

National Balancing Indicators Project

Measure Additions and Refinement Final Report

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LIST OF ACRONYMS

ACA	Patient Protection and Affordable Care Act
ACL	Administration on Community Living
AHRQ	Agency for Healthcare Research and Quality
BRFSS	Behavioral Risk Factor Surveillance System
CI	Community Integration and Inclusion
CLC	Cultural and Linguistic Competency
CMS	Centers for Medicare and Medicaid Services
CT	Coordination and Transparency
FMAP	Federal Medical Assistance Percentage
HCBS	Home and Community-based Services
DALTCP	Office of Disability, Aging, Disability and Long-term Care Policy
DSW	Direct Service Workforce
I&A	Information and Assistance
LTSS	Long-term Services and Support
NBIs	National Balancing Indicators
NBIP	National Balancing Indicator Project
NCCC	National Center for Cultural Competency
OASPE	Office of the Assistant Secretary for Planning and Evaluation
NF	Nursing Facility
OC	Options Counseling
OCR	Office of Civil Rights
PCP	Person-centered Planning
SA	Shared Accountability
SAMHSA	Substance Abuse and Mental Health Administration
SD	Self-Determination
SPT	State Profile Tool
TEP	Technical Expert Panel
THA	Truven Health Analytics
HHS	United States Department of Health and Human Services

EXECUTIVE SUMMARY

Background

More than 10 million Americans with disabilities need and receive long-term services and supports (LTSS)¹ to assist them with life's daily activities and enable them to live independently in their communities. Approximately half of these individuals with disabilities are older than age 65 and half are younger than age 65 (Kaiser Foundation, June 2012). Most individuals prefer to stay in their homes as long as possible—to be community-based—rather than to receive institutional care (AARP, September 2010).

Research conducted on individuals' preferences and wellbeing, together with United States Supreme Court's 1999 decision in *Olmstead v. L.C.*, (527 U.S. 581 (1999)) in which the Court upheld an individual's right to receive services "in the most integrated setting appropriate" (Smith & Calandrio, 2001), have given States the incentive to pursue "balancing" (sometimes called "rebalancing") initiatives. Through these initiatives States may transform their LTSS systems from ones in which institutional care predominates into ones that support individual choices and the provision of person-centered home and community-based services (HCBS). The services include active engagement of the individual, his or her family, and his or her local support network (Woodcock, Stockwell, Tripp & Milligan, 2011).

The Federal government has demonstrated a commitment to LTSS balancing and the delivery of person-centered HCBS in a number of provisions of the Patient Protection and Affordable Care Act (ACA) of 2010 and other Federal mandates and initiatives (e.g., the Americans with Disabilities Act, CMS's Real Choice Systems Change, New Freedom, Money Follows the Person Initiatives, Balancing Incentive and Direct Service Worker Resource Center initiatives, and the US Department of Health and Human Services' Community Living and its Strategic Plan for Community Living). The ACA authorizes a number of new financial incentives to States to develop and implement LTSS balancing initiatives to transform their LTSS systems (Woodcock et al., 2011).

A balanced LTSS system is one that has the following characteristics:

- **Person-driven:** Provides individuals with choices regarding where and with whom they live, control over the services that they receive and the individuals who provide them, the chance to earn money, the option to include friends, and supports to help them participate in community life.
- **Inclusive:** Encourages people to live where they want to live, with access to a full array of community services and supports.

¹ Long-term services and supports (LTSS) include a range of services including assistance with activities of daily living (e.g., eating, bathing, dressing, toileting and transferring) and instrumental activities of daily living (IADLs), (e.g., shopping, food preparation, laundry, housekeeping and managing finances).

- **Effective and Accountable:** Offers high quality services that improve individuals' quality of life. Accountability and responsibility is shared between the public and private partners, and includes personal accountability and planning for LTC needs, including greater use of private funding sources.
- **Sustainability and Efficient:** Efficiently coordinates and manages a package of paid services appropriate for the individual, paid for by the right entity
- **Coordinated and Transparent:** Coordinates services from various funding streams to provide a seamless package of supports, and uses health information technology to effectively provide transparent information to individuals, providers, and payers.
- **Culturally Competent:** Provides user-friendly, culturally appropriate, accessible information and services (CMS, 2014).

This type of LTSS system provides high quality LTSS delivered by both informal and formal sources and provides a full array of choices and access to LTSS to all individuals at any point in time across their life span. However, achieving a person-centered and balanced LTSS system historically has been a challenge for States (Kassner, Reinhard, Fox-Gage, Houser & Accuis, 2008).

The most commonly cited measures for examining a State's progress in balancing its LTSS system are (1) the proportion (percentage) of LTSS Medicaid expenditures that is directed to HCBS versus institutional services compared to the proportion directed to institutional services (Woodcock, et al., 2011; Kassner, et al., 2008); and (2) changes in the number of Medicaid beneficiaries *and* dollar amounts (as opposed to percentage) in LTSS expenditures amounts (Kassner et al., 2008). However, these measures alone do not tell the whole story of how a state develops a person-centered, balanced LTSS system. Moreover, to date, there few common indicators available that can be used to examine States' efforts in achieving this goal.

CMS commissioned the implementation of two initiatives, the National Balancing Indicators Contract (NBIC) implemented from 2007 to 2010 and the National Balancing Indicators Project (NBIP) implemented from 2010 to 2014, to address the challenges that States face in implementing balanced and person-driven LTSS systems and remedy the deficiencies in the common indicators that Federal agencies and States use to examine efforts in achieving this goal.

The objective of the NBIC was to develop a conceptual framework for LTSS balancing and to develop and test the feasibility of implementing a set of National Balancing Indicators (NBIs) that CMS and States could use to measure Federal and State efforts towards attaining and maintaining balanced, person-driven LTSS systems. The objective of the NBIP was to further refine and add to the six principles and 18 NBIs developed under the NBIC. During the NBIP, the NBIP team developed, field tested, refined, and expanded upon seven principles (1 new) and 24 NBIs (9 new).

Methodology

The methodology used by the NBIP team to further refine and add to the NBIs developed under the NBIC consists of the following activities:

- Reviewed relevant literature and data on existing LTSS indicators being developed under separate initiatives.
- Implemented a collaboration and communication strategy that included consultation with, and feedback from SPT Grantee States that participated in the field testing, LTSS experts (e.g., TEP and Stakeholder Group members); and Federal Partner agencies and other not-for-profit organizations (e.g., AARP) that were developing LTSS indicators under separate initiatives.
- Prepared a crosswalk of the NBIs to LTSS indicators being developed under separate initiatives and summarized the findings in a report.
- Conducted field testing of the principles, NBIs and state self-assessment survey instrument in 2012 with seven SPT Grantee States (AR, FL, ME, MA, MI, MN & KY), reviewed the results along with feedback from the TEP and Stakeholder Group members and incorporated feedback, as appropriate.
- Conducted three conference call meetings with the TEP and conducted follow-up calls with select TEP members in the fall of 2013 to obtain feedback on the principles, NBIs and survey instrument.
- Further refined and expanded on the NBI principles, indicators and Technical Assistance Guide (TAG) for NBIs which includes self-assessment survey instrument based on TEP member feedback.
- Prepared the NBIP Measures Additions and Refinements Report.

The NBIP team implemented principle and NBI refinements and additions in two waves from 2010 through 2012 and from the latter part of 2012 through 2014.

A crosswalk prepared in 2011 mapped the NBIs developed under the NBIC to the LTSS balancing indicators that were developed by the Federal Partner agencies and other not-for-profit organizations under separate initiatives prior to 2011. The crosswalk enabled the NBIP team to identify overlapping and complementary efforts and highlighted gaps in the NBIs, as well as to identify synergies across LTSS indicators created by Federal Partner agencies and other not-for-profit organizations.

The NBIP team assessed the equivalency and relationship strength of each LTSS indicator and compared the results to the six principles and 18 NBIs developed under the NBIC. The team based LTSS indicator equivalency and strength on three criteria: (1) equivalency in scope, (2) attributes, and (3) non-equivalent indicators.

NBI Refinements and Additions

As mentioned earlier, the team field tested and developed, refined, added to seven principles (1 new) and 24 NBIs (11 new, with some replacing previous indicators) during the NBIP. The team refined and added to the existing principles and NBIs and created one new principle and nine NBIs to address new data and information that became available, lessons learned during the field testing of the NBIs and from the state self-assessment survey instrument with the STP Grantee States, feedback received from the SPT Grantee States, TEP, and Stakeholder Group members and Federal Partner agencies and other not-for-profit agencies, and changes in the LTSS policy landscape that occurred during the Project period (2010 to 2014).

Description of Principles

The following describes each of the seven principles examined under the NBIP. The ***Sustainability Principle*** is used to examine whether a state's long term services and supports (LTSS) system is financially sustainable and is supported by an adequate infrastructure and a quality workforce. The ***Shared Accountability Principle*** is used to look at the level of responsibility among and between users (older adults and individual with disabilities and chronic conditions and their families), service providers, local government agencies, State program agencies, and the Federal government agencies, and encourages personal planning for LTSS needs, including greater use and awareness of private sources of funding available.

The ***Self-Determination/Person-Centeredness Principle*** is used to consider whether the LTSS system affords people with disabilities and/or chronic illnesses the authority to decide where and with whom they live, have control over the services that they receive and the organizations and individuals who provide them, have the opportunity to work and have private incomes, and have the opportunity to have friends and supports that facilitate their participation in community life. The ***Community Integration and Inclusion Principle*** is used to examine whether a State's LTSS system encourages and supports people to reside in the most integrated setting by offering them a full array of options to access quality services and supports in the community.

The ***Coordination and Transparency Principle*** is used to consider whether the LTSS system coordinates a range of services funded by multiple funding sources to provide seamless supports to individuals with special needs across the health and LTSS systems (i.e., acute health, rehabilitation, and LTSS). The ***Prevention Principle*** encompasses States' efforts to encourage and support health and wellness programs that promote healthy living, slow functional decline, and ensure the optimal health, well-being, safety and functioning of people with disabilities. Finally, the ***Cultural and Linguistic Competency (CLC) Principle*** examines the infrastructures that States have in place to provide services and supports for diverse populations.

Exhibit 1 lists the principles and NBIs that the team developed under the NBIC and the NBIP.

Exhibit 1: National Balancing Indicators Developed and Tested Under the NBIC and NBIP

Principle	NBIC Indicators	NBIP Indicators
Sustainability	<p>S1. Global Budget</p> <p>S2. Medicaid Expenditures</p> <p>S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid LTC Spending</p> <p>S2b. Change in Per Capita Rate of Medicaid LTC Spending</p> <p>S3. Personal Care Attendant (PCA) Registry</p> <p>S4. Support for Informal Caregivers</p> <p>S5. Shared Long-Term Supports and Services Mission/Vision Statement</p> <p>S6. Quality of Long-Term Supports and Services Mission/Vision Statement</p>	<p>S1. Global Budget</p> <p>S2. LTSS Expenditures</p> <p>S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid LTC Spending</p> <p>S2b. LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility</p> <p>S2c. Medicaid Funding Sources</p> <p>S2d. LTSS Funding From Non Medicaid Sources</p> <p>S3. Direct Service Workforce</p> <p>S3a. Direct Service Workforce (DSW) Registry</p> <p>S3b. Direct Service Workforce: Volume, Compensation, and Stability</p> <p>S3c. Direct Service Workforce Competency</p> <p>S3d. Direct Service Workforce Training</p> <p>S4. Support for Informal Caregivers</p> <p>S5. Shared Long-Term Supports and Services Mission/Vision Statement</p>
Self-Determination/Person-Centeredness	<p>SD1. Nurse Delegation</p> <p>SD2. Availability of Options for Self-Determination</p>	<p>SD1. Regulatory Requirements Inhibiting Consumer Control</p> <p>SD1a. Residential Setting</p> <p>SD1b. Attendant Selection</p> <p>SD1c. Nurse Delegation</p> <p>SD2. Availability of and Use of Self-Direct Services</p> <p>SD3. Risk Assessment and Mitigation</p>
Shared Accountability	<p>SA1. Consumer and Family Empowerment</p>	<p>SA1. Fiscal Responsibility</p> <p>SA2. Personal Responsibility</p> <p>SA3. Individuals and Families are Actively Involved in LTSS Policy Development</p> <p>SA4. Government, Provider, and User Accountability</p>
Community Integration and Inclusion	<p>CI1. Waiver Waitlist</p> <p>CI2. Coordination between Long-Term Supports and Housing</p> <p>CI3a. Self-Assessment of Supportive Employment Options For Working-Age Adults with Disabilities</p> <p>CI3b. Employment Rates of Working-Age Adults with Disabilities</p>	<p>CI1. Waiver Waitlist</p> <p>CI2. Housing</p> <p>CI2a. Coordination of Housing and LTSS</p> <p>CI2b. Availability and Access to Affordable and Accessible Housing Units</p> <p>CI2c. Housing Settings</p> <p>CI3. Employment</p> <p>CI3a. Employment Rates of Working-Age Adults with Disabilities</p> <p>CI3b. Supported Employment</p>

Principle	NBIC Indicators	NBIP Indicators
		Options CI4. Transportation CI4a. Availability and Coordination of Transportation CI4b. Users Reporting on Adequate Transportation and Unmet Needs
Coordination and Transparency	CT1. Streamlined Access CT2. Service Coordination CT3. Coordination between HCBS and Institutional Care Entities	CT1. Streamlined Access CT1a. Implementation CT1b. Fully Functioning Criteria and Readiness Assessment LTSS Partnerships CT2. Service Coordination CT2a. LTSS System Coordination CT2b. Users Reporting that Care Coordinators of Case Managers Help Them Get What They Need CT3. LTSS Care Transition
Prevention	P1. Health Promotion Programs for Persons with Disabilities P2. Proportion of People with Disabilities Reporting Recent Preventative Health Care Visits	P1. Health Promotion and Prevention P2. Disaster/Emergency Preparedness
Cultural and Linguistic Competency (<i>new under NBIP</i>)		CLC1. Needs Assessment and Target Population CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups CLC3. Cultural and Linguistic Competency Training Requirements

Although the term “balancing” appears in the NBIP contract name and traditionally references Medicaid State agencies’ efforts to more equitably distribute funding from institutional to community-based settings, the objective of the NBIP was intended to focus more broadly on the myriad components of a balanced and person-driven LTSS system that can provide full access to community alternatives. CMS believes an “ideal” LTSS system must be responsive to the needs and desires of individuals, promote qualities of life, and make use of person-centered planning and service delivery strategies. Thus, NBIP was tasked with addressing all of these issues.

Challenges and Lessons Learned

While the proposed NBI principles and indicators are potentially useful criteria to examine how States perform in implementing balanced and person-centered LTSS systems, there are significant challenges that CMS must consider before applying them nationally. These challenges include the following:

- Determining the scope of an indicator;
- Disagreement between LTSS experts regarding whether a certain LTSS system infrastructure that is considered to be “optimal” is the best solution for all programs in all States;
- Difficulties in achieving and maintaining the cross-agency collaborations necessary to gather data and build shared systems;
- Differences in key definitions and terminology;
- Limitations in both process and outcome measures;
- Development of a core set of measures that tell a compelling story, while including key pieces of information that are essential to understanding a system (forest versus trees);
- Concern for how NBIs will be used; and,
- Methods of collecting complete data in a sustainable way.

Conclusions and Next Steps

The NBIs developed during the NBIC were the first step in creating a conceptual framework for developing and implementing a balanced and person-driven LTSS system and set of indicators, scores and rating that can be used by CMS and States to examine progress in developing and implementing such LTSS systems. This report describes the development, refinements and additions made to the NBIs under the NBIP and the challenges the Federal government and States face in developing and implementing a set of NBIs.

The NBIP team worked with stakeholders, including seven SPT Grantee States, the TEP and Stakeholder Group members, Federal Partner agencies, and other not-for-profit organizations, to gather feedback on refining and expanding the NBIs developed under the NBIC and to assess the feasibility of implementing them. The collaboration between the NBIP team, CMS, and the full array of stakeholders was critical to move the NBIs developed under the NBIC forward. In addition, the NBIP team revisited developmental indicators identified under the NBIC. The team worked with CMS and the stakeholders to revise and add the Cultural and Linguistic Competency Principle; to revisit 36 developmental indicators for inclusion in the NBIs; and to create the next iteration of the state self-assessment survey instrument that was developed to collect the information necessary to implement the NBIs.

While the proposed NBIs are potentially effective tools to examine the Federal and State efforts to develop and implement balanced and person-driven LTSS systems, their development continues to be a work in progress. The NBIP team identified significant challenges under the NBIC and NBIP that may impede their effective implementation. These challenges are described in Chapter 4 of this report.

The successful implementation of the NBIs also depends upon a number of other issues. First, because implementing the NBIs requires a significant investment of time, effort, and money, States must be able to see the value in implementing the NBIs and reporting the required data and information to CMS. Second, it is critical that States have the infrastructure and informational technology capabilities needed to collect complete and accurate data and information across populations and topic areas and report it in a sustainable way. Third, States must have the resources necessary to implement the NBIs. States confronted the challenge of inadequate staffing and financial resources during the recent economic crisis in 2008. These challenges and issues must be addressed before the NBIs can be implemented successfully on a national basis.

The NBIP team has a number of next steps to complete before the NBIP ends on September 30, 2014. First, the team will prepare and submit the final *Implementation Options Report*. CMS will use this report as a guide to determine the final set of NBIs, data infrastructure and data collection requirements, and other issues related to developing and implementing a balanced and person-driven LTSS system consistent with CMS' vision. The decisions that CMS makes regarding the final set of NBIs will inform the NBIP Final Report. The team also will incorporate these decisions in the Technical Assistance Guide to NBI. The final reports generated by the NBIP will be available for use by CMS, Federal and State agencies, and other stakeholders and will support future CMS work in this area.

CHAPTER 1. BACKGROUND

More than 10 million Americans with disabilities need and receive long-term services and supports (LTSS)² to assist them with life’s daily activities and enable them to live independently in their communities. Approximately half of these individuals with disabilities are older than age 65 and half are younger than age 65 (Kaiser Foundation, June 2012). Most individuals prefer to stay in their homes as long as possible—to be community-based—rather than to receive institutional care (AARP, September 2010).

In a 2010 AARP survey of adults age 45 and older, 73 percent strongly agreed with the following statement: “What I’d really like to do is stay in my current residence as long as possible” (AARP, 2010; Keenan, 2010). Research conducted on individuals’ preferences and wellbeing, together with United States Supreme Court’s 1999 decision in *Olmstead v. L.C.*, (527 U.S. 581 (1999)) in which the Court upheld an individual’s right to receive services “in the most integrated setting appropriate” (Smith & Calandrio, 2001), have given States the incentive to pursue “balancing” (sometimes called “rebalancing”) initiatives. Through these initiatives States may transform their LTSS systems from ones in which institutional care predominates into ones that support individual choices and the provision of person-centered home and community-based services (HCBS). The services include active engagement of the individual, his or her family, and his or her local support network (Woodcock, Stockwell, Tripp & Milligan, 2011).

In addition, the federal government has demonstrated its commitment to LTSS balancing and the delivery of person-centered HCBS in a number of provisions of the Patient Protection and Affordable Care Act (ACA) of 2010 and in other federal mandates and initiatives (e.g., the Americans with Disabilities Act, CMS’ Real Choice Systems Change, New Freedom and Money Follows the Person and Balancing Incentive Initiatives and the US Department of Health and Human Services’ Community Living and its Strategic Plan for Community Living). The ACA includes a number of new financial incentives to States to develop and implement LTSS balancing initiatives to transform their LTSS systems (Woodcock et al., 2011).

A balanced LTSS system is one that has the following characteristics:

- **Person-driven:** Provides individuals choice regarding where and with whom they live, control over the services that they receive and who provides them, the chance to earn money, the option to include friends, and supports to help them participate in community life.
- **Inclusive:** Encourages people to live where they want to live, with access to a full array of community services and supports.

² Long-term services and supports (LTSS) include a range of services including assistance with activities of daily living (e.g., eating, bathing, dressing, toileting and transferring) and instrumental activities of daily living (IADLs), (e.g., shopping, food preparation, laundry, housekeeping and managing finances).

- **Effective and Accountable:** Offers high quality services that improve quality of life. Accountability and responsibility is shared between the public and private partners, and includes personal accountability and planning for LTC needs, including greater use of private funding sources.
- **Sustainable and Efficient:** Efficiently coordinates and manages a package of paid services appropriate for the individual, paid for by the right entity
- **Coordinated and Transparent:** Coordinates services from various funding streams to provide a seamless package of supports, and uses health information technology to effectively provide transparent information to individuals, providers, and payers.
- **Culturally Competent:** Provides user-friendly, culturally appropriate, accessible information and services (CMS, 2014).

This type of LTSS system provides high quality LTSS from both informal and formal sources and provides a full array of choices and access to LTSS to all individuals throughout their life spans. Historically, States have faced many challenges in achieving balanced LTSS systems. For example, in 2008, a study conducted by Kassner et al., found that only one in four Medicaid LTC dollars supported HCBS for older adults and other adults with disabilities. In addition, they found that only four States were spending more than 50 percent of their Medicaid LTC dollars for HCBS. As a result, States have considerable room to improve the balance of their LTSS systems (Kassner, Reinhard, Fox-Gage, Houser & Accuis, 2008).

The most commonly cited measures in the literature for examining a State's progress in balancing its LTSS system are (1) the proportion (percentage) of LTSS Medicaid expenditures that is directed to HCBS versus institutional services compared to the proportion directed to institutional services (Woodcock, et al., 2011; Kassner, et al., 2008); and (2) changes in the number of Medicaid beneficiaries *and* dollar amounts (as opposed to percentage) in LTSS expenditures amounts (Kassner et al., 2008). However, these measures alone do not tell the whole story of how a state develops a person-centered, balanced LTSS system. Moreover, to date, there few common indicators available that can be used to examine States' efforts in achieving this goal.

CMS commissioned the implementation of two initiatives, the National Balancing Indicators Contract (NBIC) implemented from 2007 to 2010 and the National Balancing Indicators Project (NBIP) implemented from 2010 to 2014, to address the challenges that States face in implementing balanced and person-driven LTSS systems and remedy the deficiencies in the common indicators that Federal agencies and States use to examine efforts in achieving this goal.

The objective of the NBIC was to develop a conceptual framework for LTSS balancing and to develop and test the feasibility of implementing a set of National Balancing Indicators (NBIs) that CMS and States could use to measure Federal and State efforts towards attaining and maintaining balanced, person-driven LTSS systems. The objective of the NBIP was to further refine and add to the six principles and 18 NBIs developed under the NBIC. Between 2010 and

2012, the NBIP team refined and expanded the principles and NBIs developed under the NBIC. In 2012, with seven State Profile Tool (SPT) Grantee States (Arkansas, Florida, Kentucky, Maine, Massachusetts, Michigan, and Minnesota), the team field tested the principles, NBIs, and the state self-assessment survey instrument. From 2012 to 2014, the team made additional refinements and additions to the principles, NBIs, and the state self-assessment survey instrument based on feedback that the team received from the SPT Grantee States, the Technical Expert Panel (TEP), Stakeholder Group members, Federal Partners, and other not-for-profit organizations. The team finalized seven principles (1 new) and 24 NBIs (11 new, with some replacing previous indicators) under the NBIP initiative.

Exhibit 2 lists the principles and NBIs that the team developed and tested during the NBIC and the NBIP.

Exhibit 2: National Balancing Indicators Developed and Tested Under the NBIC and NBIP

Principle	NBIC Indicators	NBIP Indicators
Sustainability	S1. Global Budget S2. Medicaid Expenditures S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid LTC Spending S2b. Change in Per Capita Rate of Medicaid LTC Spending S3. Personal Care Attendant (PCA) Registry S4. Support for Informal Caregivers S5. Shared Long-Term Supports and Services Mission/Vision Statement S6. Quality of Long-Term Supports and Services Mission/Vision Statement	S1. Global Budget S2. LTSS Expenditures S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid LTC Spending S2b. LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility S2c. Medicaid Funding Sources S2d. LTSS Funding From Non Medicaid Sources S3. Direct Service Workforce S3a. Direct Service Workforce (DSW) Registry S3b. Direct Service Workforce: Volume, Compensation, and Stability S3c. Direct Service Workforce Competency S3d. Direct Service Workforce Training S4. Support for Informal Caregivers S5. Shared Long-Term Supports and Services Mission/Vision Statement
Self-Determination/Person-Centeredness	SD1. Nurse Delegation SD2. Availability of Options for Self-Determination	SD1. Regulatory Requirements Inhibiting Consumer Control SD1a. Residential Setting SD1b. Attendant Selection SD1c. Nurse Delegation SD2. Availability of and Use of Self-Direct Services SD3. Risk Assessment and Mitigation
Shared Accountability	SA1. Consumer and Family Empowerment	SA1. Fiscal Responsibility SA2. Personal Responsibility SA3. Individuals and Families are Actively Involved in LTSS Policy Development SA4. Government, Provider, and User Accountability

Principle	NBIC Indicators	NBIP Indicators
Community Integration and Inclusion	CI1. Waiver Waitlist CI2. Coordination between Long-Term Supports and Housing CI3a. Self-Assessment of Supportive Employment Options For Working-Age Adults with Disabilities CI3b. Employment Rates of Working-Age Adults with Disabilities	CI1. Waiver Waitlist CI2. Housing CI2a. Coordination of Housing and LTSS CI2b. Availability and Access to Affordable and Accessible Housing Units CI2c. Housing Settings CI3. Employment CI3a. Employment Rates of Working-Age Adults with Disabilities CI3b. Supported Employment Options CI4. Transportation CI4a. Availability and Coordination of Transportation CI4b. Users Reporting on Adequate Transportation and Unmet Needs
Coordination and Transparency	CT1. Streamlined Access CT2. Service Coordination CT3. Coordination between HCBS and Institutional Care Entities	CT1. Streamlined Access CT1a. Implementation CT1b. Fully Functioning Criteria and Readiness Assessment LTSS Partnerships CT2. Service Coordination CT2a. LTSS System Coordination CT2b. Users Reporting that Care Coordinators of Case Managers Help Them Get What They Need CT3. LTSS Care Transition
Prevention	P1. Health Promotion Programs for Persons with Disabilities P2. Proportion of People with Disabilities Reporting Recent Preventative Health Care Visits	P1. Health Promotion and Prevention P2. Disaster/Emergency Preparedness
Cultural and Linguistic Competency (<i>new under NBIP</i>)		CLC1. Needs Assessment and Target Population CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups CLC3. Cultural and Linguistic Competency Training Requirements

Although the term “balancing” appears in the NBIP contract name and traditionally references Medicaid State agencies’ efforts to more equitably distribute funding from institutional to community-based settings, the objective of the NBIP was intended to focus more broadly on the myriad components of a balanced and person-driven LTSS system that can provide full access to community alternatives. CMS believes an “ideal” LTSS system must be responsive to the needs and desires of individuals, promote qualities of life, and make use of person-centered planning and service delivery strategies. Thus, NBIP was tasked with addressing all of these issues.

This report discusses the methods that the team used to refine and add to the principles, NBIs, and state self-assessment survey instrument developed under the NBIC. The report also

presents the current version of the principles, NBIs, and the Technical Assistance Guide to the NBIs (including the state self-assessment survey instrument), discusses the challenges that CMS and States have encountered in implementing the NBIs and the state self-assessment survey instrument, and provides lessons learned, the team's conclusions, and next steps.

This report contains the following chapters and appendices. A **List of Acronyms** is included in the Report for the reader's reference. **Chapter 1** describes the issues related to LTSS balancing and the role of the NBIC and NBIP in LTSS balancing efforts. **Chapter 2** describes the methodology that the team used to develop the NBIs under the NBIC and NBIP projects. **Chapter 3** summarizes the refinements and additions that the team made to the six principles and 18 NBIs, and the state self-assessment survey instrument that it had developed under the NBIC in two waves between 2010 and 2012 and between 2012 and 2014. This chapter also provides information obtained from the literature and feedback that the team received from the STP Grantee States, TEP and Stakeholder Group members, Federal Partners, other not-for-profit organizations, and CMS. **Chapter 4** describes the challenges that the Federal government and States faced in developing the NBIs and the state self-assessment survey instrument and lessons learned. **Chapter 5** presents the team's conclusions and next steps.

Appendix A contains a list of the SPT Grantee States, TEP, Stakeholder Group, and Federal Partner Group members for the period 2010 to 2014. **Appendix B** contains the SPT Grantee Feedback Summary for 2010. **Appendix C** contains the SPT Grantee Feedback Summary for 2012. **Appendix D** contains the Summary of TEP, Federal Partners, and Stakeholder Group Feedback Summary prior to 2012. **Appendix E** contains the agenda for the three TEP meetings held in the fall of 2013. **Appendix F** contains the literature review for the Shared Accountability Principle. **Appendix G** contains the literature review for the Prevention Principle. **Appendix H** contains the literature review for the Cultural and Linguistic Competency Principle. **Appendix I** contains the NBI Refinements and Additions Summaries; and **Appendix J** contains the April 30, 2014 draft version of the Technical Assistance Guide to NBIs.

CHAPTER 2. METHODOLOGY

Under the NBIC, a working vision for a balanced, person-driven long-term services and supports (LTSS) system was developed. This vision provided the broader context for the rest of the work conducted under the NBIC and was vetted with CMS, the SPT Grantee States, the Technical Expert Panel, and other key stakeholders, including other government agencies.

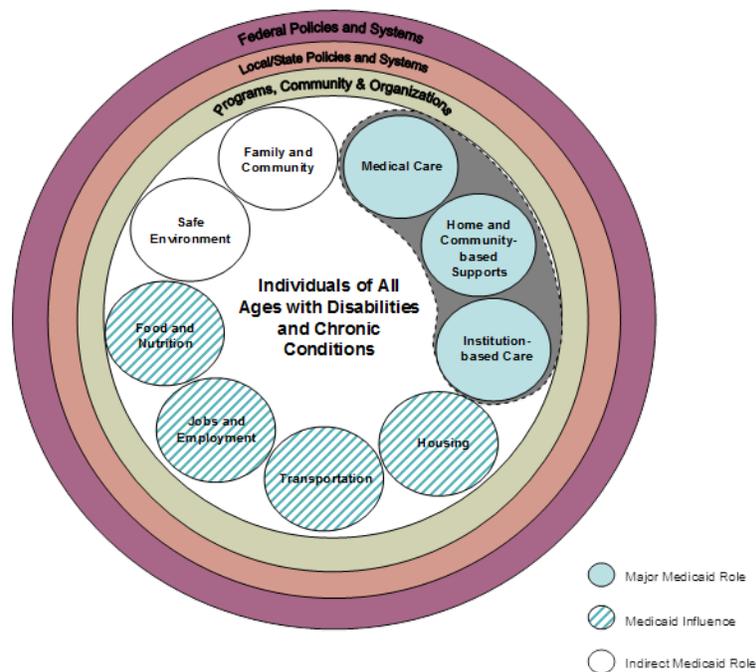
The vision developed pursuant to the NBIC is aligned with CMS's other efforts to develop a balanced, person-driven system. Examples of these efforts include the Real Choice Systems Change, New Freedom, Money Follows the Person (MFP), Balancing Incentive, and Direct Service Worker Resource Center Initiatives. The NBIC vision for a balanced, person-driven system of long-term services and supports is as follows.

A balanced, person-driven long-term services and supports system assures optimal physical and mental health, well-being, and functioning for people with disabilities and/or chronic conditions across their lifespan. High quality health and supportive services are provided in the most integrated setting, in a manner in which individuals have maximum choice and control.

The LTSS system of the future will provide extensive and varied services and supports to individuals with disabilities through a diverse range of sectors, including medical care, formal and informal home and community-based supports, institution-based care, access to housing, transportation, employment, food and nutrition, a safe environment, and family and community. The features and the types of services and supports associated with these sectors are described in greater detail in the white paper entitled *A Vision of LTC System of the Future* (2008) and the NBIC Literature-based Measure Report Draft Final (06/27/08). Both reports were prepared by IMPAQ International and Abt Associates.

