailings and phone calls - to people who do not have stable home addresses and who may not have cell phones. Will reaching fewer than 8% be viewed as successful?

In looking at why people were denied access to the DMIE program, 45% were not working and 13% did not complete the diagnostic screen. The data also show that 65% of pending cases had "not responded to outreach efforts to schedule their appointments or had not attended scheduled appointments…The number of missed appointments was high enough…to prompt DHS to establish a policy of issuing a denial letter if an applicant missed three scheduled appointments."[1]
This demonstrates lack of engagement, which is particularly hard for young adults. Will a phone call be enough?

What is particularly noteworthy is that 58% of the participants were over the age of 35 and depressive disorders were the most common psychiatric illness (52%) followed by anxiety disorders. We were not able to fully analyze the data to learn if the people who did not complete the diagnostic screen were under the age of 35. It would be even more helpful if we could look at the date for those between the ages of 18 and 25. Further analyzing the impact of this program on those under the age of 25 would provide greater insight as to if this program will truly be effective with young adults.

One of the important components of the IPS model is to conduct a rapid job search within one month. Under the DMIE program, at one point there was a delay of 63 days before their first encounter with a navigator. It can be assumed that the job search happened much later. The most common referrals after meeting with the navigator were for employment supports, mental health services and medical care and 33% needed more intensive employment supports.

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[1] DMIE Report, page 12

Of the 1494 people that were randomized into the program, 26% dropped out – mainly due to being not employed or failing to pay the ongoing premium. This leaves under 6% of those that received the initial mailing being in the program. This information is critical to the development of the eligibility criteria for this new program and its components. The eligibility criteria that is proposed will greatly limit access by requiring that someone currently have a job, have had reduced hours or pay, or not worked in a year or less. Especially in light of the economy, why would you exclude people who have not worked in more than a year or who haven't had reductions in hours or pay but would like to do better? The DMIE program lost over a quarter of its participants due to this requirement.

The components of the program should also be changed. While we would prefer that you fund the IPS model, instead of funding a "middleman," at the very least changes should be made to make it easier for someone to obtain an assessment and to not penalize those who miss appointments. For people with a criminal background, you need to address the impact of collateral sanctions.

For anyone who has any type of complex issues, DB101 is not helpful. We have heard from many mental health providers who do not recommend that their clients use DB101 because it is not accurate and does not look at all the benefits someone will use. Additionally, it is rarely used by the individual. People who do not own computers only have about 30 minutes on a computer at the library which is not sufficient time to obtain a meaningful response through DB101. Even on DB101 there is a reference to the Work Incentives Connection, recognizing that people need individual benefits planning – yet there is no funding for them to complete these assessments.

The Disability Linkage Line is not a "natural" resource for people with mental illnesses. People with mental illnesses and their families do not look up disability related sites or programs – they look for mental health or health care. Our community won't know to go there.

In the proposal the word "navigator" is used, which could be very confusing when the health care exchange is up and running and navigators are used to help people access insurance through the exchange. The qualifications for "navigators" is very high and don't line up with current definitions of mental health practitioners or mental health professionals, making it more difficult for agencies to figure out if they have qualified staff. The requirement that an organization have mental health professionals yet not be required to provide mental health services such as under IPS does not make sense. We have few too mental health professionals to be using them for nonclinical positions.

NAMI would recommend that you change this section to fund IPS. If the department proceeds with its proposal as is, at the very least it should alter the eligibility criteria, add components, and use the evaluation criteria for IPS so that you can compare the efficacy of the two programs.

6.2 Housing Stability Services

Providing a new set of benefits to people who have serious functional impairments and housing instability.

NAMI Minnesota supports developing more services to support stable housing. Stable, safe, affordable housing is an important component for achieving recovery. The department has proposed three components: 1) outreach/in-reach, 2) tenancy support services, and 3) service coordination.

Eligibility will be based on assessment through MNChoices. NAMI questions the applicability of MNChoices to people who are homeless. We do not believe that you will obtain an accurate assessment of someone's needs nor will it be easy to conduct this type of assessment on someone who is homeless.

NAMI is concerned with how the department is defining qualified service providers of housing stabilization services. Some of the very best people who provide outreach and support to people who are homeless would not meet these criteria. We would like a "reality" check in the field to make sure that some of our most successful providers of housing stabilization services are comfortable with these criteria.

NAMI is equally concerned with the eligibility criteria for these services in that it looks at ADLS and IADLS of people who are living on the street or are couch hopping. How can you even know if someone needs help getting around an apartment or needs assistance with meal planning or managing finances when they are not in housing?

NAMI does support the fact that the eligibility criteria includes people transitioning from institutional level of care, such as a jail or prison, since so many people with a mental illness are housed in the corrections system.

The benefits that will be provided do not go far enough. The proposal funds outreach activities, so that people know what options may be available. It funds assistance with finding housing and setting up a household. And it funds service plan development and coordination. What are missing are the actual services to maintain people in safe affordable housing.

The Substance Abuse Mental Health Services Administration (SAMHSA) views supportive housing for people with a mental illness as an evidence-based practice. As an evidence-based practice it requires a service plan to be developed specific to the individual and does not require a list of services for a specific location. SAMSHA does recommend that staff be available 24/7 and that services be available such as psychiatric, medical, relapse prevention, ADLs, money and medication management, education and information-sharing groups and activities, along with independent living skills, Illness Management, employment, and substance use services.

They also recommend the following supports for new tenants and tenants who may need ongoing support to maintain their housing: Tenant orientation; Tenant councils; Case management; Psychosocial assessment; Service planning; Counseling; Referrals; Crisis intervention; Peer mentoring; Support groups; and Recreational and socialization services. They also identify additional services that can be helpful such as: Legal assistance; Transportation; Nutrition; Art and music therapy; financial assistance; Money management or representative payee services; Furnishing units; and Assistance with dispute resolution (including negotiating payments for delinquent rent or resolving lease violations).

The problem that NAMI has heard in talking with providers is that the services that are needed to support someone in their home are not currently funded. This proposal only contains a partial list of the recommendations from the supportive housing community. NAMI recommends that the full list be included in order to achieve the envisioned and desired outcomes.

6.3 Project for Assistance in Transition from Homelessness and Critical Time Intervention Pilot.

Providing services to people are homeless or at-risk of being homeless and live with a serious mental illness and/or substance use disorder.

NAMI Minnesota supports this section.

7. Anoka Metro Regional Treatment Center Demonstration

Waiving the Institutions of Mental Disease (IMD) exclusion to use MA for AMRTC to allow for continuity of care.

The department seeks to waive the IMD exclusion for the Anoka Metro Regional Treatment Center (AMRTC). NAMI certainly believes that AMRTC is more like a short-term intensive hospital program in the community than it is an institution, particularly when compared to other state's institutions. In this respect it should be able to receive MA funds for the care and treatment provided. NAMI does not, however, view this section separately, but rather tied to the entire Reform 2020 proposal and how this section fits in to what else is being proposed to serve people with mental illnesses.

We are concerned that the section of the proposal to develop a 1915(i) for people with mental illnesses is not robust enough to prevent people from entering into AMRTC in the first place. Also, if we are to look at how to use our existing resources most effectively, NAMI believes that DHS must look at the Community Behavioral Health Hospitals (CBHHs) and their inability to be at capacity – using all 16 beds. When most of our other providers are full or have waiting lists, we simply cannot have beds that are not used. With the NFLOC and CADI changes, NAMI cannot support this section of the proposal without changes made to section 9, including an assurance from DHS that they will seriously consider developing a program to meet the needs of people who are experiencing their first episode of a serious mental illness.

9.1.4 1915(i) to support individuals with mental illness who are at risk for institutionalization without access to integrated community-based systems of care.

Providing a wide range of services to a select group of people with serious mental illnesses who have co-occurring or complex health care needs and no longer need hospital level of care (at AMRTC).

NAMI Minnesota has been strongly advocating that the department develop a 1915(i) specifically for people with mental illnesses, especially since people with mental illnesses having been using programs that are not designed to meet their needs and are now being pushed out of the PCA and CADI programs. If they cannot meet an institutional level of care, especially the new NFLOC, then new programs must be developed to meet their needs. Thus, we are pleased that there is a placeholder for this type of program.

We do, however, have several concerns. The first concern is that there is no 1915(i) for children with a serious mental illness. Over and over again we hear that we simply do not have adequate intensive supports for children. Data and reports back this up, including the Intensive Needs Report and the Transformation Advisory Committee Report. Key services that could be included would be IDDT for adolescents, supported education, peer specialists, parent peer specialists, respite care, a more intensive residential service, clinical case consultation and more intensive care coordination. NAMI strongly urges the department to create a proposal for children.

Our second concern is that the criteria for adults with mental illnesses are very limiting. The department is requiring that to be eligible, people have a serious and persistent mental illness and difficulty maintaining community-based services as exhibited by extensive hospital stays, AND exhibit two of the following:

- Assaults
- Verbal aggression
- Active chemical dependency
- Past criminal behavior
- Symptoms that do not respond to treatment and require eight hours of supervision per day
- The presence of another illness, condition or disability that makes it difficult to function in the community

NAMI Minnesota’s concern is that interventions and specific services are being provided after the outcomes are poor – after people have ended up in the jail or prison, after people have had multiple hospitalizations. If the mental health system is going to continue to be transformed, then we must be intervening earlier – not later. We do want to support those who are having the most difficulty, those with the most complex needs, those who are not able to leave AMRTC because there are not intensive enough services in the community.

But, NAMI believes, especially in light of MA expansion, that the state should target people who are in the early stages of their mental illness, particularly immediately following the first episode of psychosis. Intervening effectively and intensively through coordinated and aggressive treatment during the earliest stages of mental illness could fundamentally change the trajectory of people’s lives and produce the greatest outcomes – that people would not become permanently disabled by their mental illness. It takes an average of nine years from the first symptoms to an accurate diagnosis and treatment. This is unacceptable.

In the Minnesota DMIE Report published in February 2010, it states that “SSDI beneficiaries with psychiatric disabilities are the fastest-growing and larges disability group, they become disabled at a young age and remain on the rolls for many years, and they are the most costly population in the SSDI program.” According to a 2008 GAO Report entitled “Young Adults with a Serious Mental Illness” the main psychiatric illnesses of young adults on the SSDI or SSI program were schizophrenia, paranoid, and other functional psychotic disorders and affective mood disorders, such as depression or bipolar disorder.

The GAO Report also found that these young adults required multiple supports from a variety of agencies. The agencies and programs often have differing eligibility criteria – including age, income and definition of mental illness – making it even more difficult to navigate the system and on top of the fact that these young people may have, according to the report “fewer interpersonal and emotional resources with which to do so.” Families often end up being the case manager, care coordinator and advocate, at a time when they are just learning about the illness and the various systems. Four states have targeted programs to young adults with a mental illness: Connecticut, Massachusetts, Maryland and Mississippi. The state should investigate the type of services that were offered and the approaches they utilized to try to meet the needs of these young adults. Again, intervening early, with enough intensity, is paramount to reducing costs long term.

There are several demonstration projects funded by the National Institute of Mental Health (NIMH) that could inform these reform efforts. One is called Recovery After an Initial Schizophrenia Episode (RAISE) and the other The Early Treatment Program (ETP). In Minnesota both Northpoint and the Human Development Center are involved with ETP and Spectrum Community Mental Health and the U of M at Fairview have experience in first episode programs. Vail Place also has a young adult program.

Dr. Recht, from Northpoint, and his team have been working with this model as part of the RAISE ETP study for approximately two years. They use a four component, team-based approach to working with clients. The four components are as follows:

1) **Psychiatry**. Specifically using a new model (not yet publicly available) known as COMPASS which using computer images in conjunction with more traditional clinical work to determine what will have the most immediate and effective impact of psychotic symptoms. He described it as identifying psychosis as early as possible and "hitting it with all you can."

2) **Supported Education and/or Employment Services.** This involves one-on-one mentoring to help people find and/or maintain work or education activities to help people re-engage with the community. The service is designed to help eliminate any obstacles to success. It is designed to meet the person where they are at and can include everything interview coaching, skill building,

3) **Individual Therapy**. Specifically using an "individual resilience therapy model" similar to cognitive therapy and motivational interviewing. It is designed to meet people where they are and help develop skills for coping with their symptoms and understanding what underlying factors can lead to symptoms and how to deal with those.

4) **Family Education**. Family involvement, with family defined by the person receiving care, is paramount to the model. The family education is very similar to the education the individual receives in therapy. It is designed to help the family better understand their loved ones illness, provide support, help reduce stress in the home environment as well as recognize when symptoms may be coming back and what to do.

These services work as a menu of options and are dictated by the preferences and interests of the person receiving care. The person receiving the care is involved in the decision making process every step of the way. While ideally all four services can be delivered simultaneously, individual services can be started and stopped as the situation dictates.

Dr. Recht stressed the strong team-based approach to the work as one of the greatest assets this model provides. While the study is on-going and closed to new participants Dr. Recht's team continues to use this model on any new clients who would otherwise meet the criteria. "We feel very good about what we're doing" he said.

Dr. S. Charles Schulz, who is the Donald W. Hastings Endowed Chair, Professor and Head of the Department of Psychiatry at the University of Minnesota Medical School, believes in the “importance of coverage in the recognition and treatment of first episode psychosis and related serious psychiatric illness.” He points out that there is now significant evidence that early recognition of schizophrenia can significantly reduce poor outcome in these young people.

The following paragraphs are taken from a letter Dr. Schulz sent to NAMI.

Several studies have demonstrated that if there is early recognition of psychotic disorders that the outcome over the next number of years is improved. This improvement is not only a reduction of psychotic symptoms – hallucinations and bizarre thoughts – but also in functioning. Furthermore, a pilot study done in collaboration between Yale University and Norway has demonstrated a reduction in suicide rates in early recognition programs. I would like to note that all of these studies have demonstrated a highly statistically significant relationship between early recognition and outcome. I would be pleased to provide you with those articles as needed.

Related to the improved outcome of an early recognition program, I would also like to note the importance of health plans – both public and private – to recognize and provide comprehensive treatment for young people with serious psychiatric illnesses such as schizophrenia, bipolar disorder, and severe depression. It is noted in the medical world that the recognition of cancer and diabetes at an early stage is considered an important way to lead to much better outcomes. It is very important for these serious psychiatric illnesses to be treated in the same way – without prejudice or stigma.

The success of helping the seriously ill young patient includes much more than just covering a brief initial hospitalization. It order to have a highly successful outcome, services such as family psychoeducation and support groups, group therapy for the young patient, and day treatment for those young people who require it after a hospitalization is crucial to maintaining the therapeutic alliance with the young person and their family. Furthermore, I know you are fully aware of the importance of family psychoeducation in not only reducing the risk of relapse but also in providing support for the very difficult impact of a family’s child coming down with a serious illness.

It is important to note that the treatments following an initial hospitalization or an initial outpatient evaluation are crucial in the reduction of relapse of these young patients. I have visited Anoka State Hospital and reviewed with the doctors there how many young people in their early 20s have already had repeated hospitalizations because of inadequate support. There is emerging evidence that each relapse following the initial stage of schizophrenia requires more effort to bring the young person back to remission.

In summary, I would like to note that our public and private healthcare system needs to develop early stage of psychiatric illness programs in order to:

- *improve outcomes in both the short- and long-term*

- *reduce the morbidity and mortality of psychiatric illness*
- *reduce the cost of healthcare by providing early connection with the patient and by reducing relapse.*

In summary, I strongly believe it is important to intervene at the early stages of serious psychiatric illness and to provide appropriate subsequent treatment. Further it is judicious to not ignore serious psychiatric illness which can be present for up to a year before treatment. Third, I strongly believe that the impact of such programs will not only improve the outcome of these young people but will also provide a more economical healthcare system.

Generally, the model for first episode programs integrates medication, psychosocial therapies, family involvement, rehabilitation services, cognitive enhancement therapy and supported employment. There are also certain medications that are viewed as having greater success, namely Clozapine.

The third concern is that the services that are listed under this section need to be expanded and have more detail. NAMI recommends that the department refer back to the model mental health benefit set adopted by the Minnesota Mental Health Action Group. Only some – not all – of the recommendations were included in the 2007 Mental Health Initiative. Additional services recommended included clinical case consultation, IDDT, disease management and education, and supportive housing. Since then, more evidence-based practices have been developed and supported by the Substance Abuse Mental Health Administration. In checking SAMHSA's website today, there are more than 230 listed.

In addition, the department needs to seriously review Adult Rehabilitative Mental Health Services (ARMHS). This is an excellent program; however, the low rates combined with limited reimbursement of activities have led to many providers dropping out of the program. The pros and cons of including ARMHS under a 1915(i) or leaving it as a separate service must be thoroughly explored and discussed.

NAMI looks forward to working with the adult mental health division more closely on this section to fully develop the service options and eligibility options.

9.3.2 MnChoices

Providing a singe web-based assessment and planning process tool.

NAMI Minnesota appreciates the efforts that DHS has made to make changes to the MNChoices program to more accurately assess the needs of people with mental illness. NAMI believes, however, that more work needs to be done.

9.3.6 Enhancements to 1915(c) Waivers

Enhancing the current waivers (including CADI) to provide the right services at the right time.

NAMI Minnesota has been a part of the group looking at developing a common service menu. We strongly encourage the department to make sure that a "universal worker" has the skills and education needed to work with people who have a serious mental illness. In addition, your description of supported employment as a service should include IPS and not simply Pathways to

Employment services. The provider standards should also include the option to specialize in working with people with mental illnesses.

9.3.9 Crisis Intervention and Protection of Vulnerable Adults

Expanding crisis services to people with disabilities and seniors living in the community.

NAMI is wondering how this program will intersect with the current mental health crisis teams.

9.6 Intensive Residential Treatment Services

Integrating mental health and health care services in IRTS.

NAMI Minnesota has been a strong supporter of IRTS programs. Most recently there have been concerns raised about the need for more health care providers, such as nurses, to be able to be reimbursed through IRTS programs. This proposal, however, really only references the IRTS under State Operated Services and not those in the community. NAMI believes that this is a grave error and that we must allow the private IRTS providers the opportunity to meet the needs of people in their community.

9.7 Children under 21 in Residential IMD facilities

Addressing the IMD issue in children's residential facilities and increasing the intensity of care.

NAMI Minnesota supports efforts to address the IMD issue in children's facilities and to move forward our efforts to develop psychiatric residential treatment facilities.

Conclusion

This concludes the comments of NAMI Minnesota. We thank the department for the obvious amount of effort from numerous staff to develop a proposal that is this extensive and far reaching. We appreciate the leadership of the commissioner, assistant commissioners and the Medicaid Director in developing this proposal. Our comments are provided to help improve the proposal and to ensure that the needs of children and adults with mental illnesses, who heavily rely on Medical Assistance for treatment and supports, are met. Thank you again for the opportunity to comment.

Sincerely,

Sue Abderholden, MPH
Executive Director

Schels, Johanna T (DHS)

From: [redacted]
Sent: Thursday, July 12, 2012 11:39 AM
To: *DHS_Reform2020Comments
Subject: Please do not change this coverage.

To David Godfrey, Medicaid Director:

Kids don't grow out of autism by age 7 so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop *"Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.*

I am [redacted] aunt and know that he has a lot of potential. He needs more help than the school system is equipped to give him. They are pushed to the limit with so many special needs children. Please help the families give these kids the extra help that can make such a big difference. And the more help he receives now, the less help he will need later in life. That is our hope and prayer.

Thank you for you attention.

[redacted]
Concerned Aunt and retired teacher
[redacted]

From: [redacted]
Sent: Thursday, July 12, 2012 11:27 AM
To: *DHS_Reform2020Comments
Subject: Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

Dear Dr, Godfrey,

Kids don't grow out of autism by age 7, so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

It is frightening to me that these kids would stop getting much needed help at Age 7. I have a very good friend whose son is in the public school system with autism, and they don't have the resources to help him. This is wrong!