Exhibit 3 below presents all of the sectors of services and supports that comprise a balanced, person-driven LTSS system. The individual with disabilities who is the intended beneficiary of the supports described in Exhibit 3 is assured health and wellbeing through the provision of services and supports from *all* of the nine sectors displayed. The services and supports that are provided to the beneficiary are determined by three levels of influence, as represented in Exhibit 3 by the concentric circles surrounding the individual and the LTSS system sectors. These levels of influence are Federal systems and policies, state/local systems and policies, and programs, community, and organization.

Exhibit 3: Service and Support Sectors of a Balanced, Person-Driven System of LT Services and Supports



Under the NBIC, the IMPAQ International and Abt Associates project team developed a set of six principles that form the foundation of the conceptual framework to measure the envisioned person-driven LTSS system. These principles underlie the provision of services and supports delivered by all entities in all sectors of the LTSS system (IMPAQ International & Abt Associates, 2011).

The NBIC team developed these principles after thoroughly reviewing concepts and frameworks from many sources including the Agency for Healthcare Research and Quality (AHRQ) Home and Community-Based Services Measures Scan and the CMS Quality Framework.³ The team developed the principles iteratively, first by defining the features that one would expect to see within each principle and then by further refining them with input from CMS, stakeholders, and the Technical Expert Panel, and from indicators found in the literature (IMPAQ International and Abt Associates, 2011).

The NBIC team developed the initial set of indicators by conducting a literature review, which consisted of a comprehensive measures scan of published and gray literature to document

³ HCBS Quality Framework (2002) Baltimore, MD: CMS (Updated in 2004). The framework was developed in part with the National Association of State Directors of Developmental Disabilities, State Units on Aging and State Medicaid Directors. See <http://www.hcbs.org/moreinfo.php/doc/647>.

existing indicators of a balanced LTSS system and to determine the utility and feasibility of using these indicators. The team presented the results of the scan in two reports that it submitted to CMS: the NBIC Literature-Based Measures Report and the NBIC Technical Summary (IMPAQ International and Abt Associates, 2011).

The NBIC team identified a total of 575 existing indicators: 228 at the individual-level and 347 at the system-level. After extensive analysis and evaluation, the team concluded that 175 indicators across the six NBIC Principles met the evaluation thresholds set by the NBIC and recommended them for further consideration by CMS. After several iterations, the team selected the final 18 indicators. The evaluation criteria that the team used to assess the existing indicators included relevance, feasibility, technical quality, susceptibility to influence, administrative usability, and population (IMPAQ International and Abt Associates, 2011).

The National Balancing principles and indicators developed under the NBIC needed further refinement and additions to address the new data and information that was available, lessons learned during the field testing of the NBIs and the state self-assessment survey instrument, feedback received from SPT Grantee States, TEP and Stakeholder Group members, Federal Partner agencies, and other not-for-profit agencies, and changes in the LTSS policy landscape. These refinements and additions occurred in two waves (2010 to 2012, and the latter part of 2012 to 2014) during the NBIP.

The refinements and additions that the team made enhanced the existing principles, NBIs, and the state self-assessment survey instrument and enabled the team to add one additional principle (Cultural and Linguistic Competency) and nine new NBIs (SD3. Risk Assessment and Mitigation; SA1. Fiscal Responsibility; SA2. Personal Responsibility; SA3. Individuals and Families are Actively Involved in LTSS Policy Development; SA4. Government, Provider, and User Accountability; CI4. Transportation; P2. Disaster/Emergency Preparedness; CLC1. Needs Assessment and Target Population; CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups; and, CLC3. Cultural and Linguistic Competency Training Requirements).

The methodology used by the NBIP team to further refine and add to the NBIs developed under the NBIC included the following activities:

- Reviewed relevant literature and data on existing LTSS indicators being developed under separate initiatives;
- Implemented a collaboration and communication strategy that included consultation with, and feedback from SPT Grantee States that participated in the field testing, LTSS experts (e.g., TEP and Stakeholder Group members); and Federal Partner agencies and other not-for-profit organizations (e.g., AARP) that were developing LTSS indicators under separate initiatives;
- Prepared a crosswalk of the NBIs to LTSS indicators being developed under separate initiatives and summarized the findings in a report;

- Conducted field testing of the principles, NBIs and state self-assessment survey instrument in 2012 with seven SPT Grantee States (AR, FL, ME, MA, MI, MN & KY), reviewed the results along with feedback from the TEP and Stakeholder Group members and incorporated feedback, as appropriate;
- Conducted three conference call meetings with the TEP and conducted follow-up calls with select TEP members in the fall of 2013 to obtain feedback on the principles, NBIs and survey instrument;
- Further refined and expanded on the NBI principles, indicators and Technical Assistance Guide (TAG) for NBIs which includes self-assessment survey instrument based on TEP member feedback; and,
- Prepared the NBIP Measures Additions and Refinements Report.

The NBIP team's activities to refine and add to the NBIs developed under the NBIC are discussed in more detail below.

2.1 Review of Current Literature and Data Available

Under the NBIP, the project team reviewed current literature and data related to the principles and NBIs in two waves from 2011 to 2012 and from the latter part of 2012 to 2014 before the team began to make refinements and additions to the NBIs. The team's review of the literature was particularly instrumental in refining the Prevention and Shared Accountability Principles and developing the new Cultural and Linguistic Competency Principle. In addition, the review of the currently available data led to the expanded use of secondary data for several of the NBIs, including indicators examining LTSS expenditures and care coordination.

2.2 Review of NBIC Developmental Indicators

The NBIP team reviewed the developmental indicators that were deemed feasible to explore by the project team under NBIC as part of the first wave of NBI refinements and additions (2010 to 2012). The team reviewed these indicators to determine whether applicable literature and data supported their inclusion in the NBIs. For example, the team included Developmental Indicator 14, *Availability and Use of Transportation Services*, during the first wave of refinements and additions after the team determined that it could develop state self-assessment survey questions to collect appropriate and responsive data. The team declined to include developmental indicators in the first wave of refinements and additions that it determined to be infeasible, either because there was a lack of information detailing how to implement the indicators or because data were not available. Exhibits 4 and 5 below describe the developmental indicators that the team reviewed to determine whether to include them in the NBIs as part of the first wave of refinements and additions.

Exhibit 4: Developmental NBIs Deemed Feasible to Explore by the NBIC Team

#	Developmental NBI	Description
1.	Financial and Programmatic Capacity of the State System	This indicator examines the State's capacity to deliver LTSS more effectively. The indicator was developed to address the sustainability of the funding feature within the sustainability principle and to measure the sustainability of the state's LTSS system structure.
2.	Sustainability of Placement Within the Community	This indicator examines the burden experienced by the user due to continual changes in placements in HCBS and institutions.
3.	Capacity of the Informal Caregivers Support System	This indicator examines the employment status and stress levels of informal caregivers.
4.	Assessment of the Family's Ability to Have a Life Outside of Caregiving	This indicator examines the feature "Availability and Access to Relationships with Family, Friends, and Community Support Networks."
5.	Extent of Isolation When Living at Home	This indicator examines the isolation experienced by the user when living at home and in the community.
6.	Certification and Licensure Requirements Inhibiting Consumer Control	This indicator examines whether the state is minimizing the type and number of licenses or certifications required to provide LTSS, which would give individuals more freedom to choose their LTSS. This indicator highlights that choice is a critical characteristic of a balanced, person-driven LTSS system.
7.	Housing Requirements Limiting Housing Options (or Living Arrangements)	These indicators examine the ability of a user to choose housing arrangements, as well as take responsibility for his or her choice. The latter is particularly relevant to requests from stakeholders to guarantee that the "System Allows for the Dignity of Risk."
8.	Ability to Live Alone	
9.	Measurement of the Privacy and Autonomy of People With Disabilities Within Communities	This indicator examines the abilities of persons with disabilities to live within their communities with the greatest amount of personal privacy and autonomy. Similar to the housing requirement indicator(s), this indicator addresses the feature "System Affords Individual Choice and Control" of the Self-Determination/Person-Centeredness Principle.
10.	Criteria for Leaving Institutional Settings	This indicator examines the stringent criteria for leaving nursing facilities and other facilities for HCBS.
11.	Proportion of Community Dwelling Disabled (Poor) Individuals in the State that Receive Medicaid HCBS Services	This indicator examines the number of persons with disabilities who are low-income and receive HCBS compared to all HCBS recipients.
12.	People with Disabilities and at Risk (Older Adults) Are Effectively Included as Priority Populations in Community-Wide Disaster and Emergency Planning	This indicator examines the planning for potential disasters and emergencies across LTSS settings to ensure LTSS users' safety.
13.	Communication Among Providers	This indicator examines the communication requirements among providers for individuals transitioning between services. Communication is essential to ensure that transitions are seamless and effective for users.
14.	Availability and Use of Transportation Services	The indicator examines the transportation services that are provided within supported employment programs, as well as

#	Developmental NBI	Description
		state-funded initiatives that encourage and support independence and community integration through employment opportunities for persons with disabilities.
15.	Stakeholders Participate in Planning for Services: HHS Involves Stakeholders in Identifying Service Gaps and Identifying and Implementing New Service Models	This indicator examines whether stakeholders are involved in developing and implementing policies, programs and services.
16.	Direct Service Workforce Completing Training or Apprenticeship Programs	This indicator examines additional information related to DSW training requirements. Workers captured could be CNAs or HHAs working in certified provider organizations; workers not covered by Federal OBRA requirements (e.g., PCAs, home care aides, aides working in assisted living facilities); Medicaid consumer-directed programs; and universal core curriculum and specialty aide positions (e.g., medication aide, geriatric aide, senior aide); nurse supervisors/managers.
17.	Direct Service Workforce Compensation, Volume, and Stability	This indicator examines (1) LTC worker compensation (average hourly wages, benefits, including health insurance, and paid time off), (2) LTC workforce volume (number of full-time workers, number of part-time workers), and (3) LTC workforce stability (turnover rate, vacancy rate).
18.	Proportion of Caregivers Seeking Respite Services Who Receive Them	This is a Behavioral Risk Factor Surveillance System (BRFSS) Indicator.
19.	Proportion of Families Reporting that Staff or Translators are Available to Provide Information, Services, and Supports in the Family/Family Member's Primary Language/Method of Communication	This is a National Core Indicator in the Sub Domain Access and Support Delivery.
20.	Measures of Patient and Family Satisfaction with Services, as well as the Incidence of Complaints, Violations, and Deficiencies	This is an individual-level indicator that examines user satisfaction with LTSS. As part of the revision of the Shared Accountable principle, this proposed indicator was redefined and its essence was captured in the development of the Shared Accountability Indicator.

Exhibit 5: Developmental Indicators Expanded From 2010 Version *

#	NBI Developmental Indicator	Description
21.	Number of Persons in the State on the HCBS Waiting List	This indicator examines States' efforts to maintain waitlists as a tool to measure the need for waiver services and to prioritize those interested in waiver services.
22.	Requirements for Attendant Selection	This indicator examines the requirements for an individual selecting an attendant. To provide individuals with the most comprehensive set of choices, requirements for attendant selection should be minimal.
23.	Coordination of Budgetary, Programmatic, and Oversight Responsibility for Institutional and HCBS LTSS.	This indicator examines State coordination of budgetary, programmatic and oversight responsibility for institutional and HCBS LTSS.

* Note: These indicators were included as 2009 short-term developmental indicators.

2.3 Review of Results of 2010 and 2012 NBI Field Testing

The state self-assessment survey instrument served as the primary source of data for the majority of the LTSS indicators. To test the clarity of the state self-assessment instrument and, indirectly, the validity of the NBIs, the NBIP team undertook a data collection effort in 2010 and again in 2012.

The seven State Profile Tool (SPT) Grantee States (AR, FL, ME, MA, MI, MN and KY) selected to complete the state self-assessment survey instrument in 2012 also were part of the 2010 data collection and were awarded an additional grant to continue the refinement and expansion process. The data collection effort began in spring 2012 and concluded in late summer 2012. SPT Grantee States' effort in and dedication to the data collection process was substantial. Several representatives from the SPT Grantee States completed the self-assessment tool, and SPT Grantee States provided responsive feedback on the questions and indicators, particularly during the refinement process. To ensure that SPT Grantee States were able to meet the demands of the revised timeline, the NBIP team provided intensive support to the Grantee States by answering their questions, sending reminders to them, hosting a webinar that provided information on how to use the self-assessment instrument, and by participating in multiple National SPT conference calls.

Results from the 2010 and 2012 NBI field testing of the self-assessment survey instrument were instrumental in the refinements and additions made during the 2011 to 2012 wave and 2012 to 2014 wave of refinements and additions.

2.4 Collaboration and Communication Strategy

The key stakeholders in the project's collaboration and communication strategy were the State Profile Tool (SPT) Grantee States, the Technical Expert Panel (TEP), Stakeholder Group members, Federal Partners, and other not-for-profit organizations. The NBIP Team reviewed the feedback received from the various LTSS experts, SPT Grantee States, and stakeholders and determined the extent to which the feedback was incorporated. For example, although the TEP recommended eliminating a number of NBIs and related survey questions, including Indicator CI1, *Waiver Waitlist*, the NBIP team chose to retain some of these NBIs because of their possible application in the future. In some cases, the NBIP team sought guidance from CMS to determine which NBIs and survey questions should be deleted or retained based on TEP recommendations.

The NBIP team's collaboration and communication strategy with each of these groups is discussed in more detail below.

State Profile Tool Grantee States

Ten SPT Grantee States (AR, FL, IA, KY, ME, MA, MI, MN, NV and VA) participated in field testing the principles, NBIs, and state self-assessment survey instrument during the NBIC in 2010. Seven Grantee States (AR, FL, ME, MA, MI, MN and KY) participated in field testing during the NBIP in 2012. The SPT Grantee States also provided additional consultation and feedback as requested by the NBIP team and CMS.

To develop the 2012 version of the principles, principle features, NBIs, and the state self-assessment survey instrument under the NBIC, the NBIP team held regular meetings with the seven SPT Grantee States from January 2011 through March 2012. From April through July 2012, seven SPT Grantee States field tested the state self-assessment survey instrument that contained questions related to the principles, principle features, and NBIs that had been revised during the first wave of refinements and additions and provided feedback on their experiences. Finally, the NBIP team held monthly calls with the seven SPT Grantee States from fall 2011 through spring 2012 to provide the team with guidance on programmatic and data issues related to the feasibility of collecting the data required to implement the NBIs.

Technical Expert Panel (TEP)

CMS led the process of selecting new members to the TEP during the spring of 2011. Between July and September 2011, TEP members participated in regular conference calls with the NBIP team during which they provided input on the principles, principle features, NBIs, and self-assessment survey instrument developed under the NBIC, and provided guidance on programmatic, policy, and data collection issues. The discussions with TEP members and the internal review conducted by the NBIP team largely validated many of the suggestions made by the SPT Grantee States and confirmed that they were methodologically sound and reflected current LTSS research.

In fall 2013, TEP members participated in a series of three meetings and seven additional follow-up calls in which they provided additional comments and guidance on the principles, principle features, NBIs, and the state self-assessment survey instrument. During these calls, the TEP members provided specific feedback on second wave refinements and additions, and offered guidance on how each principle, principle feature, NBI, and the state self-assessment survey instrument could be strengthened and on programmatic, policy, and data collection issues. The NBIP team incorporated the TEP members' feedback into the refinements and additions that it made to the principles, principle features, NBIs, and the state self-assessment survey instrument that it submitted to CMS on February 28, 2014.

Stakeholder Group

The NBIP team selected members of the Stakeholder Group in consultation with CMS. The Stakeholder Group included representatives of consumer advocacy organizations, state agency program staff, state associations, and LTSS providers (e.g., institutional providers,

community-based organizations, and medical, nursing, allied health, and paraprofessional organizations). These individuals provided comments and guidance on the principles, principle features, NBIs, and self-assessment survey instrument during conference calls conducted in 2011. To ensure that the feedback that the NBIP team received from LTSS experts and SPT Grantee States and that the research conducted by the NBIP team was current, members were asked to identify additional issues that might affect LTSS users. The NBIP team incorporated the feedback that it received from the Stakeholder Group into the additions and refinements that it made to the principles, principle features, NBIs, and state self-assessment instrument submitted to CMS on February 28, 2014.

Federal Partner Agencies

CMS selected Federal Partner agencies with which to exchange research agendas and LTSS indicators that they were currently developing. The NBIP team contacted 13 potential Federal Partner agencies (see Appendix A). On October 13, 2011, Jennifer Burnett at CMS and the NBIP Project Director at IMPAQ International sent invitation letters to these Federal Partner agencies on CMS letterhead inviting them to serve as Federal Partners for the NBIP.

CMS and the NBIP team conducted four meetings with the Federal Partner agencies in February, April, June, and August 2011. The first meeting served as an introductory meeting, while the remaining meetings focused on preparing the NBI Crosswalk Report. The meetings included discussions of findings and feedback, gaps in LTSS research, NBI refinements, direct service workforce, the expansion of the Shared Accountability Principle, and the addition of the Cultural and Linguistic Competency Principle. The information gleaned from these meetings informed the team's recommendations for NBI refinements and additions.

Prior to implementing the state self-assessment survey instrument, Federal Partners agencies from within and outside the U.S. Department of Health and Human Services (HHS) were invited to provide input on how their agencies might use the NBIs. As a result of the collaboration with these agencies, the NBIP team expanded several NBIs. The NBIP team also conversed with and received feedback from a number of not-for-profit organizations, including AARP and Benjamin Rose Institute, to gather information on their LTSS indicators.

Crosswalk of LTSS Balancing Indicators

The crosswalk that the NBIP team prepared in 2011 mapped the NBIs developed under the NBIC to the LTSS balancing indicators developed by the Federal Partner agencies and other not-for-profit organizations prior to 2011. The crosswalk enabled the team to identify overlapping and complementary efforts and highlighted gaps in the NBIs, as well as synergies across LTSS indicators created by Federal Partner agencies and other not-for-profit organizations. The NBIP team assessed the equivalency and relationship strength of each LTSS indicator and then compared the results to the six principles and 18 NBIs developed under the NBIC. The team based LTSS indicator equivalency and strength on three criteria: (1) equivalency in scope, (2) attributes and (3) non-equivalent indicators. The following describes the three criteria.

Equivalency in Scope

The NBIP team's first step in examining the equivalency between the NBIs and the LTSS indicators developed by Federal Partner agencies and other not-for profit organization(s) was to assess the scope of the indicators. The team determined that the indicator was equivalent if the scope of a Federal Partner agency/not-for-profit organization's LTSS indicator was similar to the scope of a NBI.

Attributes

After the NBIP team assessed the equivalency in scope of the Federal Partners agencies' and not-for-profit organizations' LTSS indicators, the team further reviewed the LTSS indicators and NBIs to determine relationship strength. The team assessed 56 indicators from Federal Partner agencies and not-for-profit organizations as equivalent in scope to one of the NBIs. The team then assessed these indicators further to determine the strength of the relationship. The team assessed relationship strength by comparing the following five attributes: (1) age focus, (2) disability focus, (3) data source, (4) unit of analysis (individual-level data or system-level data), and (5) environment (HCBS or Institutional). The LTSS Indicators that the team identified as having a strong relationship with an NBI shared all five of these attributes.

Non-Equivalent Indicators

Many of the Federal Partners agencies' and not-for-profit organizations' LTSS indicators did not have an NBI equivalent based on the criteria that the team used to assess LTSS indicator equivalency. Accordingly, the team assessed LTSS indicators without a NBI equivalent against the features of the NBI principles to determine whether there was a potential for them to complement or supplement the NBIs. The team determined that the non-equivalent LTSS indicators had the potential to enrich the NBIs because the Federal Partner agencies or not-for-profit organization(s) already were collecting or planned to collect this information, therefore minimizing the data collection burden on States.

Of the 272 Federal Partner agencies' and not-for-profit organizations' LTSS indicators that the NBIP team examined, 218 did not have an equivalent NBI. The team recommended that the 218 LTSS indicators be examined further as part of a system-wide gaps analysis to determine their applicability to the NBI principles and principle features.

Finally, Exhibit 6 below provides an example of how the NBIP team used the methods described in this chapter to further refine and/or add to an NBI (e.g., Indicator SD1. *Licensure and Certification Requirements Inhibiting Consumer Control*, included under the Self-Determination Person-Centered Principle). The first column in Exhibit 6, "Sub-indicator," identifies the sub-indicators that the team examined within the indicator. The second column, "Feedback Received," provides a summary of the feedback that the team received from the various stakeholder groups involved in the refinements and additions of the NBIs. The third column, "Modifications," describes the refinements and additions that the team made to the indicator

based on its examination of current literature, LTSS balancing indicators used by the Federal Partner agencies and not-for-profit organizations, and feedback that it received from experts in the area of self-determination. Finally, the column “New Focus of NBI” summarizes the new focus of the indicator after the team considered and incorporated all sources of information.

Exhibit 6: Process Used to Refine Indicator SD1. Licensure and Certification Requirements Inhibiting Consumer Control

Indicator SD1. Licensure and Certification Requirements Inhibiting Consumer Control Refinement			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
SD1a. Residential Setting Requirements	None reported.	The indicator was refined to eliminate institutional settings due to differences in health maintenance restrictions.	The focus of the indicator has been expanded to examine (1) residential setting requirements inhibiting consumer control, (2) attendant hiring requirements inhibiting consumer control, and (3) a broader approach to the relationship between a licensed nurse and unlicensed personnel in HCBS setting and barriers to nurse delegation.
SD1b. Attendant Hiring Requirements	None reported.	None made.	
SD1c. Nurse Delegation	<p>LTSS experts reported that the indicator’s view of nurse delegation was too narrow in its focus on the relationship between a licensed nurse and unlicensed personnel.</p> <p>In addition, they reported that institutional settings have regulations that prevent a licensed nurse from delegating duties to unlicensed personnel.</p>	<p>The indicator was expanded to examine residential setting requirements and attendant hiring requirements in addition to nurse delegation. Nurse Delegation became a sub-indicator and was expanded to examine specific health maintenance tasks rather than general categories, consistent with AARP’s LTSS Scorecard. The indicator also was expanded to examine barriers to nurse delegation, including risk of liability and legal limitations.</p>	

Additional exhibits, found in Chapter 3 of this Report, summarize the feedback that the team received from SPT Grantee States and LTSS experts on how best to refine and/or add to the NBIs, discuss modifications that the team made to the indicators, and summarize the new focus of each of the NBIs.

CHAPTER 3. NBI REFINEMENTS AND ADDITIONS

The NBIP team further refined the National Balancing Indicators (NBIs) developed under the NBIC in two waves between 2010 and 2012 and from the latter part of 2012 to 2014. The NBIP team work addressed and incorporated new data and information, lessons learned during the field testing of the NBIs and the state self-assessment survey instrument with the STP Grantee States, feedback received from the SPT Grantee States, TEP and, Stakeholder Group members, Federal Partner agencies, and not-for-profit agencies, and changes in the LTSS policy landscape that occurred during the project period from 2010 to 2014. This chapter describes the refinements and additions that the NBIP team made to the NBIs during the two waves of the NBIP: 2010 to 2012, and the latter part of 2012 to 2014.

3.1 Sustainability Principle

3.1.1 Overview

The Sustainability Principle contains five indicators that examine whether a state's LTSS system is financially sustainable and is supported by an adequate infrastructure and a quality workforce. The indicators also are used to examine flexible financing (e.g., global budgeting) and LTSS expenditures, as well as the size and quality of the direct service workforce and support provided for informal caregivers. This section discusses the principle features and indicators included in the Sustainability Principle, including the feedback that the NBIP team received from LTSS experts and refinements and additions that the team made to the indicators during the NBIP.

3.1.2 Principle Features and Indicators

The NBIC team developed the following five principle features for the Sustainability Principle:

- Flexible Financing of LTSS
- Sustainability of Funding for LTSS
- Supported by a Highly Qualified, Motivated, and Sustainable Workforce
- System is Efficient and Contains Costs (e.g., Prevents Fraud and Abuse)
- System Provides Support for Informal Caregivers

The team initially developed one additional principle feature for the Sustainability Principle. The additional principle feature was, "System is efficient and contains costs (e.g., prevents fraud and abuse)." This principle feature was not implemented because either the team or the Federal Partners were unable to develop an indicator that was related to it.

The NBIC and NBIP teams developed the following five indicators to examine these principle features five indicators were developed. They include:

- Indicator S1. *Global Budget*
- Indicator S2. *Medicaid Expenditures*
- Indicator S3. *Direct Service Workforce (New)*
- Indicator S4. *Support for Informal Caregivers*
- Indicator S5. *Shared Long-Term Supports and Services Mission/Vision Statement*

The NBIP team made refinements and additions to these indicators based on discussions with LTSS experts, as well as a review of current data and literature. These refinements and additions are summarized below. Additional information related to the refinements and additions for each of the indicators included in the Sustainability Principle is presented in Appendix I.

Indicator S1. Global Budget

Indicator S1. *Global Budget* examines the “Flexible Financing” Feature of the Sustainability Principle included in the NBIC Conceptual Framework. Global budgeting is a financing mechanism that can be used by States to promote more balanced LTSS programming and improve cost effectiveness. Also known as “pooled financing,” global budgeting has two dimensions. The first is a limit or cap on total spending. The second is the administrative freedom to manage costs within the spending limit (Hendrickson, 2004). A global budget may apply to certain services within the LTSS system (i.e., in the case of services administered by a State Department of Intellectual and Developmental Disabilities Services) or the LTSS system as a whole.

A State can use a global budget to target LTSS funds based on projected need and program and policy initiatives. Using a global budget approach also may enable a State to respond to changes in demand for LTSS by reallocating budget funds, for example, from institutional care to home and community-based services (HCBS) or vice versa, within an overall spending limit (Ohio Department of Aging Unified Long-term Care System Planning, 2009).

2011 to 2012 Refinements and Additions

The NBIP team did not make any refinements or additions to Indicator S1. *Global Budget* prior to the 2012 NBI field test.

2012 to 2014 Refinements and Additions

The NBIP team made minor refinements and additions to Indicator S1. *Global Budget* during the period from 2012 to 2014 to examine how managed care and fee-for-service funding schemes

may affect the implementation of a global budget. These refinements and additions are summarized in Exhibit 7 below.

Exhibit 7: Summary of Refinements and Additions Made to Indicator S1 from 2012 to 2014

Indicator S1. Global Budget Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members requested clarification on what is meant by “global budget,” and specifically who and what are covered by one. They also were concerned that a global budget may not be an appropriate indicator of a balanced, person-driven LTSS system. Finally, they suggested that the indicator be expanded to examine managed care as well as fee-for-service funding mechanisms.	The team expanded the indicator to examine the implementation of global budgeting under both managed care and fee-for-service payment systems.	The focus of this indicator remained the same.

Indicator S2. Medicaid Expenditures

Indicator S2. *LTSS Expenditures* examines States’ Medicaid spending for institutional services and HCBS to determine States’ priorities in funding a balanced LTSS system. Recent literature has reported that States that offer Medicaid-funded HCBS as an alternative to Medicaid-funded institutional services are complying with the *Olmstead* decision and meeting the demands of those in need of LTSS. The expansion of HCBS appears to indicate a short-term increase in Medicaid spending, followed by a reduction in institutional spending, and an increase in long-term cost savings (Kaye, 2009). In addition, States that utilize non-Medicaid LTSS funding can provide LTSS to individuals who otherwise might not be eligible to receive Medicaid-funded LTSS and thus be at risk for institutional placement.

This indicator includes the following four sub-indicators:

- S2a. *Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending;*
- S2b. *LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility;*
- S2c. *Medicaid Funding Sources;* and,
- S2d. *LTSS Funding From Non Medicaid Sources.*

The four sub-indicators report on Medicaid LTSS expenditures and changes in expenditures at the Federal and state levels. The fourth sub-indicator reports on LTSS Funding received by the States from non-Medicaid sources. Due to the differences in claims reporting and services taxonomy, these are not perfect measures. However, they provide a context for the use of Medicaid and other resources across LTSS institutional services and HCBS.

2011 to 2012 Refinements and Additions

The NBIP team substantially refined and added to Indicator S2 prior to the 2012 field test. The indicator that the team developed under NBIC examined coordination efforts between LTSS and housing. During the 2011 to 2012 refinements and additions, based on feedback provided by LTSS and housing experts, the team expanded Indicator S2 to examine the availability of and access to housing, as well as coordination. The refinements and additions that the team made to S2 are summarized in Exhibit 8 below.

Exhibit 8: Summary of Refinements and Additions Made to Indicator S2 Prior to 2012

Indicator S2. Medicaid Expenditures Refinement			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
S2a. Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending	SPT Grantee States suggested that combining expenditures across population groups can mask gaps in Medicaid spending for specific populations. They also suggested that the team include individual level data and expand the services included in the calculation to include additional services, such as hospice.	The indicator was expanded to include information from Truven Health Analytics (THA). THA reports Medicaid expenditure that examine HCBS and institutional expenditures by the ID/DD and A/D (aging and physically disabled) populations. In addition, calculations of HCBS and institutional expenditures were revised to include the full range of LTSS expenditures as reported in THA Medicaid expenditure reports using 2010 CMS Report 64 data.	The focus of the indicators remained the same.
S2b. LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility	None reported.	None made.	
S2c. Medicaid Funding Sources	LTSS experts raised concerns that the funding sources only addresses services for seniors and suggested that it be expanded to include additional services for other age groups and disability types.	The indicator was expanded to include an additional sub-indicator S2c that examines Federal Medical Assistance Percentage (FMAP), grant funds made available under the Affordable Care Act (ACA) and other sources, as well as to reflect changes in eligibility requirements caused by a State's fiscal environment.	

2012 to 2014 Refinements and Additions

The team made several refinements to the indicator during the period 2012-2014 in order to better understand States' LTSS expenditures. These refinements are summarized in Exhibit 9 below.

Exhibit 9: Summary of Refinements and Additions Made to Indicator S2 from 2012 to 2014

Indicator S2. Medicaid Expenditures Refinement			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
S2a. Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending	In order to align LTSS expenditures with services provided, the TEP suggested that the NBIP team review the services provided under the Balancing Incentive Payment (BIP) program. TEP members felt that it would strengthen sub-indicator S2a if assisted living expenditures were included.	The indicator was refined to include updated THA data.	The focus of the indicator remains the same.
S2b. LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility	TEP members reported that the direction of sub-indicator S2b was unclear and that increased LTSS expenditures might not be good indicators of sustainability.	None made.	
S2c. Medicaid Funding Sources	A TEP member suggested that it would be useful to know the proportion of LTSS funding that is non-Medicaid.	None made.	
S2d. LTSS Funding From Non-Medicaid Sources	None reported.	The indicator was expanded to include sub-indicator S2d, <i>LTSS Funding From Non-Medicaid Sources</i> , to more closely examine the balance of LTSS funding sources from Medicaid and non-Medicaid sources.	

Indicator S3. Direct Service Workforce

Indicator S3. *Direct Service Workforce* examines the sizes and sustainability of States' workforces. This indicator includes four sub-indicators: S3a. *Direct Service Workforce Registry*; S3b. *Direct Service Workforce: Volume, Compensation and Stability*; S3c. *Direct Service Workforce Competency*; and S3d. *Direct Service Workforce Training*.

2011 to 2012 Refinements and Additions

The NBIP team substantially refined and made additions to Indicator S3. *Direct Service Workforce*, prior to its 2012 field test. During the 2011 to 2012 refinements and additions, the team expanded Indicator S3. *PCA Registry* based on feedback provided by LTSS experts so that it would better examine additional aspects of a sustainable workforce. The team changed the name of the indicator to be more inclusive of various workforce types. The refinements and additions made to S3 are summarized in Exhibit 10 below.

Exhibit 10: Summary of Refinements and Additions Made to Indicator S3 Prior to 2012

Indicator S3. Direct Service Workforce			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
S3a. Direct Service Workforce Registry	<p>SPT Grantee States suggested that the indicator capture legislation that prohibits the implementation of a state-maintained direct service worker (DSW) registry, the geography covered by the registry, and the usefulness of the registry for providers and users.</p> <p>TEP members suggested that private registries should be included and that States should use a registry to monitor to assess DSW capacity.</p> <p>Finally, TEP members suggested that workforce types be expanded and the name of the indicator be modified to DSW to reflect this expansion.</p>	<p>The indicator was expanded to examine the option for States to have multiple DSW registries covering multiple geographic areas or worker types. It also was expanded to examine policies in place that prohibit States from implementing a state-maintained DSW registry and if alternative mechanisms for providing a DSW registry exist. Finally, the title of the indicator was modified to Direct Service Workforce to include the full range of LTSS workforce types.</p>	<p>The focus of this indicator was expanded to examine not only the existence of a DSW registry, but the volume, compensation, and stability of the direct service workforce.</p>
S3b. Direct Service Workforce: Volume, Compensation, and Stability	None reported.	None made.	

2012 to 2014 Refinements and Additions

Indicator S3. *Direct Service Workforce* underwent only a few refinements during the period of 2012 to 2014. The refinements are summarized in Exhibit 11 below.

Exhibit 11: Summary of Refinements and Additions Made to Indicator S3 from 2012 to 2014

Indicator S3. Direct Service Workforce			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
S3a. Direct Service Workforce Registry	<p>TEP members suggested that the indicator be refined to examine whether training is provided to the DSW workforce, the type(s) of training provided, if any, how training is paid for, etc. They also suggested that the indicator examine registries that identify qualified and available workers, as well as other screening services that identify workers who are poor performers and/or who have been convicted of a felony.</p> <p>TEP members questioned whether a state-wide registry is really ideal.</p>	The indicator was refined to better capture information related to registry and LTSS workforce characteristics.	The focus of this indicator was expanded to examine not only the existence of a DSW Registry and the volume, compensation, and stability of the direct service workforce, but workforce competency and training.
S3b. Direct Service Workforce: Volume, Compensation, and Stability	None reported.	None made.	
S3c. Direct Service Workforce Competency	None reported.	The indicator was expanded to include sub-indicator S3c, which was added to capture information related to DSW competency.	
S3d. Direct Service Workforce Training	None reported.	The indicator was expanded to include sub-indicator S3d, which was added to capture information related to DSW training.	

Indicator S4. Support for Informal Caregivers

The Indicator S4. *Support for Informal Caregivers* examines the “Support for Informal/Family Caregivers” Feature of the Sustainability Principle included in the NBI Conceptual Framework. Informal or family caregivers, referred to as “informal caregivers” throughout this indicator, are unpaid individuals who have no requirements for clinical certification or licensure and who provide assistance with ADLs and/or IADLs to people of all ages with disabilities and chronic conditions. This group includes legally responsible adults, including spouses, parents of minor children, and other family members, and other nonrelated adults, such as friends, or neighbors, of the individual receiving LTSS. Informal/family caregivers are an important group of “providers” in the LTSS system.

Informal/family caregivers donate labor hours and help contain LTSS costs and delay or prevent the nursing facility (NF) placements and/or hospitalizations. Approximately three-quarters (78 percent) of adults living in the community and in need of LTSS depend on informal caregivers as their only source of help, and 14 percent receive a combination of informal and formal care (Thompson, 2004). In 2007, the value of the services provided by family caregivers was estimated to be \$375 million (AARP, 2008). The mental and physical health and economic stability of informal caregivers may be negatively affected by caregiving, which threatens their ability to maintain their own wellbeing as well as that of the individual for whom they care.

States that provide financial, social, and other supports to informal caregivers will be better able to retain this essential “workforce,” and thereby meet the LTSS needs of the target population(s) in an optimal and cost-effective manner.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator S4. *Support for Informal Caregivers* during the period from 2011 to 2012. This team added this new Indicator S4 based on evidence of the importance of care provided by informal caregivers, including significant cost savings and delays in institutionalization. The importance of this NBI is evident in the research and recommendations from several LTSS experts and special volumes in top journals. The team field tested Indicator S4 along with the other NBIs in 2012. The refinements and additions made to Indicator S4 prior to 2012 are summarized in Exhibit 12 below.

Exhibit 12: Summary of Refinements and Additions Made to Indicator S4 Prior to 2012

Indicator S4. Support for Informal Caregivers Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>LTSS experts pointed out that tax incentives are not available in all States since some States do not have a state income tax. They suggested that additional caregiver supports such as information and assistance, training and education, support groups, and counseling be examined in this indicator.</p> <p>TEP members voiced concern about a State’s authority to provide support to informal caregivers who are not enrolled in programs targeted to caregivers. They also reported that it is impossible to know the number of people who receive services from informal caregivers, the number of informal caregivers per user, or the number of informal caregivers providing care to individuals who are not enrolled in publicly-funded programs.</p>	<p>The indicator was expanded to examine additional informal caregiver supports that are available in lieu of tax incentives. In addition, it was expanded to examine the combination of eligibility criteria and public awareness of informal caregiver supports and include BRFSS data to report the “percent of family caregivers usually or always getting needed support.”</p>	<p>The focus of the indicator remained the same.</p>

2012 to 2014 Refinements and Additions

The team made few refinements to Indicator S4. *Support for Informal Caregivers* during the period from 2012 to 2014. The few refinements made are summarized in Exhibit 13 below.

Exhibit 13: Summary of Refinements and Additions Made to Indicator S4 from 2012 to 2014

Indicator S4. Support for Informal Caregivers Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>TEP members reported that Indicator S4 did not thoroughly examine informal caregiver burden. They also reported that the indicator should more closely examine services provided by population type. They suggested that services, such as crisis services, may be provided to some LTSS users but not others.</p>	<p>The indicator was refined to examine programs and services that are available in a state to support informal caregivers. In addition, it was expanded to examine state requirements for informal caregivers to receive state-funded, Medicaid-funded, or other Federally-funded supports and services that are targeted for informal caregivers.</p>	<p>The focus of the indicator remained the same.</p>

Indicator S5. Shared Long-Term Supports and Services Mission/Vision Statement

A State agency's Mission or Vision Statement represents its commitment to a set of values and shared goals. It can be beneficial to States to have and disseminate a mission or vision statement that mandates and supports the implementation and maintenance of a person-centered and balanced LTSS system to provide services to individuals with disabilities in the most integrated settings.

Indicator S5. *Shared Long-term Supports and Services Mission/Vision Statement*, is used to examine whether a State agency has a mission and/or vision statement expressing its commitment to creating and maintaining a person-centered and balanced LTSS system that provides LTSS in the most integrated settings, which is used to guide policy and budgeting decisions.

2011 to 2012 Refinements and Additions

The NBIP team made substantial refinements and additions to Indicator S5. *Shared Long-term Supports and Services Mission/Vision Statement* prior to the 2012 field test. During the 2011 to 2012 refinements and additions, the team refined Indicator S5 to encompass Indicators S5. *Shared Long-term Supports and Services Mission/Vision Statement* and S6. *Quality of Long-Term Supports and Services Mission/Vision Statement*. These refinements and additions to S5 are summarized in Exhibit 14 below.

Exhibit 14: Summary of Refinements and Additions Made to Indicator S5 Prior to 2012

Indicator S5. Shared Longer-Term Supports and Services Mission/Vision Statement Refinement		
Feedback Received	Modifications	New Focus of Indicator
SPT Grantee States indicated that multiple agencies and programs provide LTSS and not all have Mission/Vision Statements. An agency or program may not necessarily establish its LTSS goals through a Mission or Vision Statement, but may do so through a strategic plan. They also noted that the degree to which a state complies with the tenets of the Mission/Vision Statement is not examined.	The indicator was expanded to examine various methods that States may have employed to establish their LTSS missions and visions, as well as methods to assess formal processes that are in place within each state to assess its compliance with its stated goals.	The focus of the indicator was expanded to include the implementation of a shared LTSS Mission or Vision Statement, as well as the quality of that Mission or Vision Statement.

2012 to 2014 Refinements and Additions

The team made few refinements to Indicator S5. *Shared Long-term Supports and Services Mission/Vision Statement* during the period from 2012 to 2014. The minor refinements that the team made to Indicator S5 are summarized in Exhibit 15 below.

Exhibit 15: Summary of Refinements and Additions Made to Indicator S5 from 2012 to 2014

Indicator S5. Shared Longer-Term Supports and Services Mission/Vision Statement Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members reported that a Mission or Vision Statement may be an important tool if stakeholders are involved in its development and it is implemented properly. TEP members reported that a Mission or Vision Statement that is not implemented in and publicized to the populations that the State intends to serve may not be effective.	The indicator was refined to more clearly examine the process in which a shared LTSS Mission or Vision Statement is developed and implemented by a State.	The focus of the indicator remained the same.

3.2 Self-Determination/Person-Centeredness Principle

3.2.1 Overview

Self-determination and control over one’s life is important for all individuals, including those with disabilities (Kennedy, 1996). Self-determination provides a conceptual framework for the development of a LTSS system that is person-centered and enables individuals, including those with disabilities, to make choices free from undue external influence or interference (Wehmeyer, 2003). This section discusses the SD Principle’s principle features and indicators, including feedback that the team received from LTSS experts and refinements and additions that it made during the NBIP.

The Self-Determination/Person-Centeredness Principle examines whether the LTSS system affords people with disabilities and/or chronic illness the authority to make the following decisions and determinations:

- where and with whom they live;
- the services that they receive and the organizations and individuals who provide those services;
- the opportunity to work and have private income; and,
- the opportunity to have friends and access supports that facilitate their participation in community life.

3.2.2 Principle Features and Indicators

The NBIC team developed the following seven principle features for the Self-Determination/Person-Centeredness Principle:

- Opportunities to Attain/Maintain Economic Self-Sufficiency
- Availability and Use of Self-Directed Services
- Person-Centered Planning is Available and Used by all Service Recipients

- Opportunities to Manage One’s Own Budget Funds
- Availability and Access to Relationships with Family, Friends, and Community Support Networks
- System Affords Individual Choice and Control
- System Allows for the “Dignity of Risk”

The NBIC team initially developed two additional principle features for the Self-Determination/Person-Centeredness Principle:

- Opportunities to attain/maintain economic self-sufficiency
- Availability and access to relationships with family, friends and community support networks

These principle features were not implemented because either the team or Federal Partners were unable to develop an indicator that was related to them.

To examine these Principle features, the NBIC and NBIP teams developed the following three indicators:

- Indicator SD1. *Regulatory Requirements Inhibiting Consumer Control*
- Indicator SD2. *Availability and Use of Self-Directed Services*
- Indicator SD3. *Risk Assessment and Mitigation (New)*

The NBIP team refined and added to these indicators based on its discussions with LTSS experts and its review of the most current literature. These refinements and additions are summarized below. Additional information related to the refinements and additions for each of the indicators included in the SA Principle is presented in Appendix I.

Indicator SD1. Regulatory Requirements Inhibiting Consumer Control

User choice is a major component of a balanced, person-driven, LTSS system (Woodcock, 2011). State LTSS regulatory requirements in some instances may provide individuals with less freedom to “customize” the LTSS that they receive and the organizations and individuals who provide them.

There are three sub-indicators under the Indicator SD1. *Regulatory Requirements Inhibiting Consumer Control*: (1) residential setting requirements, (2) attendant hiring requirements, and (3) nurse delegation. These sub-indicators measure the extent to which consumers or users are able to access LTSS in the least restricted environment of their choice.

2011 to 2012 Refinements and Additions

The team made several refinements and additions to Indicator SD1. *Licensure and Certification Requirements Inhibiting Consumer Control* between 2011 and 2012, including expanding the indicator’s focus. The refinements and additions that the team made to the Indicator SD1 prior to the 2012 field test are summarized in Exhibit 16 below. The team field tested Indicator SD1 along with the other NBIs in 2012.

Exhibit 16: Summary of Refinements and Additions Made to Indicator SD1 Prior to 2012

Indicator SD1. Licensure and Certification Requirements Inhibiting Consumer Control Refinement			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
SD1a. Residential Setting Requirements	None reported.	The indicator was refined to eliminate institutional settings due to differences in health maintenance restrictions.	The focus of the indicator has been expanded to examine (1) residential setting requirements that inhibit consumer control, (2) attendant hiring requirements that inhibit user control, and (3) a broader approach to the relationship between a licensed nurse and unlicensed personnel in HCBS settings and barriers to nurse delegation.
SD1b. Attendant Hiring Requirements	None reported.	None made.	
SD1c. Nurse Delegation	LTSS experts reported that the indicator took too narrow a view of nurse delegation by focusing on the relationship between a licensed nurse and unlicensed personnel. In addition, experts reported that institutional settings have regulations that prevent a licensed nurse from delegating duties to unlicensed personnel.	The indicator was expanded to examine residential setting requirements and attendant hiring requirements in addition to nurse delegation. Nurse Delegation became a sub-indicator and was expanded to examine specific health maintenance tasks, rather than general categories, consistent with AARP’s LTSS Scorecard. The indicator was expanded to examine barriers to nurse delegation, including risk of liability and legal limitations.	

2012 to 2014 Refinements and Additions

The team made several refinements and additions to Indicator SD1. *Regulatory Requirements Inhibiting Consumer Control* between 2012 and 2014, including a change in the name of the indicator. These refinements and additions are summarized in Exhibit 17 below.

Exhibit 17: Summary of Refinements and Additions Made to Indicator SD1 from 2012 to 2014

Indicator SD1. Regulatory Requirements Inhibiting Consumer Control Refinement			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
SD1a. Residential Setting Requirements	<p>TEP members questioned what was “bad” about licensure and certification regulations and suggested that there would be chaos without them. They also pointed out that the name of the indicator did not match the description of the indicator or what was included in the survey.</p> <p>Related to the Sub-indicator SD1a. Residential Setting, a TEP member suggested that the team review the final rules promulgated by CMS (§ 1915(i) and (c)) that were released on 1/10/14 related to residential settings and refine the sub-indicator accordingly.</p>	The sub-indicator SD1a was refined to include a reference to the new § 1915(i) and (c) final rules promulgated by CMS. The team deleted questions related to provider licensure and certification requirements from the survey.	The focus of the indicator was refined to examine regulatory requirements that inhibit consumer control rather than licensure and certification.
SD1b. Attendant Hiring Requirements	Related to the Sub-indicator SD1b. Attendant Selection, TEP members suggested that the NBIP team look more closely at self-directed services.	Sub-indicator SD1b was expanded to include additional questions related to person-driven personal attendant services, including activities that users are allowed to perform related to their attendants.	
SD1c. Nurse Delegation	TEP members suggested that the NBIP team remove questions related to training from the Sub-indicator SD1c. Nurse Delegation and put them in a central location related to the direct service workforce.	Sub-indicator SD1c was expanded to include additional questions to capture additional information related to a state’s Nurse Delegation Act.	

Indicator SD2. Availability and Use of Self-directed Services

States that offer a broad array of self-directed services to large numbers of individuals through their Medicaid State Plan, State Plan Amendments (SPAs), and/or HCBS Waivers may provide greater opportunities for users and their representatives, when appropriate, to exercise choice

and control over the LTSS they receive, the manner in which the LTSS are delivered, and the organizations and individuals who provide the supports and services.

Indicator SD2. *Availability and Use of Self-directed Services* examines whether the state offers home and community-based services using a self-directed approach under their Medicaid State Plan or one or more Medicaid SPA or HCBS Waivers. The indicator also examines the authority under which these self-directed Medicaid State Plan, Medicaid SPA, and/or HCBS Waiver services are offered (e.g., employer authority, budget authority, or both).

2011 to 2012 Refinements and Additions

The NBIP team refined and added to Indicator SD2 prior to the 2012 field test. The refinements and additions made to SD2 are summarized in Exhibit 18 below.

Exhibit 18: Summary of Refinements and Additions Made to Indicator SD2 Prior to 2012

Indicator SD2. Availability of Options for Self-Directed Services Refinement		
Feedback Received	Modifications	New Focus of Indicator
LTSS experts suggested that the NBIP team collect information on how often person-centered planning, employer authority and budget authority are utilized. They also suggested that the NBIP team refine the indicator to capture state funded programs and services that offer SD.	The indicator was expanded to include additional Medicaid waivers beyond § 1915(c), (e.g., special population waivers), as well as non-Medicaid funded programs, such as Veterans services and state-funded programs. The options for self-determination have been expanded to capture information on the components that exist within each program and service and the extent to which they are utilized.	The focus of the indicator was expanded to include non-Medicaid programs and services to capture options for self-determination within a wider range of LTSS programs and services available to users.

2012 to 2014 Refinements and Additions

The NBIP team made several refinements to Indicator SD2 from 2012 to 2014. These refinements are summarized in Exhibit 19 below.

Exhibit 19: Summary of Refinements and Additions Made to Indicator SD2 from 2012 to 2014

Indicator SD2. Availability and Use of Self-direct Services Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members felt that because this indicator examines the extent to which self-directed services are offered throughout a state’s LTSS system, it should include § 1915(c) waivers, §1915 HCBS SPAs, and §1115 waivers or the consolidation of these programs (e.g., Vermont’s comprehensive §1115 waiver).	The indicator was expanded to include a reference to the new rules promulgated by CMS [CMS 2249-F-§1915(i) and CMS 2296-F §1915(c)] as they relate to person-centered planning. Additional questions were added to the survey related to the new requirements for person-centered planning. The indicator also was expanded to examine the number and type of active Medicaid HCBS SPAs that exist in the state and whether they offer person-centered planning and/or self-directed services, and non-Medicaid programs and services that may provide self-directed services.	The focus of the indicator remained the same.

Indicator SD3. Risk Assessment and Mitigation

Indicator SD3. *Risk Assessment and Mitigation* examines the “Dignity of Risk” and “Individual Choice and Control” Features of the Self-Determination/Person-Centeredness Principle included in the NBI Conceptual Framework. These concepts recognize that under the philosophy of Self-Determination, older adults and individuals with disabilities and chronic conditions should have the right to exercise choice and control related to the delivery of their LTSS. However, with rights come responsibilities, many of which are mandated by federal and state regulation (e.g., being an employer of direct service providers). States and users must exercise shared accountability for potential risks associated with users’ choice and control to ensure users’ health and safety.

Because there are potential risks associated with an individual with a disability or chronic condition exercising self-determination, States should assess, monitor, and mitigate any risks associated with an individual using self-directed services and living in the community to ensure that individual’s health and safety. The goal of these activities should be to identify and mitigate potential risks and not impede or hamper the individual’s self-determination and use of self-directed services. Activities related to risk assessment and mitigation include, but are not limited to, the following:

- assessing and re-assessing, as needed, potential risks for an individual;
- developing a risk management plan and agreement during the person-centered planning process; and,
- monitoring the effectiveness of risk management plans and agreements and updating them periodically, as needed.

Additional mechanisms to address an individual's health and safety may include implementing a 24-hour direct service worker back-up strategy, a call-in and complaint/grievance reporting system, and a critical incident reporting and management system.

2011 to 2012 Refinements and Additions

The NBIP team did not include Indicator SD3. *Risk Assessment and Mitigation* in the NBIs during the refinements and additions that it made during the period from 2011 to 2012.

2012-2014 Refinements and Additions

The NBIP team added Indicator SD3. *Risk Assessment and Mitigation* to the NBIs during the refinements and additions that it made during the period from 2012 to 2014. The team added Indicator SD3 based on the evidence of the importance of the assessment and mitigation of risk that is inherent in self-determination. The importance of this NBI is evidenced by the research and recommendations from several LTSS experts. The team has not field tested Indicator SD3.

3.3 Shared Accountability Principle

3.3.1 Overview

The Shared Accountability Principle focuses on responsibility among and between users (older adults and individual with disabilities and chronic conditions and their families), service providers, local government agencies, state program agencies, and Federal agencies, and encourages personal planning for LTSS needs, including greater use and awareness of private sources of funding. There are four principle features and four indicators under the Shared Accountability Principle. The team describes each of them below and provides the survey questions that will be used to examine them. This section discusses the principle features and indicators included in the SA Principle, including feedback that the team received from LTSS experts and refinements and additions that the team made during the NBIP.

3.3.2 Principle features and Indicators

The NBIP team developed the following four principle features for the Shared Accountability Principle:

- The System Encourages Fiscal Responsibility on the Part of all Entities Responsible for LTSS
- System Encourages and Supports Personal Responsibility through Training and Education about the Best Use of Resources
- Individuals and Families are Actively Engaged in Policy Development

- System has Mechanisms in Place to Hold Government and Providers Accountable for Meeting the Needs of Individuals. Conversely, Individuals have the Responsibility to Voice their Expectations, Needs and Grievances.

To examine these principle features, the NBIP team developed the following four indicators:

- Indicator SA1. *Fiscal Responsibility (New)*
- Indicator SA2. *Personal Responsibility (New)*
- Indicator SA3. *Individuals and Families are Actively Engaged in Policy Development (New)*
- Indicator SA4. *Government, Provider and User Accountability (New)*

The NBIP team refined and added to these indicators based on its discussions with LTSS experts, as well as a review of the most current literature. The refinements and additions are summarized below, and additional information related to each of the indicators included in the SA Principle is provided in Appendix I.

Indicator SA1. Fiscal Responsibility

Fiscal responsibility is an important consideration when considering shared accountability. Users, providers, and Federal, state, and local governments share responsibility to ensure that users' needs are being met and that funds are being spent in the most responsible, efficient, and effective manner. Although cost sharing is a part of shared fiscal responsibility for the user, fiscal responsibility for the user extends beyond his or her contribution to LTSS. An analysis of fiscal responsibility should consider what mechanisms are in place to assess whether providers and governments are using funds and providing services responsibly and efficiently. The Indicator SA1. *Fiscal Responsibility*, examines whether the system encourages fiscal responsibility on the part of all entities responsible for LTSS.

2011 to 2012 Refinements and Additions

The NBIP team made several refinements and additions to Indicator SA1. *Fiscal Responsibility* between 2011 and 2012. The refinements and additions that the team made to the Indicator SA1 prior to the 2012 field test are summarized in Exhibit 20 below. The team field tested Indicator SA1 along with the other NBIs in 2012.

Exhibit 20: Summary of Refinements and Additions Made to Indicator SA1 Prior to 2012

Indicator SA1. Fiscal Responsibility Refinement		
Feedback Received	Modifications	New Focus of Indicator
SPT Grantee States had difficulty distinguishing this indicator from Indicator SD2, an indicator that examines self-determination. They suggested combining the two indicators. They also suggested that the name of the indicator be changed. TEP members found that examining waivers for shared accountability did not fit precisely within the indicator.	Expanded to examine the specific responsibilities associated with employer and budget authority, such as setting wages. The indicator also was expanded to examine incentives to encourage the responsible use of the authority available, as well as penalties to discourage abuses. Cost-sharing was added to the indicator. The NBIP team noted that this indicator did not measure all of the principle features that were identified in the NBIC.	In order to more fully examine the concept of Shared Accountability, the principle was expanded and further developed. New features were identified and old features were removed. Based on the changes to the principle, the team determined that Indicator SA1, <i>Consumer and Family Empowerment</i> could be dropped. The team developed new measures for each of the new features identified under the Shared Accountability Principle.

2012 to 2014 Refinements and Additions

The team made minor refinements and additions to Indicator SA1. *Fiscal Responsibility* during the period from 2012 to 2014. These further refinements and additions are summarized in Exhibit 21 below.

Exhibit 21: Summary of Refinements and Additions Made to Indicator SA1 from 2012 to 2014

Indicator SA1. Fiscal Responsibility Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members were concerned that process measures such as Indicator SA1 were not demonstrated to be the best measures of LTSS balancing. Some TEP members suggested that the team delete Indicator SA1.	The indicator was expanded to capture information related to the LTC Partnership Program, how users are informed about the program, and how many individuals are enrolled in the program. Also, the team expanded the indicator to examine how a state ensures that language services are available to those who need them and how those services are funded.	The focus of the indicator remained the same.

Indicator SA2. Personal Responsibility

Indicator SA2. *Personal Responsibility* examines mechanisms in a LTSS system that provide training and educational opportunities to empower individuals and caregivers to effectively use self-directed LTSS. Self-directed LTSS enable individuals and caregivers to exercise greater choice and control over the LTSS received and enable individuals to live the most integrated settings possible. For example, individuals who receive HCBS waiver services that provide the

opportunity for employer and/or budget authority would benefit from the receipt of supports such as employer skills training to facilitate their use of self-directed LTSS. In addition, States are required to provide both information and assistance and financial management services as supports when providing self-directed HCBS waiver services.

2011 to 2012 Refinements and Additions

The team added Indicator SA2. *Personal Responsibility* to the NBIs during the refinements and additions made between 2011 and 2012. The NBIP team added this indicator to the NBIs based on the evidence published in the literature and feedback from LTSS experts regarding the importance of an individual’s ability to effectively use self-directed LTSS. The team field tested this NBI along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team made several refinements to Indicator SA2 from 2012 to 2014. These refinements are summarized in Exhibit 22 below.

Exhibit 22: Summary of Refinements and Additions Made to Indicator SA2 from 2012 to 2014

Indicator SA2. Personal Responsibility Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>TEP members suggested that States are not consistently providing orientation and training for individuals to empower them to effectively use self-directed LTSS.</p> <p>Also, TEP members suggested that this indicator examine whether individuals are getting the information that they need to make good decisions about using LTSS. However, TEP members were concerned that this might be a difficult question for States to answer.</p>	<p>The indicator was expanded to capture information related to the Own Your Own Future LTC Awareness Campaign, as well as the LTC Partnership Program.</p>	<p>The focus of the indicator remained the same.</p>

Indicator SA3. Individuals and Families are Actively Engaged in Policy Development

An individual’s involvement in the development and provision of LTSS is a key aspect of an LTSS system that encourages self-determination and shared responsibility. Input from the individual receiving LTSS and his or her representative, when appropriate, is an important element of developing a person-driven LTSS system and providing self-directed LTSS. Indicator SA3. *Individuals and Families are Actively Engaged in Policy Development* examines aspects of cultural and linguistic competency to determine the specific populations that are engaged in policy development.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator SA3. *Individuals and Families are Actively Engaged in Policy Development* to the NBIs during the refinements and additions made between 2011 and 2012. The team added this indicator to the NBIs based on the evidence published in the literature and feedback from LTSS experts regarding the importance of individual's engagement in LTSS policy development. The team field tested this NBI along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team made only a few refinements to Indicator SA3 from 2012 to 2014. These refinements are summarized in Exhibit 23 below.

Exhibit 23: Summary of Refinements and Additions Made to Indicator SA3 from 2012 to 2014

Indicator SA3. Individuals and Families are Actively Engaged in Policy Development Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members raised concerns that States may not include individuals using LTSS and families in developing policies with the exception of sending out documents for public comment. TEP members also questioned the relevance of this Indicator to LTSS balancing.	The indicator was expanded to capture information related to input provided by individuals using LTSS and families and how the input was used, including how users individuals and families were included in and provided input regarding the development of the <i>Olmstead</i> plan.	The focus of the indicator remained the same.

Indicator SA4. Government, Provider, and User Accountability

Indicator SA4. *Government, Provider, and User Accountability* examines whether governments and LTSS providers are transparent with respect to reporting and their follow up with individuals who use the services.

A LTSS system must have mechanisms in place to ensure the delivery of high quality LTSS that meet individuals' needs and preferences. Transparency in reporting by governments and providers serves to hold these entities accountable to the public and other government entities and ensures that these entities provide such high quality LTSS. For example, an incident and complaint reporting system should not only log complaints or incidents, but document that these have been reported to the appropriate entity(ies), addressed and resolved to the satisfaction of the government and users. Similarly, specific goals and outcomes should be noted on an individual's service plan, and whether these goals and outcomes have been met should be documented so that providers of high quality LTSS and governments may be monitored and held accountable.

Individuals, with the assistance of their representatives if the individual is not able to communicate, are responsible for communicating their needs and preferences. When

individuals’ needs and preferences are not met, they should report these deficiencies to the applicable government agencies and provider(s) through the entities’ complaint or incident reporting systems, or to the State Ombudsman Program, as appropriate.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator SA4. *Government, Provider, and User Accountability* to the NBIs during the refinements and additions that the team made between 2011 and 2012. The team added this indicator to the NBIs based on the evidence published in the literature and feedback from LTSS experts emphasizing the importance of ensuring that supports and services are delivered based on individuals’ needs and preferences. The team field tested this NBI along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

Indicator SA4. *Government, Provider and User, Accountability* underwent few refinements from 2012 to 2014. The few refinements that the team made are summarized in Exhibit 24 below.

Exhibit 24: Summary of Refinements and Additions Made to Indicator SA4 from 2012 to 2014

Indicator SA4. Government, Provider, and User Accountability Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members reported that the dignity of risk and risk mitigation are different. Also, they reported that transparency about quality performance is absolutely critical, but that prospectively obtaining this information may be problematic because under managed care some of this information is considered proprietary.	The indicator was expanded to capture additional information related to incident reporting and quality assurance protocols.	The focus of the indicator remained the same.

3.4 Community Integration And Inclusion Principle

3.4.1 Overview

The Community Integration and Inclusion (CI) Principle examines whether a state’s LTSS system encourages and supports people to reside in the most integrated setting by offering them a full array of options to access quality services and supports in the community. This section discusses the principle features and indicators included in the CI Principle, including feedback received from LTSS experts and refinements and additions that the team made during the NBIP.

3.4.2 Principle Features and Indicators

The NBIC team developed the following six principle features for the Community Integration and Inclusion Principle:

- Availability of and access to (or opportunities for) the full-range of LTSS, including medical, dental, mental health, assistive technology, transportation, and affordable housing with supports
- Opportunities to attain/maintain employment within the community
- People of all ages with disabilities and/or chronic conditions reside and participate in the most integrated community settings
- Freedom to move within the community (e.g., accessible buildings, parks, sidewalks)
- People of all ages with disabilities and/or chronic conditions are safe to walk, work, and play without fear of attack or increased burden of illness (from environmental risk)
- Assistance with instrumental activities of daily living (IADLs), as needed

The NBIC team initially developed four additional principle features for this principle:

- Opportunities to attain/maintain recreational, educational, and vocational services to enable and enhance community living (e.g., church, clubs)
- Freedom to move within the community (e.g., accessible buildings, parks, sidewalks)
- People of all ages with disabilities and/or chronic conditions are safe to walk, work and play without fear of attack or increased burden of illness (from environmental risk)
- Assistance with instrumental activities of daily living, as needed

These principle features were not implemented because either the team or Federal Partners were unable to develop an indicator related to them.

To examine the six principle features described above, the NBIC and NBIP teams developed the following four indicators:

- Indicator CI1. *Waiver Waitlist*
- Indicator CI2. *Housing (New)*
- Indicator CI3. *Employment*
- Indicator CI4. *Transportation (New)*

The NBIP team refined and added to these indicators based on discussions with LTSS experts and stakeholders. The refinements and additions are summarized below, and additional information related to each of the indicators included in the CI Principle is provided in Appendix I.

Indicator CI1. Waiver Waitlist

Indicator CI1. *Waiver Waitlist* examines the “most integrated community settings” Feature of the Community Integration and Inclusion Principle, which is included in the NBI Conceptual Framework. HCBS waivers provide people with disabilities the option to receive LTSS in community settings (i.e., outside of institutions). The number of people who wish to receive LTSS may exceed the number of participants who are approved to receive them under a Medicaid HCBS waiver within a state fiscal year. As a result, government authorities responsible for administering these waivers must balance multiple priorities to achieve equitable access to LTSS, such as balancing an individual’s need for LTSS with the length of time an individual spends on the waitlist.

2011 to 2012 Refinements and Additions

The NBIP team made several refinements and additions to Indicator CI1. *Waiver Waitlist* in 2011 and 2012. The refinements and additions that the team made to the Indicator CI1 prior to the 2012 field test are summarized in Exhibit 25 below. The team field tested Indicator CI1 with the other NBIs in 2012.