Please do not take away the basic right of proper care for these children. Please do the right thing and DO NOT pass this waiver.

Sincerely,

[redacted]

From: [redacted]
Sent: Thursday, July 12, 2012 10:58 AM
To: *DHS_Reform2020Comments
Subject: STOP Reform 2020 Section 1115

To Whom It May Concern to Make a Significant Impact:

Kids don’t grow out of autism by age 7 so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop “Reform 2020 Section 1115 Medicaid Waiver,” from limiting our kids.

Sincerely,

[redacted]
Human Resources Manager
[redacted]

From: [redacted]
Sent: Thursday, July 12, 2012 10:36 AM
To: *DHS_Reform2020Comments
Subject: Autisim - ³Reform 2020 Section 1115 Medicaid Waiver,²

Kids don't grow out of autism by age 7 so the state would be making a major mistake by ending the funding? These kids deserve need support and I am supportive of my tax dollars going to help these kids. I am doing this for [redacted] ***-Age 8. He is a non-verbal child with autism and he deserves and needs all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop*** *"Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.*

Thank you.

[redacted]

From: [redacted]
Sent: Thursday, July 12, 2012 10:02 AM
To: *DHS_Reform2020Comments
Subject: Please stop Reform 2020 Section 1115 Medicaid Waiver, from limiting our kids

Dear State Representatives:

Kids don't grow out of autism by age 7 so why should the state end the funding? These kids deserve every opportunity to get help and I want my tax dollars to help these kids. I am doing this for [redacted]-Age 8. He is a non-verbal kid with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop "Reform 2020 Section 1115 Medicaid Waiver," from limiting our kids.

Thank you.
[redacted]

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Thursday, July 12, 2012 9:59 AM
To: *DHS_Reform2020Comments
Subject: Please Don't Change Autism Funding

I have several friends who are raising children with different levels of Autism.

I cannot say enough how much of an affect it would have on their lives at home and their ability to help their children grow if this funding is taken away after the age of 7.

These kids deserve every opportunity to get help and I want my tax dollars to help these kids.

I am writing this specifically for [redacted]-Age 8. He is a non-verbal child with autism and he deserves all the help he can get. Please do not limit these kids by their age. Look at what they need! Please stop “Reform 2020 Section 1115 Medicaid Waiver,” from limiting our kids.

[redacted]

[redacted]

From: Jami Moon <jmoon@btsofmn.com>
Sent: Wednesday, July 11, 2012 8:42 PM
To: *DHS_Reform2020Comments
Subject: Autism

To whom it may concern:

I have been touching lives of children and families with Autism for several years now and I am truly appalled that these children could be essentially told "I am sorry you are over 7years old there is no hope for a future. Good luck in an overcrowded school system where you may not survive because you were not given the proper tools to do so." Shame on you for giving up on any child's future. What if it were your child?
Could you look them in the eye knowing you put an age limit and funding limit on their success? I do not support what this state is trying to do to this population. They deserve a fighting chance. They are worth the money at 2 years old and at 13 years old. At no age should a child be given up on. What does that teach them? They are people too, just because they may not be able to advocate for themselves does not mean we should throw them away. I hope legislation takes a good look at their proposal and realizes that this is a disgrace to Minnesota.

Sincerely,
Jami Moon

From: [redacted]
Sent: Wednesday, July 11, 2012 7:44 AM
To: *DHS_Reform2020Comments
Subject: Autism coverage should NOT be age based

Dear Mr. Godfrey:

In May, we received the letter all autism parents fear: our private insurance [redacted] would no longer cover our son's ABA therapy. We were grateful that he also had medical assistance so that he could continue his treatment. Just weeks later we learned that since [redacted] is 7 MA proposes to eliminate coverage for this same therapy.

With both private insurance and MA eliminating coverage for autism treatments such as MA we--and many families--will be left with no options other than our public school district. As a teacher, I know first hand that schools are not prepared for the influx of children with autism, especially those like my son who are non-verbal. Even in a quality district, [redacted] day will be spent primarily with an aide who likely has no training in autism. For most students, the sole focus is on behavior. As long as a student is compliant, they will receive little individual attention by someone qualified to create programs to meet his needs. Special education is little more than babysitting.

This is a sharp contrast to services [redacted] currently receives at [redacted], which is worth the 45 minute drive from our home. From the leadership who have master's degrees and create programs tailored to his needs to the therapists who work with him one on one, everyone is trained not only in autism but on [redacted] specifically. This is not a "one size fits all" program. Kids at [redacted]--and other autism treatment programs--have a huge range of skills and needs. [redacted] can meet this needs on an individual basis, which would not happen in our underfunded school systems.

Placing an age cap on autism treatment is bad for our kids and our public schools. It will have long term impact not only on our family, but on our society as children with autism will grow up with less skills and ultimately need more long term support. I urge you to reconsider this portion of the Reform 2020 proposal.

Thank you-
[redacted]

From: [redacted]
Sent: Tuesday, July 10, 2012 6:57 PM
To: *DHS_Reform2020Comments
Subject: Autism needs to been covered no matter what the age of the child

We need to stay focused on making sure that treatment for kids will not be disrupted. Both private and public health insurance should cover medically necessary care for autism. Children who have autism benefit from different types of treatment and services - our daughter is proof of that. She has benefited from early intervention. She is currently receiving ABA and intensive early intervention behavior therapy (IEIBT). Those services have made a difference for both her and our family! Children need autism services regardless of age.

Thank you for your consideration.

[redacted]

[redacted]

From: [redacted]
Sent: Tuesday, July 10, 2012 4:39 PM
To: *DHS_Reform2020Comments
Subject: Autism Wavier 1915i comments from [redacted] family

[redacted]

Minnesota department of Human Serives do not cut Autism coverage David Godfrey

1 message

To David Godfrey (Medicaid Director) & TEAM-

My name is [redacted]. My husband [redacted] and I have a three in a half year old Son [redacted] who has Autism.
I went to Regina Wagner's Question and Answer Session and shared my story in May 19th, 2012. I was one of the five parents who was chosen to speak.
I know that Proposal Children with Autism would be routed into a 1915i waiver to access treatment services. Limiting treatment with Autism after the age of 7 should not even be a consideration. ***PLEASE ALL CHILDREN WITH AUTISM SHOULD HAVE AFFORDABLE ACCESS TO EFFECTIVE MEDICALLY NECESSARY TREATMENT.*** **Please change the waiver 1915i so all Children get the therapy's that they need.**

My Husband [redacted] and myself like many other new parents started going to ECFE classes with our 2 month old son [redacted]. He was in a class of 0-12 months Babies. By the time the six month ages and stages questioner came around to filling it out when [redacted] was six months old he was already falling behind. When he was 9 months old the School District which we lived in [redacted], MN at the time took us aside and asked if they could do a evaluation for [redacted] through ECSE program. We started have the school district come out to our house 1 time a week for 45 mintues which averaged 3 times a month. At [redacted] 9 month appointment [redacted] Doctor also told us to get him into PT, OT to see if that would help his development Delay that he was in. By 12 months he kept falling behind and Behind. At 15 months we started taking him to a kids therapy program for OT, Speech in [redacted]. When [redacted] was 16months My husband finally had enough, [redacted] was not able to put rings in a bucket which the school district was working on since he was 9 months old, [redacted] was swiping food across any table, and [redacted] was a runner. He would run Miles down sidewalks and I could not physically hold his hand because he was getting stronger or he would bite me. At [redacted] 18 month appointment [redacted] doctor diagnosed [redacted] as having Autism after conducting a couple of tests on [redacted]. She wanted him to be seen at the [redacted] Clinic ASAP. She said it would take a few months to get in but try to work on getting some intensive behavioral Health Treatment. At that time I had no idea what that was. The [redacted] called 2 months later and since he was so young they wanted to get him in right away for testing and get [redacted] going on some other services. When [redacted] turned 2 he has a very limited ability to communicate would scream all day long, was overactive and over stimulated, had NO SELF CARE SKILLS and was preoccupied with self-stimulating behaviors (Known as Stimming). [redacted] stimming behaviors included mouthing everything, running back and fourth on lines or seems along the floor or ground. [redacted] inability to process different sensations made wearing clothes that had tags, raised seems, or too loose fitting a constant annoyance for him and would cause him to scratch himself so much that it interfered with the ability to play and learn. [redacted] would scratch himself until he would bleed. [redacted] struggled to learn the simplest skills and had no meaningful vocabulary. He would act so aggressively and bite. For example when [redacted] went from infant size shoes to toddler shoes we could not get the exact same shoe.

We would be a stride Ride and I would have Bite marks all over my necks, arms, hands, and I would be bleeding just to try to get a new pair of shoes on [redacted]. I also held back tears because I didn't understand why it was horrible for [redacted] to get a new pair of shoes. I always enjoyed going shoe shopping as a child and for many other normal children it is just the case. Once we started ABA through [redacted] in January 2011 we saw almost an immediate change in [redacted] behaviors. He learned to sit in a chair with in one month. He was learning how to play with toys and control his urge to put objects in his mouth. His biting decreased significantly and he started to play with people. He was making great gains with full time therapy. Last November 2011 I took [redacted] back to Stride ride and I can say I was able to find a pair of boots for the first time in his life that he would accept and wear with no biting or scratching me. I was so excited.

Then in November 2011 [redacted] progress slowed do to low hours and no funding. See when we started ABA therapy our [redacted] policy picked up all the hours, they would not pay for all of the hours so then we had to apply for MA- Tephra. By December 31.2012 we were do happy to start up Therapy again full time. [redacted] during the six weeks he had reduced hours and started regressing in his Independent play skills. Now we are in July of 2012 and we are started to work back up to the 10 minutes of [redacted] playing indepently for 10 minutes by himself without any behaviors such as mouthing, biting, or stimming.

The Doctor's and medical community not only recognize the effectiveness of this therapy but recommend it.

In focusing on the uniqueness of Autism it is important not to forget what Autism has in Common with other conditions. Autism is a brain disorder, a condition where genes and environment combine to cause a disability. As Autism shares the same biological ground as other brain disorders, it should share the same legal space in the Affordable Care act. Science can not justify placing behavioral health treatment for Autism outside behavior health treatments for other mental health and & substance abuse disorders. Behavioral Health treatments help to reinforce wanted behaviors and reduce unwanted behaviors. the treatments are critical for indivduals affected by Autism, Down Syndrome, and a variety of other disorders. They can help a child communicate and care for themselves: they can help that child from stopping him from hitting himself and those around him, the can enable a child to attend regular education classes, rather then special education classes; they can enable a child to live at home, rather then an institution. All of these alternatives save money in the long run, and this effort to decrease long-term health costs. Effective health is often beyond the reach of individuals on the Autism spectrum. According to the 2005/2006 National Study of Children with Special needs.

ALL CHILDREN WITH AUTISM SHOULD HAVE AFFORDABLE ACCESS TO EFFECTIVE MEDICALLY NECESSARY CARE FOR AUTISM. DHS SHOULD ACT TO ENSURE THAT BOTH PUBLIC HEALTH CARE PROGRAMS AND PRIVATE INSURANCE COVER TREATMENT FOR AUTISM.

Please change the 1915i waiver SO THAT ALL CHILDREN CAN GET THE THERAPYS THAT THEY NEED. LIMITING TREATMENT SHOULD NOT EVEN BE A CONSIDERATION.

PLEASE DAVID GODFREY and TEAM LOOK AT THE PROPOSAL AND CHANGE HOW MEDICAL ASSISTANCE MA/MA-TEPHRA COVERS AUTISM. I am writing this letter to you today because my Son [redacted] is TREMENDOUSLY BENEFITING FROM IEIBT TREATMENT otherwise known as Skills Training.

Thank You for your time today to read this email.

[redacted]

You have the patience, the strength and the passion, to achieve your ambitions, your goals and your dreams.
All you need to do now, is try.

[redacted]

[redacted]

[redacted]

[redacted]

From: [redacted]
Sent: Tuesday, July 10, 2012 9:04 AM
To: *DHS_Reform2020Comments
Subject: Autism Benefit Set Concerns

Hello,

I would like to thank you for the opportunity to allow me to share my story with you, and ask that you please consider the changes that you are about to make to the services that children require MA. My name is [redacted], and am the mother of two beautiful daughters, one of whom was diagnosed with autism in January at the age of 2. Watching my happy, smiley baby lose all of her language and expression was horrible. I knew something was wrong, for months, but everyone told me she would catch back up. That was an awful time. After 6 months, when I was finally able to get an appointment with a developmental pediatrician to voice my concerns, and the subsequent testing leading up to the diagnosis was devastating. All of these things helped to shape one of the darkest times in my husband and I's life...but it got even worse. We dealt with the diagnosis, and decided we would do whatever we had to to help our daughter. Then we figured out how hard these families have it.

My husband and I are highly educated, and work long hours at well respected jobs. Our professions allow us to see Autism from both the medical and educational facets that it holds. I work as a nurse at a large hospital in town and have wonderful health insurance. My husband is a full time teacher at a large catholic high school and also carries full health insurance. We soon learned that NONE of the suggested therapies for our daughter would be covered, despite the fact that we were both paying almost $700 a month in insurance premiums. [redacted] would not cover my daughters speech therapy (she is non verbal) because they deemed it to be a habilitative therapy and not a REhabilitative therapy. The ABA therapy that my childs doctor so strongly recommended was also not covered, and in our denial letter, we were told "sorry, we do not cover this service" but were not given any sort of alternatives! She receives speech therapy from the school district, one hour per week, with no more time allowed. That is not enough. These kids need hours of hands on, consistent therapy. The school district has a large case load (in fact our district outsources our child to another district because they do not even offer birth-2 services)

Through my job I see blatant welfare abuse from patients. Patients that know how to work and abuse the system. Patients who have Iphones and fancy purses and clothes, yet insist they need prescriptions for Ibuprofen because they cannot afford it. To save the state money, I suggest the state look into allowing health care providers to report such abuse, and look into how badly the system is taken advantage of in some cases. We are not trying to abuse any system. We are trying to get our children help from the only place we can.

MA through TEFRA has made this therapy possible for us, and my daughter started just over a month ago. We are early in the game, but feel it holds so much promise for her. Please, the system is so broken for us parents. ABA therapy is one of the most studied, and effective forms of treatment for these kids. Please keep it as an option for those of us that have no other options. Autism is devastating enough, we need help and support because this is how the system has been set up. The state allows the insurance companies to deny us coverage, and we have NOWHERE left to go. I don't know when insurance companies gained all of the power, and why the politicians allow it, but we need help! The fact is without these therapies our daughters future will only be a shadow of what it could be. Help to pay for these kids now, or pay for them later as the non productive adults they will become, because of the skills they have not gained. 1 in 88 children, likely to be many of your children and grandchildren over the next few years. The diagnosis is hard enough, please, please don't make this any harder for us!

Thank you so much,

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Monday, July 09, 2012 11:45 PM
To: *DHS_Reform2020Comments
Subject: Minnesota department of Human Serives do not cut Autism coverage David Godfrey

Hello -

Please read this email. All Children with Autism should have affordable access to effective, medically necessary care for Autism. DHS should act to ensure that both public Health Care programs and private insurance cover treatment for Autism. I know that DHS has issued a proposal to change how Medical Assistance (MA) covers Autism. Under the Proposal Children who have Autism would be routed into 1915i waiver to access treatment,services, and supports.Early Intervention would be available only to children under the age of 7. Once Children turn 7, children would have to access therapeutic treatment through their public school district. I am writing this because my Great Grandson [redacted] is benefiting Tremendously from IEIBT--- My Grandson insurance policy covers a lot of hours for therapy but not all. They have to use MA-Tephra to cover the rest. They could NEVER afford this on their own. My Grandson who is 3 years old is gaining hundreds of skills and improves Daily. Limiting early intervention and putting age limits would be detrimental and shouldn't even be a consideration.

When I was a kid my friends and I would spend all day in the yard, and when we got hot enough we'd run to the back patio, open the water spigot, get down on our hands and knees and open our months up for a drink of water that splashed all over our faces. Like me you probably hope for a life that would exceed your dreams, but those dreams collapsed along the way. You simply settled into your routine in a culture of ungrace. That is not a word but it should be. Ungrace pulsates in our offices, communities, schools, homes, and the media and it tells us that regardless of what has happened we must do more!!! We must be better, look better, and make ourselves better. But to love someone regardless of their quirks and mistakes is a breath of hope in a world that turns more upside down that right side up. That is a gift of grace.
At some point, life blindsides us with something, (Autism), Abuse, Foreclosure, disease, unplanned divorce, death, job,loss, or financial collapse that takes our breath and buckles our knees. But isn't there more? We still need to have Joy after the Diagnosis of Autism, and still have hope after day after day or redirecting behavior in hopes that it will get better. With What strength you have left, turn your face up toward the spigot of Grace and let it splash all over you.

A friend of mine shared this story with me and I thought I would share it with you in a Autism point of view. (When I was a kid my friends and I would would spend all day in the yard. (In a Autism world my grandson does not understand Friends, and could not be left alone in a backyard with other kids). My grandson is afraid of Water Spigots which is something ABA therapy is going to help him with not to be afraid of Water coming out of a hose, bathtub, sink, a loud toilet flushing in a public bathroom, elevators, loud sounds and the other sensory issue's that my Great Grandson is currently working on. My Grandson is afraid of Water being splashed all over his face. My Grandson and Granddaughter have a tight routine they do with my Great Grandson [redacted] and don't have much free time to go off on there own. They love there son [redacted] regardless of his quirks and silly things he does each day because he has Autism. They take a deep breath and hope that there will world will turn right side up and they will have the medically necessary care needed for [redacted]. All of the other things that were mentioned Abuse, Foreclosure, disease, unplanned divorce, Job Loss, and Financial collapse is all things that families with Autism deal with each Day, Month, Year.

PLEASE ALL CHILDREN WITH AUTISM SHOULD HAVE AFFORDABLE ACCESS TO EFFECTIVE MEDICALLY NECESSARY TREATMENT. PLEASE CHANGE THE WAIVER 1915i SO ALL CHILDREN CAN GET THE THERAPY'S that they need. My grandson is No longer a runner, and is making huge gains each day he does his the therapy. Limiting treatment should not even be a consideration. Please David Godfrey and your team please looks at the comments that I am making and other families who deal with Autism on a ongoing basis as well.

Thank You

[redacted]

From:	[redacted]
Sent:	Monday, July 09, 2012 3:11 PM
To:	*DHS_Reform2020Comments
Subject:	DHS changes to autism care

Dear Mr. Gregory,
I am unable to be at the July 11th meeting where Reform2020 issues related to services for children with autism is being held. But I did want to inform you of my thoughts and observations.

Our dearest friends have a grandchild who was diagnosed at age 2 and a half with autism just this last spring. He is currently enrolled at the [redacted]. The strides he has made have been remarkable to me--where there was NO eye contact, now there is a great deal of it. He is beginning to learn sign language, and has developed some ability to repeat words. The changes in just a few months seem nearly miraculous to those of us who know this sweet little guy! And we know the early intervention has been an extremely important part of that.

I am a retired nurse, and know that funding in these times is so critical, and everyone has the desire for funding for their "pet" issue. Considering the huge and alarming increase in the numbers of children with autism in the last 20 years, it truly seems crucial to me that we as a society find a way to serve these children and give them the chance to be able to join the "mainstream" by virtue of early and intense intervention.

Thus, I am writing to ask that DHS allow choices in services for these families in need, and for as much funding as possible to support these families who want nothing more than an opportunity for their children to thrive and learn, and one day, to be very productive members of our society. To leave them behind would be a travesty.