Exhibit 25: Summary of Refinements and Additions Made to Indicator CI1 Prior to 2012

Indicator CI1. Waiver Waitlist Refinement		
Feedback Received	Modifications	New Focus of Indicator
LTSS experts suggested expanding prioritization of a person’s position on the waiver waitlist because many programs use a combination of factors. They also suggested examining how people fare while on the waiver waitlist and expanding the indicator to examine Medicaid and non-Medicaid-funded services available to users on the waiver waitlist.	<p>A new section was added to examine the number of current waiver participants receiving LTSS for each waiver reported during a waiver period.</p> <p>A section on alternative LTSS options was added to examine options and information available to individuals on a waitlist. A method for prioritizing the receipt of waiver services was included in the indicator.</p> <p>Finally, a section was added to examine whether a state’s waitlist provides current information about users and their eligibility status and if this information is used by the State as a monitoring tool.</p>	The focus of the indicator has been expanded to (1) examine the specific characteristics of a waiver waitlist, (2) the types of individuals who are on it, (3) whether individuals on the waiver waitlist are offered information on and access to alternative LTSS services, (4) what methods States use to prioritize individuals on the waiver waitlist, and (5) whether States use the waiver waitlists to monitor the demand for waiver services in their respective States.

2012 to 2014 Refinements and Additions

The team made minor refinements and additions to Indicator CI1. *Waiver Waitlist* from 2012 to 2014. These further refinements and additions are summarized in Exhibit 26 below.

Exhibit 26: Summary of Refinements and Additions Made to Indicator CI1 from 2012 to 2014

Indicator CI1. Waiver Waitlist Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members raised the following concerns about the Indicator CI1. <i>Waiver Waitlist</i> : (1) the lack of an examination of the nature of the waitlist, and (2) whether the indicator is a good measure of a balanced, person-driven LTSS system. They also were concerned that not all States have waiver waitlists because they are not required by CMS requirement. In those States in which waitlists exist, information may be out of date over time, or individuals may be receiving other services.	Minor refinements and additions were made to expand the indicator to examine whether a waiver waitlist accounts for various disability types and diverse populations, who is eligible for the waiver waitlist, and if and how often waiver waitlist information is updated and used by States as a monitoring tool.	The focus of the indicator remained the same.

Indicator CI2. Housing

Indicator CI2, *Housing* examines the “Availability and Access to LTSS” Feature of the Community Integration and Inclusion Principle. Coordination of the provision of LTSS with affordable and accessible housing enables individuals with disabilities to live in the community and may prevent or delay institutional placement. Researchers theorize that if affordable and accessible housing is available to individuals with disabilities or chronic conditions who are at risk of institutionalization, and if the number and types of partnerships between housing and LTSS provider agencies at the state and local level increase to support these individuals, more individuals who wish to remain in their communities will be able to do so.

This indicator examines several aspects related to the availability of and access to LTSS and housing services. For example, the indicator assesses whether the state has, or is developing, resources for affordable and accessible housing options for LTSS users, and whether state LTSS program agencies have formalized partnerships with housing agencies to accomplish this objective.

2011 to 2012 Refinements and Additions

The NBIP team made substantial refinements and additions to Indicator CI2 prior to the 2012 field test. The team expanded Indicator CI2 during 2011 to 2012 based on feedback provided by LTSS and housing experts to better examine the availability of and individuals’ access to

housing, as well as the coordination of these efforts. The refinements and additions that the team made to CI2 are summarized in Exhibit 27 below.

Exhibit 27: Summary of Refinements and Additions Made to Indicator CI2 Prior to 2012

Indicator CI2. Housing Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>Federal Partners suggested that the team expand the indicator to measure a State’s interest in increasing the supply of affordable and accessible housing by adding survey questions on this issue. They also suggested expanding the indicator to collect information on LTSS/housing coordinators.</p>	<p>The indicator was expanded to include questions on the availability of and incentives for States to provide affordable, accessible, and universally designed housing; and assess who is living in affordable and accessible housing.</p> <p>Questions regarding the housing registry were expanded to examine the usefulness of the registry and to capture States’ efforts to employ LTSS/housing coordinators and assess the services that they provide to users.</p>	<p>The focus of this indicator was expanded to examine the availability of and individuals’ access to affordable and accessible housing and to examine States’ efforts to support the construction of universally designed housing.</p> <p>The indicator’s focus was expanded to include additional areas to examine related to the coordination between housing and LTSS, on housing registries, and on States’ efforts to provide quality coordination services by employing and/or training coordinators who are knowledgeable about housing and LTSS programs and services.</p>

2012 to 2014 Refinements and Additions

The team made several refinements to Indicator CI2 from 2012 to 2014. These refinements are summarized in Exhibit 28 below.

Exhibit 28: Summary of Refinements and Additions Made to Indicator CI2 from 2012 to 2014

Indicator CI2. Housing Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>LTSS experts suggested that the indicator more closely examine housing as it relates to LTSS users and the level of consistency between housing and human service agencies in determining eligibility to receive services and services provided. They also recommended that the indicator be refined (1) to clarify the goal of housing and LTSS coordination, and (2) to be less biased towards the disability community by including a focus on housing for older adults (e.g., assisted living residences).</p>	<p>The indicator was refined to examine better the coordination of housing and LTSS, and in particular, to examine States’ efforts to ensure that their regulations, policies, and procedures are consistent across housing and health and human service agencies that provide long-term services and supports.</p>	<p>The focus of the indicator remained the same.</p>

Indicator C13. Employment

This indicator examines States' efforts to integrate individuals with disabilities into the community through supported employment options. In addition, it examines the effect that those programs and services have in enabling working-aged adults with disabilities to be gainfully employed.

2011 to 2012 Refinements and Additions

The NBIP team substantially refined and added to Indicator C13. *Supported Employment* prior to conducting the 2012 field test. During this time, based on feedback provided by LTSS experts, the team expanded Indicator C13 to examine additional aspects of the Medicaid buy-in program, as well as other services available to users. A summary of the refinements and additions that the team made to C13 can be found in Exhibit 29 below.

Exhibit 29: Summary of Refinements and Additions Made to Indicator C13 Prior to 2012

Indicator C13. Supported Employment Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>A LTSS expert suggested adding a question on whether a States' Medicaid Buy-In Program has a threshold level for maximum allowable assets that users cannot exceed to participate in the program.</p> <p>LTSS experts also suggested exploring non-Medicaid services rather than just focusing on Medicaid services.</p>	<p>This indicator was expanded (1) to examine States' Medicaid Buy-In Allowance by including questions regarding the annual co-payment amount and the maximum allowable asset level for eligibility, and (2) to use more inclusive program language by changing pre-vocational support to "Assessment and Skills Development," adding "transportation" and "travel training" as services provided by States, and "demonstration program" to capture new or alternative programs not previously included.</p>	<p>The focus of the indicator was expanded to include an examination of States' Medicaid Buy-In Allowance.</p>

2012 to 2014 Refinements and Additions

The NBIP team made only a few refinements to Indicator C13 from 2012 to 2014. The refinements made are summarized in Exhibit 30 below.

Exhibit 30: Summary of Refinements and Additions Made to Indicator CI3 from 2012 to 2014

Indicator CI3. Supported Employment Refinement		
Feedback Received	Modifications	New Focus of Indicator
<p>TEP members suggested that sheltered workshops be removed since these are not considered supported employment.</p> <p>They also suggested that it be clarified that the indicator is examining competitive supported employment and that it include evidence-based programs for individuals with mental illness, specifically Individual Placement Services (IPS).</p>	<p>The indicator was refined by deleting sheltered workshop as a supported employment option and by replacing it with prevocational services.</p> <p>In addition, assessment skills development was deleted and replaced with job replacement.</p> <p>Finally, the team expanded the indicator to examine States' efforts to provide supported employment services funded through other mechanisms outside of Medicaid.</p>	<p>The focus of the indicator remained the same.</p>

Indicator CI4. Transportation

Indicator CI4. *Transportation* examines the “Availability and Access to LTSS” and “Opportunities to Obtain/Maintain Employment, Recreation, Education, and Vocational Services” Features of the Community Integration and Inclusion Principle. Finding accessible, affordable, and convenient transportation is one of the most difficult challenges facing an individual who needs LTSS. Medicaid may pay for transportation services for medical appointments, but fees for non-medical transportation services are often paid out-of-pocket by users. The out-of-pocket fees paid by users for transportation services combined with the limited availability of these services makes it difficult for older adults and persons with disabilities to attend professional activities (e.g., employment) and independently perform instrumental activities of daily living (e.g., grocery shopping), thus limiting their options for living in the community.

This indicator also examines States' efforts to provide Medicaid-funded transportation services beyond medical transportation. Information collected for this indicator will facilitate an examination of a state's efforts to utilize Federal and other funding sources to provide transportation services for older adults and adults with disabilities, as well as evaluate the types of transportation services available and the types of needs that are met (i.e., professional and personal).

2011 to 2012 Refinements and Additions

The NBIP team added Indicator CI4. *Transportation* to the NBIs during the refinements and additions made during the period 2011 to 2012. The team added the new Indicator CI4 based on evidence of the importance of an individual's access to transportation in his or her ability to be fully integrated and included in the community. The importance of this NBI is evident in the

research and recommendations from several LTSS experts and that published in top journals. The team field tested Indicator CI4 along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team made minimal refinements to Indicator CI4. *Transportation* from 2012 to 2014. These few refinements are summarized in Exhibit 30 below.

Exhibit 31: Summary of Refinements and Additions Made to Indicator CI4 from 2012 to 2014

Indicator CI4. Transportation Refinement		
Feedback Received	Modifications	New Focus of Indicator
TEP members commented that this indicator was important but difficult for States to report. They stated that the availability of transportation services varies county by county, region by region, and that the State staff responsible for collecting the information would have to be very knowledgeable to collect this information accurately.	The indicator was expanded to examine how States coordinate and fund transportation services.	The focus of indicator remained the same.

3.5 Coordination and Transparency Principle

3.5.1 Overview

The Coordination and Transparency (CT) Principle examines whether the LTSS system coordinates a range of services funded by multiple funding sources to provide seamless supports across the health and LTSS systems (i.e., acute health, rehabilitation, and LTSS). It also examines how a State’s LTSS system makes effective use of health information technology to provide transparent information to users, providers, and payers. This section discusses the principle features and indicators included in the CT Principle, including feedback received from LTSS experts, and refinements and additions that the team made during the NBIP.

3.5.2 Principle Features and Indicators

The NBIC team developed the following three principle features for the Coordination and Transparency Principle:

- Universal, timely access to information and services
- Federal/state/local governments collaborate and communicate effectively regarding the provision of LTSS
- Promotion of continuity of care and seamless transitions from setting to setting and across major developmental stages throughout the lifespan

The NBIC and NBIP teams developed the following three indicators to examine these principle features:

- Indicator CT1. *Streamlined Access*
- Indicator CT2. *Service Coordination*
- Indicator CT3. *LTSS Care Transition*

The NBIP team refined and added to these indicators based on discussions with LTSS experts and stakeholders. These refinements and additions are summarized below, and additional information related the indicators is provided in Appendix I.

Indicator CT1, Streamlined Access

Indicator CT1. *Streamlined Access* examines the “Universal, Timely Access to Information and Services” Principle feature in the Coordination/Transparency Principle, which is included in the NBI Conceptual Framework. In addition, it examines whether a state has, or is developing, a streamlined LTSS system. Individuals in need of LTSS must navigate complicated and separate eligibility, service delivery, and payment systems.

2011 to 2012 Refinements and Additions

The refinements that the NBIP team made to Indicator CT1 during the period 2011 to 2012 are summarized in Exhibit 32 below.

Exhibit 32: Summary of Refinements and Additions Made to Indicator CT1 Prior to 2012

Indicator CT1. Streamlined Access			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
CT1a. Streamlined Access System Availability	TEP reported some of the indicator's language was confusing.	The indicator was expanded to include the core functions of a streamlined access system.	The NBI examines six functions and partnership data. Also, it includes secondary data on ADRC functionality (The Lewin Group) and examines partnerships between the streamlined access system and other LTSS partners.
CT1b. Streamlined Access System Functionality	None reported.	None made.	
CT1c. Partnerships	Both SPT and TEP were unsure whether the partnership data would be meaningful.	The indicator was expanded to capture information on partnerships among streamlined access systems.	

2012 to 2014 Refinements and Additions

Overall, the NBIP team made only a few refinements and additions NBI CTI from 2012 to 2014. While TEP members felt that the Aging and Disability Resource Center (ADRC) fully functioning criteria was reasonable, they felt that it does not examine the available streamlined access systems and the level of functioning for individuals with intellectual and/or developmental disabilities or mental illness. The team discussed implementing The Lewin Group's Fully Functioning Criteria & Readiness Assessment within the developmental disability agencies and community mental health agencies as a possible solution. However, at the time that this report was written, the team had not made a final decision.

The refinements that the NBIP team made to Indicator CT1 during the period 2012 to 2014 are summarized in Exhibit 33 below.

Exhibit 33: Summary of Refinements and Additions Made to Indicator CT1 from 2012 to 2014

Indicator CT1, Streamlined Access			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
CT1a. Streamlined Access System Availability	None reported.	None made.	The focus of the indicator remained the same.
CT1b. Streamlined Access System Functionality	TEP members reported that IDD services may not be represented in The Lewin Group’s Fully Functioning Criteria Assessment in Sub-indicator CT1b.	None made.	
CT1c. Partnerships	TEP members noted that services for persons with mental illness may be missing from the assessment. Regarding Sub-indicator CT1c, TEP members commented that I/DD agencies were missing. They suggested that a No Wrong Door System may not necessarily mean that a State has a formal partnership with every entity. They reported that it may be more important to determine whether there are people who can navigate the system within each entity.	Only minor modifications were made to this NBI, including updating terminology and reorganizing questions.	

Indicator CT2. Service Coordination

One aspect of providing coordinated and transparent LTSS is the degree to which users receive assistance in developing their LTSS plans. Indicator CT2. *Service Coordination* examines the variety of service coordination options that a state may provide to users. In addition, the indicator examines whether service coordination exists and the quality of LTSS provided.

2011 to 2012 Refinements and Additions

The refinements that the team made to Indicator CT2 from 2011 to 2012 are summarized in Exhibit 34 below.

Exhibit 34: Summary of Refinements and Additions Made to Indicator CT2 Prior to 2012

Indicator CT2. Service Coordination			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
CT2a. Type of Coordination	SPT Grantee States reported that measures of “case management quality” were not useful.	This team expanded this NBI to include Options Counseling, Medicare Case Management, Medicaid Targeted Care Management, State-Only Funded Care Management, and Care Coordination.	This indicator was expanded to examine five measures of service coordination availability and expenditures per participant.
CT2b. Expenditures of Coordination	None reported.	The team expanded the indicator to include expenditures per participant (Medicaid Case Management, Medicaid Targeted Case Management).	
CT2c. Outcome of Coordination	None reported.	None made.	

2012 to 2014 Refinements and Additions

Overall, the team made very few refinements and additions NBI CT2 between 2012 and 2014. These are summarized in Exhibit 35 below.

Exhibit 35: Summary of Refinements and Additions Made to Indicator CT2 from 2012 to 2014

CT2. Service Coordination			
Sub-indicator(s)	Feedback Received	Modifications	New Focus of Indicator(s)
CT2a. Type of Coordination	None reported.	Options included in Sub-indicator CT2a were expanded to include the Medicaid State Plan Amendment (SPA) service.	The focus of the indicator remained the same.
CT2b. Expenditures of Coordination	None reported.	None made.	
CT2c. Outcome of Coordination	TEP members suggested the NBIP team collect the data from States as well because some States can answer this question without using the NCIs.	None made.	

Indicator CT3. LTSS Care Transition

Indicator CT3. *LTSS Care Transition* examines promoting continuity of care and seamless transitions from setting to setting throughout major developmental stages across the lifespan. The team describes the refinements and additions that it made to this indicator below.

2011 to 2012 Refinements and Additions

Indicator CT3. *LTSS Care Transition* went through several refinements from 2011 to 2012 in order to better examine continuity of care. These refinements are summarized in Exhibit 36 below.

Exhibit 36: Summary of Refinements and Additions Made to Indicator CT3 Prior to 2012

Feedback Received	Modifications	New Focus of Indicator(s)
TEP felt that the old indicators related to service coordination between institutional settings (old name for Care Transitions indicators) were confusing and difficult to interpret.	Six new areas representing the availability of best practices or efforts that CMS currently is supporting replaced the NBIC Indicator CT3: Guaranteed Waiver Slots; Notification System for Dual Eligibles, Management of MDS 3.0 Section Q Referrals, Presumptive Eligibility for Medicaid Applicants; Single Instrument for Conducting Functional Assessments; Systems to Track, Facilitate and Monitor Participant Program. Indicator was expanded to cover area on Guidelines or Protocols of Discharge Planning and Availability of Health Homes.	The focus of this indicator was expanded to examine the availability of best practices in care transitions.

2012 to 2014 Refinements and Additions

Overall, the team made only a few additional refinements and additions to Indicator CT3 from 2012 to 2014. The refinements are summarized in Exhibit 37 below.

Exhibit 37: Summary of Refinements and Additions Made to Indicator CT3 from 2012 to 2014

Feedback Received	Modifications	New Focus of Indicator(s)
TEP members suggested that the care transition programs be expanded to include other care transition programs beyond the Coleman Care Transitions Model.	The indicator was broadened to examine multiple care transitions models.	The focus of the indicator remained the same.

3.6 Prevention Principle

3.6.1 Overview

The Prevention Principle examines States' efforts to encourage and support health and wellness programs that promote healthy living, slow functional decline, and ensure the optimal health, well-being, safety, and functioning of people with disabilities. A state's support of these types of programs indicates that state's commitment to promoting health and preventive health for people with disabilities and reducing health disparities. This section discusses the principle features and indicators included in the Prevention Principle, including the literature reviewed, feedback received from LTSS experts, and refinements and additions that the team made during the NBIP.

3.6.2 Principle Features and Indicators

The NBIC team developed the following two principle features for the Prevention Principle:

- Universal Availability and Utilization of Community, Clinical, and Preventive Services
- State and Local Communities are Free from Preventable Illnesses and Injury

The NBIC and NBIP teams developed the following two indicators to examine these principle features:

- Indicator P1. *Health Promotion and Prevention*
- Indicator P2. *Disaster/Emergency Preparedness (New)*

The NBIP team refined and made additions to these indicators based on its review of current literature and discussions with LTSS experts and stakeholders. Below, the team provides a summary of the literature examined, and describes the refinements and additions that it made to each of the indicators. Additional information is provided in Appendix I.

3.6.3 Literature

The U.S. Surgeon General's 2005 Call to Action, *To Improve the Health and Wellness of Persons with Disabilities*, States that "persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles. People with disabilities need healthcare and health programs the same reasons anyone else does – to stay well, active and a part of the community." Persons with disabilities are less likely to engage in regular moderate physical activity than people without disabilities (US DHHS, 2005).

The Healthy People 2020 initiative has a section solely dedicated to Disability and Health that focuses on the well-being of individuals with disabilities. The Disability and Health objectives highlight areas for improvement and increase opportunities for people with disabilities so that they can be included in public health activities, receive well-timed interventions and services,

interact with their environment without barriers, and participate in everyday life activities (Healthy People, 2020).

Studies have shown that LTSS users living in the community may be less likely to receive preventive health and health promotion services than those living in institutions. One study conducted by Bershadsky and Kane (2010) found that LTSS users with an intellectual and/or developmental disability living in the community with their families are less likely to receive preventive dental cleanings than those living in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/ID) or adult group homes (Bershadsky & Kane, 2010).

Indicator P1. Health Promotion and Prevention

Indicator P1. *Health Promotion and Prevention* examines whether a State provides health promotion and prevention programs to individuals with disabilities of all ages. In addition, the NBI examines the availability of programs supported by a full array of funding sources. The refinements and additions that the team made to this indicator are described below.

2011 to 2012 Refinements and Additions

The NBIP team refined and added to Indicator P1. *Health Promotion and Prevention* prior to the 2012 field test based on feedback that it received from multiple sources, including the seven State Profile Tool (SPT) Grantee States, TEP members, and Stakeholder Group members, and its review of available literature and data. The team made the following refinements to the indicator:

- the expansion of the availability and access to health promotion and preventive programs and services;
- whether information related to such services were being provided as part of Information and Referral or Information and Assistance Services; and,
- the percentage of people receiving preventive services.

The refinements and additions that the team made to the Prevention Principle and Indicators prior to the 2012 field test are summarized in Exhibit 38 below. The team field tested Indicator P2 along with the other NBIs in 2012.

Exhibit 38: Summary of Refinements and Additions Made to Indicator P1 Prior to 2012

Indicator P1. Health Promotion and Prevention		
Feedback Received	Modifications	New Focus of NBI
SPT Grantee States recommended that the team examine what EBPs are available; however, the TEP recommended leaving the definition of programs broad. SPT Grantee States and TEP members also suggested making language related to the health promotion programs and services more specific so that it can be objectively measured. Finally, the TEP suggested that the availability of programs and services be connected to outcome measures of improved access and/or health.	<p>Availability and access to health promotion and preventive programs and services was expanded to examine barriers to access and States’ efforts to facilitate access to programs and services. Examples of the expansions include collecting information on state funding for transportation to and from programs and services, funding for assistive technology, and incentivizing health care providers to serve individuals with disabilities. The indicator was expanded to capture whether health promotion and preventive programs and services were being provided by I&A and I&R specialists or as part of options counseling.</p> <p>The indicator was expanded to capture information on the percentage of Medicaid beneficiaries with disabilities who received preventive services in the previous year.</p>	The indicator was expanded to examine the availability of to both EBP and non-EBP, state identification of barriers to programs and services, as well as States’ efforts to facilitate access to programs and services.

2012 to 2014 Refinements and Additions

The NBIP team further refined Indicator P1. *Health Promotion and Prevention* between 2012 and 2014 based on results from the 2012 field test, TEP member feedback, and an additional review of updated literature. Overall, TEP members reported that while the indicator effectively examined health promotion and preventive programs and services, it did not examine these programs and services by population type. The team’s refinements to this NBI made between 2012 and 2014 are summarized in Exhibit 39 below.

Exhibit 39: Summary of Refinements and Additions Made to Indicator P1 from 2012 to 2014

Indicator P1. Health Promotion and Prevention		
Feedback Received	Modifications	New Focus of Indicator
TEP members recommended examining differences in health promotion and preventive programs and services among types of disabilities.	Questions related to the health promotion and preventive programs and services for persons with disabilities were made more specific to capture information by type of disability and, where applicable, by age and type of disability.	The focus of the indicator remained the same.

Indicator P2. Disaster/Emergency Preparedness

Indicator P2. *Disaster/Emergency Preparedness* examines whether a State includes individuals with disabilities and other at-risk groups in their statewide disaster/emergency planning efforts and policies. In addition, it examines States' approaches to planning for potential disasters and emergencies for individuals with disabilities.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator P2. *Disaster/Emergency Preparedness* to the NBIs during the refinements and additions that it made between 2011 and 2012. The new Indicator P2 replaced the indicator *Proportion of People with Disabilities Reporting Recent Preventative Health Care Visits* and was added based on evidence that it is important for States to have disaster/emergency preparedness systems. The importance of this NBI is evident in the research and recommendations from several LTSS and public health organizations and special reports in top journals. The team field tested Indicator P2 with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team refined Indicator P2. *Disaster/Emergency Preparedness* to better examine disaster/emergency preparedness. The refinements that the team made to Indicator P2 between 2012 and 2014 are summarized in Exhibit 40 below.

Exhibit 40: Summary of Refinements and Additions Made to Indicator P2 from 2012 to 2014

Indicator P2. Disaster/Emergency Preparedness		
Feedback Received	Modifications	New Focus of Indicator
TEP members suggested that the team examine ways in which contacts are identified and reached in an emergency by LTSS users living in the community. They also suggested that while all States are required to have a Disaster/Emergency Preparedness Plan in place, many State program agencies might not be aware of it, and this should be examined. Finally, TEP members suggested that this indicator examine more closely which populations the state's Disaster/Emergency Preparedness Plan addresses and in which settings.	This indicator was expanded to capture State program agencies' awareness of and compliance with a requirement to have a Disaster/Emergency Preparedness Plan in place. In addition, the team expanded this indicator to examine requirements for back-up contacts for vulnerable populations and in which settings those requirements exist.	The focus of the indicator remained the same.

3.7 Cultural and Linguistic Competency Principle

3.7.1 Overview

The Cultural and Linguistic Competency (CLC) Principle examines the infrastructure that States have in place to provide services and supports for diverse populations. This section discusses the principle features and indicators that the team included in the CLC Principle, including the literature reviewed, feedback received from LTSS experts, and the refinements and additions that the team made during the NBIP.

3.7.2 Principle Features and Indicators

The NBIP team developed the following four principle features for the Cultural and Linguistic Competency Principle:

- Service offerings are available for diverse populations
- Users of services and their families and community members are engaged in planning, implementing and evaluating services. Support is provided for their engagement (i.e., language access, disability access, accommodations for literacy levels, and financial supports) when needed to facilitate their participation
- State and local organizations provide ongoing education, training, and awareness activities in cultural and linguistic competence for providers and others
- Procedures are in place to address prejudice and prevent discrimination in the workplace or living and community spaces

The team did not implement two principle features, *Users of services and their families and community members are engaged in planning, implementing and evaluating services. Support is provided for their engagement (i.e., language access, disability access, accommodations for literacy levels, and financial supports) when needed to facilitate their participation* and *Procedures are in place to address prejudice and prevent discrimination in the workplace or living and community spaces* because either the team or the Federal Partners did not develop a related indicator.

The NBIP team developed the following three indicators to examine these principle features:

- Indicator CLC1. *Needs Assessment and Target Population (New)*
- Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups (New)*
- Indicator CLC3. *Cultural and Linguistic Competency Training Requirements (New)*

The NBIP team refined and added to these NBIs based on its review of current literature and discussions with LTSS experts and stakeholders. The team provides a summary of the literature examined and describes the refinements and additions made to each of the indicators below.

Additional information related to the refinements and additions for each of the indicators is provided in Appendix I.

3.7.3 Literature

The diverse populations covered and the definition of cultural competence are constantly evolving. Cultural competence is defined as “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of [health] services, thereby producing better outcomes” (Davis & Donald, 1997). However, many agencies and researchers suggest that agencies not wait for a conclusive definition, but rather recognize that cultural competence “is never fully realized, achieved, or completed, but rather [is] a lifelong process” (NASW, 2001).

The concept of cultural competence also has been expanded to include new groups, such as the LGBT community (see <http://www.hrc.org/issues/cultural-competence.htm>). The idea that cultural competence is never fully realized allows providers of LTSS to move from concerns about language or similar background to sexual orientation and the intersection of vulnerable populations.

Indicator CLC1. Needs Assessment and Target Population

Indicator CLC1. *Needs Assessment and Target Population* examines whether diverse groups of users are included in LTSS and if a state is mandated to provide services to these users. The indicator also assesses whether a state collects and reports data on the diverse groups of users that it serves through its LTSS programs.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator CLC1. *Needs Assessment and Target Population* to the NBIs during 2011 and 2012. The team added this indicator to the NBIs based on evidence that it is important for States to provide LTSS to diverse groups of users. The importance is evidenced by the research, recommendations from several LTSS experts, and special publications in top journals. The team field tested this NBI with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team further refined Indicator CLC1 *Needs Assessment and Target Population* between 2012 and 2014 based on results from the 2012 field test and TEP member feedback. The refinements that the team made to this NBI between 2012 and 2014 are summarized in Exhibit 41 below.

Exhibit 41: Summary of Refinements and Additions Made to Indicator CLC1 from 2012 to 2014

Indicator CLC1. Needs Assessment and Target Population		
Feedback Received	Modifications	New Focus of Indicator
TEP members suggested removing the table in Question 8 (population table) to simplify the survey and avoid the possibility of missing population groups. TEP member Dr. Suzanne Bronheim, a CLC expert from Georgetown University, suggested revising the terminology throughout to make questions more clear to collect the information intended. She also provided specific changes to capture information related to CLC needs and users targeted for supports and services.	The terminology was updated and revised throughout the indicator to make questions more clear. Questions were also added to capture information on how and in what phase of policy the State includes users, families, and advocates. A question was added to examine how a state ensures that language services are available to those who need them and how those services are funded. Other questions were simplified.	The focus of the indicator remained the same.

Indicator CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups

Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups* examines whether States design their LTSS systems to address the needs of diverse groups of users based on mandates and evidence-based practices. In addition to the design, this indicator examines whether States' agencies provide staff to support the diverse groups of users that are targeted.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups* to the NBIs during the refinements and additions that it made between 2011 and 2012. The team added this indicator to the NBIs based on evidence concerning the importance of States providing LTSS to diverse groups of users. The importance is evidenced by the research and recommendations from several LTSS experts and publications in top journals. The team field tested the indicator along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The team significantly refined Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups* between 2012 and 2014 so that it would better examine States' efforts to design a culturally and linguistically competent LTSS system. The team's refinements to Indicator CLC2 are summarized in Exhibit 42 below.

Exhibit 42: Summary of Refinements and Additions Made to Indicator CLC2 from 2012 to 2014

Indicator CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups		
Feedback Received	Modifications	New Focus of Indicator
TEP members suggested that Indicator CLC2 more closely examine how a state integrates cultural and linguistic competency into everything that it does and whether a state provides training to facilitate that integration. TEP member Dr. Bronheim offered specific suggestions related to the incorporation of CLC in a needs assessment or person-centered plan and how those needs may change over time. It was also suggested that questions related to the same topic (e.g., training) be placed together with references to that information throughout the NBIs as appropriate (e.g., CLC training in CLC).	The indicator was expanded to look at CLC in an individual's person-centered plan or needs assessment. The indicator also was modified to reference staff training that was refined in Sub-indicator S3d. <i>DSW Training</i> , and Indicator CLC3. <i>Training Requirements</i> .	The focus of the indicator remained the same.

Indicator CLC3. Cultural and Linguistic Competency Training Requirements

Indicator CLC3. *Cultural and Linguistic Competency Training Requirements* examines training requirements for LTSS and vocational rehabilitation providers that address cultural and linguistic competency.

2011 to 2012 Refinements and Additions

The NBIP team added Indicator CLC3. *Cultural and Linguistic Competency Training Requirements* to the NBIs during the refinements and additions that the team made between 2011 and 2012. The team added the indicator to the NBIs based on evidence of the importance of States providing LTSS to diverse groups of users. The importance of the NBI is evidenced by the research and recommendations from several LTSS experts and special publications in top journals. The team field tested this indicator along with the other NBIs in 2012.

2012 to 2014 Refinements and Additions

The NBIP team substantially refined Indicator CLC3. *Cultural and Linguistic Competency Training Requirements* between 2012 and 2014 so that it would better examine training requirements. The team's refinements to the NBI are summarized in Exhibit 43 below.

Exhibit 43: Summary of Refinements and Additions Made to Indicator CLC3 from 2012 to 2014

Indicator CLC3. Cultural and Linguistic Training Requirements		
Feedback Received	Modifications	New Focus of Indicator
The TEP suggested that training be examined more broadly within the NBI and that CLC training related questions be included within that set of questions. In addition, during the team’s discussion of Indicator CLC3 with Dr. Bronheim, Dr. Bronheim recommended that all DSW training and education information be examined in one place within the NBIs.	The indicator was simplified to examine staff training with a reference to DSW training information now located in Sub-indicator S3d.	The focus of the indicator remained the same.

3.7.4 Current Principles and NBIs

As a result of the refinements and additions that the NBIP team made to the NBIs developed under the NBIC, the team developed, in most cases field tested, and refined, and added seven principles (1 new) and 24 NBIs (9 new) to the NBIP. The team presents current principles and NBIs as of April 30, 2014 in Exhibit 44 below.

Exhibit 44: Principles and NBIs Refined and Added to Under the NBIP

Principle	Indicators
Sustainability	S1. Global Budget S2. LTSS Expenditures <ul style="list-style-type: none"> ▪ S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid LTC Spending ▪ S2b. LTSS Spending Changes: Per Capita, Sources, and Medicaid Eligibility ▪ S2c. Medicaid Funding Sources ▪ S2d. LTSS Funding From Non Medicaid Sources S3. Direct Service Workforce <ul style="list-style-type: none"> ▪ S3a. Direct Service Workforce (DSW) Registry ▪ S3b. Direct Service Workforce: Volume, Compensation, and Stability ▪ S3c. Direct Service Workforce Competency ▪ S3d. Direct Service Workforce Training S4. Support for Informal Caregivers S5. Shared Long-Term Supports and Services Mission/Vision Statement
Self-Determination/ Person-Centeredness	SD1. Regulatory Requirements Inhibiting Consumer Control <ul style="list-style-type: none"> ▪ SD1a. Residential Setting ▪ SD1b. Attendant Selection ▪ SD1c. Nurse Delegation SD2. Availability of and Use of Self-direct Services SD3. Risk Assessment and Mitigation
Shared Accountability	SA1. Fiscal Responsibility SA2. Personal Responsibility SA3. Individuals and Families are Actively Involved in LTSS Policy Development SA4. Government, Provider, and User Accountability
Community Integration and Inclusion	CI1. Waiver Waitlist CI2. Housing <ul style="list-style-type: none"> ▪ CI2a. Coordination of Housing and LTSS ▪ CI2b. Availability and Access to Affordable and Accessible Housing Units ▪ CI2c. Housing Settings

Principle	Indicators
	<ul style="list-style-type: none"> ▪ C13. Employment ▪ C13a. Employment Rates of Working-Age Adults with Disabilities ▪ C13b. Supported Employment Options ▪ C14. Transportation ▪ C14a. Availability and Coordination of Transportation ▪ C14b. Users Reporting on Adequate Transportation and Unmet Needs
Coordination and Transparency	<p>CT1. Streamlined Access</p> <ul style="list-style-type: none"> ▪ CT1a. Implementation ▪ CT1b. Fully Functioning Criteria and Readiness Assessment LTSS Partnerships <p>CT2. Service Coordination</p> <ul style="list-style-type: none"> ▪ CT2a. LTSS System Coordination ▪ CT2b. Users Reporting that Care Coordinators of Case Managers Help Them Get What They Need <p>CT3. LTSS Care Transition</p>
Prevention	<p>P1. Health Promotion and Prevention</p> <p>P2. Disaster/Emergency Preparedness</p>
Cultural and Linguistic Competency	<p>CLC1. Needs Assessment and Target Population</p> <p>CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups</p> <p>CLC3. Cultural and Linguistic Competency Training Requirements</p>

CHAPTER 4. CHALLENGES IN IMPLEMENTING THE NBIS AND LESSONS LEARNED

This chapter describes the challenges that CMS will face in implementing a set of national balancing indicators (NBIs). The proposed NBIs have the potential to measure consistently how States perform in implementing a balanced LTSS system. Nevertheless, there are significant challenges that CMS must consider before the NBIs are applied nationally. These challenges include the following:

- Scope of indicator;
- Disagreement between LTS experts regarding whether a certain LTSS system infrastructure that is considered to be “optimal” is the best solution for all programs in all States;
- Difficulties in achieving and maintaining the cross-agency collaboration necessary to gather data and build shared systems;
- Differences in key definitions and terminology;
- Limitations in both process and outcome measures;
- Development of a core set of measures that tell a compelling story and include key pieces of information that are essential to understand a system (forest versus trees);
- Concern for how NBIs will be used; and,
- Methods of collecting complete data in a sustainable way.

4.1 Scope of the Indicator

The NBIP team identified as a challenge that the scope of some indicators did not adequately examine the objective(s) of the indicator. For example, some TEP members reported that Indicator P1, *Health Promotion and Prevention*, as written, did not adequately examine the differences in health promotion and prevention activities by population. One TEP asked:

Will prevention cover people of all ages? This would be very broad and you might do a better job on one population and not another. This is a very complicated issue.

Another TEP member reported:

Prevention related programs for one population may not be the same as for another. Vaccination Programs for kids are different than Tai Chi Programs for adults and elders. The questions are too generic.

It is important that the questions developed for each indicator adequately address the scope of the indicator and the related principle.

4.2 Disagreement Between LTSS Experts Regarding What Is Optimal

One of the core assumptions that the NBIP team used to develop the LTSS indicators was that certain types of systems' infrastructures are necessary to create a balanced system that is person-centered. For example, a state may receive a higher score if it has a DSW registry that is implemented statewide, is regularly updated, and is available free of charge to program participants.

Under the NBIC, not all of the SPT Grantee States believed that all of the systems' infrastructures for which points were given were necessary or desirable for programs serving all populations in all States. The SPT Grantee States contended that this approach penalized States that had already met the needs of the target populations using different mechanisms or that chose not to build systems because they did not believe that the target populations needed or desired the tools that the prescribed systems' infrastructures offered. For example, one State argued that because its LTSS system was designed to provide access to direct service workers through agencies, having a registry that had information about individual direct service workers would offer a confusing array of choices that would overwhelm program participants. In this case, the State provided program participants with information about agencies rather than about individual direct service workers.

SPT Grantee States reported similar comments under the NBIP during the 2012 field test, as did TEP members during the meetings held in 2013. For example, concerning the topic of DSW registries included in Indicator S3. *Direct Service Worker*, one TEP member commented:

A statewide registry may not be necessary. County-wide or locality-based may be better and that is what California has. However, the State may transition to statewide registry and I think that may be bad.

In addition, regarding Indicator S1. *Global Budget*, another TEP member commented:

Having a global budget is being proposed as a promising practice as a tool for rebalancing a state's LTSS system. Okay, it is nice that they [the State] ha[ve] that and it makes it easier for them to do the rebalancing. However, if they don't have it, it is not necessarily bad. Maybe they are a state that is already pretty balanced and they do not need that [global budgeting] to achieve a balanced LTSS system.

Moreover a number of TEP members asked whether a State would receive a lesser score if it had not implemented a number of LTSS systems' infrastructures considered to be "promising practices."

Ultimately, the LTSS experts and stakeholders who provided feedback on the NBIs judged that it was important to develop them so that they would provide guidance on which systems to build and how to construct them. However, this should not be interpreted to mean that there is only one optimal way to design a person-centered and balanced LTSS delivery system. Each LTSS

system should incorporate the specific needs and preferences of the state's populations of individuals with disabilities, as well as reflect the structure and capacity of the provider network and the state agencies or other entities that are responsible for overseeing the system. In addition, it is important to recognize that LTSS delivery systems are dynamic and continually evolving. Some of the indicators that were selected as part of this effort may not be meaningful in the future because other systems and approaches may be developed, making the current indicators irrelevant. Other indicators may become so commonly adopted that measuring them will reveal very little about the relative strength of a State's LTSS system. Thus, it is important to continually review and modify the indicators so that they reflect how these systems evolve.

4.3 Cross-Agency Collaboration

Implementing the NBIs will require a substantial amount of cross-agency collaboration at both the State and Federal levels. Some of the indicators, notably the measures of global budgets, nurse delegation, housing, transportation, shared mission and vision statements, and coordination between HCBS and institutional entities, may require that multiple agencies collaborate and design systems in tandem to report data accurately in order to achieve a higher score.

All of the SPT Grantee States said that obtaining cross-agency collaboration was one of the major challenges that they faced. They reported significant obstacles in obtaining data from other agencies and had difficulty working collaboratively on a shared project. Also, the TEP members questioned whether States could maintain the cross-agency collaboration necessary to obtain and report data in an accurate and timely manner. Related to Indicator CI2. *Housing*, one TEP member commented:

States will have to go through their housing authorities to gather this information that are multiple in many States. In some States they are not coordinated with each other and some States have a State Authority that has some coordination and oversight responsibility. Medicaid staff is not going to know how to answer these questions.

Meaningful cross-agency collaboration likely will be difficult to achieve if the NBIs are implemented nationally.

Cross-agency collaboration, however, likely will produce some positive results. Agencies are more likely to learn from each other and make their LTSS systems more efficient if they build a shared infrastructure. On the other hand, some LTSS system changes may be more difficult to implement if doing so requires the approval and cooperation of multiple agencies and their respective stakeholders.

Implementing comprehensive indicators for an entire LTSS system will require substantial collaboration at the Federal level. CMS must collaborate with other Federal agencies that provide funding or guidance to support States' efforts to build these systems. Varying States' agencies may be more likely to collaborate if they receive the same guidance from the

respective Federal agencies to which they report. In addition, it would be helpful if the Federal agencies asked for similar information, where appropriate, in their reporting requirements.

4.4 Differences in Definitions/Terminology

Differences in the definitions and terminology across States and across programs supporting different populations of individuals with disabilities present a challenge in applying the NBIs and will affect Federal and State agencies' ability to develop more sophisticated indicators. While there was general agreement on terminology used for the NBIs that the team developed and selected under both the NBIC and NBIP, differences in terminology may be a factor in some cases at the state level. For example, the project teams conducting both the NBIC and NBIP relied on States to self-report whether they had mission and/or vision statements for their person-centered LTSS systems. It is likely that there are substantial differences among the States regarding what constitutes a person-centered LTSS system.

Under the NBIP there was a lack of consensus regarding common terminology. As a result, the SPT Grantee States relied on the NBIP team to provide, and in some cases clarify, definitions for certain terms. For example, the NBIP team identified common terminology for terms related to housing (e.g., universal design), transportation (e.g., paratransit) and supported employment (e.g., Medicaid-Buy-in) programs.

The lack of common definitions for core concepts, services, and worker types at both the Federal and state levels will make comparisons difficult when the NBIs are implemented nationally.

4.5 Process/Outcome Conundrum

Both the NBIC and NBIP Project teams struggled to identify meaningful outcome measures given the limitations of the available data. As a result, many of the NBIs are measures of processes that are designed to achieve a given outcome, but do not measure the actual outcome. For example, a DSW registry (a promising practice included in Indicator S3. *Direct Service Workforce*) that is statewide and includes accurate and up-to-date information may be available to all program participants, but it does not guarantee that individuals are able to exercise self-determination and achieve greater community integration.

On the other hand, the indicators that measure actual outcomes, which were developed using existing data, in some cases are so broad that it is impossible to determine whether a State's LTSS system is a key factor driving the outcome. For example, the measure of the level of employment among individuals with disabilities may be more strongly affected by factors beyond the control of State agencies, such as the overall economy, than by programs offered by the State.

TEP members echoed the team’s concern that the majority of indicators were process indicators that were not “scorable.” One TEP member commented:

I looked at your measures and they are all over the map—‘loosey-goosey.’ A lot [indicators] are process-based and not scorable. Wouldn’t we be better off with fewer measures that are outcome-based and have greater strength?

Implementing a comprehensive set of NBIs will require the development and/or refinement of the NBIs so that more of the key measures are outcome-based.

4.6 Forest Versus Trees

The NBIC and NBIP teams worked to develop a set of indicators that provided meaningful information about the States’ LTSS systems while presenting a compelling overall story of the States’ progress. A goal of the NBIs, as articulated by CMS, was to develop a set of indicators that could assess the presence of an “ideal” LTSS system. Two characteristics of an “ideal” LTSS system are that the LTSS system is person-driven and balanced.

The NBIP team sought to provide necessary descriptive information to accomplish the goal described above but not to present so much detail that it is burdensome for States to report the requisite information and difficult to assess the relative strength of each state. For example, the ability of nurse delegation to facilitate the development of a cost-effective LTSS system and to promote greater self-determination may be affected by a number of factors that were not measured in this effort, such as the degree to which the authority for nurse delegation is incorporated into a State’s § 915(c) HCBS waivers and/or §1915 SPAs or state plan personal care services, or how the language in the nurse delegation act is perceived as protecting nurses from adverse actions.

The seven SPT Grantee States that participated in the 2012 field test of the self-assessment survey instrument found the survey to be arduous to complete. They reported that this was because of the following factors:

- the length of the survey,
- the number of state agencies required to be involved to adequately respond to the survey, and,
- the complexity of the survey structure.

A number of TEP members echoed similar concerns regarding the state self-assessment survey instrument. One TEP member commented:

Look at some of the questions and think through if they really can be answered. To me some are just plain too hard to answer and there is a lot there. Just looking at them and paring them down would be helpful.

Another TEP member commented:

It seemed the questions [for Indicator S4] are a bit disproportionate from the rest [of the indicators included in the Sustainability Principle]. There is a lot of detail for these questions compared to questions for the other indicators in this Principle.

However, one TEP member who served on both the NBIC and NBIP commented:

I wonder if we don't have an opportunity here and we don't want to lose it. I don't see other efforts out there that would be able to address the issues we are addressing here in the short term. I wonder if we need to consider having a "short" survey instrument [minimum indicator and question set] and a "long" survey instrument and use the short form to focus in on the few variables we think are essential to balancing. Make the short version a requirement for States to complete. Then have a "long" form of the survey that is voluntary for States to use or provide some incentives for States to complete it so we can get more information for research and analysis. I feel we are talking about some important information here and don't know other ways to get at it besides this effort. We have spent five years here contributing to items that we now may not think are the most important factors to look at.

Finally, TEP members commented on the absence of quality indicators in the NBIs and thought that these needed to be included in any set of NBIs developed. However, early in the project, the NBIP team was instructed not to develop quality indicators so as not to duplicate efforts of other CMS-funded projects. In response to this explanation one TEP member stated:

If that is the case that fact should be clearly stated up front to point out that quality indicators were purposely left out. However, I do not know how you can have a project like this and not address quality.

4.7 Concern for How NBIs Will Be Used

Both STP Grantee States and TEP members asked and expressed concerns about how CMS would use the NBIs, and, in particular, if CMS would use them to make comparisons across States. CMS staff stated that the information would be used to inform them and States on issues and promising practices related to developing person-centered and balanced LTSS systems and not to penalize States based on their performance in achieving this goal.

However, with that said, one TEP member commented:

I think to the extent that they [NBIs] are used to help States think through their systems and to move forward to determine what is the most parsimonious

[cost effective] and reliable set of indicators, that all make sense. I just worry that someone might take this and think 'now we are ready to compare States.

Another TEP member added:

Once there is information available, people will use it for all sorts of purposes for which it is not designed. Even if we say this is not meant for intra state comparisons it does not mean people are going to do it.

CMS and States should clarify how a set of NBIs for LTSS will be used and make sure that they are not being used inappropriately.

4.8 Sustainable Data Collection

States will need to develop data collection and reporting systems and infrastructure in order to facilitate sustainable data collection. This likely will be a significant challenge. Based on the NBIP team's experience with the SPT Grantee States, it is unlikely that all States will submit these data on a voluntary basis. This sentiment was echoed by TEP members during the fall 2013 meetings. One TEP member commented:

States respond to surveys when they are simple and straightforward. The more complex the survey questions are the harder it is to get them [States] to respond and provide reliable information. Thus, there is greater variability in the data reported.

However, as the National Core Indicators effort suggests, there may be a subset of States that are willing to participate.

CMS might be able to collect a substantial amount of the data as part of existing CMS' reporting requirements. Descriptive information could be incorporated into the applications and/or required reports for §1915(c) waivers, §1915 SPAs, and State Plan personal care. CMS also could work with other government agencies to encourage them to collect similar information. For example, the CMS §1915(c) waiver application and the 372 Report could include a subset of information gathered by the Administration on Community Living as part of the State Plan development process and the National Aging Program Information Systems (NAPIS) State Program reports.

CMS also could optimize data in existing systems, particularly a State's Medicaid Information Statistical System (MSIS), if standardized definitions of services are adopted and standardized assessment measures are mandated and collected from the States.

Finally, the key factor that will determine if this approach is sustainable is whether these indicators help to improve LTSS delivery systems. States and the stakeholders who are invested in improving the LTSS available in their States must embrace this effort and use the data to

guide their strategic planning. Thus, to achieve success in this area, CMS must work with States to obtain buy-in and commitment from these States, relevant stakeholders, and other associations that represent them.

CHAPTER 5. CONCLUSIONS AND NEXT STEPS

The NBIs developed during the NBIC were the first step in creating a conceptual framework for developing and implementing a balanced and person-driven LTSS system and set of indicators, scores and rating that can be used by CMS and States to examine progress in developing and implementing such LTSS systems. This report describes the development, refinements and additions made to the NBIs under the NBIP and the challenges the Federal government and States face in developing and implementing a set of NBIs.

The NBIP team worked with stakeholders, including seven SPT Grantee States, the TEP and Stakeholder Group members, Federal Partner agencies, and other not-for-profit organizations, to gather feedback on refining and expanding the NBIs developed under the NBIC and to assess the feasibility of implementing them. The collaboration between the NBIP team, CMS, and the full array of stakeholders was critical to move the NBIs developed under the NBIC forward. In addition, the NBIP team revisited developmental indicators identified under the NBIC. The team worked with CMS and the stakeholders to revise and add the Cultural and Linguistic Competency Principle; to revisit 36 developmental indicators for inclusion in the NBIs; and to create the next iteration of the state self-assessment survey instrument that was developed to collect the information necessary to implement the NBIs.

While the proposed NBIs are potentially effective tools to examine the Federal and State efforts to develop and implement balanced and person-driven LTSS systems, their development continues to be a work in progress. The NBIP team identified significant challenges under the NBIC and NBIP that may impede their effective implementation. These challenges are described in Chapter 4 of this report.

The successful implementation of the NBIs also depends upon a number of other issues. First, because implementing the NBIs requires a significant investment of time, effort, and money, States must be able to see the value in implementing the NBIs and reporting the required data and information to CMS. Second, it is critical that States have the infrastructure and informational technology capabilities needed to collect complete and accurate data and information across populations and topic areas and report it in a sustainable way. Third, States must have the resources necessary to implement the NBIs. States confronted the challenge of inadequate staffing and financial resources during the recent economic crisis in 2008. These challenges and issues must be addressed before the NBIs can be implemented successfully on a national basis.

The NBIP team has a number of next steps to complete before the NBIP ends on September 30, 2014. First, the team will prepare and submit the final *Implementation Options Report*. CMS will use this report as a guide to determine the final set of NBIs, data infrastructure and data collection requirements, and other issues related to developing and implementing a balanced and person-driven LTSS system consistent with CMS' vision. The decisions that CMS makes regarding the final set of NBIs will inform the NBIP Final Report. The team also will incorporate these decisions in the Technical Assistance Guide to NBI. The final reports generated by the

NBIP will be available for use by CMS, Federal and State agencies, and other stakeholders and will support future CMS work in this area.

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APPENDIX A. SPT GRANTEE, TEP, STAKEHOLDER GROUP, AND FEDERAL PARTNER GROUP MEMBERS

State Profile Tool (SPT) Grantee States

- Arkansas
- Florida
- Kentucky
- Maine
- Massachusetts
- Michigan
- Minnesota

Federal Partner Group Members

- Office of Special Education and Rehabilitation
- Immediate Office of the Secretary
- Substance Abuse and Mental Health Services Administration
- Administration on Developmental Disabilities
- Administration on Aging, Office of General Secretary
- Housing and Urban Development
- Department of Veterans Affairs, Office of Disability
- Office of the Assistant Secretary for Planning and Evaluation.

Technical Expert Panel (TEP) Members

- Alexih, Lisa - The Lewin Group
- Bartolic, Alexandra - Minnesota Department of Human Services
- Bradley, Valerie - HSRI
- Bronheim, Suzanne - Center for Cultural Competence, Georgetown University
- Castle, Nicholas - University of Pittsburgh Graduate School of Public Health
- Conroy, Jim - Center for Outcome Analysis
- Eikens, Steve - Truven Health Care Analytics
- Flanagan, Susan - Westchester Consulting Group (NBIP Project Director 2013-2014)
- Fralich, Julie - Muskie School of Public Service, University of Southern Maine
- Frieden, Lex - ILRU

- Jackson, Vivian - Center for Cultural Competence, Georgetown University
- Kane, Rosalie - University of Minnesota, School of Public Health
- Kane, Robert - University of Minnesota, School of Public Health
- Kaye, Stephen - University of California, San Francisco
- Moseley, Charles - National Association of State Directors of Developmental Disabilities Services
- Mor, Vincent - Brown University School of Medicine
- Murtaugh, Chris - Visiting Nurse Association of NYC
- Reinhard, Susan - AARP
- Stone, Robyn - LeadingAge
- Folkemer, Donna - Hilltop Institute
- Woodcock, Cynthia - Hilltop Institute
- Wotring, Jim, Georgetown University, Center for Child Development and Human Development

Stakeholder Group Organizational Members

- ADAPT.org
- Alzheimer's Association
- American Association on Intellectual and Developmental Disabilities
- American Network of Community Options & Resources
- Assisted Living Consumer Alliance
- Brain Injury Association of America
- CARF International
- Center for Medicare Advocacy
- Family Voices of Iowa
- Friends of Residents in Long-Term Care
- National Alliance on Mental Illness
- National Institute on Disability and Rehabilitation Research
- National Institute on Disability and Rehabilitation Research
- NCCNHR/Ombudsman Resource Center
- The Associations for Persons with Severe Handicaps (TASH)
- People First of Washington

- Association of Maternal and Child Health Programs
- National Association of State Directors of Developmental Disabilities Services
- National Association of Area Agencies on Aging (n4a)
- National Conference of State Legislatures (NCSL)
- National Association of State Medicaid Directors (NASMD)
- National Governor's Association (NGA)
- Prior-Year Real Choice Systems Change Grantee: NC Dept of HHS
- Prior-Year Real Choice Systems Change Grantee: South Dakota Parent Connection
- American Association of Homes and Services
- Assisted Living Federation of America (ALFA)
- National Hospice & Palliative Care
- American Congress of Community Supports and Employment Services (ACCSES)
- Service Employees International Union (SEIU)
- National Association for Home Care and Hospice (NAHC)
- National Programs of All-Inclusive Care for the Elderly (PACE) Association
- American Medical Directors' Association
- Direct Care Alliance
- Paraprofessional Healthcare Institute (PHI)
- Visiting Nurses Association of America
- The American Health Care Association (AHCA) & National Center for Assisted Living
- Association of University Centers on Disabilities (AUCD)
- National Association of Sub-acute/Post-Acute Care

APPENDIX B. SUMMARY OF SPT GRANTEE FEEDBACK (2010)

Overall Summary

Generally, where states made small corrections to the indicators, they referenced their State Profile Report to support those corrections. However, there were some changes without references to the State Profile Report that could benefit from follow-up with the states. There are a significant number of items for discussion, especially from Massachusetts, Minnesota, and Nevada, about the validity/applicability of some of the indicators. The indicators for the Sustainability principle (S1–5) and the Community Integration principle (especially CI2) drew comments from several states.

Arkansas:

Comment: It would be helpful if each state had a summary—a page or two summarizing the findings specific to the state and with a total score for all grantee states for each indicator for reference.

Florida:

The Florida grantee offered some minor corrections/updates (renewals of some waivers, ending of others). Some issues may need follow-up either because there was no reference in the State Profile Report or there was an issue with definition.

One issue brought up by Florida was the manner in which HCBS expenditures are calculated for the S2b indicator. In general, the range of programs considered for this indicator was thought to be too narrow, and the methodology that was used to decide which programs would be included presented problems.

This grantee, like a number of others, noted the mission statement indicator as problematic. The grantee opined that mission statements may be more appropriate at the program level than at the agency level, since the agency's responsibilities are so broad.

Iowa:

Feedback has yet to be provided by the Iowa grantee.

Kentucky:

The Kentucky grantee sent two brief comments (adding check marks) that should be checked against the AARP survey before being implemented.

Massachusetts:

Half of the Massachusetts grantee's comments can be implemented without follow-up; for example, the grantee suggested rewording of descriptions of state services. Follow-up is needed for some of the indicator scoring methodologies—how the team decided what to

include, what the data was based on, missing primary scoring methodologies in descriptions, etc.

Maine:

The Maine grantee's comments on Tables 1 through 4 sought more clarification on the short sentences describing the tables. The respondent asked for specific feedback on the comments on Tables 1 and 2, and offered suggestions to rewrite Tables 3 and 4 that should be followed up on (for references). The respondent also had questions about the methodology and data that the team used to calculate the scores for Indicators S2a and S2b.

Michigan:

Several corrections should be followed up on, because there are no references to the State Profile Report to support the grantee's suggestions. (The respondent did offer some references for the suggested corrections, so those can be implemented.) The following items may require discussion:

- Indicator S2, page 26 and Exhibit 2, page 31 – Indicator would be more useful if states were able to drill down to determine percentages by each individual HCBS program.
- Indicator S3, page 32 – Scoring doesn't reflect nuances. Michigan has a registry in place, but it is only accessible to consumers in one waiver and the State Plan personal care program, not in the A/D waiver or children's waiver. The team considers the system to be less than optimal. The score doesn't reflect the limitations or what the team envisions the Registry to be in the future.
- Indicator CT1, page 64 – Scoring methodology doesn't acknowledge when risk of institutionalization is embedded within a prioritization system.
- Indicator CI2, page 68 – Scoring methodology that weighs legislative/executive order, mandate, Task Force, or Commission may be flawed.
- Indicator CT2, page 87 – Recommend deleting this indicator. Too few states use NCI, the source of data for the indicator.

Minnesota:

The Minnesota grantee provided comments on each of the indicators, as well as overall comments on the report. The actionable items in these comments have been highlighted, and all require either minor or substantive discussion by the team.

Nevada:

The Nevada grantee's suggested corrections all involve references to its State Profile Report and should be implemented. (A few corrections are editorial/grammatical.) The grantee also noted the missing primary scoring methodology in indicator descriptions. Finally, the grantee asked for discussion/clarification on the following items:

- Indicator S3: This indicator, PCA Registry, indicates this is a target or ideal setting. Nevada uses an agency and agency with choice service model, and a PCA registry at an individual level is not a target for Nevada.
- Indicator S4: The grantee is not sure that tax incentives are a good balancing indicator; not all states have a state income tax. Nevada does not.
- Indicator SA1: This indicator assumes that the common law employer with the ability to set wages is the goal, which it may not be in all programs, in all states.
- Options for Self Direction seems duplicative to Consumer and Family Empowerment
- Indicator CI2 Questions 1 and 2a-b: What is not scored in 2a? Could 1 and 2b be melded together?
- Indicator S2 Medicaid Expenditures: How are the provider taxes paid by nursing facilities accounted for here?

Virginia:

The Virginia grantee's wording suggestions can be implemented. The comments on indicators will need further discussion:

- Indicator S1: Global Budget: With the vast majority of states having little to no control over their budget, is this indicator valid in gaining insight into LTSS sustainability?
- Indicator S5: Shared LTSS Mission/Vision Statement: Existence of such a document says nothing about the policies and implementation practices of a state's LTSS Program. Consider omitting.
- Indicator SD1: Nurse Delegation: Although an important component to self-determination, this indicator is not typically controlled by a state's Medicaid agency, and therefore, consideration should be taken on how to assign this type of data gathering at the state level so as to not over-burden state Medicaid agency staff.

APPENDIX C. SUMMARY OF SPT GRANTEE FEEDBACK (2012)

While specific feedback related to the survey content is provided below, overall, the seven State Profile Tool (SPT) Grantees that participated in the Phase II field testing of the state self-assessment survey instrument that occurred from April to June 2012, found the survey to be arduous. The Grantees reported that this was due in part to the following reasons:

- the length of the survey,
- the number of state agencies required to be involved to adequately respond to the survey, and
- the complexity of the survey structure.

For example, Grantees reported that Indicator CI1. *Waiver Waitlist* not only requires multiple agency representatives to respond to the questions, but also requires that the set of question be repeated (or looped) in response to the number of programs (or waivers) that exist in the state.

Below, the NBIP team provides more specific feedback provided by the SPT Grantees in response to the team's request after completing the state self-assessment survey instrument in 2012 and findings identified as a result of the NBIP team's review of the initial survey results. This feedback summarizes the challenges that the seven SPT grantees reported in completing some of the more difficult components of the survey.

Sustainability

- Overall, the SPT Grantees offered minor comments on the Sustainability Principle.
- For S1. Global Budget, Michigan suggested that questions referring to the shift of budget between separate lines with legislative approvals should be followed-up with "how often has this happened in your state?" Asking this question may be helpful for reporting and provide context to the question.
- Both Michigan and Massachusetts gave additional detail on their registries (S3-Direct Service Workforce).
- Massachusetts had some difficulty with its interpretation of S4.Support for Informal Caregivers, particularly regarding financial benefits to informal caregivers and mandated paid and or informal family and medical leave allowances for family caregivers.
- Massachusetts also suggested that other states may have had difficulty interpreting the question as well, suggesting that the question may require greater specificity.
- Furthermore, Massachusetts believed that this section should include more information and data about the National Family Caregiver Support Program, as the AOA has extensive data from this program that could be used in future data collection efforts. This project is over now.

Self-Determination

- Massachusetts had a general comment about SD1a.Residential Settings, suggesting that the indicator does not consider the types of community living options within a state.
- Massachusetts argued that community living options that meet the diverse needs of the population by providing a mix of housing and services are essential to a balanced system.
- Further, Massachusetts felt that the indicator should capture the array of options available in a state including options such as Adult Foster Care, Group Adult Foster Care, and Supportive Housing, arguing that the addition would more accurately depict the extent to which a system is balanced.
- There was some difficulty with the self-determination, Availability of Options for Self-determination Indicator (SD2).
- In some instances, Grantees needed to explain or revise the number of participants enrolled in HCBS waivers (FL, MI, MA).
- Massachusetts wanted to clarify that information that was not provided was unavailable at the time of the survey, and was not due to no response on the Grantee's part. This may indicate the difficulties regarding specific components of this indicator for Grantees.

Community Integration

- Michigan was confused about questions regarding income and asset eligibility in indicator C13.Supported Employment Options.
- In Michigan's feedback on the Draft Findings Report, the state provided their formula for various Supported Employment Options income and asset eligibility.

APPENDIX D. SUMMARY OF TEP, FEDERAL PARTNERS AND STAKEHOLDER GROUP FEEDBACK (UP TO 2012)

The tables below summarize the feedback that the team received from TEP members and the Federal Partners on the NBIs developed under NBIC. The feedback informed the team’s assessment and identification of the NBIs that it considered feasible to refine or expand. The summary table, organized by NBI Principle, concentrates on the team’s recommendations for additions, deletions, or changes in the focus of the indicators.

TEP Members’, Federal Partners’, and Stakeholder Group Members’ Feedback by Principle

Sustainability

S2a. Proportion of Medicaid HCBS Spending of the Total Medicaid Long-Term Care Spending Refinements	
Total HCBS Expenditures	It was noted that combining expenditures across population groups can mask gaps for specific populations. Others States recommended the inclusion of individual-level data. States also suggested the expansion of services included in the calculation, such as hospice.

S2b. Per Capita Medicaid Long-Term Care Spending Refinements	
Medicaid Funding Sources	It was suggested that the funding sources focused on services for seniors be expanded to include additional services for other age groups.

S3a. Direct Service Workforce Registry Refinements	
Existence	It was suggested that the indicator should be state-wide and include services offered. SPT Grantee States also recommended that the indicator capture legislation that prohibits the implementation of a state-maintained DSW registry.
Functionality (Coverage, Usefulness, and Workforce)	TEP members suggested that private registries should be included. SPT Grantee States added that registries must be useful to the provider (updated regularly and able to register preferences) and must be useful to consumers (search capabilities, certification/training, and preferences). Finally, it was recommended that registries be used as a monitoring tool to assess the DSW size.
Comprehensiveness	TEP members recommended that the workforce types should be expanded to include Personal Care Attendant and Direct Service Provider with a definition of each.