Sincerely,
[redacted]

--
"A settled plan to deprive the people of all the benefits, blessings, and ends of the contract, to subvert the fundamentals of the constitution, to deprive them of all share in making and executing laws, will justify a revolution."
John Adams, Novanglus Papers, 1774

From: Adella Usher <arusher1@comcast.net>
Sent: Monday, July 09, 2012 1:18 PM
To: *DHS_Reform2020Comments
Subject: Autism Coverage

I support that the DHS proposal be revised to reflect Reggie Wagner's June 22 statement. If DHS does not intend to reduce coverage for treatment, services and supports for children who have autism, then they should say so in writing. The MA reform proposal should be rewritten to clarify that there will be NO REDUCTION in MA coverage for children in Minnesota.

Adele Usher

From: Mary Richards <richards.mej@gmail.com>
Sent: Sunday, July 08, 2012 11:23 AM
To: *DHS_Reform2020Comments
Subject: Autism coverage suport

I support that the DHS proposal be revised to reflect Reggie Wagner's June 22 statement. If DHS does not intend to reduce coverage for treatment, services and supports for children who have autism, then they should say so in writing. The MA reform proposal should be rewritten to clarify that there will be NO REDUCTION in MA coverage for children in Minnesota.

Mary Richards
13502 Postier Dr.
Oronoco MN 55960

MNABA
Minnesota Northland Association
for Behavior Analysis

July 6, 2012

To: Alex Bartolic, Director of Disability Services
Reggie Wagner, Deputy Direct of Chemical and Mental Health Services
Jean Wood, Director of Aging and Adult Services

Re: Reform 2020 – Home and Community Based Services Redesign

Dear Alex, Reggie, and Jean,

The executive council of the Minnesota Northland Association for Behavior Analysis (MNABA) has reviewed the proposed redesign of Home and Community Based Services (HCBS) and would like to offer our comments and suggestions. The Minnesota Northland Association for Behavior Analysis is an organization of practitioners, academicians, and others who use Applied Behavior Analysis (ABA) as an evidence-based foundation for data-driven assessment and intervention practices. Our members use ABA in many professional arenas (ranging from weight loss programs to family therapy) but in this response we draw on our collective experience in the treatment of developmental and mental health disorders. Indeed, in recent years, ABA therapy has been primarily associated with our approach to comprehensive early intervention for children with autism and positive behavior support [PBS] for people with a range of developmental and mental health disorders.

In our review we identified three general themes: 1) strong ideas and opportunities for moving the state forward in its capacity to provide high-quality outcomes for people with developmental and mental health disorders, 2) gaps that risk leaving people underserved, and 3) potential roles for MNABA and our constituents to embrace the opportunities and help to fill the gaps. We address strengths, gaps, and potential roles for MNABA in each of the sections below (in parallel with the sections of the draft reforms and the powerpoint presentation to the HCBS Partners Panel on June 18, 2012).

Overall

Strengths:

- Values and vision: flexible and responsive services in support of a meaningful life for each person.
- Emphasis on treating functional impairment rather than disability categories.
- Focus on outcomes vs. process
- Promotion of person-centered planning

Gaps:

- The emphasis on improved outcomes is excellent but should not be limited to those who currently have high costs and cross-systems needs that are not well managed (as currently written). We are hopeful that the waiver will serve as a pilot and will be extended across the HCBS system.

- Limited reference to the necessary empowerment of natural/incumbent support systems to assist each individual in reaching their goals within a meaningful life at home and in the community. People with significant needs who succeed using HCBS funding do so in part because their support systems are adequately trained and empowered to meet the needs and provide an environment that promotes development toward identified goals.
- References to person-centered planning (PCP) are throughout the document with no specifics on current best-practices in PCP, who would be responsible for conducting the PCP, and what qualifications the person would need to demonstrate to be considered qualified to conduct a PCP and support the stakeholder group to carry the plan forward. In other words, meat needs to be on the bones put forth in this proposal. This is concerning because of the assumption held by many practitioners that they subscribe to/practice person-centered principles and practices when in fact their work is far from best-practice in this area. It is unclear whether the PCP components of the MnCHOICES assessment are consistent with current best practice in PCP.

Roles for MNABA:

- Promoting and serving as a resource in the development of flexible and responsive services. ABA providers are prototypes for the translation of this value and vision into measurable outcomes through individualized, tailored treatments for each person, and responsive, frequent data-driven adjustments to supporting progress towards the meaningful life they and their stakeholders identify.
- Promoting and serving as a resource for treating functional impairment vs. diagnosis. Applied Behavior Analysis is a non-categorical approach, so this emphasis is consistent with our assessment and intervention methods.
- Provide leadership in the establishment of individualized data collection and tracking, as well as formative and summative data analysis for decision-making. We are among the standard-bearers for individualized quantitative service outcomes and laud the suggested reforms in this area.
- Together with our constituents we can work with the state and individual providers to integrate ABA technology into person-centered plans. ABA-based interventions occur within person-centered planning approaches as a behavior change technology to support people with complex needs to reach their dreams and visions. For people with significant challenges, person-centered planning is necessary but often insufficient to achieve the life they've articulated.
- Offer trainings in ABA-based mediator models of service delivery. ABA-based interventions, especially our mediator models of service delivery (e.g., caregiver training) are designed to be high-impact and minimize cost. These models are collaborative and result in sustainable skill sets for caregivers and a high level of contextual fit.
- Provide leadership in the establishment of individualized data collection and tracking, as well as formative and summative data analysis for decision-making. The detailed formative data gathered in the context of ABA-based services allow providers and caregivers to make necessary and appropriate clinical adjustments very quickly, and our summative data allow for accountable outcomes for consumers, funders, and other stakeholders. Our ongoing use of observable, quantitative behavioral data allows caregivers to effectively communicate about key needs and

the impacts of interventions across all of a person's providers, which enhances the efficiency of the use of Long Term Services and Supports resources.

Demonstration Project: Reform Personal Assistance Services

Strengths:

- Emphasis on the skills of teaching, coaching, and prompting
- Support plans will align services with goals, outcomes include skill gains
- Scaffold towards self direction of services
- Emphasis on high-impact services and decreased reliance on costly services

Gaps:

- No articulation of the professional competencies and continuing education requirements of people hired to provide CFSS. People with complex needs require providers with specialized skill sets – it is unlikely that better service coordination for people with complex needs will result in better outcomes, only better service coordination.
- No reference to mediator models (training caregivers to provide ongoing behavioral support) of service delivery to achieve sustainable outcomes through incumbent supports (rather than ongoing costly services)

Roles for MNABA:

- Provide training for people providing direct behavioral support via CFSS. These people must achieve a minimum level of competence in behaviorally-based interventions in order to be effective. Indeed, without a minimum level of competency a well-meaning individual providing CFSS may unknowingly exacerbate the very problems he or she was hired to manage. Two national organizations have outlined standards for practice for direct support professionals (likely the class of professional who would be a CFSS provider in Minnesota: the National Association for the Dually Diagnosed (NADD) and the National Alliance for Direct Support Professionals (NADSP). Both organizations emphasize a minimum level of competence in positive behavior support and list competencies. In addition to requiring a nationally-recognized credential for direct support professionals involved in CFSS, the State of Minnesota should leverage the expertise available through MNABA and its constituents to provide additional training and competency evaluations for CFSS providers.
- In addition, well-trained CFSS providers should be required to consistently improve upon their skill sets, as in other professional disciplines. The expectations of this class of professional should be high. The Minnesota Northland Association for Behavior Analysis and its constituents should be leveraged as a helpful source for continuing education for these providers.

Demonstration Project: Innovative Approaches to Service Coordination

Strengths:

- Coordinating care across environments will create consistency for the child and ensure systematic communication between providers, parents, and school.

- Systematic coordination for the transition of effective practices from early intervention context into the school building which would lead to better outcomes

Gaps:

- It is unclear how schools will interface with ABA-based providers and incorporate effective ABA-based treatment methods into their practices. Despite statewide adoption of Positive Behavior Interventions and Supports, and demonstrated efficacy of ABA with individual students, schools have historically not adopted ABA-based procedures. A true coordination model must clarify the steps and roles for the transfer and maintenance of effective practices, incorporating the effective form and dose of ABA-based treatment into the school building.
- The role of the parent is not clearly defined. The parent must be empowered as a decision-maker in this model in order for maximum impact.

Roles for MNABA:

- Provide inservice training and technical assistance to districts participating in this demonstration program on application of ABA. The Minnesota Northland Association for Behavior Analysis has a productive working relationship with the Minnesota Department of Education's Positive Behavior Interventions and Supports team which could be leveraged here. The Minnesota Northland Association for Behavior Analysis should be part of the feedback loop in this demonstration project that will inform mental health professionals about the role of home and community supports in classroom success.
- Provide in-service training and technical assistance to districts participating in this demonstration project on data collection and evaluation tools that assist in communicating about behavior between home, community, and school settings. Empowering the parent as a data collector and competent communicator about the child's performance at home and in the community enables more productive contributions around the IEP table, to allow parents to communicate effectively with the professional team.

Demonstration Project: Empower and Encourage Independence through Employment Supports

Strengths:

- Focus on building independence and stability in community-based employment

Gaps:

- No reference to the ongoing problem of people with mental illness + intellectual/developmental disability languishing in sheltered workshops, and the need to employ these people meaningfully in the community at jobs consistent with their interests and skill sets.

Roles for MNABA:

- Training and technical assistance for provider partners in this demonstration project to design sufficient behavioral supports for competent job performance in a preferred/meaningful community position, especially for the most behaviorally-challenging individuals.

Demonstration Project: Anoka Metro Regional Treatment Center

Strengths:

- Articulation of the necessity to arrange the home/community environment to better support the person after transition from AMRTC treatment (i.e., the person will not be ‘fixed’ at AMRTC and return home and function successfully).

Gaps:

- No intentional connection between this initiative and the person-centered positive behavioral supports emphasis described among the values and vision of the reforms
- No description of the challenges inherent in consistent implementation and evaluation of multiple treatment modalities (medication, counseling, behavioral supports, etc)

Roles for MNABA:

- Together with our constituents, we can provide training and technical assistance to AMRTC administration and clinical leadership, community-based provider partners, and county human services in:
    - Person-centered PBS addressing challenging behavior and instructional technology to address skill deficits
    - Establishing behavioral baseline data to evaluate the individual and combined effects of multiple treatment modalities/multi or inter-disciplinary treatment. Applied Behavior Analysts are uniquely positioned to leverage the strength of single-subject experimental design in treatment evaluation.

1915(i) Waiver for Children with Autism Spectrum Disorders

Strengths:

- Functional impairments in pivotal developmental skills primary criteria for access to services
- Focus on evidence based practice and Response to Intervention (RTI) approach to outcomes monitoring
- Focus on comprehensive interventions that address core impairments in ASD.

Gaps:

- Current language creates grey areas that could result in services being denied
    - E.g. “department may initially propose benefit and service utilization criteria...and **will consider** amending**…if changes are deemed necessary…”** Does this refer to client-by-client benefits/utilization or by overall service-type benefits/utilization?
    - How will early access to services be ensured? Currently, most referrals come from physicians and psychologists who provide early diagnostic services.
    - Will coordination and non-categorical emphasis be codified to allow or require special education based early childhood services to incorporate empirically-supported services, such as ABA, when sufficient outcomes are not being produced?
    - Age specific language (e.g., references to age 7, and 0-7) has a potential to be interpreted as an age cap and conflicts with person centered treatment approach advocated in the

  introduction. Some children show therapeutic gains in early intervention but continue to require additional years of support to achieve functional communication. Many of these children display a constellation of mental health concerns that rises to the level of a "serious and persistent mental illness" and should receive the array of services to address such (as discussed in section 9.1.4). The waiver must clearly state children over the age of 7 may continue to receive medically necessary mental health services as long as their symptoms require.

  - It is unclear whether the waiver will fund medically-necessary services for doses (i.e., hours per week) determined by mental health professionals, or arbitrary dollar caps will be set.
- Section 9.1.3 Schools serving as primary case managers
    - School special education services are not overseen by DHS except where districts are billing mental health services. If schools are to become the primary case managers for both educational and mental health services, how will DHS ensure compliance with evidence based standards statewide in school settings? The current language "…would generally be included in the child's IEP and **could be informed by…"** suggests that mental health providers will be held to evidence-based methods and to produce outcomes, but the school programs are only 'informed by' evidence based practices.
    - School based services currently often rely heavily on both non evidence supported practices (e.g. sensory integration treatments) and contraindicated intervention protocols (e.g. restraint and seclusionary time out). It is unclear how better (and positive) evidence-based mental health practices will be driven into the school system.
  - Unclear whether ABA providers be reimbursed for coordination time with school teams (e.g. IEP meetings, assessing school contexts)
  - School staff are not trained to provide psychological or behavior analysis services to children.
    - Revisions to IEP requirements have continued to de-emphasize specific behavioral goals and data tracking toward these goals.
    - Identification and assessment procedures differ as well as terminology between educational and mental health arenas.
  - Unclear how will DHS train and supervise IEP goals that involve mental health aspects?

Roles for MNABA:

- Training DHS staff to evaluate ABA outcome measures. Since many ABA providers are cross trained in educational psychology programs, MNABA can help bridge educational and psychological service delivery systems.
- Consulting with DHS on indicators of quality programming and provider standards
- Developing specific language to ensure continuity of care and that implementation remains consistent with stated aims of waiver.

- Workforce development and outreach to create access to treatment in underserved populations and geographic areas.

Provider Standards

Strengths:

- Recognized need to protect the public by articulating professional standards for qualified and competent practice in a way that would protect the public.

Gaps:

- The language used in this section of the proposal indicates a movement towards specification of criteria for competent practice with respect to diagnosis rather than functional impairment, which is inconsistent with the stated objectives of these reforms in other sections of the document.

Roles for MNABA:

- Provide training and technical assistance in the non-categorical application of behavior analysis and positive behavior supports for specific functional and behavioral impairments of people with developmental and mental health disorders regardless of diagnostic category.

Crisis Intervention and Protection of Vulnerable Adults

Strengths:

- Recognized need to improve competence and quality of services for adults living in the community who experience behavioral crises.

Gaps:

- There is a missed opportunity here to articulate the need for improved Positive Behavior Support (PBS) for people with a history of challenging behavior to avert the need for crisis services, and the need for providers who serve adults who experience behavioral crises to receive additional training and technical assistance from experts in PBS and/or ABA.
- The term ‘positive behavior training’ used in this section is not specific to any recognized professional discipline such as PBS or ABA. The language should be improved to reflect the need for DHS and provider agencies to leverage the available expertise in PBS and ABA in the state.

Roles for MNABA:

- Together with our constituents, we can provide training and technical assistance to agencies serving adults with a history of challenging behavior (and to those who encounter the need for crisis services, in order to improve their capacity to better proactively serve the needs of their consumers in the future so crisis services are required less frequently).

In summary, MNABA sees the proposed reforms as a set of ambitious and important goals that have the potential to create great positive change for the people that our constituents serve. The data-based intervention practices and processes of Applied Behavior Analysis (and Positive Behavior Support – an increasingly common framework within which ABA is applied) offer a unique perspective and resource for translating these goals into reality. Our evidence base demonstrates the power of ABA practices to generate extraordinary outcomes across categorical and diagnostic lines. Using formative data evaluation to guide interventions allows Behavior Analysts to create individualize and highly successful interventions that can evolve with client needs and preferences across the lifespan. The Minnesota Northland Association for Behavior Analysis is pleased to see that the waiver sets many routine operating practices of Behavior Analysts (including and especially the use of rigorous outcome data as the primary indicator of good practice) as goals for the HCBS waiver system. We are looking forward to working in partnership with DHS to do the difficult work of creating better outcomes for people in Minnesota.

On behalf of the MNABA Executive Council,

Timothy R. Moore, PhD, LP, BCBA-D
MNABA President
tmoore@mnaba.org

From: [redacted]
Sent: Thursday, July 05, 2012 9:13 PM
To: *DHS_Reform2020Comments
Subject: Remove age cap for autism services

Dear Mr. Godfrey:

Autism is a neurological disorder, not just an educational label. My son [redacted] has a medical diagnosis of autism; as such he deserves medically necessary care. However, since he is 7 the MA reforms proposed by DHS would prevent him from receiving the daily therapy that helps him progress.

Each child with autism is unique and there is no magic age when a child will be ready to transition to a school setting. My husband and I are both public school teachers. While we work and live in exceptional school districts, we know first-hand that no school can match the intensive therapy [redacted] currently gets. Public schools are constantly asked to do more with less funding. As such, schools may lack a program developed especially for children with autism. Para-professionals—the aides who spend the most time with our children—often lack the training and resources to provide more than "babysitting" for high needs kids.

At [redacted]—an applied behavioral analysis center—[redacted] works one on one with a highly trained therapist. For 8 hours each day, he receives programs tailored just his needs. They work on speech, play skills, and behavior. [redacted] continues to make progress, but is in no way ready to a "typical" school.

[redacted] is not potty trained, speaks only in single words, and has a feeding tube. He lacks social skills, has low understanding of spoken language and regularly engages in self-stimulating behavior which makes it nearly impossible for him to stay focused on a task. It is his functional level, not his age, which should determine the level of services covered by medical assistance.

One behalf of [redacted]—and all his school aged peers receiving ABA therapy—I urge you to remove the age cap for autism treatment.

Sincerely,
[redacted]

From: [redacted]
Sent: Tuesday, July 03, 2012 2:46 PM
To: *DHS_Reform2020Comments
Subject: Autism Reform

Hi,

I am a parent to a sweet and loving 3 ½ son with autism. He is currently receiving IEBT therapy and has benefited greatly from it. I hope that he will one day be able to go to school full time and excel in his mainstream classes, but that may not be the case. All I know is that I can see the changes in my son that he is making from receiving this therapy and I want to give him the opportunity to be the best person he can be. I believe this therapy is what is going to help him the most and do not want to see that option taken away once he turns 7. I would be more than happy to stop the therapy if we no longer thought it was necessary. No parent wants to have their kid in therapy. They want their kids to be out playing, but that is not a reality for us or many parents of children with autism. Autism is hard enough to deal with knowing that you are getting the best services you can get for your children. Having to worry about how you will pay for those services is more than I can take. Please help us help our children. Thank you.

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Monday, July 02, 2012 10:31 AM
To: *DHS_Reform2020Comments
Subject: PLEASE READ!
Attachments: DSCN1043.JPG

Hello David Godfrey, Medical Director

I would like to comment on the MA Autism Proposal as this affects our 8 year old son [redacted] with Autism.

Our son [redacted] was diagnosed at age 3 years old we did aggressive early intervention of ABA therapy, OT, PT, Speech and Special Diet and supplements. We have tried many things and most successful for him. We promised him we would do everything in our power to heal him as long as it didn't hurt him. [redacted] has gone from being severely autistic on the spectrum (not looking, not talking to only echolalia speech for two year) to now a high functioning boy with ASD. He can now look at us, talk to us and communicate most times which is a huge improvement. As parents, we both work but one of us has had to work part-time in order to get all the necessary treatments done for [redacted]. We are on medical assistance to help us meet the needs of our son. Without it he would go right back to being barely functional as we did have to stop therapies for awhile when he was not covered by MA and he regressed severely. The school system will not provide all the things necessary for [redacted] to remain high functioning as we have been fighting that battle the last (3) years since the medical diagnosis and educational diagnosis are different definitions they feel they don't have to cover things like social skills groups, speech, math help, etc unless they are at least 2-3 years behind grade level. This is not acceptable. A couple key points to make:

- ALL children enrolled in Medical Assistance are entitled to coverage for medically necessary treatment prescribed by their treating clinician.
- Coverage for health care should be based on medical necessity not age and early intervention is important but keeping them functioning is just as important.
- If a treatment is evidence-based – such as intensive early intervention behavior therapy or ABA applied behavior analysis, then it should be included in the "Autism benefit set" with no age restriction.
- If a treatment is a generally accepted practice, like "social skills therapy" then it should be included in the "Autism benefit set" again with no age restriction.
- Treatments, supports and services should be based NEED, NOT AGE.
- Treatments, supports and services should be based on need, not LABELS
- Children who have autism need choices for different treatments, as well as choices for different providers
- Don't limit school-age children to receiving treatment from ONLY schools – they will end up getting NO help.
- Yes! Please do look at outcome measures – in fact, please look at them NOW — before you make long lasting policy decisions about what types of treatments to cover!
- DHS should provide formal opportunities for members of the autism community to provide input before finalizing policy changes! Specifically, DHS should obtain input from the health care professional who treat individuals who have autism! DHS should also hear from individuals on the spectrum and their friends and family.

Our son has benefitted greatly from continued ABA therapy and Stanley Jones Speech and OT and social skills group that the schools will not provide. Please consider our son and other families in the long run if these children do not get the services they need it will cost our society MORE in care as they go from being self sufficient to needing Personal Care facilities when they fail to perform basic skills due to lack of services and funding and this WILL HAPPEN under your new proposed guidelines.

Thank you for listening and helping our children heal and live the best life we can give them ~ They deserve that!
Sincerely ,

[redacted]

To Whom It May Concern,

I am writing you to educate you on the improvement our family has seen in our four year old son [redacted] thanks to the ABA therapy he receives through [redacted] [redacted] My name is [redacted] and I am the mother of [redacted] who has been diagnosed with autism. For a parent to hear the words, "Your son has autism" is a very difficult thing. As a parent, we have a belief that our child will be able to achieve anything they want, and to hear your child has autism crushes all the dreams you have for your child. Thanks to ABA therapy, we now see a future for our son full of **HOPE**!

We started receiving ABA therapy, after searching for a program that had openings for 4 months, in December of 2010 when [redacted] was 3 ½ years old and have seen a huge change in our son in this time. We wanted to work with a program that is in-home in comparison to center-based because we wanted to be extremely involved in the hands-on care of our son. Thanks to the ABA therapy, my son is learning! He is able to communicate his wants and needs through the use of gestures and is less frustrated and irritable than previously! He points to body parts upon request, is able to match identical pictures, points to things to show us what he wants, taps our shoulder to get our attention, and UNDERSTANDS more and more language all of the time. He is also able to follow simple instructions such as put your coat on, sit down, and put that here. He is also beginning to play with toys in an appropriate manner and has fewer repetitive behaviors! Our daughter just turned 3 and thanks to ABA, our two children are beginning to play together! The smile on my son's face when he first understands a new program that they are teaching him is quite contagious. He is so proud of himself when he finally "gets it" and encourages me to once again dream big dreams for my son. He is finally **LEARNING HOW TO LEARN** and is beginning to understand the world around him. Our family is a much happier family than we were before! Because of his increased understanding of language and directions, we are able to go on more family outings such as boating, waterparks and the children's museum. Without these essential services, I cannot imagine where we would be today. [redacted] does participate in an Early Childhood Special Education program through our local school district, but we have found that program to be extremely inadequate in helping [redacted] improve.

Fortunately his speech therapist and teacher from the school came to observe an ABA session one day and were AMAZED at how much he actually COULD do. His teacher commented on how she was going to reframe the way she worked with [redacted] after seeing how he was successfully performing during ABA therapy. [redacted] can be amazingly intelligent yet struggles with daily living. We finally see a future for our son that is filled with great hope that he will be successful in life and accomplish great things! I know that we are setting a strong foundation for our son that will allow him to be successful and happy in the future.

I urge you to continue to support ABA therapy. This is a crucial service for our children and one that brings great rewards with it. To invest in programs that help our future generation be healthy, happy, independent from their parents, and most importantly successful in life is money well spent!

You are welcome to visit our home for a hands-on look at the differences ABA therapy brings at any time, please give me a call at [redacted] with any additional questions or to schedule a visit. Thank you for your time.

[redacted]

[redacted] [redacted] [redacted]

[redacted]

[redacted]

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Monday, June 25, 2012 1:33 PM
To: *DHS_Reform2020Comments
Subject: autism and MA reform 2020 parent comments

Dear Legislators,

I have two boys on the spectrum, they are ages 6 and 11 years.
My youngest, [redacted], has been receiving ABA intervention for the last 18 months. He continues to make great progress under the care of his ABA providers. He also receives speech, OT, audiology and vision care on a regular basis. He has been served in the school system since his birth.

My 11 year old son, [redacted], is receiving ABA intervention this summer to address some social and pragmatic language skills that were not being sufficiently addressed within school hours and through weekly clinically based speech services.

Both are covered by an employer insurance plan and by MA through TEFRA. In addition, their developmental problems qualified them for additional services through a consumer support grant. We have used these funds for additional services and supplies including music therapy, respite, teaching materials, and computerized educational interventions, to name a few.

My concern about this new model of delivering MA is that it seems to be a plan to do the opposite of what you are suggesting your goals are. I believe that this plan will reduce access to medical services and that it will create a new bureaucracy that will slow down the process and increase waste of time and money. I see it as a potential barrier to having their needs met.

I don't think medical services should be accessed through an IEP. I have problems with age being a factor in determining the level of support to be offered and I have a problem with having no choice over who is delivering medical services to my child.

My experience with school systems in general is that as a stand-alone treatment for autism it has not proven to be especially effective or efficient for our kids, nor are they in any way prepared to handle this proposed additional responsibility.

There are many problems with assuming school personnel can somehow manage the medical needs of autism children. The school system was designed to teach able bodied children a high level of academic and cognitive functioning. It has been deemed necessary to deliver at least 6 hours of instruction daily to accomplish this. The needs of disabled children have been patch-worked into this system. Individualized special services delivered in schools are designed to support the <u>academic needs</u> of the child. This is what school systems are prepared to handle. (For my boys the school OT works on handwriting and the Speech Pathologist works on vocabulary). A therapist working in a clinic has the task of aiding a child to be able to function in any environment and throughout their entire lives (for my boys this is dressing and eating with the OT and simple conversation skills with the Speech Pathologist). They have been asked to coordinate their services with school, but as a parent I see the need to have the service providers divide and conquer. The schools and clinics serve different functions and this is not an overlap in services. Our children will exit the school system at no later than 21 years of age. They will be expected to communicate and care for themselves for 60 years more. Merging these services into a school building may seem efficient, but are you ready to provide the needed physical space and extend their school day to provide medical services?

a. It has been my experience that case managers at school have a full schedule. Often when IEP negotiations fail and the staff needs to address these concerns, the student services drop out for all the children served by the IEP staff while meetings take place. It seems an unnecessary additional burden to the system to ask for them to add medical services to the discussions.

Also, IEP's right now can take *months* to revise and several meetings to meet with the current legal requirements of satisfying all the parties involved. The IEP process is designed to safeguard parents' rights to advocate for the needs of the children, but the process can cause lengthy delays in school supplied services, <u>even if you follow the law to the letter.</u> Under the current model of service, medical services can begin, stop or change without group consensus. If the IEP process is to include medical services, the child could go without medically necessary services for months.

c. IEP staff are not medical staff and though many professions overlap the medical industry, medical services are not well supplied during a school day. Schools after all need to teach academic skills during the limited number of hours that children are at school. You suggest that this new model will ensure an expansion of ABA therapy, but I think it's misguided to think that an IEP team would add it to a student's service plan. School staff in general are not terribly supportive of rote memorization nor of rewards for learning which is considered mandatory for most ABA models. Most school staff personnel have very limited training in behavioral approaches and are not well versed in integrating the techniques. The strategies are not what they learned through their professional development and are often in conflict with what they "know." It would be in conflict with many education trained staff to admit that a behavioral approach is a better model for any but the most impaired. School districts would not dispense ABA therapy in a reliable manner. They are not prepared to handle this change in how we serve our children.

If the purpose is for increased use of medically sound interventions, like ABA I suggest that, rather than creating barriers to ABA by inserting an uninformed gatekeeper, you could consider expanding ABA services by providing facilities or other cost saving or incentive programs to entice providers to serving in outlying communities. Also, getting the word out to parents is critical. Pediatricians and school staff should be identifying and suggesting to parents that they seek ABA services for their patients and students who need them. ABA services can be very helpful in getting a child started and learning ready. I have witnessed many many school staff struggling with preschoolers who cannot sit in a chair or attend to the teacher. A worthy goal for the entire community serving children with autism would be to prevent children on the spectrum from reaching age 5 without a means of communication. ABA would be a good beginner's intervention for many. In addition, parents need more training in <u>specific strategies</u> to increase their child's functioning. I've been to school based parent training which provided a lot of vague generalities, expounding the latest theory in child development, and had a parent ask at the end of the session "who is going to tell me how I can help my child?" Our teachers are not prepared to adapt what they have learned for a parent/child interaction and how to train adults. All of the parent training sessions have mostly focused on accepting your child and learning how important it is to play with your child. Nice, but not as useful as teaching your child what "block" or "doll" means or how to say "I have to go potty". It takes a village to achieve lasting results; quality school interventions, <u>informed and involved parents</u>, and carefully chosen medical services. Both educational and medical service models are important pieces to getting our kids from dysfunctional child to functional adult. I suggest that parent training be a community project. A rotation of medical personnel from various service providers could provide much needed <u>content</u>.

F

I have a problem with allocating services based upon age. My youngest was an early preemie and though he received various medical services for all of his early life, he didn't receive professional ABA therapy until he was diagnosed with autism at age 4 and a half. To arbitrarily cut off medically delivered services to [redacted] at age 7 would create unnecessary delays to his last few months of needed treatment. It could be detrimental to his continued development. In addition, to deny or limit access to ABA therapy for my 11 year old would be tragic. School interventions have not been successful in increasing his social skills to the point that most children accept him as a friend, and yet nobody suggests that the school services that are not evidence based be discontinued. Accountability is in the details, [redacted] clearly benefits from periodic episodes of behavioral based therapy. My older son is friends with a boy who, though he received special education services since he was 3 years old, had no language until he started ABA services <u>at age 8 years</u>. He had been on waiting lists for 5 years. His parents decided to drive him 90 minutes daily to a clinical based ABA provider, and after 2 years of ABA he became fully verbal and a fairly good conversationalist! I have seen many children in the waiting room of an ABA provider who are in the same situation he was 2 years ago. Under the new model of service delivery these school aged children would likely never be able to communicate their needs.

Removing provider choice from the family is a bad approach to controlling costs. During my 8 years of learning about and treating autism I learned that <u>who</u> you choose to treat your child can have a profound impact on their learning. We, as parents have all shared stories about medical or school personnel who have been ineffective and entirely off-base in their approaches for our kids. To reduce the negative impact of a poor choice in providers, it would be helpful for parents of newly diagnosed parents to have training in how to determine if a provider is a good fit for the family, how to monitor progress, and how to end a bad relationship in a timely manner.

I understand some have concerns about duplicate testing for children on the spectrum since they are tested to access school services and to access medical services. I have my children seen at the [redacted] specialty clinic once every 2 years for a solid testing of IQ, language and other skills. It is important to have access to an opinion from people not involved in the treatment and from people who have a good grasp on what services are offered in the community. The [redacted] staff fills the bill on this. They make evidence based recommendations, and as a parent I choose what we can afford and what our priorities are. This medical testing and recommendation list is also shared with the school IEP team so they can learn more about how best to serve my boys at school. The school system has to read it and that is all. So which testing is duplicated? In our case almost none. The only instance that the same test was administered more than one time in a year is when BCBS required it for continuation of ABA services every 6 months.

Please rethink this MA delivery proposal for children with autism. I think that if the current systems did a better job of training parents to select the right services for their child, to spot deficiencies in treatment providers, as well as deliver important skills training to their own children, we would have better results. Training parents to become better case managers would cost less than having a case manager take over the decision making process and save money today and every day into the future, not by reducing needed services, by reducing service <u>needs</u> of school aged children and eventually with the adults born with autism spectrum disorder.

Sincerely,

[redacted]

Schels, Johanna T (DHS)

From: [redacted]
Sent: Thursday, June 21, 2012 10:48 PM
To: *DHS_Reform2020Comments
Cc: [redacted]
Subject: DHS Proposed "Autism Benefit Set"

It has been brought to our attention that the Department of Public Health Services is proposing that therapeutic services for the treatment of behaviors associated with Autism be termiated at age 7. The proposal indicates that those services would then become the responsibility of the public school systems. We as parents of a 13 year old non-verbal child with Autism have concerns with the proposed changes. We thought that you should consider our story as you assess this proposal.

Our son [redacted] started to lose his ability to communicate verbally when he was 2. Before reaching his 3rd birthday he was completely non-verbal and he was diagnosed with Autism. We enrolled him in early childhood programs through our school district and a program for children with Autism at the [redacted]. Through these programs he made progress in the areas of early academics, occupational therapy, and behavior control. At age 7, the [redacted] no longer had a program for him and we enrolled him full time in the special needs program of our local school district. Our local school district has done a reasonably good job with [redacted] in the areas academics and occupational therapies. Where the local schools have failed in our eyes is in the areas of communication and behavior management. They are not adequately funded or trained to address the daily difficulties that these students face. It has long been our contention that [redacted] most important needs are communication and behavioral therapies yet he only receives two direct ½ hour sessions with a professional communications therapist weekly. Behavior therapy is nonexistent in the school special needs program.

[redacted] behaviors have ranged from violently hitting himself in the head to biting himself to soiling his pants in protest to avoid undesirable activities. When [redacted] has had behavior issues at school the typical solution is to call us or send us a note and ask how they should deal with the issues. Unfortunately we are no more experts in the world of behavior therapy than the team at the local school. This lack of expertise in these areas has lead to considerable frustration for all parties and especially for [redacted].

We managed to get by for a number of years doing the best we could to deal with [redacted] problems as they arose. Around [redacted] 12th birthday there was a sudden and dramatic change in him for the worse. [redacted] had reached puberty. His inappropriate and self injurious behaviors had escalated to levels that were not manageable in the home or at school. We began to wonder if we would be able to continue to care for him. After a couple of extremely frustrating months we pulled [redacted] out of school after ½ of each day was completed and began 1:1 sessions for 25 hours per week in our home with therapists from [redacted]. The resulting turnaround has been astounding. He is doing things now that he has never done before. His behaviors at home, at school, and in the community have shown dramatic improvement.

The proposal to put the onus for providing these necessary therapies on the schools will be a complete disaster for many students and their families. We can tell you that if behavior therapy is treated and funded in a similar manner as speech therapy in the schools, the two ½ hour sessions weekly will not be remotely adequate for children like [redacted]. Not every child on the Autism spectrum or in the special needs programs requires a comparable level of therapy to [redacted] His case is extreme. It is not reasonable to hire full time professionals in each and every school special needs program to work with these kids for the number of hours that is required. The fact of the matter is that the schools will not and cannot provide adequate services for children like [redacted] Just because there is a desire to save money does not mean that these children of extreme special need should not get appropriate and meaningful treatment simply because they have passed by their 7th birthday.

Thank you for your consideration. Please feel free to contact us if you have and questions.

Regards,

[redacted]

From:	Charles Oakes <Charlie@wciservices.org>
Sent:	Thursday, June 21, 2012 9:54 AM
To:	*DHS_Reform2020Comments
Cc:	MN DACA
Subject:	Comments from Charles N. Oakes

The Reform2020 proposal for Waivered Services employment reform is too vague to inform and it makes no mention of current vocational programs that are operated as either Day Training and Habilitation programs or Community Rehabilitation programs. Both of those models are licensed nonprofit corporations that have provided the vast majority of successful work, job placement, and community integration in Minnesota for the last 40-50 years, yet they are not even mentioned in the employment reform recommendation. It is as if the Department of Human Services independently waves a magic wand to create employment for people with chronic disabilities. To completely ignore the partnership with the organizations that actually perform the work, the nonprofit providers that actually produce the positive outcomes is both insulting and, unfortunately, also traditional rude behavior by MN DHS.

Sincerely,

Charles N. Oakes, CEO
WCI JobLink
1300 22nd Street SW
PO Box 813
Willmar, MN 56201-0813

Phone 320-235-5310 Ext 203
www.westcentralindustries.com
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Cell 320-894-5520

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From:	Pfannenstein, Margee (DEED)
Sent:	Wednesday, June 20, 2012 12:30 PM
To:	*DHS_Reform2020Comments
Subject:	Referral to Services for the Blind - before reinforcing complete dependence on support services that are costly and create candidates for assisted living or nursing home care.

In the past year, as a Senior Service Career Rehabilitation Counselor with Services for the Blind, several referrals of persons who are middle-aged (40-55) have been received by DHS. These referrals were received long after the blindness had occurred . Support services were being provided over years that assumed that because these folks were blind, they were helpless and needed to depend on others for everything. This attitude is much more disabling than the blindness because it , not only interferes with independent living, it prevents any potential of suitable training and employment. Progressive dependence on others eventually results in a nursing home and/or assisted living candidate - even before this person becomes a senior citizen. Customized care that only provides services that are required is less apt. to have institutionalization as an outcome. An early referral to Services for the Blind is highly recommended to prevent this scenario. DHS staff should be aware that persons with vision loss/blindness can generally function without support services if they are given access to the proper tools and training. Please consider consulting SSB to assess the situation and educate those that would reinforce dependence inappropriately at a high cost to low vision/ blind individuals, as well as , a high cost to the taxpayers. M. W. Pfannenstein, CRC, SSB –Senior Services Unit

July 11, 20012

To: DHS and the “Autism Listening” Community
From: Anne Harrington

On behalf of children with autism and their families I am extremely grateful to have the opportunity to share in the “community dialogue” regarding autism treatment and needs of our community. After years of working to bring access to a **range** of evidence-based treatment options for families of young children with autism in Minnesota it was so gratifying to hear the open-minded and forward thinking perspective of DHS including consideration for providing coverage of treatment approaches that may be well-founded, science-based, and time-tested treatment approaches, but lack the rigor of controlled-trial evidence and are still in the “evidence development” stages.

Thank you for the opportunity to bring to your attention the evolving treatment practice for children with ASD’s and the evidence supporting a variety of approaches including developmental approaches for the treatment of autistic spectrum disorders and other special needs conditions.   There is a growing body of evidence supporting treatment approaches that go beyond the long-standing behavioral/skill acquisition approach (ABA) to treatment. Developmental approaches incorporate research based on well-founded developmental theory such as Piaget and Bowlby. Examples of some of the developmental approaches—including but not limited to DIR (Greenspan), SCERTS (Prizant), Responsive Teaching (Mahoney), PACT (Aldred), Denver (Rogers) and Hanen models—focus on building the foundations of development for successful social relationships, communication, and thinking and problem-solving while also addressing the regulatory/behavioral challenges of children with ASD. They capitalize on the natural motivation of primary relationships between children and parents as well as children and primary professionals. In doing so, they harness the child’s interests, emotions, and natural motivators. Because of their complexity and focus on overall developmental progress rather than discreet skill building, these developmental approaches are more difficult to operationalize and measure than the more straightforward, skill-based behavioral (e.g. ABA) methods. This helps explain the challenges in data collection and relative paucity of research evidence to date when comparing behavioral vs developmental treatment models. Over the last decade, however, the practice of developmental intervention has created fertile ground for research initiatives that are now emerging and showing equally positive and promising outcomes for children with this type of intervention as well.