S4. Support for Informal Caregivers Refinements	
Supports and Services Available	Tax incentives do not apply to all states since some states do not have a state income tax. Furthermore, additional caregiver supports should be added, such as information and assistance, training/education, support groups, and counseling.
	TEP members voiced concern about the state's authority to provide support to caregivers who are not enrolled in Medicaid or waiver programs.
	It was suggested that the term "informal caregiver" be refined to reflect the level of care provided to the care recipient.
	There was inquiry about whether it would be possible to identify the number of people receiving services who have caregivers, rather than the number of caregivers per recipient.

S5. Mission/Vision Statement Refinements	
Sharedness	It was indicated that some agencies provided LTSS in addition to other programs and services, so there would not be a mission or vision statement specific to LTSS. LTSS often were provided by several agencies/sub-agencies, so one mission or vision statement might not be possible since these agencies may have divergent goals.
	The indicator was refined and cognitive interviews were conducted to guide further refinement. States indicated that LTSS goals may not be established through mission or vision statements, but rather through strategic plans.
Quality	It was noted that the degree to which a state complied with the tenets of the mission/vision statement was not examined.

Shared Accountability

SA1. Consumer and Family Empowerment Refinements	
Employer Authority	TEP members found the examination of HCBS waivers under the Shared Accountability Principle to be an inappropriate placement.

Self-Determination

SD1c. Nurse Delegation Refinements	
Regulations	It was suggested that the indicator has a narrow view of nurse delegation by focusing on the relationship between a licensed nurse and unlicensed personnel.
Community Settings	Some institutional settings have regulations that prevent a licensed nurse from delegating duties to unlicensed personnel.

SD2. Options for Self-Determination Refinements	
Employer Authority	There was a suggestion to collect information on how often components are utilized. In addition, clear definitions for the components should be provided. For example, "Non-Medicaid programs and services that offer SD" should be clarified and defined. The indicator should be refined to capture programs and services offering SD that receive state funding. Language should be adjusted to distinguish between Medicaid waivers and non-Medicaid programs (e.g., Veterans services).

Coordination and Transparency

CT1. Streamlined Access Refinements	
Availability (Implementation Status, Age and Disability Groups Covered, Sustainability Plan)	TEP noted that some of the indicator language was confusing. Both SPT Grantees and TEP were unsure whether the partnership data would be meaningful. SPT Grantees requested that they not be required to upload partnership agreements because with hundreds of documents the burden would be too great.
Functionality (Information, Referral, Awareness; Options Counseling and Assistance; Streamlined Eligibility Determination for Public Programs; Person-Centered Transition Support; Consumer Populations, Partnership and Stakeholder Groups; Quality Assurance and Continuous Improvement)	

CT2. Service Coordination Refinement	
Type of Coordination (Options Counseling, Care Coordination, Care Management)	[Entity] suggested that measures of "case management quality" were not useful. These measures were removed from the indicator.
Expenditures of Coordination (Expenditures per Recipient)	
Outcome of Coordination (NCI Data—Percentage of Respondents Receiving What They Need)	

CT3. Care Transitions Refinements	
Availability (Best Practices; Lewin Data of State Coverage Areas for Evidence-based Care Transition Support)	TEP noted that the old indicators for "Service Coordination Between Institutional Settings" (former name for Care Transitions indicators) were confusing and difficult to interpret.
Promotion (Mechanism for Delivering Best Practices)	

Community Integration

CI1. Waiver Waitlist Refinements	
Prioritization Methods	Suggestions included adding the category of “other” to prioritization methods because many programs use a combination of factors to examine how people fare while on the waitlist.
Usefulness of Waitlist	There was a suggestion for a new question about other Medicaid-funded services and supports.

CI2. Housing Refinements	
Availability	Some Federal partners suggested expanding the indicator to measure the state’s interest in increasing the supply of affordable and accessible housing by adding questions about the availability of affordable and accessible housing.
Coordination Type	Federal partners generally believed that this portion of the indicator should be kept as it is.
Coordination Quality	One of the Federal partners recommended that the team expand the indicator to collect information on LTSS/housing coordinators.

Prevention

P1. Health Promotion and Prevention Refinements	
Availability and Access	TEP members suggested that the team make the language related to health promotion programs and services more specific and capable of being objectively measured. Finally, the TEP suggested that the availability of programs and services be connected to outcomes measures of improved access and/or health.

APPENDIX E. 2013 TEP MEETING AGENDAS



National Balancing Indicator Project (NBIP)

Technical Expert Panel Meeting Agenda

Date: 10/10/2013

Time: 2:00 PM-4:15 PM EST

Call-In Number: 1-800-977-8002

Participant Code: 44238253#

Attendees

Lisa Alexih – The Lewin Group

Alex Bartolic – Minnesota Department of Human Services

Suzanne Bronheim – Georgetown University – National Center for Cultural Competence

Valerie Bradley – HSRI

Nicholas Castle – University of Pittsburgh

James Conroy – Center for Outcome Analysis

Steve Eikens – Truven Health Analytics

Sue Flanagan – IMPAQ, NBIP Project Director

Julie Fralich – University of Southern Maine, Muskie School

Lex Frieden – IRLU

Jennifer Howard – IMPAQ NBIP Project Manager

Robert Kane – University of Minnesota

Steve Kaye – University of California – Institute for Health and Aging

Chas Moseley – NASDDDS – Institute on Community Integration

Robyn Stone – LeadingAge

Cynthia Woodcock – UMBC - Hilltop Institute

AGENDA ITEMS:

- Introductions (10 Minutes)
- TEP Role for Meetings (5 Minutes)
 - Role/Responsibilities-What is needed from TEP members?
 - Desired Outcomes
 - Points of Contact @ CMS & IMPAQ
- NBIP Overview (25 Minutes)
 - Principles

- Principle features
- Original, Refined and Additional/Expanded Indicators

***Questions to consider:**

1. What is missing from the proposed final list of balancing principles, principle features, and indicators?
2. Has anything changed since the original discussion of indicators?
3. How can they be strengthened or clarified?
4. Do you know of any additional resources (e.g. data or literature) you would like to bring to our attention that may benefit the project?

▪ Self-Assessment Survey Tool (90 Minutes)

- Principle 1: Sustainability (45 minutes)
- Principle 2: Shared Accountability (45 minutes)

***Questions to consider:**

1. Are the state self- assessment survey tool questions for the indicators included in the Sustainability and Shared Accountability principles clear?
2. Are there any alternative ways to collect the data?

▪ Next Steps (15 Minutes)

▪ Wrap-Up (5 Minutes)



National Balancing Indicator Project (NBIP)

Technical Expert Panel Meeting Agenda

Date: 10/23/2013

Time: 2:00 PM-3:40 PM EST

Call-In Number: 1-800-977-8002

Participant Code: 44238253#

Attendees

Lisa Alecxih – The Lewin Group
Alex Bartolic – Minnesota Department of Human Services
Steve Eikens – Truven Health Analytics
Sue Flanagan – IMPAQ, NBIP Project Director
Julie Fralich – University of Southern Maine, Muskie School
Lex Frieden – ILRU
Jennifer Howard – IMPAQ, NBIP Project Manager
Robert Kane – University of Minnesota
Steve Kaye – University of California – Institute for Health and Aging
Chris Murtaugh – Visiting Nurse Association of NYS
Robyn Stone – LeadingAge
Shawn Terrell – Administration on Community Living
Cynthia Woodcock – UMBC - Hilltop Institute

AGENDA ITEMS:

- Introductions (10 Minutes)
- TEP Role for Meetings-Refresher (5 Minutes)
 - Role/Responsibilities
 - Desired Outcomes
 - Points of Contact @ CMS & IMPAQ
- NBI Overview-Refresher (10 Minutes)
 - Principles
 - Principle features
 - Refined and Expanded Indicators

***Questions to consider:**

1. What is missing from the proposed final list of principles, principle features, and indicators?
 2. How can they be strengthened or clarified?
 3. Do you know of any additional resources (e.g., data or literature) you would like to bring to our attention that may benefit the project?
- Survey (105 Minutes)
 - Principle 1: Self-Determination (35 Minutes)
 - Principle 2: Prevention (35 Minutes)
 - Principle 3: Cultural and Linguistic Competency (35 Minutes)

***Questions to consider:**

1. Are the self-assessment survey questions for the indicators included in the Self-Determination, Prevention, and Cultural and Linguistic Competency principles clear?
 2. Are there any alternative ways to collect the data?
- Next Steps (15 Minutes)
 - Wrap-Up (5 Minutes)



National Balancing Indicator Project (NBIP)

Technical Expert Panel Meeting Agenda

Date: 11/6/2013

Time: 2:00 PM-4:05 PM EST

Call-In Number: 1-800-977-8002

Participant Code: 44238253#

Attendees:

Steve Eikens – Truven Health Analytics
Julie Fralich – University of Southern Maine, Muskie School
Lex Frieden – ILRU
Robert Kane – University of Minnesota
Chas Moseley – NASDDDS – Institute on Community Integration
Chris Murtaugh, Visiting Nurse Association of NYC
Sue Flanagan – IMPAQ, NBIP Project Director
Jennifer Howard – IMPAQ NBIP Project Manager
Annette Shea – CMS Project Officer
Shawn Terrell- Administration on Community Living

AGENDA ITEMS:

- Introductions (10 Minutes)
- TEP Role for Meetings-Refresher (5 Minutes)
 - Role/Responsibilities
 - Desired Outcomes
 - Points of Contact @ CMS & IMPAQ
- NBI Overview-Refresher (10 Minutes)
 - Principles
 - Principle features
 - Refined and Expanded Indicators

*Questions to consider:

1. What is missing from the proposed final list of principles, principle features, and indicators?

2. How can they be strengthened or clarified?
 3. Do you know of any additional resources (e.g., data or literature) you would like to bring to our attention that may benefit the project?
- Survey (100 Minutes)
 - Principle 1: Community Integration and Inclusion (50 Minutes)
 - Principle 2: Coordination and Transparency (50 Minutes)

***Questions to consider:**

1. Are the self-assessment survey questions for the indicators included in the Community Integration and Inclusion and Coordination and Transparency principles clear?
 2. Are there any alternative ways to collect the data?
- Next Steps (20 Minutes)
 - Wrap-Up (5 Minutes)

APPENDIX F. RATIONALE FOR THE EXPANSION OF THE-SHARED ACCOUNTABILITY PRINCIPLE

NBI Definition of Shared Accountability

The system reflects shared accountability and responsibility among and between people, their families, service providers, local governments, state program agencies, and the Federal government, and encourages personal planning for long-term care needs, including greater use and awareness of private sources of funding.

NBI Definition of Self-Determination

The system affords people with disabilities and/or chronic illnesses the authority to decide where and with whom they live, to control the services that they receive and the people with whom they work, to avail themselves of opportunities to work, have private incomes, and to have friends and supports to help them participate in community life.

Rationale for Shared Accountability as a Separate Principle:

The definition used by the NBI for self-determination does not include the responsibility component of self-determination that has been identified in the literature. Instead, it focuses on the freedom and authority that individuals are afforded by LTSS systems. This definition aligns with that used by Harkins (2002) to generate discussion: self-determination means *“assisting people who receive support from the human services system to compose their own lives, in the company of others they care about, in the company of others who care about them.”*⁴

The responsibility and accountability aspect of self-determination is a growing area of examination. While not always discussed in the context of self-determination, fields such as business and education have focused on shared accountability to improve outcomes, like student achievement. The implementation of Accountable Care Organizations (ACOs), as a result of the Patient Protection and Affordable Care Act (ACA), has brought shared accountability to the forefront of public consideration. In consultation with stakeholders, states, and a technical expert panel, the NBIP team determined that shared accountability was a concept that warranted exploration as a separate principle.

A comparison of measures used by Federal agencies demonstrated that shared accountability is an area that few agencies investigated. The lack of available measures of shared accountability makes this an important area to examine.

⁴ Harkins, D. (2002, April 1). Organizing a Movement. . Retrieved July 12, 2011, from <http://www.centerforself-determination.com/docs/sd/Organizing%20a%20Movement.pdf>

Examining shared accountability as a separate principle facilitates a more in-depth exploration of each of the features identified rather than including it as an aspect of self-determination/person-centeredness.

Rationale for Shared Accountability as a Sub-Principle of Self-Determination:

Self-determination has historically been comprised of four principles and has included the concept of responsibility. These concepts have been inextricably linked in the literature: associated with the freedom that comes with self-determination is the responsibility to use this authority wisely. The below are excerpts from documents that support this understanding.

1. Defining the “help that is needed at this time” as what is needed to transform our system to enable people with disabilities who rely upon services to experience self-determination in their lives. The changes needed are based upon four primary principles:
 - Freedom of individuals to choose where and with whom they live, as well as what to do with their lives;
 - Authority of individuals over a targeted amount of dollars sufficient to provide necessary supports;
 - Support that is individually designed to meet the unique needs of an individual with a disability and support from freely chosen family and friends to obtain and monitor this support;
 - Responsibility for the wise use of public dollars and for exercising the benefits of citizenship.⁵
2. The meaning of self-determination since its inception a decade ago has always rested on a set of principles: Freedom, Authority, Support, Responsibility, and now Confirmation of the important role that individuals with disabilities must play in the development of this movement.

⁵ Nerney, T, & Harris, K. (N.D.). *Policy analysis of New Jersey’s self-determination effort*. Retrieved at <http://www.centerforself-determination.com/docs/sd/CENTER%20for%20SELF%20Jersey.pdf>.

APPENDIX G. LITERATURE REVIEW-PREVENTION PRINCIPLE

For years, the most widely accepted definition of health was the absence of disease. This antiquated definition may be one of the strongest reasons underlying the lack of attention given to people with disabilities in health promotion. If health is considered a dynamic status, as opposed to a static one, then people with disabilities are equally able to improve their health outcomes. It is especially important to provide health promotion services to people with disabilities since people with disabilities often start at the lower end of the health continuum due to secondary conditions that overlap with their primary disabilities.

A health promotion program for people with disabilities aims to reduce their secondary conditions (e.g., obesity, hypertension, pressure sores), to enable them to maintain their functional independence, to provide them with opportunities for leisure and enjoyment, and to enhance their overall quality of life by reducing environmental barriers to good health. Over the last few years, there has been an increase in health promotion initiatives directed at individuals with disabilities, including several CDC-funded programs. However, there still exists a significant gap in health promotion activities as compared to the general population. A greater emphasis must be placed on community-based health promotion initiatives for people with disabilities in order to achieve a thoroughly comprehensive health promotion network.

Background

The U.S. Surgeon General's 2005 Call to Action, *To Improve the Health and Wellness of Persons with Disabilities*, states that "persons with disabilities can promote their own good health by developing and maintaining health lifestyles. People with disabilities need healthcare and healthy programs [for] the same reasons anyone else does – to stay well, active and a part of the community."⁶ However, persons with disabilities are less likely to engage in regular moderate physical activity than people without disabilities.⁷ The largest set of U.S. health data for people with disabilities, DATA2010, measures health at the population level. These data highlight improvements in health over the previous decade and clearly reveal specific health disparities for people with disabilities. Compared with people without disabilities, people with disabilities are more likely to:

- Experience difficulties or delays in getting the health care they need;
- Not have had an annual dental visit;
- Not have had a mammogram in the past two years;
- Not have had a Pap test within the past three years;

⁶ U.S. Department of Health and Human Services. (2005). *The 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities: What It Means to You*. Retrieved at <http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/whatitmeanstoyou508.pdf>

⁷ "Persons with Disabilities Fact Sheet."

- Not engage in fitness activities;
- Use tobacco;
- Be overweight or obese;
- Have high blood pressure;
- Experience symptoms of psychological distress;
- Receive less social-emotional support; and,
- Have lower employment rates.⁸

The Health People 2020 initiative has a section solely dedicated to Disability and Health which focuses on the well-being of individuals with disabilities. The Disability and Health objectives highlight areas for improvement and opportunities for people with disabilities to be included in public health activities, receive well-timed interventions and services, interact with their environment without barriers, and participate in everyday life activities.⁹ The figure below contains the objectives from the Health People 2020 document.

Figure 1: Health People 2020 Disability and Health Objectives¹⁰

Healthy People 2020 Disability and Health Objectives	
Systems and Policies	
DH1	Include in the core of Healthy People 2020 population data systems a standardized set of questions that identify people with disabilities.
DH2	Increase the number of Native American tribes, states, and the District of Columbia that have public health surveillance and health promotion programs for people with disabilities and their caregivers.
DH2.1	Increase the number of health departments in states and the District of Columbia that have at least one health promotion program aimed at improving the health and well-being of people with disabilities.
DH2.2	Increase the number of health departments in states and the District of Columbia that conduct health surveillance for caregivers of people with disabilities.
DH2.3	Increase the number of health departments in states and the District of Columbia that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities.
DH2.4	(Developmental) Increase the number of Native American tribes that conduct health surveillance for people with disabilities.
DH2.5	(Developmental) Increase the number of Native American tribes that have at least one health promotion program aimed at improving the health and well-being of people with disabilities.
DH2.6	(Developmental) Increase the number of Native American tribes that conduct health

⁸ U.S. Department of Health and Human Services. *Health People 2020*. U.S. Department of HHS, Office of Disease Prevention and Health Promotion, 2010.

⁹ *Healthy People 2020*.

¹⁰ *Id.*

Healthy People 2020 Disability and Health Objectives	
	surveillance of caregivers of people with disabilities
DH2.7	(Developmental) Increase the number of Native American tribes that have at least one health promotion program aimed at improving the health and well-being of caregivers of people with disabilities.
DH3	(Developmental) Increase the proportion of U.S. master of public health (M.P.H.) programs that offer graduate-level courses in disability and health.
Barriers to Health Care	
DH4	(Developmental) Reduce the proportion of people with disabilities who report delays in receiving primary and periodic preventive care due to specific barriers.
DH5	Increase the proportion of youth with special health care needs whose health care provider has discussed transition planning from pediatric to adult health care.
DH6	(Developmental) Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.
DH7	(Developmental) Reduce the proportion of older adults with disabilities who use inappropriate medications.
Environment	
DH8	(Developmental) Reduce the proportion of people with disabilities who report physical or program barriers to local health and wellness programs.
DH9	(Developmental) Reduce the proportion of people with disabilities who encounter barriers to participating in home, school, work, or community activities.
DH10	(Developmental) Reduce the proportion of people with disabilities who report barriers to obtaining the assistive devices, service animals, technology services, and accessible technologies that they need.
DH11	Increase the proportion of newly constructed and retrofitted U.S. homes and residential buildings that have visitable features.
DH12	Reduce the number of people with disabilities living in congregate care residences.
DH12.1	Reduce the number of adults with disabilities (aged 22 years and older) living in congregate care residences that serve 16 or more persons.
DH12.2	Reduce the number of children and youth with disabilities (aged 21 years and under) living in congregate care residences.
Activities and Participation	
DH13	(Developmental) Increase the proportion of people with disabilities who participate in social, spiritual, recreational, community, and civic activities to the degree that they wish.
DH14	Increase the proportion of children and youth with disabilities who spend at least 80 percent of their time in regular education programs.
DH15	Reduce unemployment among people with disabilities.
DH16	Increase employment among people with disabilities.
DH17	Increase the proportion of adults with disabilities who report sufficient social and emotional support.
DH18	(Developmental) Reduce the proportion of people with disabilities who report serious psychological distress.
DH19	(Developmental) Reduce the proportion of people with disabilities who experience nonfatal unintentional injuries that require medical care.
DH20	Increase the proportion of children with disabilities, birth through age two, who receive early intervention services in home or community-based settings.

In the past, one of the main reasons persons with disabilities did not engage in health promotion activities was due to frequently cited barriers to such services,¹¹ including the following:

- Too tired
- Lack of transportation
- Feeling what I do doesn't help
- Lack of money
- Impairment
- No one to help me
- Not interested
- Lack of information
- Embarrassment about my appearance
- Lack of time
- Feeling I can't do things correctly
- Difficulty with communication
- Bad weather
- Lack of help from health care professionals
- Concern about safety
- Lack of support from family/friends
- Interferes with other responsibilities

The Health People 2020 initiative specifically attempts to address this issue in the objectives above, as does the Centers for Disease Control and Prevention (CDC). The CDC's National Center on Birth Defects and Developmental Disabilities aims to provide community-based programs to meet the needs of persons with disabilities; ensure that environments and facilities conducive to being physically active are available and accessible to people with disabilities, such as offering safe, accessible, and attractive trails for bicycling, walking, and wheelchair activities; ensure that people with disabilities are involved at all stages of planning and implementing community physical activity programs; provide quality, preferably daily, K-12 accessible physical education classes for children and youths with disabilities; and encourage health care providers to talk routinely to their patients with disabilities about incorporating physical activity into their lives.¹²

Available Health Promotion Programs for Persons with Disabilities

With technical assistance from the Association of University Centers on Disabilities (AUCD), the CDC supports 16 state-based programs the ultimate goal of which is to improve health, well-being, independence, productivity, and full societal participation among people with disabilities. These programs ensure that individuals with disabilities are included in ongoing state disease prevention, health promotion, and emergency response activities.

¹¹ Becker, H., Stuijbergen, A.K., & Sands, D. (1991). Development of a scale to measure barriers to health promotion activities among persons with disabilities. *American Journal of Health Promotion* 5(6), 449-454.

¹² Centers for Disease Control and Prevention. "Physical Activity and Health: Persons with Disabilities Fact Sheet." CDC, NCCDPHP, Division of Nutrition and Physical Activity.

Arkansas

Arkansas's health promotion programming for persons with disabilities includes the following activities:¹³

- Implementing *Living Well with a Disability*, an eight-week workshop using goal-setting and problem solving to manage and prevent secondary conditions, at Independent Living Centers around the state and the Stanford Chronic Disease Self-Management program.
- Promoting breast cancer awareness and encouraging recommended screening among women 40 years of age or older who have a disability through the *Right to Know* campaign, with partners, including Arkansas BreastCare.
- Working at the county level to improve emergency preparedness and plan for people with disabilities that will serve as a model for the state, and training first responders on effective inclusive response for people with disabilities.

California

California's health promotion programming for persons with disabilities includes the following activities:¹⁴

- The Living Health with a Disability project aims to build capacity for disability health promotion programs, as well as a specialized program, Training for Professionals and Paraprofessionals. This module addresses: 1) changing nursing practice by integrating a disability-focused curriculum into schools for nursing and other allied health professionals; 2) imbedding oral health care for people with disabilities into the nursing curriculum; and, 3) increasing the knowledge and comfort of oral health professionals in providing preventive treatment services for people with disabilities.
- Improving health-related surveillance activities in California by ensuring that survey respondents with disabilities are identified as such and that survey procedures enable participation of people with all types of disabilities as respondents.

Delaware

Delaware's health promotion programming for persons with disabilities include the following activities:¹⁵

- The Health Delawareans with Disabilities project aims to prevent secondary diseases and improve the health and well-being of individuals with disabilities;
- Creating systems-level change through active participation on statewide councils, committees, and workgroups that address health and disability issues and implementation of goals and objectives of the Plan for Action, A Strategic Plan for

¹³ University of Arkansas for Medical Sciences. "Health Promotion." UAMS, Arkansas Disability and Health Program. Retrieved from http://www.uams.edu/ar_disability/health_promo.asp

¹⁴ California Office of Public Health, Office of Disability and Health. Retrieved from <http://www.cdph.ca.gov/PROGRAMS/Pages/DisabilityandHealth.aspx>

¹⁵ Health Delawareans with Disabilities. Retrieved from <http://www.gohdwd.org>

Delaware to Promote Health and Prevent Secondary Health Conditions in Individuals with Disabilities.

- Providing technical assistance for health care, fitness, and recreation providers and facilities to improve accessibility and inclusion of individuals with disabilities in health examinations, exercise programs, and recreation activities.
- Providing education, raising awareness, and sharing resources through the program's interactive website www.gohdwd.org and email newsletters to individuals with disabilities, family members, professionals, policymakers, and legislators.

Florida

Florida's health promotion activities for persons with disabilities include the following activities:¹⁶

- Promoting breast cancer awareness and encouraging recommended screening among women 40 years of age or older who have a disability through the Right to Know Campaign with partners such as the Florida Centers for Independent Living and the Florida Area Health Education Centers.
- Increasing the capacity of health care providers in Florida to provide quality health care to people with disabilities by training medical students, as well as medical and allied health professionals.
- Increasing the quantity and quality of disability- and health-related data in Florida and providing the epidemiologic capacity to analyze these data.

Illinois

Illinois's health promotion activities for persons with disabilities include the following activities:¹⁷

- Monitoring the health status and health-related behaviors of people with disabilities and sustaining and expanding the statewide infrastructure to prevent secondary conditions and promote the health of people with disabilities in Illinois.
- Increasing evidence-based health promotion and prevention opportunities and resources available for people with disabilities to promote healthy lifestyles and reduce the risk of chronic disease and secondary conditions.
- Assisting health professionals to gain the knowledge and tools necessary to work effectively with people with a disability to increase the availability and accessibility of health promotion and prevention services, interventions, and resources.

¹⁶ Florida Office on Disability and Health, University of Florida, <http://fodh.php.ufl.edu/>

¹⁷ Illinois Disability and Health Program, Illinois Department of Public Health
<http://www.idph.state.il.us/idhp/index.htm>

Iowa

Iowa's health promotion activities for persons with disabilities include the following activities:¹⁸

- Developing a statewide network of community providers that offer the Living Well with a Disability intervention program.
- Identifying evidence-based strategies to increase awareness among and education opportunities for health professionals.
- Promoting accessible health care and support services to increase independence among people with disabilities.

Kansas

Kansas's health promotion activities for persons with disabilities include the following activities:¹⁹

- Collaborating with Kansas's Cardiovascular, Cancer, and Diabetes Programs to recruit Kansans with disabilities to participate as members of state-level health promotion advisory councils. As members, individuals with disabilities will help to suggest, shape and "do the work" of addressing health disparities among Kansans with disabilities.
- Working with community-based partner organizations, Living Well with a Disability has been delivered to Kansans with disabilities in rural and urban communities, including during workshops on a Federal Indian reservation. The course also has been provided to disability youth organizations, seniors in assisted living, and people with disabilities who receive services from community homeless shelters.
- Kansas is developing a strategic plan to extend training and education on emergency management for people with disabilities at the county level. Kansas counties also are receiving information related to known best practices in the areas of disability and disaster management.

Massachusetts

Massachusetts's health promotion activities for persons with disabilities include the following:²⁰

- Designing and implementing training and technical assistance programs for health care providers and public health programs on the Americans with Disabilities Act to ensure inclusion of people with disabilities in state funded programs, services, and activities.

¹⁸ Disability and Health Program, Iowa Department of Public Health,
http://www.idph.state.ia.us/bh/disability_health.asp

¹⁹ Disability and Health Program, Kansas Department of Health and Development,
<http://www.kdheks.gov/disability/index.htm>

²⁰ Office on Health and Disability, Massachusetts Department of Public Health,
http://www.mass.gov/?pageID=eohhs2terminal&L=5&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Department+of+Public+Health&L4=Programs+and+Services+K+-+S&sid=Eeohhs2&b=terminalcontent&f=dph_com_health_health_disability_g_disability&csid=Eeohhs2

- Providing the knowledge-base needed to design programs related to healthy aging, health and disability, and secondary health conditions.
- Working with state agencies and community partners to identify, implement, and evaluate evidence-based health promotion programs among older adults and people with disabilities (for example, the Stanford Chronic Disease Self-Management Program).

Michigan

Michigan's health promotion activities for persons with disabilities include the following:²¹

- Implementing the Stanford Chronic Disease Self-Management Program, known as the Personal Action Toward Health Program (PATH), in Michigan.
- Analyzing surveillance data on disability using the Behavioral Risk Factor Surveillance System (BRFSS), including health status and chronic disease prevalence among people with disabilities, and the health effects of caregiving.
- Promoting the inclusion of people with disabilities in existing public health programs.

Montana

Montana's health promotion activities for persons with disabilities include the following:²²

- Recruiting, training, and supporting disability advisors to participate in Montana Department of Public Health and Human Services advisory groups and integrate disability and health into public health planning and evaluation processes.
- Recruiting, training, and supporting state disability leaders to assess and improve the accessibility of community health and fitness programs.
- Conducting *Living Well with a Disability*, an eight-week peer-facilitated, health promotion workshop with Montana's four Centers for Independent Living.

New York

New York's health promotion activities for persons with disabilities include the following:²³

- Implementing the New York State Department of Health (NYSDOH) Center for Community Health Inclusion Policy, which requires all Center for Community Health programs to ensure accessibility and inclusion for people with disabilities throughout all funding opportunities. The proposed activities to implement inclusive local and statewide public health programs must also include an evaluation of the effect and reach of the policy.

²¹ Disability Health Program, Michigan Department of Community Health, http://www.michigan.gov/mdch/0,1607,7-132-2940_2955_54051---,00.html

²² Montana Disability and Health Program, Montana Department of Public Health and Human Services and The University of Montana Rural Institute, <http://mtdh.ruralinstitute.umt.edu/>

²³ Disability and Health in New York State, New York Department of Health, <http://www.health.state.ny.us/nysdoh/prevent/main.htm>

- Educating and training NYSDOH program managers, primary program implementation staff, NYSDOH contractors, and partners about the health disparities experienced by people with disabilities, and providing strategies, resources, and potential partners that will enable the integration of people with disabilities in their program areas.
- Supporting an advisory body comprising individuals with disabilities, other state agencies, community-based organizations, and providers to inform program activities, as well as representing multiple external agency advisory committees to direct consideration of health care and health promotion needs of people with disabilities.

North Carolina

North Carolina’s health promotion activities for persons with disabilities include the following:²⁴

- Supporting the collection, analysis, and dissemination of data on people with intellectual or developmental disabilities, or both, to better assess the health status of North Carolina adults.
- Promoting accessible environments to support full community participation and engaging people with disabilities by developing accessibility checklists for health care practices and by providing training on adaptive and inclusive fitness and on how to remove barriers to fitness facilities.
- Increasing access to domestic violence and sexual assault services for people with disabilities with the implementation of adaptive equipment and enhanced disability awareness among domestic violence and sexual assault agencies.

North Dakota

North Dakota’s health promotion activities for persons with disabilities include the following:²⁵

- Forming a consumer-driven advisory council that reviews the progress of the program activities and data related to the health of people with disabilities, assists with development of a strategic plan, and provides recommendations to address issues related to the health and wellness of North Dakota citizens with disabilities.
- Reducing health disparities between people with disabilities and those without disabilities, specifically targeting the areas of obesity, diabetes, and tobacco use.
- Ensuring people have accurate information on disability and health issues and promoting communication, planning, and implementation of health- and disability-related services across service systems.

²⁴ North Carolina Office on Disability and Health, FPG Child Development Institute, University of North Carolina—Chapel Hill, <http://www.fpg.unc.edu/~ncodh/>

²⁵ North Dakota Disability Health Project, <http://www.ndcpd.org/health/>

Oregon

Oregon's health promotion activities for persons with disabilities include the following:²⁶

- Conducting *Healthy Lifestyles* workshops for people with disabilities (in English and Spanish) to improve quality of life in partnership with the Centers for Independent Living and other disability organizations.
- Implementing the *Right to Know* campaign and breast health education events, providing mammography technologist training, and assessing Oregon's mammography clinics to improve breast cancer awareness and screening among women with disabilities.
- Providing individualized emergency preparedness training for Oregonians with disabilities, as well as working with key community and state partners to ensure that emergency preparedness planning and training efforts include topics relevant to the health and safety of people with disabilities.

South Carolina

South Carolina's health promotion activities for persons with disabilities include the following:²⁷

- Increasing the knowledge of professionals and paraprofessionals in South Carolina to meet the preventive, primary, and secondary health needs of people with disabilities.
- Conducting ongoing surveillance with Behavioral Risk Factor Surveillance System (BRFSS) and administrative datasets as secondary sources via the South Carolina Disability Cube Project.
- Working to achieve more livable communities for people with disabilities by facilitating access to primary care physician offices, increasing access to fitness and recreation facilities, and working with community planning agencies to improve outdoor space using principals of universal design.

Virginia

Virginia's health promotion activities for persons with disabilities include the following:²⁸

- Promoting the health of people with disabilities as a public health priority through collaborations with the Virginia Department of Health, the Virginia task force, and disability and health community partners.