The National Research Council in its’ book, “Educating Children with Autism” (2001) determined that although there is evidence that many interventions lead to improvements and that some children shift in specific diagnosis along the autism spectrum during the preschool years in particular, **there does not appear to be a simple relationship between any particular intervention technique, child characteristics and outcomes for children with ASD’s.** Rather characteristics of the most appropriate intervention for a given child must be tied to that child and family’s needs. They stated that effective services should vary considerably across individual children, depending on a child’s age, cognitive and language levels, behavioral needs, and family priorities. Their findings show a strong consensus that the following features are critical in early intervention services:

- Entry into early intervention programs as soon as an autism spectrum disorder or other developmental challenge is considered and identified;
- Active engagement in intensive, engaging, functional, developmentally appropriate, instructional programming for a minimum of at least 25 hours per week and varied according to the child’s chronological age and developmental level;
- Repeated planned teaching opportunities generally organized around relatively brief periods of time for the youngest children (15-20 minute intervals) including sufficient amounts of adult attention in one-to-one and very small group instruction to meet individualized goals;
- Low student/teacher ratios (no more than two young children with ASD’s per adult in a pre-school classroom)
- Mechanisms for ongoing program evaluation and assessments of children’s progress with results translated into adjustments in programming. Lack of documentable progress over a 3 month period should be taken to indicate a need to: increase intensity by lowering

student/teacher ratios, increase programming time, reformulate strategies, curricula or individual child goals or objectives, change of staffing or provide additional training and consultation to staff.

- Inclusion of a family component including parent training
- Appropriate educational objectives should be accomplished within 1 year and expected to affect a child's participation in education, the community, and family life

(Summary by Anne Harrington from the book; Educating Children With Autism)

There are many advantages of intensive **developmental** interventions. Developmental approaches, which focus on building healthy foundations for relating, communicating and thinking, use parents as their child's first and best play partner and have the immediately available natural environment of the home as an intervention site. Developmental models like the PACT study in England are also being studied from a rigorous economic perspective since intensive intervention when provided by professionals instead of parents can be very expensive costing between $50-75,000/year. The P.L.A.Y. Project study, based on the DIR framework of Greenspan and Weider, is a parent education model that trains parents to become more effective at engaging their child and that can be easily and quickly disseminated. Such efficient, cost effective, and family centered developmental models are desperately needed nationally. With a grant co-written with the Autism Society of MN and as Coordinator of the Minneapolis Public Schools ECSE Autism Program I was able to implement a pilot P.L.A.Y. Project in the MPS ECSE Birth to Five Autism program during school year 2007-2008. We served 40 families including our Spanish-speaking and Somali families through this parent education model and it was well received and showed promise as a positive component of intervention services in our urban school district. When the grant year ended and the project was discontinued in MPS I chose to leave my position there in hopes of expanding access to these resources through other means.

As you may be aware, the 2007 Clinical Report on Management of Children with Autism, published by the American Academy of Pediatrics Journal (Myers et al, 2007)[1], as a guidance for the clinician in rendering pediatric care, is being used politically by others to focus insurance coverage only on Applied Behavioral Analysis (ABA). It was clearly not the intent of the article to promote one type of therapy over another. Nonetheless, the Myers et al article did not sufficiently critique the limitations of ABA giving the false albeit unintended impression that ABA was the best model to treat children with autism. Clearly, the political use of the AAP clinical report is not the fault of the AAP, which in essence agrees with the National Academy of Sciences' landmark report recommending a broader "evidence-based" and comprehensive paradigm, which includes developmental, educational, and ABA approaches. (Lord, Catherine; McGee, James, 2001)[2].

Given the current state of the art of research and the diverse nature of autism spectrum disorders, it becomes vital to the future of children with developmental challenges for our communities to continue to espouse a broad-based range of models that have evidence supporting them. This diverse community needs an array of proven treatment approaches that are not only individualized but are developmentally appropriate and can be cost-effective as well and where parents in partnership with trained clinicians decide the best approach for each child. One size does not and cannot fit all. It is also painfully evident that addressing the needs of children with autism will "take a village" working together rather than as separate entities. Therefore, it is essential that agencies like the Departments of Human Services, Health, and Education, the broader medical community, and other agencies work together with parents as partners to forge an integrated, collaborative, multiagency approach with the common goal of promoting the development and successful participation of children with the complex developmental disability of autism spectrum disorders in their homes, schools and communities.

I appreciate the opportunity you have provided this community to "share and listen", to better meet the diverse needs of children and families effected by autism. As a parent, a Special Educator, a Parent Educator and a Mental Health Practitioner, I believe I bring a unique perspective to this effort and draw from years of training and experience in the field. I would be pleased to meet with you directly or to be considered for a role in your Reform 2020 Waiver Proposal development group. The lives of children and families living with autism depend on our understanding and responsiveness to their needs.

Sincerely,

Anne Harrington

Autism Resource Specialist, Mental Health Practitioner, Parent Educator, ECSE Teacher, Certified DIR/Floortime® Practitioner, Licensed P.L.A.Y. Project® Provider, Founder: Celebrate The Spectrum, Executive Director: Center for Engaging Autism (non-profit)
Contact Information: 612-298-8037, harringtonab@yahoo.com

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[1] Myers S. M., Johnson C.P., and the Council on Children With Disabilities (2007) Management of Children With Autism Spectrum Disorders. *Pediatrics*; 120; 1162-1182.

[2] Lord, Catherine; McGee, James (Editors). Committee on Educational Interventions for Children with Autism. *Educating Children with Autism.* Division of Behavioral and Social Sciences and Education, National Research Council. Washington, DC: National Academy Press (2001).

[redacted] [redacted] [redacted]

Dear David Godfrey-

I am writing to express my concern regarding eliminatins autism coverage for children over the age of 7. It is unrealistic to assume that all children can succeed in our traditional school symem

According to tile U.S. Department of Education, the number of cbildren age 3 to 21 in federally supported programs for autism increased from 22,000 in the 1993-1994 school year to 223,000 in 2005-2006. At the same time, public schools have a shortage of more than 12,000 special education teachers, and tile number is expected to grow. With so many students and so fuw teachers, the public school system often is unable to meet the needs of many children with autism spectrum disorders (ASD) like Asperger syndrome and autistic disorder.

Autism poses a challenge for schools because the disorder affects each person in different ways and to different degrees. For example, many children with autism don't speak or interact at al while children with milder furms like Asperger's syndrome may be very talkative. Special needs classrooms may focus on academics rather than social skills when in reality, autistic children need tile most help developing socially. Autistic support chlssrooms, on the other hand, tend to be segregated ftom the rest of tile school and may be so focused on building social skills they forget a child's academic abilities.

Even if services in school are adequate, mom children with autism or Asperger's require extra services to learn to apply what they learn in school to other settings. They learn one . skill at a time (e.g., organizing their backpack) and need constant repetition and one-on-one inmuction to :retain the informati<Jn and apply it to other situations. Often, children with autism spectNm disorden need supplemental support from speech, occupational, and behavioral therapists.

Schools are not the best option for children with autism. MA should COI)tinue to cover medically necessary autism treatment.

Sincerely,

[redacted]

[redacted] [redacted] [redacted] [redacted]

Dew Mr. Godfrey:

Autism is a medital diagnosis, nut an aducatiunil una. Teaching credentials don't ualify a person to diagnose autism or other medical conditions. In many &ases, biachers also lack the specialist training to help children with autism raach their full polllntial. For this reason, ij is villll that childl'lln hM acc1ms to affective autism treatment-suth as ADA-for as long as necessary.

Behavioral intarventions are inlllnsi'le. stmctured programs where a trained therapistwurlm with a child ID · systematically teach behavior and communication s'kifls. Must programs are based an behavior madillcation principles; same programs IBach parents to work with their autllllic childMin; and uther prugrams target play and communicative skills.

Duality programs im:lude the following:

- Individualized attention paid ID each child
- Broad-based curriculum that supporli social inll!raction. play, and communication
- Systematic teaching that emphiisiles autcamas (what the child shuuld know and do)
- Family partiaipatiun being encouragad bv the facintators
- A focus on functional sldlla (learning that has a purpose in the world)

Due ID budget constraints, many schools simply cannut pruvide this level of services. Wllhuut drastic changes ID the school funding model. private ABA paid fur bv MA must continue ID be an atJ!ian for children beyond the age uf 7.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey-

The proposed 2020 reforms stress the importance of early intervention for autism. A recent study from May 2010 found that more than half of school aged children were age 5 or older when first diagnosed with autism. Since MA will end private ABA coverage for children by age 7, this means that these children will have at most 2 years of intensive quality intervention.

Outside experts say there are still many gaps in the diagnosis and treatment of autism spectrum disorder among school-aged kids in the U.S. In the study, 12% of kids with autism spectrum disorder didn't receive any of the suggested services. Less than half received the kind of behavioral therapies that are believed to be most helpful.

http://www.webmd.com/brain/autism/news/20120523/most-children-with-autism-diagnosed-at-5-or-older

In my opinion, Minnesota is a leader in autism treatment for children of all ages. We owe it to these children, their families, and our entire community to continue to provide the care that will help these children live full lives.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

Despite the cliche, I think that working with autistic children may in fact be "the toughest job you'll ever love." ■ love working with children on all ends of the autism spectrum. ABA therapy is effective with children at all ages and levels of severity-whether they are non-verbal, gifted, have behavior problems, or struggle with social skills, ABA therapists create an individualized program for each child.

For many of the children at the ABA center where I work, medical assistance is all that allows them to receive this effective treatment. Proposed reform from DHS would eliminate coverage for these children above age 7 who need and deserve it.

Please revise the Reform 2020 proposal so it no longer ends ABA services for seven year olds and above.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

Each day I work with an amazing group of children with autism. They amaze me with their hard work as they struggle with the skills that so many of us take for granted.

Many children with autism benefit from ABA therapy. In all the children I work with, progress is ongoing. While there is much focus on early intervention, many of these children will continue to need this intensive therapy well beyond the "early intervention" stage. I have worked with children who have lost ABA therapy due to insurance reductions. After participating in other therapies or school based services, many experienced a loss in skills. Receiving medical assistance allowed these children to return to the ABA therapy that had proven effective with them.

The proposed reforms will force many of these "school age• children into a system which is not prepared for them. Ending autism coverage at age 7 simply shifts the problem to another location.

Thank you for your continued support in our fight against autism.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey;

Autism is a medical diagnosis. not an educational one. Teaching credentials don't qualify a person tu agnose autism or othar madical onditions. In many cases. teachers also lack the speciali:!llraining to help children with autism reach theirfull plltl!ntial. Fur this n!Bson: it is vital that children have access te Blhictive autism hil1ment-such as AHA--lor as long as necessary.

Behavioral illlei'VBntiuns are intensive. structured programs where a trained therapilll wurlal with a child to systematically teach behovior and communication skills. MDIII programs are based on behavior modification principles; some programs teach parents to work with their autistic children: and other programs target play and communicative skills.

Duality programs include the following:

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- Systematic teaching that emphasizes outoomes (what the child should kllow and do)
- Family pal'licipatiun being encouraged by the facilitators
- A focus on functional skills (learning that has a purpose in the world)

Due to budget constraints. many schools simply cannot provide this level of servicas. Without drastic changes to the school funding model. private ABA paid lor by MA must continue te be an option for chndren beyond the age of 7.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey:

ABA therapy is recommended and supported by the Surgeon General, the American Academy of Pediatrics and the National Research Council, to name a few. Also, numerous studies and reports have shown its long-term cost benefits. In addition. ABA therapy coverage is already mandated by some US states, and extended by a number of companies in the private industry.

Despite the studies showing the effectiveness of ABA, the recent MA proposal cuts this important service for children above age 7. This "one size fits all" approach doesn't work with the autism spectrum. Each child has a range of skills and weaknesses, as well as varying speeds of progress.

Children with autism deserve this high quality therapy that will help them reach their full potential! Determine level of service far school aged children on an individual basis, not solely on age.

Sincerely,

[redacted]

[redacted]

[redacted]

Dear Mr. Godfrey-

1in 88 children are now diagnosed with autism.
I am proud to provide quality intensive therapy for them!

I, and the many families I work with, are concerned about whether medical assiStance will continue to cover the intensive ABA therapy that is helping so many children. Every day I see first-hand the difference that one on one therapy makes for these children. They have reached milestones many never thought were possible. Whether it is the child saying his first word, making a friend or transitioning successfully to a public kindergarten, we celebrate each success!

This progress happens regardless of age. I work with many children above age 7 who strive with the structure and individualsupport ABA therapy provides.

Please remove the age cap from the Reform 2020 proposal. Thank you in advance for your much-needed assistance In this important matter.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey·

I am proud to work as a therapist for auli$lic children. In my eyes, every one of these children is a success story end proof that medical assistance coverage for ABA needs to continua This progress happens in different levels and at different o tes. There Is nothing magic about the age (If 7 that would guarantee a child will no longer be in need of ABA therapy and ready for school.

Research also supports the effectiveness of PSA

"*ABA* is considered by many researchers and clinicians to be the most effective *evidence-based therapeutic approach* demonstlolted thus far for children with *autism* 1. The U.S. Surgeon General states that thirty years of research on the *ABA* approach have shown very positive outcomes when *ABA* is used as an *early intervention* tool for *autis.* This research includes verallandrnark studies showing that about 50% of Children with *autism* who were treated with the *ABA* approach before the age of four had significant increase$ in *IQ, verbal* ability, and/or social functioning. Even those who did not show these dramatic improvements had significantly better improvement than matched children in the *control* groups. In addition, some children who received *ABA therapy* were eventually able to attend classes with their peers:
(http://autism.healinqthresholds.com/!herapv/applied-behavior-analysis-aba)

As DHS considers reforms for autism treatment, please make sure that they take into account the research, as well as information from families, end skilled therapists who know that ABA therapy makes a life-long difference.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey:

According to DHS Reform 2020 proposal, MA will not cover autism treatment for children above age 7. I am opposed to this change and strongly feel that our public school system cannot meet these children's needs.

The National Research Council has noted that the ideal services for autistic children and those with Asperger's don't always match the reality of what most publicly funded education programs offer. Many schools argue they are complying with the law end providing appropriate services for children with ASD. But parents have a different definition of what adequate services means for their child. Across the country, parents have sued school districts that set up behavioral therapy progrems for autistic students because the parents found developmental therapies to be more effective. When schools set up special autism classrooms, parents argue their children should be mainstreamed into a typical classroom rather than segregated.

Most school districts cannot provide adequate specialized services because the state and federal budget simply will not cover the high costs. According to Michael Ganz, author of *Understanding Autism:* From *Basic Neuroscience* to *T eatment,* it can cost about $3.2 million to take care of an autistic person over his or her lifetime. Caring for all people with autism and Asperger's over their lifetimes costs an estimated $35 billion per year. Thus, district administrators are tom between parental demands, legal mandates, and limited financial resources in finding ways to educate students with autism.

Autism is already a national crisis. Eliminating private ABA treatment will only create children-and adults-who need more care.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Deaf David Godfrey-

I am writing to express my conoom regarding eliminating autism coverage for children over the age of 7_ It is unrealistic to assume that all children can succeed in our traditional school system

According to the U_S_ Department of Education, the number of cllildren age 3 to 21 in federally supported programs for autism increased from 22,000 in the 1?93-1994 school year to 223,000 in 2005-2006. At the same time, public schools have a shortage of more than 12,000 special education teachers, and the number is expected to grow. With so many students and so rew teachers, the public school system often is unable to meet the needs of many children with autiSlll spectrum disorders (ASD) like Asperger syndrome and autistic disorder.

Autism poses a challenge for schools because the disorder affects each person in different ways and to different degrees. For example, many children with autism don't speak or interaCt at all, while children with milder forms like Asperger's syndrome may be very talkative. Special needs classrooms may focus on academics rather than social skills when in reality, autistic children need the most help developing socially. Autistic support classrooms, on the other hand, tend to be segregated from the rest of the school and may be so focused on building social skills they forget a child's academic abilities.

Even if services in school are adequate, most children with autism or Asperger's require extra services to learn to apply what they learn in school to other settings. They learn one skill at a time (e.g., organizing their backpack) and need constant repetition and one-on-one instruction to retain the information and apply it to other situations. Often, children with autism spectrum disorders need supplemental support from speech, occupational, and behavioral therapists.

Schools are not the best option for children with autism. MA sh()uld continue to cover medically necessary autism treatment.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

Despite the cliche, I think that working with autistic children may, in fact be "the toughest job you'll ever love." I love working with children on all ends of the autism spectrum. ABA therapy *is* effective with children at all ages and levels of severity-whether they are non-verbal, gifted, have behavior problems, or struggle with social skills, ABA therapists create an individualized program for each child.

For many of the children at the ABA center where I work, medical assistance is all that allows them to receive this effective treatment. Proposed reform from DHS would eliminate coverage for these children above age 7 who need and deserve it.

Please revise the Reform 2020 proposal so it no longer ends ABA services for seven year olds and above.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey-

Public schools are required to educate children with autism. The truth is, as you'll hear from every school administrator you'll ever meet, "The law requires that we provide your child with a Chevy, not a Cadillac." In practice, this means that your child with autism is most likely to get an adequate education based on someone else's vision of what adequate looks like.

In *some* cases, what looks at first like an adequate educational program really isn't. A child with huge sensory and behavioral issues is never going to do well in a mainstream setting. A child with Asperger's is not going to thrive in a classroom filled with profoundly challenged kids. In those fairly extreme cases, it's often possible to make a case for change on your own or through an advocate or mediator. Frequenty, districts will see the problem and make changes based on your child's individual needs.

But what happens when the program is barely adequate but not very good? After all, every child with autism is different.and every parent with an autistic child has a different vision of what their child needs. That means that it's extremely difficult to set up a single, solid autism program that suits the entire autism population.

In Minnesota.children with autism have access to a range of quality autism treatment options. Why is MA insisting that they settle for "barely adequate?" urge you to remove the age 7 cap on autism treatment.

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey:

Autism is the fastest growing developmental disability in the United States. The Centers for Disease Control and Prevention now estimates that 1 in 88 children will have autism·affecting an estimated 1.7 million Americans. The estimated cost to a family to support a child with autism over their life time is believed to be minimally 3.5 million dollars.

At this time many insurance providers do not cover the cost of interventions, therapies, or services identified as medical necessities for a child who has autism. Medical Assistance recently began cover the *ABA* therapy at Holland Center, where I work. Proposed reform by DHS has us concerned that this coverage may end.

You.r leadership is needed now more than ever and I hope I can count on you to tell DHS that kids enrolled in MA must continue to receive coverage for medically necessary autism treatment.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey:

I am a therapist working in an ABA center for children with autism. According to Autism Speaks, "a number of studies have demonstrated that ABA techniques can produce improvements in communication, social relationships, play, self care, school and employment These studies involved age groups ranging from preschoolers to adults. Results for all age groups showed that ABA increased participation in family and community activities."

Many children are only able to get this effective, intensive therapy through medical assistance. These families have expressed concern that reforms proposed by DHS would eliminate coverage once a child reaches the age of 7. While my hope is that all the children I work with can be successful in school, I know that children progress at different levels. I've proudly watched kids succeed in kindergarten.but have also witnessed others return to ABA services after difficulties in the public schools. Some children even lost skills while in the school system as they needed the repetition and help in communication that we're trained to provide.

Please listen to the families and therapists who know that the needs of some "older" children with autism cannot be met by the schools.

Sincerely,

[redacted]

[redacted] [redacted] [redacted] [redacted]

Dear David Godfrey-

Your support is needed to ensure that Medical Assistance continues to cover ABA therapy for all children with autism. I oppose the proposal from DHS that will require all children age 7 and above to attend school, rather than receive private ABA services.

The facts about autism are alarming and require additional resources, not reduced coverage.

- Autism is the fastest-growing serious developmental disability in the u.s.
- Autism costs the nation over $137 billion per year, a figure expected to significantly increase in the next decade
- More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined.
- Autism receives approximately 5% of the government research funding of many less prevalent childhood diseases
- Thousands of children have shown significant improvement resulting from early diagnosis and use of effective interventions

  http;//www.tacanow.org/family-resources/latest-autism-statistics-2/

Continued coverage of ABA therapy is needed. On behalf of all children with autism, please remove the autism age cap from your reform proposal.

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey-

The proposed 2020 reforms stress the importance of early intervention for autism. A ret study from May 2010 found that more than half of school aged children were age 5 or older when first diagnosed with autism. Since MA will end private ABA coverage for children by age 7, this means that these children will have at most 2 yllll'8 of intensive quality intervention.

Outside experts say there are still many gaps in the diagnosis and treatment of autism spectrum disorder among school-aged kids in the U.S. In the study, 12% of kids with autism spectrum disorder didn't receive any of the suggested services. Less than half received the kind of behavioral therapies that are believed to be most helpful.

http://www_ webmd com/brain/autism/news/20120523/most-children-with-autism-diagnosed-at-5-or-older

In my opinion, Minnesota is a leader in autism treatment for children of all ages. We owe it to these children, their families, and our entire community to continue to provide the care that will help these children live full lives.

Sincerely,

[redacted]

[redacted] [redacted]

Dear Mr. Godfrey-

I am writing to express my concern regarding the age cap for autism treatment. ABA services are vital to children with autism! Age alone cannot predict when an autistic child will be ready for school.

Children who receive rnmr have a 48% chance of achieving "best outcomes." This means that 48% of children who receive IElBT will attain a typical IQ, will no longer need supports or services in regular mainstream education, and no longer meet the diagnostic criteria for autism. Another 40% will improve functional skills and reduce challenging behaviors — such as aggressive behaviors and self-injurious behaviors. For the children who respond well to miBT, an interruption or reduction in treatment can alter their prognosis. It could mean the difference between enabling a family to keep their child at home or not being able to care for their own child at home. It could mean the difference between a child achieving independence ("best outcomes") and needing specialized supports and services her entire life.

Quality, medically necessary autism treatment cannot be based on a number. Please have MA continue to cover ABA $erapy for children of all ages.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

1 in 88 children are now diagnosed with autism. This statistic is based on prevalence rates in 8 year old children;these children will be denied autism therapy under the Reform2020 proposal.

We,and many families, are concerned about how long medical assistance will continue to cover the Intensive ABA therapy that is helping our child and so many others. While all families would love their child with autism to be ready for school at age 7,that deadline is arbitrary and often unrealistic.

Please ensure that kids enrolled in MA continue to receive autism therapy until their functionallevel,not their age,deems it unnecessary.

We thank you in advance for your much-needed assistance in this imponant and time-sensitive matter.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

I am writingj in response to the recent reform proposed by DHS- *As* a parent of a child special needs, I am concerned about the age cap for autism treatment.

As you are aware the cases of autism continue to climb. A recent Harvard study estimated the cost of raising a child with autism to be $3.2 million in comparison to the $290,000 it reportedly costs to raise a neurotypical child. During a time of great economic concern., your action to offer families with options to reduce these costs is needed. Research has proven the dramatic difference such therapies and interventions have on children with autism and other special! needs.

Please change the proposed reforms. Continue to cover autism treatment, such as ABA, for as long as a child needs it.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

According to Autism Speaks, "a number of studies have demonstrated that ABA techniques can produce improvements in commllllication, social relationships, play, self care, school and employment. These studies involved age groups ranging from preschoolers to adults. Results for all age groups showed that ABA increased participation In family and communlt;y activities."

We are fortunate that Medical Assistance has covered qualit;y, intensive ABA for our child With autism. The proposed reforms would eliminate this since our child Is over the age of 7.

We have witnessed first-hand the continued Impact of effective therapy. We ask that MA continue to cover this medically necessary treatment that schools simply cannot provide.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

We need your support to ensure that Medical Assistance continues to cover ABA therapy for children with autism. The proposal from DHS includes an age limit that could eliminate therapy from many school-aged children who still need intensive treatment. Autism is not going away and effective intensive treatment must be funded.

Did you know?

- More children will be diagnosed with autism this year than with AIDS, diabetes & cancer combined
- Autism is the fastest-growing serious developmental disability in the U.S.
- Autism costs the nation over $137 billion per year, a figure expected to significantly increase in the next decade
- Autism receives approximately *5%* ofthe government research funding of many less prevalent childhood diseases
- Boys are four times more likely than girls to have autism
- While there is no medical detection or known cure for autism, thousands of children have shown significant improvement resulting from early diagnosis and use of effective interventions
- The increase in prevalence rate cannot be explained by better diagnosis alone. Some have suggested that autism is just being better diagnosed today versus years ago and that many cases of mental retardation are now being coded as autism. This would also assume that the experts diagnosing autism before did not know what they were doing. This is NOT TRUE. Autism is the only disorder dramatically on the rise while mental retardation, Down syndrome and cystic fibrosis remain relatively the same
- While the cause of autism remains unclear, current studies show genetics and environment both play a role in the autism prevalence increase.

  http://www.tacanow.orWfamily-resources/latest-autism-statistics-2/

The above statistics show the need for effective, intensive autism treatment. This need does not end at age 7. We ask that coverage of autism treatment be based on a child's needs, not their age.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

Children do not outgrow autism, yet the Reform 2020 proposal would end coverage for autism treatment at age 7.

Reform 2020 assumes that all children will be ready for a school based program by 7. Many children with autism may be able to transition to a school for kindergarten. have seen students thrive in such situations based on the skills that they developed in ABA therapy. While we would love this to be true for all kids, many will need additional years of intensive therapy. The amount of ABA therapy cannot be determined on age, but rather by looking at the needs for each individual child.

Reform 2020 needs to be reformed! Intensive intervention is needed for autism without age limits.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear Mr.Godlrev:

Each child with autism is unique, They maka progress at different rates and with different types nf then py. Becaus11 of this, it is impossible to set me crimria for all children with autism. This.however, is alllllllly what the OHS propDSal dues. It states that by age 7. a child with autism must l'l!l:aive semces through the school system. not MA. Two readiness iss1.11s are raised by this. is the child mdy for school? Is the schDDI ready fur these children?

To anSMr these questions, OHS must understand the true di!Jerence in the 111'1111 of sal'lices at a private ABA cmr compared tu a public schuol.

- All ABA therapists hm at least B 4 year dB!IrBB in psychology, education or other related field. In a school setting, the majority of a child's day is spent with a paraprofessional who likely has only a high school diploma and no prior ASD expurience.
- AHA tlrlrepists work on with children with autillllll: they are indeed specialists. Spacial nnds children in schools have a wide range of disabilities and are often Sllrvad by the same staff. This requires machers and aides to have knowledge that may be a mile wide, but only an inch deep.
- ABA s trvices are provided in home or in centers designed to meet the special needs nf children with autism. These children have special diets, sensory nBBds, and bnhavior issues. If a child with autism cannot handle the1W9Nihalmlng activity of a typical school he is often isolated in a single classroom leading Ia reduced options for therapy.

Even in the best districts.schools are not the best setting ftr all children wilh auUsm. Services for school aged children must be dacidad based on needs, not age.

[redacted]

[redacted] [redacted] [redacted]

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Even in the best districts, schools are not tha best slllting far all children with autism. Services filr school aged children must be decided basad on needs. not age.

Sincerely.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey

I am writing in response to the recent reform proposed by DHS. As a parent of a child with special needs, am concerned about the age cap for autism treatment.

As you are aware the cases of autism continue to climb. A recent Harvard study estimated the cost of raising a child with autism jo be $3.2 million in comparison to the $290,000 it reportedly costs to raise a neurotypical child. During a time of great economic concern, your action to offer families with options to reduce these costs is needed. Research has proven the dramatic difference such therapies and interventions have on children with autism and other special needs.

Please change the proposed refonns. Continue to cover autism treatment, such as ABA. for as long as a child needs it.

[redacted]

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

1 in 88 children are now diagnosed with autism. This statistic is based on prevalence rates in 8 year old children; these children will be denied autism therapy under the Reform2020 proposal.

We, and many families, are concerned about how long medical assistance will continue to cover the intensive ABA therapy that is helping our child and so many others. While all families would love their child with autism to be ready for school at age 7, that deadline Is arbitrary and often unrealistic.

Please ensure that kids enrolled in MA continue to receive autism therapy until their functional level, not their age, deems it unnecessary.

We thank you in advance for your much-needed assistance in this important and time-sensitive matter.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godftey -

We are writing to express our concern over a proposed DRS reform that will impact our child's access to quality autism therapy beyond the age of 7.

Our child receives applied behavioral analysis (ABA) which is often referred to as intensive early behavior intervention treatment (IEIBT). This daily one on one therapy has led to increased communication and social interaction. Without it, the quality of life of our entire family would be impacted!

Children who receive IEIBT have a 48% chance of achieving "best outcomes." This means that 48% of children who receive IEIBT will attain a typical IQ, will no longer need supports or services in regular mainstream education. and no longer meet the diagnostic criteria for autism. Another 40% will improve functional skills and reduce challenging behaviors — such as aggressive behaviors and self-injurious behaviors. For the children who respond well to IEIBT, an interruption or reduction in treatment can alter their prognosis. It could mean the difference between enabling a family to keep their child at home or not being able to care for their own child at home. It could mean the difference between a child achieving independence ("best outcomes") and needing specialized supports and services her entire life.

ABA therapy is beneficial at all ages. We ask that MA continue to cover this medically necessary treatment beyond the age of 7.

[redacted]

[redacted] [redacted] [redacted]

Dear Mr. Godfrey-

In May, new figures were released highlighting a huge increase in the annual costs of autism which have soared to $137 billion a year. This represents a three-fold increase within the last decade.

If you ask "who pays for autism?" my answer would be everyone. We know many families living with autism are carrying much of these costs. They put a second mortgage on their home, sell their home to move into an apartment or with relatives, take out multiple credit cards, borrow from family members, and often one parent ends up taking a second job to help make ends meet. Some families have opted to double-up households with two families living together sharing expenses so they can put most of their housing funds into their children's needs.

It is important to note that an estimated 80% of those living with autism are ages 22 years or younger. We don't have enough data to calculate the lifetime costs of autism. Based on what we know today, it is estimated that these costs are $3-5 million per affected individual. Sadly, with articles highlighting the tripling of costs, we don't see this trend slowing down anytime soon.

With the recent downturn in the economy, special needs families are being hit hard; support services are drying up. Assistance for families is dwindling while the pool for those needing help is soaring. Here is an excerpt from a recent article featured in the Disability Scoop online news site highlighting the soaring costs of autism: *"We are paying for the costs of inaction and the costs of 'inappropriate""'tion,'" said David Mrmdell of the University of PennsylvanitJ, who is behind the re&'f.D'Ch.*

Families rely on Medical Assistance to pay for autism treatment such as ABA. These intensive, quality treatments must continue beyond the age of 7; please remove this arbitrary age limit from the Reform 2020 proposal.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

As you may know, autism is the fastest growing developmental disability in the United States. The Centers for Disease Control and Prevention now estimates that lin 88 children wUl have autism-affecting an estimated 1.7 million Americans. The estimated cost to a family to support a child with autism over their life time is believed to be minimally 3.5 million dollars.

At this time many insurance providers do not cover the cost of interventions, therapies, or senrices identified as medical necessities for a child who has autism. Our family has incurred many out of pocket expenses for our child even though we have a private health insurance policy.

We are fortunate that Medical Assistance recently began covering the ABA therapy that our child receives at Holland Center. Proposed reform by DHS would eliminate this coverage for children age 7 and older.

On behalf of my family, please continue to cover medically necessary autism treannent for children of all ages.

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

Children who have autism benefit from different types of treatment and services. Our child has benefitted from ABA therapy. We continue to see progress and know that he wi!! need this intensive therapy well beyond the "early interventionn stage.

Under the "Reform 2020proposal, the school district-not MA-would be responsible for his care. Schools cannot meet the needs of children with autism. They are underfunded and lack the training and experience that ABA providers can offer.

Children who have autism should not have reduced coverage for medically necessary treatment, regardless of their age.

Thank you for your continued support in our fight against autism.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey-

We need your support to ensure that Medical Assistance continues to oover ABA therapy for children with autism. The proposal ftom DHS includes an age limit that could eliminate therapy ftom many school-aged children who still need intensive treatment Autism *is* not going away and effective intensive tfe!ltment IIIUSt be funded.

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  http:Uwww_tacanow.org/family-resources/latest-autism-statistics-2/

The above statiStics show the need for effective, intensive autism treatment. This need does not end at age 7. We ask that coverage of autism treatment be bued on a child's needs, not their age.

Sincerely,

[redacted]

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey:

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We have witnessed first-hand the continued impact of effective therapy. We ask that MA continue to cover this medically necessary treatment that schools simply cannot provide.

Sincerely,

[redacted]

[redacted] [redacted] [redacted]

Dear David Godfrey -

Children do not outgrow autism, yet the Reform 2020 proposal would end coverage for autism treatment at age 7.

Reform 2020 assumes that all children will be ready for a school based program by 7. Many children with autism may be able to transition to a school for kindergarten. I have seen students thrive in such situations based on the skills that they developed in ABA therapy. While we would love this to be true for all kids, many will need additional years of intensive therapy. The amount of ABA therapy cannot be determined on age, but rather by looking at the needs for each individual child.

Reform·2020 needs to be reformed! Intensive intervention is needed for autism without age limits.

[redacted]

**Minnesota
Autism
Center**

☎: 952-767-4200
🖷: 952-767-4211
: www.mnautism.org

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Medicaid Director's O

July 13, 2012

REFORM 2020

Waiver 1915(i) comments:

Although The Minnesota Autism Center (MAC) recognizes the need to expand funding options for children with Autism Spectrum Disorders (ASD), concerns exist over the implementation of the 1915(i) and limitations of service beyond age 7. The issues facing each child with autism are as diverse as the children themselves, requiring individualized programming. The rate of success depends on individual factors surrounding each child and their family components. Although rates of acquisition can be estimated, they in no way can be guaranteed and each child's need and issues change as they age. What is clearly established, however, is that intensive ABA programs allow children to reach goals of greater independence and quality of life far in comparison to their peers with autism who do not access ABA-based treatment programs.

The covered services under 1915(i), including improving a child's communication skills, increasing social interaction and reducing maladaptive behaviors, are those that all ABA programs provided at MAC address. The concern is to provide only "time–limited early intervention services that taper off as children reach school age". Currently, MAC programs reach children ages 2 – 21. All data supporting progress is graphed and analyzed and clearly demonstrates that need and success are achieved throughout the teenage years.

To conclude that after age 7 it is expected that a child be enrolled in school and receiving services in a school environment, does not contemplate the child that continues to need intensity to address their needs associated with their ASD diagnosis; an intensity that public schools are ill-prepared to provide.

Over the past five years, efforts have been underway to secure dedicated funding for autism treatment in all fifty states. Across the nation, states have rallied to enact legislation to cover treatment costs. To date, 31 states have enacted legislation to mandate coverage for autism treatment.[1] Of these 31 states who have enacted insurance coverage laws, NOT ONE limits services or coverage at the age of 7, in fact, most laws cover services well into the teenage years. Minnesota's own component for Individual and Family skills coverage, Children's Therapeutic Service and Supports (CTSS), provides coverage for medically necessary services into adulthood.

As with any other medical or mental health disorder, the determining factor for services is the threshold of medical necessity of service. Tying the hands of our states' medical and mental health professionals with an arbitrary, one-size-fits-all age determination appears to be in conflict with the broader intent of

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[1] See www.autismvotes.org./site

Reform 2020. Shifting services from a specialist to generalist would never be considered appropriate treatment for a child if the disorder were cancer, diabetes, depression, etc. Autism is broadly recognized as a medical and mental health disorder and as such should allow treatments options consistent with any other childhood disorder.

Additionally, to expect the personnel of our over-crowded and under-funded schools to be able to meet the growing needs of the burgeoning autism population is not a realistic expectation. Taking a child with autism making progress under the supervision and care of an autism specialist and replacing the care with an autism generalist in the public schools is not creating a pathway to success for the school or the child. As with any other medical or mental health issue, primary care and direction of a child with autism should remain under the direction of a recognized specialist for the condition treated. We ask that Reform 2020 more clearly acknowledge the need and right to specialized autism care into adulthood.

MAC has always valued its relationship with The Department of Human Services (DHS) and the support MAC receives for its programs and the children it services. Families in Minnesota have been fortunate to have the support of the Legislature and DHS in covering services for ASD. As the prevalence of autism increases, so will the demand for quality and data-driven services. MAC is committed to the continuing expansion of programming and providing therapeutic support for children, adolescents and families. It is our hope that together we can continue to make positive strides in the fight against autism.

About the Minnesota Autism Center:

The Minnesota Autism Center is a Minnesota 501(c)(3) non-profit which has been providing therapeutic services for children, adolescents and families affected by autism for over 16 years. Programs through MAC provide therapeutic supports and are based upon the principles of Applied Behavioral Analysis (ABA). The Mission of MAC is to promote and provide home, school and center-based behavioral and academic service for children and adolescents affected by Autism Spectrum Disorders. MAC promotes the general education and welfare of persons challenged by Autism Spectrum Disorders and supports the development of healthy families.

Currently, MAC services over 250 families, in 31 Minnesota Counties. Services provided by MAC include assessment and diagnosis at MAC's assessment facility located in Minnetonka, Minnesota. Assessments are conducted by one of MAC's highly trained and experienced Mental Health Professionals. Working with the family, MAC's Clinicians assess, diagnosis, and provide advice for treatment based on each child's individual diagnostic profile and the medical necessity of services.

MAC provides a variety of service options for families in a variety of locations that fit best with the needs of each individual family. MAC Centers are located in Minnetonka, Woodbury, and Rochester. The MAC School, which provides services to adolescents in grades 4th through 12th, is located in Eagan, Minnesota. MAC also provides in-home support ranging from full service intensive intervention to consultation, in 31 Minnesota Counties.

In addition to traditional ABA therapeutic supports, MAC provides comprehensive services including speech and occupational therapy. This unique service model allows MAC's clinical team to work together and create an integrated treatment plan, thus creating a fully rounded therapeutic program for each child. In line with the MAC Mission to address the needs of the entire family unit, MAC provides Parent Support Groups, Sibling Support Groups and Individual Therapy for Parents and family members. All groups are facilitated by one of MAC's trained clinicians.

Additionally, MAC works hand- in-hand with each child's social worker, pediatrician and school district personnel, to develop a comprehensive approach to therapy services. The goal of all MAC programs is to achieve the highest outcome possible for each individual child based upon their individual characteristics.

Currently, MAC employs over 330 Mental Health Practitioners and Professionals across the State of Minnesota. Many of these clinicians are BCBA or BCaBA certified and hold advanced degrees in behavioral studies.

As the prevalence of autism continues to rise[2], MAC has made strides to assure that programming is as clinically progressive and effective as possible. MAC has recently partnered with the nation's largest autism service provider, the Center for Autism and Related Disorders (CARD), and has acquired CARD's state-of-the-art online curriculum tool, *"Skills"*. *Skills* provides an assessment and corresponding curriculum that addresses every skill a child learns in typical development from infancy to adolescence across every area of human development. *Skills* offers the first and only ABA-based comprehensive social skills, social cognitive and executive functions curricula available. It is also one of the only on-line programs available that provides the ability to write behavioral intervention plans for challenging behaviors. Nearly 4000 lessons including IEP goals, tracing forms and charts and graphs are encompassed in the program.

The *Skills* curriculum tool will allow MAC to provide the most effective therapy program available today. MAC clinicians will undergo an extensive training on the tool and begin implementing the curriculum in August.