²⁶ Oregon Office on Disability and Health, Oregon Health and Sciences University,
<http://www.ohsu.edu/oidd/cca/oodh/>

²⁷ South Carolina Interagency Office of Disability and Health, South Carolina School of Medicine,
<http://sciodh.com/>

²⁸ Partnerships for People with Disabilities, Partnership for People, Virginia Commonwealth University; Virginia's University Center for Excellence in Developmental Disabilities <http://www.vcu.edu/partnership/>

- Improving the accessibility of public health programs and services for people with disabilities through outreach to mammography sites, dissemination of survey accessibility results, and provision of technical assistance and training resources.
- Raising awareness of the health promotion needs of people with disabilities by expanding websites, disseminating media resources, and implementing training activities and community outreach.

Effectiveness Research on Health Promotion Activities for Persons with Disabilities

While health promotion activities for persons with disabilities are limited, researchers have made several efforts to study their effects. Most of these studies, however, have focused on a particular disability type, in the same manner as most interventions, as opposed to an overall view of the broader community of individuals with disabilities. These studies reveal that community-based, outcome-targeted approaches are most successful.²⁹ Self-efficacy, which can be strengthened through health promotion activities, and social supports also predict the likelihood of behavioral change. In one study that attempted to quantify the relationship between self-efficacy, social support, and physical activity among intellectually disabled persons, the targeted outcome, social support, was measured by three groups of family, paid direct-care staff, and peers with a similar disability type. The study found that social supports positively influenced physical activity and also was mediated by self-efficacy. According to the research, social supports can help persons with intellectual disabilities overcome barriers and increase the potential for healthy behavior change.³⁰

Not only do studies show that health promotion activities improve the health status of and positively influence health behavior changes among individuals with disabilities, but a study analyzing the effects of the Living Well with a Disability program found that within the first six months of implementation, there were noticeable financial savings based on Medicare cost estimates.³¹ Another study of the Living Well with a Disability program found that those who participated in the Living Well program were more than twice as likely to be below the median for post-secondary conditions, almost twice as likely to be below the median for post-unhealthy days, and more than one and a half times as likely for below median post-health care costs.³²

An RCT that sought to promote physical activity in women with mobility impairments through a 6-month home-based program that included day-long workshops, counseling, weekly progress reports, and built in social supports, revealed that the experimental group that nearly doubled

²⁹ Capella-McDonnall, M. (2007, March). The need for health promotion for adults who are visually impaired. *Journal of Visual Impairment and Blindness*. 133-145.

³⁰ Peterson, J.J., Lowe, J.B., Peterson, N.A., Nothwehr, F.K., Janz, K.F., & Lobas, J.G. (2008, September/October). Paths to leisure physical activity among adults with intellectual disabilities: self-Efficacy and social support. *American Journal of Health Promotion*. 23(1), 35-42.

³¹ Ipsem, C., Raveslout, C., Seekins, T., & Seninger, S. (2006). A financial-cost-benefit analysis of a health promotion program for individuals with mobility impairments. *Journal of Disability Policy Studies*. 16(4), 220-228.

³² Raveslout, C.H., Seekins, T., Cahill, T., Lindgren, S., Nary, D.E., & White, G. (2007). Health promotion for people with disabilities: Development and evaluation of the living well with a disability program. *Oxford Journal, Health Education Research*. 22(4). 522-531.

their physical activity although program adherence varied (average of 57 percent continual participation) and that there were no measurable effects on weight, body fat, depression, stress levels, cholesterol and blood pressure levels, and secondary conditions. However, qualitative follow-up data found that 78 percent of participants felt that the increased physical activity fostered positive changes in other areas.³³

Several studies reveal that a well-received model for health promotion for those with disabilities is the Transtheoretical Model (TTM), which is composed of four constructs: 1) stages of change or the current status, 2) processes of change or those actions necessary to change behavior, 3) self-efficacy and 4) decisional balance or perceived pros and cons. One particular study sought to analyze the stages of the TTM as predictors for health promotion and behavior change. The study found that self-efficacy was one of the most predicting factors of behavior change. Further, the earlier the stage of change (further from the health promotion goal) the more difficult it was to change behavior. Overall the TTM model was effective in producing behavior change in persons with physical disabilities.³⁴

Most studies, regardless of the disability audience and health promotion outcome, emphasize the need for social support and continual guidance built into the health promotion program model.

Additional sources of information include the following:

1. Elinder, L.S., Bergström, H., Hagberg, J., Wihlman, U., & Hagströmer, M. (2010). Promoting a Healthy Diet and Physical Activity in Adults with Intellectual Disabilities Living in Community Residences: Design and Evaluation of a Cluster-Randomized Intervention. *BMC Public Health*. 10 (761), 1-7.
2. Drum, C.E., Peterson, J.J., Culley, C., Krahn, G., Heller, T., Kimpton, T. & White, G.W. (2009, November/December). Guidelines and Criteria for the Implementation of Community-based Health Promotion Programs for Individuals with Disabilities. *American Journal of Health Promotion*. 24(2). 93-101.
3. Almomani, F., Brown, C., & Williams, K.B. (2006, Spring). The Effect of an Oral Health Promotion Program for People with Psychiatric Disabilities. *Psychiatric Rehabilitation Journal*. 29(4). 274-281.
4. Krahn, G.L., & Drum, C.E. (2007). Translating Policy Principles into Practice to Improve Health Care Access for Adults with Intellectual Disabilities: A Research Review of the Past Decade. *Mental Retardation and Developmental Disabilities Research Reviews*. (13), 160-168.

³³ White, G.W. & Figoni, S. *Health promotion for persons with disabilities and prevention of secondary conditions: executive summary*. Centers for Disease Control and Prevention. Project Number: # R04/CCR717707-01.

³⁴ Kosma, M., Cardinal, B.J., & McCubbin, J.A. (2004, November/December). Predictors of physical activity stage of change among adults with physical disabilities. *American Journal of Health Promotion*. 19(2). 114-117.

APPENDIX H. LITERATURE REVIEW-CULTURAL AND LINGUISTIC COMPETENCY PRINCIPLE

Due to the fact that states have unique terminologies to represent a culturally competent LTSS system, the team used the general definition, which defines a culturally competent LTSS system as a system that provides accessible information and services that take into account people's cultural and linguistic needs. The team used a measures scan to identify indicators of cultural competence in the first phase of the project. Specifically, the team determined that a culturally competent LTSS system includes the following key components:

1. Service offerings to a diverse population, supported by staff who reflect that diversity;
2. State and local communities provide ongoing education, training, and awareness activities in cultural competence for providers and others;
3. Prevention of prejudice and discrimination related to disability or accommodation in the workplace; and,
4. Successful communication with people of all ages with disabilities and/or chronic conditions.

The Changing Concept of Cultural Competence

The populations that are included and the definition of cultural competence is *constantly evolving*. An operational definition of cultural competence defines it as “the integration and transformation of knowledge about individuals and groups of people into specific standards, policies, practices, and attitudes used in appropriate cultural settings to increase the quality of services, thereby producing better outcomes” (Davis & Donald, 1997). However, many agencies and research suggest that it is important that no agency delay action and wait for a conclusive definition, but rather recognize that culture competence, “is never fully realized, achieved, or completed, but rather . . . a lifelong process . . .” (NASW, Standards for Cultural Competence). Georgetown University's Child Development Center describes five essential elements that contribute to a system's, institution's, or agency's ability to become more cultural competent. The ideal system (1) values diversity, (2) has the capacity for cultural self-assessment, (3) is conscious of the dynamics inherent when cultures interact, (4) has institutionalized cultural knowledge, and (5) has developed adaptations to diversity. For a listing of definitions of cultural competence, please visit The Minnesota Department of Human Services at <http://tinyurl.com/4vo5ztt>. Cultural competence also has expanded to provide services to new groups, such as the LGBT community (see <http://www.hrc.org/issues/cultural-competence.htm>). The notion that cultural competence is never fully realized allows providers of LTSS to move from concerns about language or workers or similar background to sexual orientation and the intersection of vulnerable populations.

National Center for Cultural Competence

Georgetown University's National Center for Cultural Competence (NCCC, see <http://nccc.georgetown.edu/foundations/frameworks.html>) provides national leadership and contributes to the body of knowledge on cultural and linguistic competency within systems and organizations. Its website provides information for 1) organizations and programs, 2) providers and practitioners, 3) faculty and trainers, and 4) families and communities. Major emphasis is placed on translating evidence into policy and practice for programs and personnel concerned with health and mental health care delivery, administration, education and advocacy. The NCCC provides training, technical assistance, and consultation, contributes to knowledge through publications and research, creates tools and resources to support health and mental health care providers and systems, supports leaders to promote and sustain cultural and linguistic competency, and collaborates with an extensive network of private and public entities to advance the implementation of these concepts.

The mission of the NCCC is to increase the capacity of health care and mental health care programs to design, implement, and evaluate culturally and linguistically competent service delivery systems to address growing diversity, persistent disparities, and to promote health and mental health equity. The NCCC provides services to local, state, federal, and international governmental agencies, family advocacy and support organizations, local hospitals and health centers, healthcare systems, health plans, mental health systems, universities, quality improvement organizations, national professional associations, and foundations. In addition, the NCCC's on-line training, publications, and products are accessed by tens of thousands of individuals each year.

SPT Grantees and Cultural Competence

In phase one of the balancing indicator project, states were not explicitly asked to include information on cultural competence in their SPT tools. Therefore, this section includes a brief scan of state Public Health websites to understand *what may be happening in* each state that is not captured in existing SPT tools. Very few states include information on cultural competence for LTSS, but many of the ongoing state discussions are related or applicable to balancing LTSS. A majority of states reference cultural competence in the context of workforce and service delivery and frequently within the domain of quality of care. The information available from SPT grantees varies substantially: Minnesota has provided clear examples of leading the path in Cultural Competency, whereas Nevada has made minimal attempts to address Cultural Competence.

The Minnesota Department of Human Services goes to great lengths to describe and encourage health and human services providers and organizations to demonstrate their abilities to serve diverse populations before they serve individuals from diverse cultures. *They argue that an organization cannot be clinically or programmatically competent unless it is culturally competent.* Health and human services organizations can enhance their cultural competence by

employing culturally competent personnel, performing culturally appropriate services, and funding culturally competent organizations. More information on cultural competence efforts in Minnesota can be found at <http://tinyurl.com/4mf27fb>.

Michigan Department of Community Health (MDCH) utilizes a *diversity workgroup* that was created to promote diversity and to increase cultural competence across the department. In June 2010, MDCH released a “strategic diversity plan” that focuses on diversity requirements and cultural competence in health care delivery (see plan at <http://tinyurl.com/4v88jij>). In Massachusetts, the state websites and University of Massachusetts Medical School and state websites publish information on cultural competence in providing health services (for example, see <http://tinyurl.com/4rxdt4v>).

Goal five Of the Iowa’s Department of Public Health Strategic Plan (for report see <http://tinyurl.com/49e6rvh>) is to “assure access for *ethnic and racial minorities*” with cultural competence being a key to the guiding framework.

Virginia’s Department of Behavioral Health and Development Services houses an Office of Cultural Competence (<http://tinyurl.com/4nkhrav>) with an interest group, key reports, a steering committee, and an *Ideas into Action* Newsletter.

Recently, the Kentucky Cabinet for Health and Human Services released grants that center on providing culturally competent care (<http://chfs.ky.gov/news/Health+Equity+Grant.htm>).

Nevada’s Depart of Health and Human Services defines cultural competence in state manuals (<http://tinyurl.com/4lyp3f7>) but provides few guidelines.

The Arkansas Department of Human Services has little discussion of culture competence outside of state human resource recommendations (<http://tinyurl.com/46vspc2>) to expand the mental health workforce.

The Maine Department of Health and Human Services includes resources (<http://tinyurl.com/4gaek39>) on their website, as well as a Cultural Competency Assessment Tool for Organizations (<http://tinyurl.com/4lee9fv>).

The Florida Department of Elder Affairs asks that each Area Agency on Aging (AAA) specify a plan to assure cultural competence and the state has a Cultural Competency Checklist for Success (<http://tinyurl.com/4uakpxj>) adapted from materials from Georgetown University’s National Center for Cultural Competence.

Development of the NBIC Indicator: Cultural Competence

Based on the conceptual framework and vision for future LTSS, the team conducted a comprehensive literature review on an extensive reference list (e.g., peer reviewed articles, gray literature, surveys) during the first phase of NBIP in 2008 and 2009. The team’s steps in

conducting this literature review included the following: 1) assemble a master literature source document; 2) specify a set of items to be gleaned from each data source reviewed; 3) review and document identified indicators; 4) categorize identified indicators; 5) specify criteria for evaluating indicators identified during the review; and 6) preliminarily apply these criteria to identified indicators.³⁵ Subsequent to the team's completion of the literature review, the NBIC continued to evaluate and assess the existing Cultural Competence indicator for its relevance, feasibility, technical quality, susceptibility to influence or action, administrative usability, and population.

There were fewer Cultural Competence indicators (n=12) in the literature review than for any of the other seven principles of the LTSS system. To give a comparison, there were approximately 104 indicators to measure Quality of Care and 223 indicators of Sustainability. In addition to an overall lack of indicators for Cultural Competence in the literature prior to 2010, there were varied results across the features of the CC Principle.

1. Service offerings to a diverse population, supported by staff, which reflect that diversity (42 percent, 5 indicators).
2. State and local communities provide ongoing education, training and awareness activities in cultural competence for providers and others (0).
3. Prevention of prejudice and discrimination related to disability or accommodation in the workplace (25 percent).
4. Successful communication with people of all ages with disabilities and/or chronic conditions (33 percent).

Despite the comparatively low number of indicators for this principle, the indicators that address Cultural Competence fared very well when evaluated using the criteria listed above. Upon completion of the evaluation, 11 of the 12 literature-based indicators were included in the final list of indicators for the Cultural Competency principle. The eleven indicators within the Cultural Competence principle that were feasible for testing and data collection were the following:

1. The one-stop center has a culturally competent approach to information and referral and service delivery;
2. There is a diverse user demographic (based on target populations served as well as underserved populations);
3. Proportion of Case Managers who can communicate in other languages matches the proportion of clients who prefer other languages;
4. Staff sensitivity to cultural/ethnic background;

³⁵ The methods and summary findings of this literature review are presented in "National Balancing Indicator Contract: Literature-Based Measure Report." IMPAQ International LLC and Abt Associates Inc., June 27, 2008.

5. Degree to which consumers report that staff are sensitive to their cultural, ethnic, or linguistic backgrounds;
6. Composite measure: People's experiences with how well their doctors communicate;
7. The proportion of families reporting that staff or translators are available to provide information, services and supports in the family/family member's primary language/method of communication;
8. The proportion of families/consumers who report they are informed about the array of existing and potential resources (including information about their family member's disability, services and supports, and public benefits), in a way that is easy to understand;
9. The proportion of people served, by race and ethnicity, relative to their proportions in the general population;
10. Are you concerned that employers have negative attitudes toward people with disabilities?
11. How often do you feel you experience prejudice or discrimination because of your disability or health problem?

As can be seen from the list above, two data sources (surveys) were the primary source of the team's analysis because the NCI was available only to few SPT grantees. The indicators selected for this principle were postponed for further testing and data collection.

APPENDIX I. NBIP REFINEMENTS AND ADDITIONS SUMMARIES (2012-2014)

Sustainability Principle

Overview

The Sustainability Principle examines whether a state's long-term supports and services (LTSS) system is financially sustainable and is supported by an adequate infrastructure and a quality direct service workforce. This objective of the principle has remained the same over time. However, some refinements have been made to the background section to reduce biased statements at the request of Jennifer Burnett and Annette Shea at CMS.

Principle Features

Four Principle Features were developed for the Sustainability Principle:

- Flexible Financing of LTSS (related to Indicator S1)
- Sustainability of Funding for LTSS (related to Indicator S2)
- Supported by a Highly Qualified, Motivated, and Sustainable Workforce (related to Indicator S3)
- System Provides Supports for Informal Caregivers (related to Indicator S4)

No additional changes were made to these Principle Features.

One other Principle Feature initially was developed for this Principle:

- System is efficient and contains costs (e.g., prevents fraud and abuse)

This principle was not implemented because the team or the Federal Partners either did not develop an indicator for it or that was related to it.

Indicators and Refinements and/or Expansions Made

There are five indicators for the Sustainability Principle, and two indicators (Indicator S2 and S3) have four sub-indicators. The five indicators are as follows:

- Indicator S1. *Global Budget*
- Indicator S2. *LTSS Expenditures*
 - Sub-indicator S2a. Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending;
 - Sub-indicator S2b. LTSS Spending Changes: Per Capita, Sources and Medicaid Eligibility;

- Sub-indicator S2c. Medicaid Funding Sources; and
- Sub-indicator S2d. LTSS Funding From Non Medicaid Sources
- Indicator S3. *Direct Service Workforce*
 - Sub-indicator S3a. Direct Service Workforce Registry
 - Sub-indicator S3b. Direct Service Workforce: Volume, Compensation and Stability
 - Sub-indicator S3c. Direct Service Workforce Competency
 - Sub-indicator S3d. Direct Service Workforce Training
- Indicator S4. *Support for Informal Caregivers*
- Indicator S5. *Shared LTSS Mission/Vision Statement*

The following discusses these indicators and related sub-indicators, why refinements and/or expansions were necessary, and what refinements and/or expansions were made and how.

Indicator S1. Global Budget

This Indicator examines a state’s financial flexibility. A global, unified budget enables LTSS funds to be allocated based on projected needs, policy, and program initiatives. Such a budget can enable a state’s LTSS system to respond to changes in demand for LTSS through the reallocation of budget funds (from institutional care to home and community-based services (HCBS) or vice versa) within an overall spending limit.

The flexibility to target spending towards demand within the LTSS system (across one or more programs and/or population groups) may result in a more responsive and cost-effective allocation of LTSS funds. The global or unified budget may apply to certain services within the LTSS system (i.e., in the case of services administered by a state’s Department of Intellectual and Developmental Disabilities Services) or the LTSS system as a whole.

Why were refinements necessary?

TEP members posed several questions and provided a great deal of feedback for Indicator S1. The first question raised was, “What is meant by a “global budget?” TEP members wanted clarification as to what is meant by a global budget, and, specifically, who (which populations) and what (services) are covered by one. Also, they wanted to know what a global budget looks like and where it is currently being used.

TEP members raised concern that this indicator may not be a good measure of a balanced, person-driven LTSS system. TEP member Steve Kaye from the University of California San Francisco stated, “Having a Global Budget is being proposed as a promising practice as a tool for

rebalancing a state's LTSS system. Okay, it is nice that a state may have one and it may make it easier for a state to implement LTSS rebalancing. However, if a state does not have it, it is not necessarily bad. Maybe they are a state whose LTSS system already is pretty balanced and they do not see the need to implement global budgets. I am more concerned about the outcome (i.e., degree of balancing) and not how a state got there."

TEP members also raised the issue of managed care. Some suggested that the Indicator S1, as currently written, only focuses on fee-for-service (FFS), when managed care may be a major opportunity or hindrance to shifting funds between institutional and home and community-based settings. Also, the issue of shifting funds when both FFS and managed care services exist within a state was raised by the TEP members. Alex Bartolic from the Minnesota Department of Human Services reported, "I think that managed care is [an] interesting piece because it will vary by state. Also, it points out that if you have FFS and managed care it is going to be difficult to shift LTSS funds. We [in Minnesota] do it by the population. If we have a younger person with a disability and he/she is going to access one of our disability waivers, the money from that institutional bed technically goes over to the waivers. So it is not so much that someone on the nursing facility side has to figure out where the money goes, it is where the forecast goes and to make sure the budget is closed."

Overall, TEP members felt that it was important to incorporate managed care into Indicator S1. Global Budget, and focus the indicator less on whether a global budget exists, but rather more on how the authority is arranged to allow the shifting of funds across services (institutional settings and HCBS).

What refinements were made and how were they made?

Overall, refinements and/or expansions made for Indicator S1 included the following:

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to make questions clearer.
2. Revised flow of questions.
 - Questions 1 and 2 were formerly just Question 1. As such the question would not have been answered by all respondents so it was broken into two questions to make sure all respondents answered Question 1.

Specific Changes Made to Indicator S1

1. Questions were added.
 - Questions 5-11 were added to capture additional information related to managed LTSS and how it has been incorporated into a state's global budget.

Indicator S2. Medicaid Expenditures

This indicator examines states' Medicaid spending for institutional services and home and community-based services (HCBS) to determine states' priorities in funding balanced LTSS systems. The indicator includes the following four sub-indicators:

- Sub-indicator S2a. Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending
- Sub-indicator S2b. LTSS Spending Changes: Per Capita, Sources and Medicaid Eligibility
- Sub-indicator S2c. Medicaid Funding Sources
- Sub-indicator S2d. LTSS Funding from Non Medicaid Sources

The first three sub-indicators report on Medicaid LTSS expenditures and the fourth sub-indicator reports on spending for a limited number of other LTSS funding sources (e.g., Federal and state appropriations, Older Americans Act). Due to the differences in claims reporting and services taxonomy used by the various payers, these are not perfect measures. However, they provide a context on the use of Medicaid and other resources across LTSS institutional services and HCBS.

Why were refinements necessary?

In order to align LTSS expenditures with services provided, TEP members suggested that the NBIP team review services and supports provided under the Balancing Incentive Payment (BIP) program. TEP members reported that the current Truven data being captured for the indicator will align with BIP services, therefore capturing additional services and populations (e.g., individuals with mental illness receiving services not otherwise captured in other expenditure data).

Sub-indicator S2a. Proportion of Medicaid HCBS Spending of the Total MA LTSS Spending

TEP members felt that it would strengthen the sub-indicator if assisted living expenditures were included. TEP members reported that the direct service expenditures associated with assisted living are commonly reported as Medicaid waiver expenditures (sometimes as Group Adult Foster Care) or sometimes under State Plan Personal Care in the Truven Medicaid LTSS expenditure reports.

Sub-indicator S2b. LTSS Spending Changes: Per Capita, Sources and Medicaid Eligibility

A TEP member, Steve Eikens from Truven Health Analytics, reported that the direction of sub-indicator S2b is unclear and that increased LTSS expenditures may not be good for sustainability. He also reported that he did not think including per capita LTSS expenditures is useful.

Sub-indicator S2c. Medicaid Funding Sources

TEP members felt that questions related to changes to Medicaid eligibility criteria included in Sub-Indicator S2c were important but felt that the order of the questions may need to be reorganized or revised to be open-ended responses requiring respondents to describe the changes. In addition, a TEP member thought that it would be good to know the proportion of LTSS funding that is non-Medicaid.

Sub-indicator S2d. LTSS Funding from Non Medicaid Sources

TEP members suggested that this indicator be expanded to capture non-Medicaid funds as well as Medicaid funds. Alex Bartolic from the Minnesota Department of Human Services stated, “I think it tells an important story [i.e., capturing non-Medicaid funding for LTSS] because many state and locally-funded programs focus on prevention and that is a really important strategy to understand.” Ms. Bartolic went on to say that getting data on non-Medicaid funds could be difficult. “A significant amount of LTSS is provided to individuals with mental illness and these services may or may not be paid for by Medicaid. However, we need to get this information to be able to tell the whole story.”

What refinements were made and how were they made?

Overall, refinements and/or expansions made for Indicator S3 included the following:

1. Updated terminology and revised language used.
 - The background was revised to more clearly describe the purpose of the indicator and its sub-indicators, data sources utilized, and limitations of that data.
 - Language was revised throughout the indicator to make secondary data collection requirements clearer.
 - Language was revised throughout the indicator to make questions more clear (S2c, Questions 1-2).
2. Revised flow of questions.
 - Questions 1 and 2 of Sub-Indicator S2c were formerly questions 4, 4a, and 4b.
3. Simplified survey questions.
 - Questions 1 and 2 of Sub-Indicator S2c were formerly questions 4, 4a, and 4b. Questions 1 and 2 are now yes/no questions that request that the respondent describe changes in Medicaid eligibility if a change has occurred.

Indicator-specific Changes Made

1. Developed a new Sub-Indicator S2d. *LTSS Funding from non-Medicaid Sources*.
 - Respondents are asked if additional LTSS funding exists in the state. If so, the respondent is asked to describe the types of funds received.

Indicator S3. Direct Service Workforce (DSW)

The purpose of the Indicator S3. *Direct Service Workforce (DSW)* is to examine whether a state has a high quality workforce and maintains a DSW Registry. The Sub-Indicator S3a. *DSW Registry* examines whether the state maintains a DSW registry that is available and useful to users and service providers. Sub-Indicator S3b. *DSW Volume, Compensation and Stability* examines the need for DSWs that is projected to outpace the number of DSWs available to provide LTSS, the stability of the workforce, and the compensation that workers receive. Sub-Indicator S3c. *DSW Competency* examines whether and in what settings written competencies exist for DSWs. Sub-Indicator S3d. *DSW Training* examines if a state has written DSW training requirements in place.

Why were refinements necessary?

Three themes emerged during the NBIP team’s meetings with the TEP regarding Indicator S3. The first theme was training. TEP members felt that training is an important component when examining direct service workforce issues. Specifically, TEP members suggested that the indicator be refined to examine whether training exists, and, if so, what type of training exists and who is paying for training, etc.

The second theme to come out of the discussions was the need to examine both types of registries: one that identifies qualified and available workers and the other that identifies direct service workers who have been penalized for misconduct in the past or have a criminal record. Valerie Bradley from HSRI pointed out that the term “registry” could mean a registry of workers who have problems (i.e., poor performance, found guilty of abuse, neglect, or exploitation of an individual), or a resource for users to find workers. Valerie Bradley said she would prefer to know about the “bad apples.”

Another issue raised by TEP members was whether a state-wide registry is really ideal. Steve Kaye commented, “A statewide registry may not be necessary. County-wide may be (locality) better and that is what California has. However, the state may transition to a statewide registry and I think that may be bad. The other thing to point out is worker registries are only relevant in self-directed service programs. There may be states that have no self-directed service option or a minimal one. So they would not care about having a registry. As regards to terminology, to distinguish between the two types of registries, PHI calls the worker recruitment type a ‘matching service registry.’”

What refinements were made and how were they made?

The team made the following refinements to Sub-Indicator S3a:

Survey-wide Changes Made

1. Simplified survey questions.
 - Removed multiple options that required referring to a “tip box” for instructions on how to complete the survey; questions were simplified (e.g., Question 7 formerly part of Question 7a table).
2. Revised flow of questions.
 - If respondents have a state law prohibiting the implementation of a registry, they skip to the next Sub-Indicator without needing to respond to additional questions.

Indicator-specific Changes Made

1. Simplified and revised questions capturing the registry characteristics and workforce characteristics.
 - Respondents are no longer asked to complete five questions (four of which included tables) for each registry. Questions have been streamlined and simplified to capture information related to the geographic coverage, population coverage, DSW types, DSW characteristics, and DSW registry access for both public and private registries.
 - These questions are no longer looped based on the response provided to the number of registries that exist in the state in order to reduce confusion and improve data collection efforts.
2. Added sub-indicators to capture additional information.
 - Sub-Indicators S3c and S3d were added to capture information related to DSW competency and training (S3c. DSW Competency and S3d. DSW Training).

Indicator S4. Support for Informal Caregivers

Indicator S4. *Support for Informal Caregivers* examines the state’s effort to support informal caregivers. Informal or family caregivers are unpaid individuals who are not required to have clinical certifications or licenses, who provide assistance with ADLs and/or IADLs to people with disabilities and chronic conditions. This group includes legally responsible adults (e.g., spouses, guardians, or parents of minor children) and other family members, and other nonrelated adults, such as friends or neighbors of the individual receiving LTSS. Informal/family caregivers are an important group of “providers” in the LTSS system.

States that provide financial, social, and other supports to informal caregivers are better able to retain this essential “workforce,” and thereby meet the LTSS needs of the target population(s) in a preferred and a cost-effective manner.

Why were refinements necessary?

TEP members felt that Indicator S4 did not thoroughly examine the burdens on caregivers. For example, Val Bradley reported, “What we are finding from doing surveys of families of individuals with ID/DD is the big issue for them is the availability of crisis services and I don’t think I saw this included in this indicator. Thirty-three percent of the families interviewed for the National Core Indicators (NCIs) reported having difficulty getting crisis services and supports when they need [them]. This could mean a person having to go into a facility or not.”

TEP members also felt that this indicator should take a closer examination of services by population type. It was suggested that services, such as crisis services, may be provided to some LTSS users but not others.

What refinements were made and how were they made?

Survey-wide Changes Made

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to reflect more current terminology (e.g., use of the terms informal and family caregivers).
2. Simplified survey questions.
 - Questions formerly with multiple sub-questions within large tables were simplified by removing the table and options and asking respondents to describe their responses (e.g., family supports available in Question 4, formerly table in question 4).

Indicator-specific Changes Made

1. Removed questions related to respite care and pre-designated options of services provided to support informal caregivers. These were replaced by open-ended questions allowing respondents to describe programs and services that exist in the state.
2. Added questions.
 - Additional questions were added to Indicator S4 to examine requirements that the state has in place for informal caregivers in order to receive state-funded, Medicaid-funded, or other Federally-funded supports and services targeting caregivers (e.g., Questions 4c, 6c and 8c).

There is no Principle Feature associated with Indicator S5.

Indicator S5. Shared LTSS Mission/Vision Statement

An organization's mission and/or vision statement represents a commitment to a set of values and shared goals. Entities responsible for LTSS may be more likely to achieve sustainability if they create and disseminate mission and/or vision statements that mandate and support the implementation and maintenance of a balanced LTSS system that provides services in the most integrated settings.

The Indicator S5. *Shared Long-term Supports and Services Mission/Vision Statement* examines whether the organization has a mission and/or vision statement for a person-centered LTSS system that provides LTSS in the most integrated settings and is used to guide policy and budgeting decisions.

Why were refinements necessary?

TEP members felt that a mission or vision statement may be an important tool if stakeholders are involved and it is implemented properly. If a mission or vision statement is not publicized and operationalized as close to the populations being served as possible, it isn't effective.

What refinements were made and how were they made?

The team made the following minor refinements to this indicator:

Survey-wide Changes Made

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to be clearer and more concise (e.g., response options listed as part of Question 1).

Indicator-specific Changes Made

1. Added and refined options.
 - Options were added to and refined within Question 1 to examine the development and implementation of a Mission and/or Vision Statement.

Shared Accountability Principle

Overview

The Shared Accountability Principle examines the level of responsibility among and between users (older adults and individual with disabilities and chronic conditions and their families), service providers, local government agencies, state program agencies, and the Federal government agencies, and encourages personal planning for LTSS needs, including greater use and awareness of private sources of funding available.

The objective of this principle has changed over time and now examines shared accountability at a global level rather than just as it relates to self-determination and self-directed services. The team reshaped the principle's objective in response to feedback from the Technical Expert Panel and a review of current literature. In addition, at the request of Jennifer Burnett and Annette Shea at CMS, the team refined the principle's language as appropriate to reduce biased statements.

Principle Features

The team developed the following four Principle Features for the Shared Accountability Principle:

- *The LTSS System Encourages Fiscal Responsibility on the Part of All Entities Related to the Financing Provision and Receipt of LTSS* (related to Indicator SA1);
- *The LTSS System Encourages and Supports Personal Responsibility Through Public Awareness and Education About the Best Use of LTSS Resources* (related to Indicator SA2);
- *Individuals and Families are Actively Involved in LTSS Policy Development and Implementation* (related to Indicator SA3); and,
- *The LTSS System has Mechanisms in Place to Hold Caregivers and Providers Accountable for Meeting the Needs of Users. Conversely, Users Have the Responsibility to Voice Their Expectations, Needs, and Grievances, and Comply with Federal and State Rules and Regulations* (related to Indicator SA4).