The composition of the families and children MAC services is diverse. <u>Over 33% of families serviced by MAC are minorities, with the Somali community representing 9% of all MAC families.</u> The average age of a MAC child is 8.6 years. The average hours of services per child per/ per week are 27.5. As a 501(c)(3) organization, MAC is committed to serving all sectors of our states' autism population regardless of race, ethnicity, or social/economic status in not only the metro Twin Cities, but throughout Greater Minnesota.

---

[2] See www.cdc.gov./autism

From:	Kari Weddle <mail@change.org>
Sent:	Monday, July 09, 2012 1:39 PM
To:	*DHS_Reform2020Comments
Subject:	Don't Cut Autism Coverage!

Greetings,

I just signed the following petition addressed to: Minnesota Department of Human Services.

Autism is treatable! All children who have autism should have affordable access to effective, medically necessary care for autism. DHS should act to ensure that both public health care programs and private insurance cover treatment for autism.

I am joining the Autism Advocacy & Law Center, LLC in petitioning the Minnesota Department of Human Services to ask them to revise their proposal to create an "Autism Benefit Set" under Medical Assistance. Medical Assistance coverage for children who have autism should be based on medical necessity and should include, at a minimum, coverage for evidence-based, clinically effective treatment.

Also, DHS should provide formal opportunities for members of the autism community to provide input before finalizing policy changes! Specifically, DHS should obtain input from the health care professional who treat individuals who have autism! DHS should also hear from individuals on the spectrum and their friends and family.

Don't Cut Autism Coverage!

Sincerely,

Kari Weddle
Minneapolis, Minnesota

Note: this email was sent as part of a petition started on Change.org, viewable at http://www.change.org/petitions/minnesota-department-of-human-services-don-t-cut-autism-coverage. To respond, click here

[redacted] Diagnosis

At first, everyone around us kept saying that [redacted] is delayed and will talk eventually. We wanted to believe that, but certain symptoms made us really suspicious that something has gone wrong. Little eye contact, sensitivity to noise and crowds, very limited preferred foods, and very few vocabularies gave us more assurance that [redacted] is being lost. At age 3, we began to see regression in the few words he had, no interaction with others, and lack of interest in pretty much any activities a typical age child would do. [redacted] took on a private speech therapy and was also enrolled in a public school district on a part time basis. [redacted] did not show any progress, in fact there was more regression. Through our perseverance to do what is best for our son, the ABA program was recommended to us. Our son needed intense treatment and different methods and techniques as they were vital in his case. [redacted] needs are enormous, in fact, he is on a very structured schedule on a daily basis. Part of the ABA program is not only intense but very structured and personalized.

[redacted]

[redacted] sparkling eyes at age 3

Message for Lawmakers

Hope and, more importantly, results are often found in Applied Behavior Analysis (ABA) and Intensive Early Intervention Behavior Therapy (IEIBT). A study by Chasson, Harris, and Neely in the State of Texas approximate that 47% of children treated recover "typical" function and 40% make significant improvement. Various studies indicate lifetime costs of autistic children can reach $3 million if left untreated. These costs can be more than halved if ABA/IEIBT is applied to the child's care.

Please support the Autism Healthcare Protection Act H.F. 1071 (Rep. Norton) S.F. 1020 (Se. Higgins) or other such legislation that provides coverage for medically necessary autism treatment.

Follow link to find your legislatures:

http://www.gis.leg.mn/OpenLayers/districts

[redacted] *Parents*

[redacted]

[redacted]

Our Autism Story

[redacted]

[redacted] loves the water

[redacted] [redacted]
July 2010

[redacted] was born on [redacted] [redacted] made his first steps at age 13 months. He counted 1 thru 10 and said few words. At 24 months, we started seeing less eye contact, solitude, tip toe walk, plugging ears, flapping hands, and sensory input. He was not interested in playing too much, in fact he preferred being alone. We realized something is serious as [redacted] began to slip away from us. From that day, [redacted] had begun an unpredictable journey.

What is Autism? What is Autism Spectrum Disorder?

Autism spectrum disorder (ASD) and Autism are both general terms for a group of complex disorders of brain development. These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and non-verbal communication and repetitive behaviors. They include autistic disorders, Rett syndrome, childhood disintegrative disorder, pervasive developmental disorder-not otherwise specified (PDD-NOS) and Asperger Syndrome. ASD can be associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances. Some persons with ASD excel in visual skills, music, math, swimming, and art. According to autism science foundation, 1 in 88 Diagnosed with ASD, CDC reports (1 in 54 are Boys). March 29, 2012

[redacted]

[redacted] jumping while flapping hands

What is A.B.A

Applied behavioral analysis is a scientific approach to understanding behavior and how it is affected by the environment. "Behavior" refers to all kinds of actions and skills (not just misbehavior) and "environment" includes all sorts of physical and social events that might change or be changed by one's behavior. The science of behavior analysis focuses on principles about how behavior works, or how learning takes place. For example, one principle of behavior analysis is positive reinforcement. When a behavior is followed by something that is valued (a "reward"), that behavior is likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may be harmful or that interfere with learning. Applied behavior analysis (ABA) is the use of those techniques and principles to address socially important problems, and to bring about meaningful behavior change.

[redacted]

[redacted] requesting during ABA session

Who can benefit from ABA?

ABA methods have been used successfully with many kinds of learners of all ages, with and without disabilities, in many different settings. Those methods or techniques are used in both structured situations (such as formal instruction in classrooms) and in more "natural" everyday situations (such as during play or mealtime at home), and in 1-to-1 as well as group instruction. They are used to develop basic skills like looking, listening and imitating, as well as complex skills like reading, conversing, and taking the perspective of others.

[redacted]

[redacted] closely paying attention
"love those eyes"

AUTISM ADVOCACY
& LAW CENTER

212 2nd Street SE, Su1te 220
Minneapolis, MN 55414
tel. 612.200.9920
1n fo@ aut 1smlawcenler.com
www.aul1smlawcenter.com

Executive Director

Amy Dawson

Carolyn Westra

Katie Olson

DATE: JULY 17, 2012

To: David Godfrey, Medicaid Director
Minnesota Department of Human Service
PO BoxM6 998
St. Paul, Minnesota 55164

Re: Comments on Reform2 020 and the Proposed Autism Benefits Set.

Dear Mr. Godfrey,

On behalf of the 1150 people who signed the petition urging the Minnesota Department of Human Services to revise its MA Reform 2020 proposal, the Autism Advocacy & Law Center, LLC submits these written comments. A copy of the petition and the names of 1150 signatories is attached, along with 157 additional written comments collected by the Autism Advocacy & Law Center.

The Autism Advocacy & Law Center, along with more than 1,150 Minnesotans and numerous parents who testified at public hearings, has urged DHS to revise its MA 2020 Reform proposal.

The MA Reform 2020 proposal as written would route children diagnosed with autism into a 1915(i) Autism Benefit Set to provide access to treatment, services and supports. Early intervention would be available only to children under the age of 7. Once children turn 7, children would have to access therapeutic treatment through their public school district. Medical Assistance is intended to provide coverage for treatment based on medical necessity, however, and access to treatment needs to be expanded in Minnesota -- not restricted. Recent court decisions have made it clear that this means that coverage must include treatment prescribed by a child's treating clinician.

Thank you for meeting with me personally last Friday. Thank you also for your assurances that the revised DHS proposal will not result in any reductions in MA coverage for children who have autism and that there will be no age cap on treatment.

As you know, the Autism Advocacy & Law Center, LLC is particularly concerned about the imposition of any arbitrary limitations on MA coverage, and also about any changes that would limit the choice of providers for children who have autism. **I am very relieved by the Depart-**

ment's commitment to revising its proposal to remove the age cap of 7 for early intervention and to make it clear that school-aged children will not be limited to schools as their only choice for treatment of their autism symptoms. Thank you for agreeing to make these revisions.

As the Department moves forward with revising its proposal to develop a 1915(i) Autism Benefit Set, it is my hope that the focus will be on ensuring that children have improved access to timely and effective medically necessary care. I am particularly pleased to learn that the proposed 1915(i) Autism Benefit Set will improve access to treatment for children enrolled in MA-PMAP. I encourage DHS to address this problem now, however, rather than await reform efforts that may not take effect until 2014 at the earliest. Children enrolled in MA-PMAP are legally entitled to the same benefit set as those enrolled in MA-FFS.

DHS should act to ensure that MA reform contributes toward improved outcomes for children who have autism by guaranteeing that all children, at any age, have access to medically-necessary care that is evidence-based and clinically effective. Both public health plans and private health insurance should cover treatment and therapy to the extent prescribed by the child's physician as medically necessary -- with no limits on intensity of treatment or arbitrary age caps.

Specifically, the Autism Advocacy & Law Center requests that the revised 1915(i) proposal for an Autism Benefit Set be consistent with the following principles:

1. Any limits to coverage should be based on functional need and medical necessity -- not on arbitrary distinctions such as an age cap or a diagnostic label;
2. The proposal should clearly state that there will be no reduction of coverage for treatments, services or supports for children who have autism;
3. Coverage should clearly include treatment recommended as medically necessary by a child's treating clinician;
4. Children who have autism need more choices for various treatments from different providers -- no child should be limited to school-based services or be forced to wait 12 months for early intervention;
5. The Department should focus on outcome measures to ensure that treatments are clinically effective -- this will ensure that children are receiving high quality services and that tax dollars are being well spent;
6. If a treatment is evidence-based – such as intensive early intervention behavior therapy or applied behavior analysis -then it should be specifically included for coverage in the "Autism Benefit Set;"
7. Generally accepted practices, like "day treatment" and "social skills therapy," should also be included in the "Autism Benefit Set;"
8. Experts who typically diagnose, treat, and manage care for children who have autism should be consulted and included in developing the "Autism Benefit Set;"
9. Members of the autism community should be included in the process of policy change -- especially individuals who have autism and their families.

As the Department moves forward with revising its proposal for a 1915(i) Autism Benefit Set, the most important step is to receive meaningful public input. The development of the 1915(i) Autism Benefit Set proposal was conducted without any public input and without any transparency whatsoever. On a going forward basis, DHS should develop autism related policy with input from the experts from the Mayo Clinic and the Autism Spectrum Disorders Clinic at the University of

Minnesota, as well as from providers of the various types of treatment and services currently covered under MA. Since the proposal has a clear emphasis on early intervention, the Department should specifically engage providers of early intervention and ask them for outcome data and standards of care. This information will help ensure that policy changes are well-informed and that children receive high-quality care.

DHS has a responsibility to tax payers to be a good steward of resources. As such, the De partment should act not only to ensure that treatments covered by MA are clinically effective, but also to ensure that children have meaningful private insurance coverage. As part of its reform effort, DHS should act to ensure that a!! state-regulated health insurance plans cover, at a minimum, evidence-based medically necessary care and treatment for individuals who have autism. If private health insurance covered evidence-based early intervention alone it would save the state at least $1.6 million dollars annually.

During the past several weeks since the MA Reform 2020 proposal was released for public comment, DHS has shown a willingness to listen to the Autism Community and to revise its positions based on public input. Thank you for your responsiveness. The Autism Advocacy & Law Center looks forward to reviewing the revised proposal and toworking with the Department to improve access to health care coverage for individuals who have autism.

Very Truly Yours,
AUTISM ADVOCACY & LAW CENTER, *L.L.C.*

Amy Dawson

To: The Governor of MN and Minnesota Department of Human Services

Subject: **Don't Cut Autism Coverage!**

Letter: Greetings,

I just signed the following petition addressed to: Minnesota Department of Human Services.

Autism is treatable! All children who have autism should have affordable access to effective, medically necessary care for autism. DHS should act to ensure that both public health care programs and private insurance cover treatment for autism.

I am joining the Autism Advocacy & Law Center, LLC in petitioning the Minnesota Department of Human Services to ask them to revise their proposal to create an "Autism Benefit Set" under Medical Assistance. Medical Assistance coverage for children who have autism should be based on medical necessity and should include, at a minimum, coverage for evidence-based, clinically effective treatment.

Also, DHS should provide formal opportunities for members of the autism community to provide input before finalizing policy changes! Specifically, DHS should obtain input from the health care professional who treat individuals who have autism! DHS should also hear from individuals on the spectrum and their friends and family.

Don't Cut Autism Coverage!

Sincerely,

Why People Are Signing The Petition: Don't Cut Autism Coverage!

- [redacted]
  4days ago

  1 person likes this reason

  Our son, age 11, made SIGNIFICANT PROGRESS using ABA for the last 4 years. He may now possibly be able to get a job and be a functioning member of society in the future. We now homeschool him because services in the public school system are so rotten. He was making ZERO progress using public schools previously. Intense, one on one therapy works. Listen to the parents!!!

- [redacted]
  6 days ago

  Mom of a child with Autism. Early invention has changed my child's life, for the better! He was non verbal, at age 9 he responds to closed ended questions, he never was able to say the words, "I love you", as a toddler, now he does! There should be no age cap on his treatments/learning. There is non on yours.

- [redacted]
  5 days ago

  We recently moved from Minnesota, where my son received ABA services from the [redacted]. He made tremendous gains and has been attending school with no supports at all! Autism is absolutely treatable and curable!

- [redacted]
  7 days ago

  My grandaughter has autism and she has shown great improvements in her speech due to early intervention and therapy. This needs to continue to be available to all children with autism.

- [redacted]
  6 days ago

  I have more than one child that has received treatment after the age of 7. We have seen tremendous growth in our children. The school district was not qualified to treat our children and we even saw them getting worse while receiving special education. Children with autism deserve access to effective medical treatment. This will only save money for everyone in the long run.

- [redacted]
  6 days ago

  I have seen the outcomes firsthand. Children make unbelievable progress with this therapy. To stop funding would without a doubt be more expensive for the state in the long run.

- [redacted]
  2 days ago

  Our 4 year old grandson was diagnosed as having autism two years ago and with the help of therapy has made great progress. Please continue to help him get this service.

- [redacted]
  about 20 hours ago

  I have a boy with autism who have greatly benefited from ABA therapy in [redacted] [redacted] and who because of that will be able to lead a fulfilled life, will have a job as a next computer designer or will be a next Mozart :o) and will pay taxes to the government instead of draining resources to fund his living in a group home. Do not.cut the funding, by doing so it will cost the government more money in the long run.

- [redacted]
  6 days ago

  Mom of a child with Autism.
  Kids need therapy coverage at ALL ages there should never be a stop to giving people with autism what medical coverage they need. Everyone has the right to be successful for those with autism that means access to medical treatments at all ages!

- [redacted]
  2 days ago

  I think there is a lot that could be done to help autistic people live more useful and fulfilling lives.

- [redacted]
  about 13 hours ago

  I have a 16 year old son with autism

- [redacted]
  about 5 hours ago
  Grandson age 9lives in MN.

- [redacted]
  about 7 hours ago

  It is unfathomable to think that a child's potential ,to learn ends at age 7. In what other realm would this be considered acceptable? Teaching our children with autism with effective therapies today helps them to reach their full potential and increase their quality of life. If that isn't reason enough, it also decreases the cost of caring for an adult with autism for their entire lives, which will be a colossal financial strain on the next generation, as 1 in 88 children with autism becomes 1 in 88 adults with autism.

- [redacted]
  7 days ago

  My daughter has autism!

- [redacted]
  4days ago

  I know the public schools cannot give all the help needed for children with autism. It is a condition which needs intensive therapeutic treatment.

- [redacted]
  about 23 hours ago

  If it were not for the Early Childhood Programs, my daughter, who has autism, would not of progressed as far as she has. It was amazing what was accomplishe for her in these programs. To eliminate this programs would border on being inhumane.

- [redacted]
  1 day ago

  Nothing should be left out. I hope who wants to cut this has someone in life to deal with autism so they understand

- [redacted]
  6 days ago

  My son has shown dramatic improvement becuase of his home therapy program. He is doing things now he has never done before. Schools are not adequately funded or trained to address the daily difficulties that these students face. The proposal to put the onus for providing necessary therapies on the schools will be a complete disaster for many students and their families. Just because there is a desire to save money does not mean that these children of special need should not get appropriate and meaningful treatment simply because they have passed by their 7th birthday.

- [redacted]
  6 days ago

  I work with children with autism providing IEIBT and I've seen firsthand the lives that are changed because of this therapy. Not allowing children to access this medically necessary therapy is shameful and antipathetic.

- [redacted]
  1 day ago

  I am a teacher that works with lots of various amazing children.

- [redacted]
  1 day ago

  People with autism can make make great improvement with the proper therapy.l've seen it in my daughter and believe every child with autism should have the opportunity to reach their fullest potential.

- [redacted]
  7 days ago

  My autistic grandson is 7 112 and is still benefiting greatly from ABA services that he began at age 3 112. His treatment is covered by private insurance which would not pay if he weren't making progress. Educational intervention by school districts is necessary but is not the same. Studies have shown that the cost of treatment is FAR LESS than the cost of lifetime public services for an untreated autistic child. I know that cost is a big concern at this time but treatment must continue as long as the child is benefiting from it. If not, the cost will be far more down the road! ·

- [redacted]
  4 days ago

  I work with kids in Minnesota who have Autism. Kids with Autism need all the help they can get in those early years!

- [redacted]
  6 days ago

  My friend's son has autism, I want him to get all the available medical assistance.

- [redacted]
  2 days ago

  This condition stuns families emotionally and financially. Even with an income well above average it is impossible to pay for the necessary treatment which needs to be done as early as possible in a child's life for it to do good.

- [redacted]
  2 days ago

  These children need this funding.

- [redacted]
  about 11 hours ago

  Friend's child is autistic

- [redacted]
  1 day ago

  I have a great-nephew who is 7 and still needs such services to help him function. I don't believe the public schools will be enough to help him gain the skills he needs to grow into a person who can get along in society.

- [redacted]
  about 22 hours ago
  Intervention is the key. Children with Autism deserve it!

- [redacted]
  6 days ago
  My son has Autism and receives ABA

- [redacted]
  7 days ago

  We have personal experience with our son's intensive, evidence-based treatment for autism that only started at age 7. The treatment he received was highly effective and was provided with skill and intensity not available through any school district; school districts are no more qualified to directly "treat" autism than they are to treat cancer, for example. These kids desperately need treatment from those qualified to provide it using scientifically validated methods. Please help!

- [redacted]
  1 day ago

  As a mother with a son with Autism. I understand the importance.

- [redacted]
  6 days ago

  My seven year old still benefits from therapies, especially ABA therapy, and deserves to have coverage for the therapies that his providers have recommended as medically necessary for his continued development and quality of life.

- [redacted]
  1 day ago
  My son has autism. While living in Minnesota, he had intense behavioral therapy. IT WORKS. I can't imagine where we would be now without it, and no family or child should be denied the opportunity. Ignoring the long-term ramifications of not providing prescribed therapy for these children is foolish.

- [redacted]
  2 days ago

  A family that I love dearly depends upon this coverage in order to give their son the best life he can possibly have. Losing this coverage would crush them.

- [redacted]

  My two son's have Autism,

- [redacted]
  1 day ago

  My son is autistic and has had many medical issues. I do not have insurance that covers **him** and we have badly needed medical assistance.

- [redacted]

  I have seen the benifits of autism treatment time and time again. I know it works and I know how important it is for these families to have affordable access to effective, medically necessary care for autism!!

- [redacted]
  about 1 hour ago

  My husband nephew has autism and he lives in MN

- [redacted]
  6 days ago

  Children with autism need early intervention services to give them the skills they need to function in their environments. The earlier they receive services the better it is for the child with autism. What is the states plans for children with autism if they will not fund early intervention services? Put them in school at the age 5? Let the school system teach the child how to communicate? Each child with autism is different, earlyintervention is specific to the child. School systems do not have the resources they need to teach all children with autsim. Early intervention programs do.

- [redacted]
  about 24 hours ago

  Because I have first-hand seen the positive results that these programs can have

- [redacted]
  2 days ago

  I am a constituent and a mother of an autistic son.

- [redacted]
  3 days ago

  Because Early intervention works

- [redacted]
  about 11 hours ago

  My son [redacted] age 4, diagnosis PDD-NOS, would be lost without autism coverage, and so would we. It's ridiculous to think that he would get all the treatment he needs from the school district. There aren't enough teachers or funding for that. He has greatly improved since being in an autism day program and we look forward to seeing more progress with him!!

- [redacted]
  1 day ago

  Because services should be based on medical necessity and functional need, not age. Also, schools are not equipped to provide either the expertise or the resources necessary for effective treatmetn.

- [redacted]
  6 days ago

  Our son has been diagnosed with Autism and ABA intervention helped him greatly in many areas such as communication, calming down, and self care to mention few. This service needs to be available for all who needs it as they are not able to ask for themselves so we parents do inbehalf of them.

- [redacted]
  4 days ago

  I have a dear friend with an amazing child who happens to be autistic. The public school system just brushed **him** under the rug. Programs are needed with trained professionals so these children can flourish!

- [redacted] [redacted]
  about 8 hours ago

  grandson has autism

- [redacted]
  4 days ago

  Who would ever say a child in need, can not have the necessary medical, therapy, or other necessities to grow healthy and productive is living in the dark ages. America as a country has always pulled together to help those in need, and the children with Autism are in desperate need to have the proper therapy/treatments in order to grow as healthy and strong physically and mentally as possible. The program should be increased if nothing else.
  My adorable grandson has improved greatly in many areas with early intervention and therapy.
  If anything, the question that should be asked is how can we help children with Autism more.
  The reality of the situation must be faced once and for all- we are talking about children in need and who could say no with·a clear conscious?

- [redacted]
  [redacted]

  [redacted]

- [redacted]
  4 days ago

  ALL children deserve the Best!!

- [redacted]
  7 days ago

  ask your self WWJD enough said

- [redacted]
  2 days ago

  My nephew has autism, and his parents are fighting really hard to make sure his development accelerates now, while he's young.lt's a crucial time, and I'd hate to see any tools taken away from them after all the hard work and sacrifice they've put in.

- [redacted]
  about 21 hours ago

  One of our grandsons has an autism spectrum disorder. We have seen first hand the value of the programs for which funding is sought, and recognize the burden borne by families with these children.

- [redacted]
  1 day ago

  Without early intervention, my son would have been in serious trouble when he entered school. Plus, so many parents don't have an opportunity to know what might be going on with their child without the help of experts.

- [redacted]
  1 day ago

  Supporting my friends touched by autism - specifically [redacted]

- [redacted]
  4 days ago
  iam a mother of a child with autism. the ABA therapy has changed my kid to verbal.this should continue to available to get the resources for my kid.

- [redacted]
  1 day ago

  I have 2 grandchildren that are Jiving proof of how early intervention is an absolute need to progress and be productive citizens.

- [redacted]
  about 11 hours ago

  As an educator, I am aware of cuts in spending in our public schools. The classes are getting larger and aides' time is stretched. Also, the idea of kids not having the opportunity for diagnosis after the age of 7 is bad.

- [redacted]
  5 days ago

  Therapy and early intervention works! Support treatments like Applied Behavior Analysis and Applied Verbal Behavior Therapies.!

- [redacted]
  about 8 hours ago

  We have a son with autism

- [redacted]
  5 days ago

  for my 5 year old nephew.

- [redacted]
  7 days ago

  For my son, [redacted], for the autistic kiddos of my good friends & for all the amazing kids and families facing this challenge.
  I've watched early education & therapy WORK first hand.
  The financial investment in these kids, early...is essential
  :)

- [redacted]
  about 12 hours ago

  My child was diagnosed with autism at age 5. If you cap autism services at age 7, my daughter will no longer be eligible for the ABA services which have helped her already so much!

- [redacted]
  5 days ago
  Our aS year old son with Autism still needs OT and speech that the school will not provide!

- [redacted]
  6 days ago

  My Autistic son has made the most significant progress in the last year and a half. He is 8. Please don't give up the fight.

- [redacted]
  7 days ago

  On behalf of my 9 year old son, who lives with Autism.

- [redacted]
  3 days ago

  This is a critical public health issue, and restricting access to services will have an extremely negative effect on many families with autistic children.

- [redacted]

  My child with autism was born [redacted] years ago. There were few others then, now there are many children with this disorder. Treatment is important at all ages. Please do not cut back on this treatment.

- [redacted]
  2 days ago

  I know young people with autism who are thriving in late teen/early adulthood because they have had this access to treatment.

- [redacted]
  6 days ago

  We are part of a ERISA insurance plan which means that our insurance is part of the loophole that does not have to cover things even with a mandate. Should we have to go the public route for coverage for our son with autism, we will have nowhere else to get coverage if DHS stops covering autism treatments. 1 in 88 children are.diagnosed every· single day with anASD. They are not second-class citizens and they deserve treatment· and a fulfilling life!

- [redacted]
  6 days ago

  Because I've been a therapist and have seen families struggle to treat their child.

- [redacted]
  1 day ago

  Great Grandson is autistic

- [redacted]
  7 days ago

  My son needs coverage! I owe all of his amazing progress to early intervention strategies!

- [redacted]
  about 4 hours ago

  . My nephew lives in Minnesota and is severely autistic and his parents need the coverage for his care.

- [redacted]
  1 day ago

  My 7 year old grandson has severe non verbal autism.

- [redacted]
  7 days ago

  Autism families are suffering in countless ways. They are silently trapped in our homes with children who are sick, nonverbal, needy 2417 and sometimes violent. Autism is treatable, but the most effective medical treatments often are not covered by insurance. Please do not add to the suffering of these families -- please do not cut what little coverage they have.

- [redacted]
  8 days ago

  I have a 6 year old son with autism.

- [redacted]
  about 10 hours ago

  My daughter is an autistic young adult.

- [redacted]
  2 days ago

  We have Autism in our family, it's a growing epidemic, please don't cut the coverage!

- [redacted]
  about 21 hours ago

  I have an 18 year old son with severe autism who benefited greatly from early intervention ABA. In addition, I have a 3 year old neice who was also diagnosed. with Autism and who is currently receiving ABA service which are having a tremendously positive impact on her condition. I know firsthand that Early Intervention ABA works and feel strongly that all children diagnosed with autism must have access to this vital resource.

- [redacted]
  5 days ago

  Kids with Autism should be treated with the evidence-based methods regardless their age. I respect and appreciate every teacher's hard work. However, I don't think that the public school systems have the enough experts and expriences to provide the adequate therapy/ treatment to this unique and challenging group of kids. My son went to the special ed when he was 3. This is the year that he did the worst, almost no improvement. He even got worse in lots of areas. In addition, I am feeling very disappointed and sad that our beloved state tries to cut the Autism service by adding the age limit while most of other states moving forward by passing their AUTISM mandates law. Can our state moving forward instead of moving backward?

- [redacted]
  4 days ago

  I discovered this therapy via U of M, & it gave my great nephew a real life. My older niece and dozens of my past students were not lucky enough to have this, and will therefore be disabled all their lives,needing much public funding for support and care.. The money spent for little [redacted] therapy will yield a self supporting, taxpaying citizen.

- [redacted]
  5 days ago

  My 4 year old son, [redacted], is benefiting tremendously from early intervention therapy, primarily ABA. To select an arbitrary date to cut off treatement regardless of a child's unique needs and expect the schools to treat these kids is not a workable solution.

- [redacted]
  5 days ago

  My Friend's son has autism and he is making good progress with the therapy. Do not stop the Coverage..

- [redacted]
  3 days ago

  I support access to medically necessary treatment such as Intensive Early Behavioral Intervention for children with autism spectrum disorders.

- [redacted]
  5 days ago

  Only effective, evidence-based treatment can help people with autism achieve their full potential. Please don't set the age cap at 7 as it is just unfair to others who are older.

- [redacted]
  2 days ago

  Because autism is treatable and curable!

- [redacted]
  5 days ago

  As a teacher, I see how difficult life and learning can be for those on the spectrum. We need tro continue research into causes and treatment.

- [redacted]
  7 days ago

  I am signing because autism has already affected my family, friends and will affect every· taxpayer when children with autism grow up to be adults with autism that mainstream society CANNOT handle! I have seen first hand autism intervention for my little cousin who has benefited greatly from it.

- [redacted]
  about 5 hours ago

  [redacted] asked me to

- [redacted]
  1 day ago
  I believe that this cause needs support

- [redacted]
  6 days ago

  Medical provider of children with ASD who looks at measurable outcomes at ANY age to determine the medical necessity of continuing an evidence-based intervention

- [redacted]
  1 day ago

  I have spent the last two years as an ABA behavior therapist and I have seen how enormously it changes lives. We had a 6 year old start at our facility and she had 1 sign- 'movie'- and no vocals.lt was assumed that she was severely mentally retarded because of her lack of communication. We probed out 75 pictures of common .items with her and were shocked to discover that she was able to identify 59 of them! There was so much knowledge locked up in her little head and she had no way to let it out. In just six months she's learned about 25 signs and can finally communicate her interests, wants, and needs with her family. Recently, her speech pathologist got her to form her very first word: 'mom'. Speech, ABA, and occupational therapy are what made her amazing progress possible; don't take that away from these wonderful children.

- [redacted]
  6 days ago

  For all my friends that struggle daily!

- [redacted]
  7 days ago

  My goddaughter has autism and i've seen the remarkable progress that can be made with appropriate therapy.All children should have equal access.

- [redacted]
  6 days ago

  I know parents of children with autism. Raised with the benefit of services to ameliorate my own [redacted], I understand the critical need for medically-necessary therapy. We may not--we cannot--compromise support for medically-necessary therapy because of ideological stances that government has no place in our lives. Medically-necessary therapy is vital to fostering the highest level of respect for life. Quality of life is vital. Support for medically-necessary therapy may not be compromised.

- [redacted]
  7 days ago

  For my 3 autism angels. [redacted]

- [redacted]
  5 days ago

  one of my grandsons is autistic

- [redacted]
  3 days ago

  Autism can be a life long condition, choosing to stop coverage after a very young age is ludicrous!

- [redacted]
  6 days ago

  My son deserves quality autism treatment based on his needs--not his age!

[redacted] [redacted] has autism.

  - [redacted]
    5 days ago

    I have a son age 6 with autism who has responsed very positively to early interventions inducing ABA. The schools are not equipped for this type of itensity, and we need to keep providing medically necessary treatments for kids of ALL ages to help give them a happy and independent future.

- [redacted]
  1 day ago

  I've taken care of children with Autisin, there is hope and families need to have proper coverage in order to seek treatment in order to live a normal life.

- [redacted]
  about 8 hours ago

  My 5 yr old grandson has autism, he needs to be able to attend a special school that fits his needs.

- [redacted]
  [redacted] days ago

  I have 2 children with Autism, one is 21 years old. Autism doesn't go away at age 7. They all need ongoing support and services, particularly medical coverage.

- [redacted]
  1 day ago

  "All children who have autism should have affordable access to effective, medically necessary care for autism." My nephew is early 30's and deserves the best service and treatment as afforded to ALL others. Age should never be a factor -It is real and alive and this petition needs support.

- [redacted]
  2 days ago

  So many more children have been diagnosed with autism.lt is time for us to recognize it as a treatable condition, and make qualified, recognized treatments available, regardless of income level or age of the child.

- [redacted]
  2 days ago

  Often times, autism is slow to be diagnosed. Putting age caps on treatments unfairly penalizes children and families whose diagnosis came later in the child's development.

  - [redacted]
    5 days ago

    I have seen many lives improved by Autism Therapy Services!

- [redacted]
  about 1 hour ago

  A family member has autism.

- [redacted]
  2 days ago
  My sister works for an ABA center and constantly tells me how much progress the kids are making! I'm also a Clinical Psychology PhD student and the important of mental health funding cannot be overstated.

- [redacted]
  1 day ago

  Early intervention is crucial in treating kids who have Autism. We need to ensure that these kids are guaranteed the treatment(s) and services they deserve.

  - [redacted]
    4 days ago

    For over 50 years children with autism have been treated successfully. Over half of children treated can live productive, independent lives. We wouldn't think of eliminating cancer treatement for children that has a 50% recovery rate. Why would we elimnate this treatment and devastate our society by needing to care for 1 in 88 people.It is unthinkable.

- [redacted]
  5 days ago

  As an educator, I can see that a healthy child is a learning student. Ergo,ALL children, regardless of their medical challenges DESERVE optimal and effective medical care. Our children, ALL our children, are the future of our country. Support them!!

  - [redacted]
    6 days ago

    I know it works

  - [redacted]
    about 7 hours ago
    I am a teacher. Please continue to fund treatment for children with autism, without an age cap for early intervention. These children need and deserve to achieve the highest level of functionality. It benefits that child, their family, their teachers, and their classmates.

  - [redacted]
    6 days ago

    I am signing because our amazing grandson has benefited from Autism therapy that wouldn't of been possible without Autism coverage. It changes lives of families.touched by Autism.

  - [redacted]
    2 days ago

    On behalf of friends in MN whose autistic son is benefiting from this program.

- [redacted]
  4 days ago

  Autism is to vast of a condition to abandon them or their parents

- [redacted]
  4 days ago

  my son was diagnosed with autism when he was 2 and is now mainstreamed with minimal symptoms of autism.

- [redacted]
  about 16 hours ago

  To help children with autism. I'm much rather my taxes went toward helping children rather then lazy adults who just don't want to work.

- [redacted]
  2 days ago
  I have a grandson who has autism.

- [redacted]
  4 days ago

  One of my closest friends has a son who was born with autism, and I have seen how difficult and expensive it is for families with autistic children to live their lives and help their child thrive. The parents are afraid of what will happen when he reaches 7, he deserves and will need more care than the public school district can provide. This is not an area where we should be saving money. There is a lot of waste within human services. As a person with a disability, may I point out the extreme markup of any product labeled "medical" as one place to save countless dollars.

- [redacted]
  4 days ago

  Every child matters....,

- [redacted]
  1 day ago
  For my son

- [redacted]
  6 days ago

  My grandson is three and newly diagnosed. he does not speak or communicate. My daughter is a wonderful advocate for him but they are on a very limited budget. he needs therapies to help his developmental disabilities.

- [redacted]
  6 days ago

  I have a son with autism. He has received both private and school based services and has progressed well because of both. He would have received greater benefits from earlier treatment, if it was readily available and covered. I also believe that he would have continued to progress if some of his treatment wasn't stopped when he reached a certain age. There may not be a cure but there really are treatments that are very helpful and make the person with autism more successful and productive.

- [redacted]
  1 day ago

  I have a family member who has Autism and my family works closely with the issue through a non-profit organization: [redacted].

- [redacted]
  about 13 hours ago

  For autism. We have a family member who is doing great because of ABA...you take this away and where does he go from here?

- [redacted]
  1 day ago

  My son is autistic. We desperately rieed this coverage. He is tremendously benefitting from intensive therapy.

- [redacted]
  about 11 hours ago
  My autistic grandson lives in Minnesota and needs treatment. What if someone in the governor's family had autism??

- [redacted]
  2 days ago
  My son is currently being treated through ABA and has made great strides. This therapy is changing his life and ours!

- [redacted]
  about 13 hours ago
  This negatively affects many families I personally know and how they care for their autistic children.

- [redacted]
  2 days ago
  Our 4 year old son has autism. Without this coverage our family, along with many others, won't be able to get the intensive therapy our children need to overcome their autism diagnosis.

- [redacted]
  4days ago
  My dear friends daughter has an autistic child and although God is with her and her husband making them wonderful, strong parents-we sure don't need to make it anymore difficult on them. GOod luck and thank you for your fight.

- [redacted]
  5 days ago
  Applied Behavior Analysis is a evidence-based treatment that allows individuals with Autism and other developmental disabilities to make improvements in socially significant · behavior, including language, as well as reduction of problem behavior. I speak from the perspective of both a sibling of a young adult with autism and a Board Certified Behavior Analyst, and have seen the impact that a well-managed ABA program can have on the lives of individuals and their families dealing with Autism. Please continue to allow us to help these families by providing quality support.

- [redacted]
  5 days ago
  I am the parent of 2 sons with Aspergers. My oldest was killed at his workplace.

- [redacted]
  1 day ago
  Friends, students, and family deserve this!

- [redacted]
  6 days ago
  My son 8, has autism. We have utilized multiple therapies including ABA, it, pt, speech to help him become a contributing citizen and become the best hecan be. We have paid extremely large premiums to TEFRA in order provide him with the care he needs and will continue to need through adulthood. Taking services from [redacted] and other children like him will be detrimental. Please continue to support our kids. They deserve to learn, grow and succeed like all children do.

- [redacted]
  4days ago

  For my son! Autism doesn't end at age 7 and neither should treatments.

    - [redacted]
      1 day ago
      I am the parent of a child with autism
- [redacted]
  7 days ago
  Support of Autistic children and my grandson.

- [redacted]
  1 day ago
  I support both awareness and understanding of all forms of mental illness. The issues are not easy ones, but the families who are profoundly affected by a relative with this problem need both hope and assistance.

- [redacted]
  1 day ago
  I have a child with autism who has benefitted greatly from ABA.
- [redacted]
  2 days ago
  I have 6 friends or family that have an autistic child.

- [redacted]
  about 4 hours ago
  I am adding my name because I believe each child should be treated as an individual and have the access they need to the medical system. Arbitrary decisions based on an age is not a fair policy to those who may fall outside the boundaries.

- [redacted]
  6 days ago
  I am signing for my twin boys who began ABA therapy at age 8 and have made amazing progress in the past 11 months.
  The medical needs of individuals living with autism do not magically end at age 7 nor. when they enter school, so medically necessary care and its coordination should not end. at that time either.
  Many are not even diagnosed until age 7. or later.
  Most school districts have neither the budget, personnel, or training to provide the intensity of treatment that so many of these individuals need to become independent students and adults. Medically necessary care should not end at any particular age.

- [redacted]
  6 days ago
  For all the little rock stars out there that are affected by Autism...you are loved and you deserve this!

- [redacted]
  3 days ago
  My son has autism. He didn't speak at all until he was 3 years old, if it wasn'tfor these services he would be non verbal. We need this support, without it would be a detriment to society.

- [redacted]
  5 days ago

  I'm a provider of Early Intensive Behavioral Intervention (EIBI) services and firmly support the effectiveness of Applied Behavior Analysis (ABA) as an evidence-based treatment that children with autism should be able to access.

- [redacted]
  6 days ago
  My grandson continues to progress due to quality intensive ABA therapy. The need doesn't stop just because he is 7. We must continue to fund autism therapy.

- [redacted]
  7 days ago
  Signing because my son is benefiting TREMENDOUSLY from IEIBT --our private insurance pays a lot but not all so need to use the TEFRA for some of it. Could NEVER afford it on our own. He is 7 years old but is gaining hundreds of skills and improves daily. Limiting early intervention and putting age limits would be detrimental and shouldn't even be a consideration.

- [redacted]
  7 days ago
  For my amazing son

- [redacted]
  about 22 hours ago ·
  I know ma.ny autistic childing and they need our help!

- [redacted]
  5 days ago

  My nephew and many others I am aware of have benefited from therapies outside of school after age 7. Many kids with autism struggle greatly once puberty hits and the therapeutic support to families is ever so important then as well as when younger. They don't stop learning at 7. Also schools don't have professionals who are adequately trained to meet the needs of the kids and often wom't outside of the school setting.