The team made slight changes to the Principle Feature *LTSS System Encourages Fiscal Responsibility on the Part of All Entities Related to the Financing, Provision and Receipt of LTSS*. Previously the Principle Feature was stated as *System Encourages Fiscal Responsibility on the Part of All Entities Responsible for LTSS*.

Slight changes were made to the Principle Feature, *The LTSS System Encourages and Supports Personal Responsibility through Public Awareness and Education about the Best Use of LTSS Resources*. The Principle Feature was formerly *System Encourages and Supports Personal Responsibility through Training and Education about the Best Use of LTSS Resources*.

The team made slight changes to the Principle Feature *Individuals and Families are Actively Involved in LTSS Policy Development*. The Principle Feature was formerly *Individuals and Families are Actively Engaged in Policy Development*.

The team made slight changes to the Principle Feature *The LTSS System has Mechanisms in Place to Hold Government and Providers Accountable for Meeting the Needs of Individuals*. Conversely, *Individuals Have the Responsibility to Voice their Expectations, Needs and Grievances and Comply with Federal and State Rules and Regulation*. The Principle Feature was formerly *System has Mechanisms in Place to Hold Government and Providers Accountable for Meeting the Needs of Individuals*. Conversely, *Individuals have the Responsibility to Voice their Expectations, Needs and Grievances and Comply with Federal and State Rules and Regulation*.

Indicators and Refinements and/or Expansions Made

The Shared Accountability Principle has the following four indicators:

- Indicator SA1: *Fiscal Responsibility*
- Indicator SA2: *Personal Responsibility*
- Indicator SA3: *Individuals and Families are Actively Involved in LTSS Policy Development*
- Indicator SA4: *Government, Provider, and User Accountability*

The following discusses these indicators, why refinements and/or expansions were necessary, and what refinements and/or expansions the team made and how.

Indicator SA1. Fiscal Responsibility

This indicator examines whether the LTSS system encourages fiscal responsibility on the part of all entities related to the provision and receipt of LTSS.

Why were refinements necessary?

TEP members were concerned that process measures such as Indicator SA1 have not been demonstrated to be the best measures of LTSS balancing. TEP members even suggested that the team delete Indicator SA1 completely.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made to Indicator SA1 include the following.

1. Updated terminology and revised language used.
 - Language was revised throughout the Indicator to make questions clearer.

Specific Changes Made to Indicator SA1

1. Questions were added.
 - Question 2 was added to capture information related to the LTC Partnership Program, how users are informed about the program, and how many individuals are enrolled in the program.
 - Question 6 was added to examine how a state ensures that language services are available to those who need them and how those services are funded.

Indicator SA2. Personal Responsibility

This indicator examines the mechanisms in a state’s LTSS system that provide outreach and educational opportunities that empower individuals and caregivers (users) to effectively use LTSS.

Why were refinements necessary?

TEP members suggested that states aren’t consistently providing orientation and training for users to empower them to effectively use self-directed LTSS. A TEP member, Robert Kane from the University of Minnesota, asked, “Should we be asking what decision support system and materials should be in place? This [user orientation and training about using self-directed services and being an employer] is not traditional training. It is providing information and tools and supports of various types. The question is fundamentally miscasted. Are cashed-out services and self-directed services considered the same?” Sue Flanagan, a member of the NBIP team, suggested that the team include a Yes/No question and ask states to report what they provide regarding user orientation and training.

Also, TEP members suggested that this indicator examine if people are getting the information they need to make good decisions about using LTSS. However, TEP members were concerned this question may be difficult for states to answer.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made to Indicator SA2 include the following:

1. Updated terminology and revised language used.
 - Language was revised throughout the Indicator to make questions clearer.
 - Revised terminology throughout the survey, including replacing “consumer” with the term “user” to encompass not only consumers, but family members and others.

Specific Changes Made to Indicator SA2

1. Questions were added.
 - Questions 1a-1d were added to capture information related to the Own Your Own Future LTC Awareness Campaign, as well as the LTC Partnership Program.
2. Questions were deleted.
 - The Table for Question 1 was deleted and the information collected was relocated to Questions 2a-2c.

Indicator SA3. Individuals and Families are Actively Involved in LTSS Policy Development

This Indicator examines users' involvement in the development and provision of LTSS as a key aspect of an LTSS system that encourages self-determination and shared responsibility.

Why were refinements necessary?

A TEP member, Valerie Bradley from HSRI, asked Sue Flanagan on the NBIP team, "What would constitute for you users and families being involved in policy? I think it is rare for states to do this except for sending out documents for public comment."

Sue Flanagan responded, "Actually through the CMS Real Choice Systems Change Grants, including the Systems Transformation and PCP Implementation Grants, I believe there has been a culture change related to users and families being involved in policy development. I am seeing more states including user and family stakeholders in a meaningful way. For example, a number of PCP grantees said that the information/feedback received from user/family stakeholders was invaluable to getting it right. It may not always be the best level of involvement but better than it was in the 1980s and 1990s."

The relevance of this Indicator to LTSS balancing was raised by a TEP member. In response, it was reported that users would rather live and receive LTSS in the community than in an institution. If users are involved in LTSS policy development, implementation, and monitoring effectiveness of LTSS policy, states may be more willing to let people live in the community. TEP members were concerned that not all population groups may be included equally or moving in the same ways on issues and these differences are not captured in the indicator as it is currently stated. Therefore, it would be helpful to examine variations of stakeholder involvement by population.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made to Indicator SA3 include the following:

1. Updated terminology and revised language used.

- Revised terminology throughout the survey, including replacing “consumer” with the term “user” to encompass not only consumers, but family members and others.

Specific Changes Made to Indicator SA3

1. Questions were added.
 - Questions 4 to 7 were added to capture information related to input provided by users and how it was used, including how users were included in and provided input regarding the development of the *Olmstead* plan.
2. Questions were deleted.
 - The Table for Question 2 was deleted and the information collected has been relocated to Questions 1 to 3 and 8 to 12.

Indicator SA4. Government, Provider, and User Accountability

This Indicator examines the transparency in reporting and following-up with users.

Why were refinements necessary?

A TEP member, Val Bradley from HSRI commented, “The dignity of risk and risk mitigation are two very different things.”

Ms. Bradley also reported that “transparency about quality performance is absolutely critical and going forward it is going to be problematic with managed care because some of this information is considered proprietary. This is going to make it difficult to figure out what is really going on under the hood.”

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made to Indicator SA4 include the following:

1. Updated terminology and revised language used, as appropriate.

Specific Changes Made to Indicator SA4

1. Simplified and revised questions capturing licensure requirements, rating systems, and user reporting.
 - Table comprising Questions 1 to 8 was reorganized, specifically:
 - Questions 4 to 8 were reorganized and are no longer listed in a table format; and

- Secondary data was relocated to a separate section within Indicator SA4.
2. Questions were added.
- Questions 1 to 3 were added to capture additional information related to incident reporting and quality assurance protocols.

Self-Determination/Person-Centeredness Principle

Overview

The Self-Determination/Person-Centeredness Principle examines whether the LTSS system enables people with disabilities and/or chronic illness to exercise authority over the following:

- decide where and with whom they live;
- have control over the services they receive and the organizations and individuals who provide them;
- have the opportunity to work and have private income; and,
- have the opportunity to have friends and supports that facilitate their participation in community life.

The objective of this principle has remained the same throughout the project. However, the team has made some refinements to the principle. Indicators reflect feedback received from members of the Technical Expert Panel.

Principle Features

The team developed the following two Principle Features for the Self-Determination/Person-Centeredness Principle:

- *System Affords Individuals Choice and Control* (related to Indicators SD1 and SD2)
- *System Allows for the “Dignity of Risk”* (related to Indicators SD3)

The team developed the following other Principle Features initially for this Principle:

- Opportunities to attain/maintain economic self-sufficiency
- Availability and access to relationships with family, friends and community support networks

These Principles were not implemented because either the team was unable to develop an indicator or the Federal Partners did not develop an indicator that was related to it.

No additional changes were made to either of these Principle Features.

Indicators and Refinements and/or Expansions Made

There are three indicators for the Self-Determination/Person-Centeredness Principle and one Indicator (Indicator SD1) has three Sub-Indicators. The three Indicators are:

- Indicator SD1: *Regulatory Requirements Inhibiting Consumer Control*
 - Sub-Indicator SD1a: Residential Setting
 - Sub-Indicator SD1b: Attendant Selection
 - Sub-Indicator SD1c: Nurse Delegation
- Indicator SD2: *Availability and Use of Self-directed Services*
- Indicator SD3: *Risk Assessment and Mitigation*

The following discusses these Indicators and related Sub-Indicators, why refinements and/or expansions were necessary and what refinements and/or expansions were made and how.

Indicator SD1. Regulatory Requirements Inhibiting Consumer Control

This Indicator examines user choice in a balanced, person-driven LTSS system. There are three Sub-Indicators under the Indicator SD1. *Regulatory Requirements Inhibiting Consumer Control*: (1) Residential Setting Requirements, (2) Attendant Selection, and (3) Nurse Delegation. These Sub-Indicators examine the extent to which users have control over accessing LTSS in the least restricted setting of their choice and without undue external influence or interference.

Why were refinements and/or expansions necessary?

The original title of Indicator SD1 was *Licensure and Certification Requirements Inhibiting Consumer Control*. Overall, TEP members questioned what was “bad” about licensure and certification regulations and said there would be chaos without them. One TEP also pointed out that the questions listed under Indicator SD 1 were not related to state licensure and certification regulatory requirements but rather state program requirements. “In the Introduction it mentions licensure and certification requirements but I don’t think this Indicator is about that. It seems to be more about program regulations. I think you need to amend this.” However, state program requirements may be considered by some to be a barrier to user choice and control. As a result, the title of Indicator SD1 was broadened to address TEP feedback and the title of the indicator was changed to be *Regulatory Requirements Inhibiting Consumer Control*.

Sub-Indicator SD1a. Residential Setting

Related to the Sub-Indicator SD1a. Residential Setting, it was suggested by a TEP member to review the final CMS § 1915(i) and (c) rules that were released on January 10, 2014 related to residential settings and refine the Sub-Indicator accordingly. A TEP member also felt that

Question 1 was too vague and thought that states would have difficulty answering the question. He also said the questions did not ask about proportions, which he felt was important.

Sub-Indicator SD1b. Attendant Selection

Related to the Sub-Indicator SD1b, Attendant Selection, TEP members suggested that the NBIP team look more closely at self-directed services and in particular, they asked and/or suggested:

- “What proportion of participants in a state use self-directed services? What proportion of participants is allowed to hire and fire their attendant(s)? You could ask for an unduplicated count and then you would have to compute the proportion yourself.”
- In Question 3a or b you could ask, “Can a spouse or parent provide services and receive compensation?”
- Question 4 needs to be broken into two questions, one for family and one for nonfamily.
- Define the term “benefit” in Question 4.

Sub-Indicator SD1c. Nurse Delegation

TEP members suggested that the NBIP team remove questions related to training from the Sub-Indicator SD1c, Nurse Delegation and put them in a central location related to the direct service workforce. They felt that training questions did not belong under Nurse Delegation. The TEP also felt that Table 4 should replace Table 1 because it was more complete.

What refinements and /or expansions were made and how were they made?

Overall, the refinements and/or expansions that the team made for Indicator SD1 included the following:

1. Updated terminology and revised language used, as appropriate.
 - Language was revised for the indicator to make the purpose more clear and concise and to reduce bias.
 - Language was revised or deleted in the tip boxes to make the instructions clearer for respondents.
 - Terminology was revised throughout the indicator to be more consistent (e.g., LTSS user).

Specific Changes Made to Sub-Indicator SD1a

1. Questions were added.

- A reference to the new CMS § 1915(i) and (c) final rules was added and new questions that reflect the information regarding residential settings were included.
2. Questions were deleted.
 - Deleted questions related to provider licensure and certification requirements.

Specific Changes Made to Sub-Indicator SD1b

1. Questions were added.
 - Additional questions were included related to person-driven personal attendant services, including activities that users are allowed to perform related to their attendants.

Specific Changes Made to Indicator SD1c

1. Questions were added.
 - Additional questions were included to capture additional information related to a State's Nurse Delegation Act.
2. Questions were deleted.
 - Deleted some questions in Sub-Indicator SD1c. Nurse Delegation, because the TEP members, in particular Susan Reinhard, felt that they were too difficult for states to answer accurately.
 - Deleted Table 1 and inserted Table 4 in its place because the TEP felt it was more complete.
3. Simplified responses.
 - In Sub-Indicator SD1c. Nurse Delegation, Table 4 related to activities that may be delegated under a state's Nurse Delegation Act was deleted and options from table were listed under question 4 as check boxes.

Indicator SD2. Availability and Use of Self-Directed Services

Indicator SD2. *Availability and Use of Self-Directed Services* examines whether the state offers home and community-based services using a self-directed approach under their Medicaid State Plan or one or more HCBS Waivers or HCBS State Plan Amendments (SPAs). It also examines under what authority these self-directed Medicaid State Plan and/or HCBS Waiver and/or SPA services are offered (e.g., employer authority, budget authority, or both).

Why were refinements necessary?

TEP members felt that if the purpose of this indicator is to examine the extent to which self-directed services are being offered throughout a state's LTSS system, it should include § 1915(c) waivers, § 1915 HCBS SPAs, and § 1115 waivers, or the consolidation of said programs (e.g., Vermont's comprehensive § 1115 waiver). In addition, all of these program options should be better spelled out so that respondents are aware that the Medicaid SPAs options include the (i), (j), and (k) SPAs.

In addition, TEP members suggested that the indicator take a closer look at the relationship between self-directed services and person-centered plans. Some TEP members also felt that every user, no matter their use of self-directed services, should have a person-centered plan in place in order to understand user's goals and whether or not supports and services being provided facilitate an individual achieving his/her goals. Then they felt the outcomes achieved under a person-centered plan should be monitored by the state.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made for Indicator SD2 included the following:

1. Updated terminology and revised language used.
 - The language of the indicator description was revised to make the purpose of the indicator clearer and more concise.
 - Language was revised and/or deleted in the tip boxes to make the instructions clearer for respondents.

Specific Changes Made to Indicator SD2

1. Questions were added.
 - The original Question 3 regarding person-centered planning was deleted and Questions 4 and 8 were modified to include a reference to the new CMS § 1915(i) and (c) final rules as they relate to person-centered planning. Additional questions were added related to the new requirements for person-centered planning.
 - Added Question 5 to examine the number and type of active Medicaid HCBS SPAs that exist in the state and determine whether they offer person-centered planning and/or self-directed services.
2. Refined Questions.
 - Refined Questions 9 to 13 examining non-Medicaid programs and services that may provide self-directed services.

Indicator SD3. Risk Assessment and Mitigation

Indicator SD3. *Risk Assessment and Mitigation* examines the right of users to exercise choice and control related to the delivery of their LTSS, while they assume responsibility for potential risk associated with their choices and actions related to their receipt of LTSS. However, with rights come responsibilities, many of which are mandated by Federal and state regulations (e.g., being an employer of direct service providers). States and users must exercise shared accountability for potential risks associated with users' choices and control so that users' health and safety can be ensured.

Why were refinements necessary?

Prior to the 2013 to 2014 refinements, there was no examination of a user's role in assuming responsibility for potential risk associated with his or her choices, control, and actions related to the receipt of LTSS.

What refinements were made and how were they made?

Indicator SD3 is a new indicator. It was developed using information from a CMS MFP Grantee Discussion Group Webinar entitled, *Managing Risk in the MFP Program: Balancing Individual Autonomy and Choice with Health and Welfare* conducted by Sue Flanagan, PhD, of the Westchester Consulting Group and Jason Rachel, PhD, National Quality Enterprise and Truven Health Analytics.

Community Integration and Inclusion Principle

Overview

The Community Integration and Inclusion Principle examines whether a state's LTSS system encourages people to reside in the most integrated setting and supports them by offering a full array of options to access quality services and supports in the community. The objective of the principle has remained the same over time. However, the team made some changes to the indicators based on feedback received from the Technical Expert Panel (TEP) members and to reduce biased statements at the request of Jennifer Burnett and Annette Shea at CMS.

Principle Features

The team developed the following three Principle Features for the Community Integration and Inclusion Principle:

- *Availability of and Access to (or Opportunities for) the Full-Range of LTSS Including Medical, Dental, Mental Health, Assistive Technology, Transportation (related to Indicators CI 1, 2, and 4)*

- *Affordable Housing with Supports and People of all Ages with Disabilities and/or Chronic Conditions Reside and Participate in the Most Integrated Community* (related to Indicators CI1, 2, and 4)
- *Opportunities to Attain/Maintain Employment within the Community* (related to Indicator CI3).

The team did not make any changes to the Principle Feature *Availability of and Access to (or Opportunities for) the Full-Range of LTSS Including Medical, Dental, Mental Health, Assistive Technology, Transportation*, Principle Feature *Affordable Housing with Supports and People of all Ages with Disabilities and/or Chronic Conditions Reside and Participate in the Most Integrated Community Settings*, or Principle Feature *Opportunities to Attain/Maintain Employment within the Community*.

The team developed the following four Principle Features initially for this principle:

- Opportunities to attain/maintain recreation, education and vocational services to enable and enhance community living (e.g., church, clubs)
- Freedom to move within the community (e.g., accessible buildings, parks, sidewalks)
- People of all ages with disabilities and/or chronic conditions are safe to walk, work and “play” without fear of attack or increased burden of illness (from environmental risk)
- Assistance with Instrumental Activities of Daily Living, as needed

These Principle Features were not implemented because either the team was unable to develop an indicator or the Federal Partners did not develop an indicator that was related to them.

Indicators and Refinements and/or Expansions Made

The team refined or expanded the following four Indicators for Community Integration and Inclusion and seven related Sub-Indicators:

- Indicator CI1. *Waiver Waitlist*
- Indicator CI2. *Housing*
 - Sub-Indicator CI2a. *Coordination of Housing and LTSS*
 - Sub-Indicator CI2b. *Availability and Access to Affordable and Accessible Housing Units*
 - Sub-Indicator CI2c. *Housing Setting*
- Indicator CI3. *Employment*
 - Sub-Indicator CI3a. *Employment Rates of Working Aged Adults with Disabilities*
 - Sub-indicator CI3b. *Supported Employment Options*

- Indicator CI4. *Transportation*
 - Sub-Indicator CI4a. *Availability and Coordination of Transportation*
 - Sub-Indicator CI4b. *User Reporting on Adequate Transportation and Unmet Needs*

The following discusses these Indicators and related Sub-Indicators, why refinements and/or expansions were necessary and what refinements and/or expansions were made and how.

Indicator CI1. Waiver Waitlist

This indicator examines whether a state has implemented a waitlist to track and prioritize individuals who wish to receive services that exceed the number of participants that are approved to receive HCBS within a state’s fiscal year.

Why were refinements necessary?

TEP members had several concerns about the Indicator CI1. *Waiver Waitlist*. TEP member Chas Moseley from the National Association of State Directors of Developmental Disability Services (NASDDDS) commented, “I do not see any questions related to the nature of the waitlist. For example, are there people receiving services but not receiving enough services—are they on the wait list? If someone [is] getting service A and [she] want[s] to get service B [is she] on the waitlist? Is it only for people who have not received any services before and they have been determined to be eligible but there is no funding to support them? What are they waiting for and how often is the wait list information gathered and reviewed? So states have the same list for years. When they do get some funding they might go back and find out half of the people on the list no longer exist. Some state wait lists move people chronologically while others prioritize individuals based on need.”

TEP members were concerned that individuals on waiver waitlists may not meet HCBS waiver eligibility. In addition they were concerned that not all states have waitlists because it is not a CMS requirement or in those instances in which waitlists exist, information may be out of date over time, or individuals may be receiving other services. “In some states where waitlists exist, waitlist information may not be reported.” Chas Mosley reported, “The Minnesota Research and Training Center (RTC) gathers wait list information for individuals with IDD and not all states report it. For example, ten states with large wait lists did not report the data.”

Specific feedback from TEP members included the following:

- The way Question 10 is written is very confusing.
- There is a typo in the chart for line 10ag that references lines 8ab-8af when it should be 10ab-10af.
- Line 10ae ‘aging caregivers’ is not accurate and a more accurate description would be caregiver burnout.

Overall, TEP members questioned the whole concept of considering waitlists as a balancing indicator. An example given by one TEP member was two states that have 3,000 people on their wait lists. “The legislature feels they want to eliminate the wait list and authorized funds for 3,000 people. A year later you have 3,000 new people on the waiver and 3,000 new people on the waitlist.” It was suggested that a waitlist also is an indicator of outreach, people’s willingness to be on the waitlist, of people who are not eligible for services who might hope to be in the future. Finally, it was reported that a waitlist is “more an example of elastic demand and is a function of the funds allocated for direct support services rather than an external force. If a state has more funds there will be more needs to be addressed.”

What refinements were made and how were they made?

Overall refinements and/or expansions that the team made for Indicator CI1 include the following:

1. Updated terminology and revised language used.
 - Language was revised for the indicator description to make the purpose of the Indicator clearer and more concise.
 - Language was revised or deleted in the tip boxes to make the instructions clearer for respondents.
 - Language was revised throughout the indicator to make questions clearer for respondents.

Specific Changes Made to Indicator CI1

1. Questions added.
 - Added questions related to whether a waitlist accounts for various disability types and diverse populations.
 - Added a question to examine who is eligible for the waiver waitlist.
 - Added a question to examine if and how often waiver waitlist information is updated.

Indicator CI2. Housing

The Housing Indicator examines several aspects related to the availability of and access to LTSS and Housing Services. For example, whether the state has, or is developing, resources for affordable and accessible housing options for LTSS users, and whether state LTSS program agencies have more formalized partnerships with housing agencies.

Why were refinements necessary?

Overall, TEP members were concerned that many of the questions would be difficult for states to respond to. One reason for this was the number of agencies responsible for the services and, therefore, the data. Shawn Terrell, a TEP member from the US Administration on Community Living reported, “States will have to go through their housing authorities which are multiple in many states. In some states they are not coordinated with each other and some states have a state authority that has some coordination and oversight responsibility. Medicaid staff is not going to know how to answer these questions.”

In addition, TEP members reported that at times subsidized housing may be “warehouse” housing rather than a true community setting. To address this, it was suggested that the NBIP team review the § 1915(i) final regulations for clarification on “community” and “home.”

TEP members questioned how housing fits into balancing. It was asked if it is important to know how many affordable and accessible units are available in a state. TEP members suggested that this indicator and its sub-indicators are too detailed and the information may not be able to be interpreted as it relates to balancing. Therefore, it was suggested to simplify the indicator and its sub-indicators to capture what is important and related to balancing. Chas Mosley from NASDDDS said, “The questions in this section seem overly complex. States respond to surveys when they are simple and straightforward and you can get some reliable responses. The more complex the survey questions are the harder it is to get them to respond and provide reliable information and the great the variability.”

In response to an example of South Dakota’s housing issues for LTSS users provided by Sue Flanagan, Robert Kane, a TEP member from the University of Minnesota, stated, “You make a very good case for why housing is important. Now the question is what kind of data would you like to collect? Suppose you start out asking a simple question like ‘To what extent are people’s diversions and transitions from institutions impeded by a lack of affordable, accessible housing?’ Isn’t that what you want to know?”

Lex Frieden, a TEP member from ILRU, added, “The overarching question here is does the state provide a full range of LTSS? If you do not ask about housing, supportive employment and some of the other things on this list, then you really cannot answer this question. What questions do you ask?”

Annette Shea from CMS commented, “Keep in mind, what we are looking for is to understand what the states are doing regarding their system activities and business processes to create the collaborations, partnerships, and relationships in the community needed to help people live in the community successfully. You may have all the states saying they do not have any affordable, accessible housing where some might say they do and this is how they know.”

Specific suggestions from the TEP included the following:

- Take a closer examination of housing at it relates to LTSS users. For example, “What proportion of subsidized housing is being used by people using some type of HCBS?”
- Examine consistency between housing and human service agencies related to eligibility and supports and services provided.
- Refine the questions related to LTSS and housing coordination. TEP member, Shawn Terrell from the US Administration on Community Living asked, “What is the goal of the coordination? Services provided in house, focus on meeting housing needs to people? I am not sure what the goal of the indicator and questions are. What is the standard? If you are on a HCBS waiver and in senior housing, what needs to be coordinated?”
- Refine the housing table to be less biased towards the disability community. The NBIP team should add services that related to older adults, such as assisted living and housing with services.
- Provide additional instructions for completing the housing table to ensure that states are able to accurately respond.

It was suggested by the Project COTR, Kerry Lida, that the team switch the order of the sub-indicators, to begin with questions related to the coordination of housing and LTSS and then follow with questions related to access to and availability of housing.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made for Indicator C12 included the following:

1. Updated terminology and revised language used.
 - Language was revised for each of the indicator descriptions to make the purpose of the indicator more clear and concise.
 - Language was revised or deleted in the tip boxes to make the instructions clearer for respondents.

Specific Changes Made to Sub-Indicator C12a (Formerly C12b)

1. Questions were added.
 - Added Question 3b in Sub-Indicator C12a, to examine state efforts to ensure that regulations and procedures are consistent across housing and health and human service agencies in providing LTSS.

Specific Changes Made to Sub-Indicator C12b (Formerly C12a)

1. Revised order of questions.
 - Questions 1 to 4 were relocated to 4 to 8.

Specific Changes Made to Sub-Indicator C12c

1. Questions were revised.
 - Data for Sub-Indicator C12c. Housing Settings was revised to examine secondary data sources for information rather than request the information from state respondents.

Indicator C13. Employment

This indicator examines a state's efforts to integrate individuals with disabilities into the community through supported employment options and the impact that those programs and services have in allowing working-aged adults with disabilities to be gainfully employed.

Why were refinements necessary?

Overall, the TEP members felt that this indicator is important. However, TEP members had specific comments on how to improve the indicator that included the following:

Remove sheltered workshops, since these are not considered supportive employment.

- Clarify that this indicator is examining competitive supportive employment.
- Include evidence-based programs for individuals with mental illness, specifically Individual Placement Service (IPS).
- Andrew Houtenville at Cornell University suggested that the indicator utilize data. His research takes the ACS data for people with disabilities and for the general population and compares the two to measure the gap of employment for people with disabilities.

It was suggested by the Project COTR, Kerry Lida, that the team switch the order of the sub-indicators to begin with employment outcomes (e.g., employment rates) then follow with questions related to supports and services available that enable an individual with a disability to be gainfully employed.

What refinements were made and how were they made?

Overall, the team made the following refinements and/or expansions for Indicator C13:

1. Literature was added.
 - Literature was added to the description of the Indicator to make the purpose and importance of the indicator clearer.
2. Updated terminology and revised language used.
 - Language was revised throughout the indicator to make questions more clear and concise.
 - Language was revised or deleted in the tip boxes to make the instructions more clear for respondents.

Specific Changes Made to Sub-Indicator CI3a (Formerly CI3b)

1. Added Secondary Data Elements.
 - Additional data elements were added to Sub-Indicator CI3a. *Employment Rates of Working-Age Adults with Disabilities* in order to examine the labor force and unemployment rates of working-age adults with disabilities compared to the general population across states.

Specific Changes Made to Sub-Indicator CI3b (Formerly CI3a)

1. Options were deleted.
 - Deleted Sheltered Workshops and replaced with Prevocational Services.
 - Deleted Assessment Skills Development and replaced with Job Replacement.
2. Options were added.
 - Added Assessment and/or Discovery.
3. Questions were added.
 - Added Question 9 to examine states' efforts to provide supported employment services funded through other mechanisms outside of states' Medicaid State Plan, Medicaid State Plan Amendments, and Medicaid Waivers.

Indicator CI4. Transportation

This indicator examines a state's efforts to provide Medicaid-funded transportation services beyond medical transportation. Information collected for this indicator will facilitate an examination of a state's efforts to utilize Federal and other funding sources to provide transportation services for older adults and adults with disabilities, as well as examine the types of transportation services available and the types of needs that they meet (i.e., professional and personal).

Why were refinements necessary?

TEP members felt that the questions in Indicator CI4. *Transportation* may be difficult for respondents to answer accurately. Julie Fralich, a member of the TEP from the University of Southern Maine, commented, "These are hard questions to answer particularly when not related to Medicaid. Tough to wrap your arms around but transportation is an important concept. You may need more work to pin down what exactly might be reported and what would be best to report on. You may have to be a bit of a qualitative question such as 'To what degree is transportation available? Does it vary by region?'"

Lex Frieden, a TEP member from ILRU, added that, "Transportation availability can vary county by county; region by region and the person collecting the information will have to be pretty knowledgeable in the area."

What refinements were made and how were they made?

Overall, the team made the following refinements and/or expansions Indicator CI4:

1. Literature was added.
 - Literature was added to the description of the indicator to make the purpose and importance of the indicator clearer.

Specific Changes Made to Sub-Indicator CI4a

1. Tables were deleted.
 - Deleted Table in 1e and created a list of response options to simplify question.
2. Questions were added.
 - Added Question 2a to examine whether state funds to provide transportation services are statewide or regional.
 - Added Question 3a to examine how a state coordinates transportation and LTSS.

Specific Changes Made to Sub-Indicator CI4b

None made.

Coordination and Transparency Principle

Overview

The Coordination and Transparency Principle examines whether the LTSS system coordinates a range of services funded by multiple funding sources to provide seamless supports across the health and LTSS systems (i.e., acute health, rehabilitation, and LTSS). The LTSS system also makes effective use of health information technology to provide transparent information to users, providers, and payers.

The objective of this principle has remained the same over time. However, at the request of Jennifer Burnett and Annette Shea at CMS, the team made some minor changes to the background of the principle to reduce biased statements.

Principle Features

The team developed the following three Principle Features for the Coordination and Transparency Principle:

- *Universal, Timely Access to Information and Services*
- *Federal/State/Local Governments Collaborate and Communicate Effectively Regarding the Provision of LTSS*

- *Promotion of Continuity of Care and Seamless Transitions from Setting to Setting and Across Major Developmental Stages across the Lifespan.*

The team did not change the Principle Feature *Universal, Timely Access to Information and Services*.

The team made slight changes to the Principle Feature, *Federal/State/Local Governments Collaborate and Communicate Effectively Regarding the Provision of LTSS*. The Principle Feature previously was *Federal/State/Local Governments Collaborate and Communicate Effectively Regarding LTSS*. The team did not change the Principle Feature, *Promotion of Continuity of Care and Seamless Transitions from Setting to Setting and Across Major Developmental Stages across the Lifespan*.

Indicators and Refinements and Expansions Made

There are three indicators for the Coordination and Transparency Principle. In addition, CT1 has three sub-indicators and CT2 has two sub-indicators. The three indicators and five related sub-indicators are as follows:

- Indicator CT1. *Streamlined Access*
 - Sub-Indicator CT1a. Implementation
 - Sub-Indicator CT1b. Fully Functioning Criteria and Readiness Assessment
 - Sub-Indicator CT1c. LTSS Partnerships
- Indicator CT2, *Service Coordination*
 - Sub-Indicator CT2a. LTSS System(s) Coordination
 - Sub-Indicator CT2b. Users Reporting That Care Coordinators and Case Managers Help Them Get What They Need
- Indicator CT3. *LTSS Care Transition*.

The following section discusses these indicators and related sub-indicators, why refinements and/or expansions were necessary, and what refinements and/or expansions the team made and how.

Indicator CT1. Streamlined Access

This Indicator examines whether a State has, or is developing, a streamlined LTSS system.

Why were refinements necessary?

TEP members reported that intellectual and developmental disability services may not be represented in Lewin's *Fully Functioning Criteria Assessment* in Sub-Indicator CT1b. Also, it was

noted that services for the population of individuals suffering from mental illness also may be missing from the assessment.

Regarding Sub-Indicator CT1c, TEP members commented that developmental disability agencies were missing. It was suggested that state, regional (such as CA), and county (such as PA and OH) DD Authorities be included. TEP member Shawn Terrell from the US Administration on Community Living commented, “There appears to be an assumption that there is an access center or ‘hub’ of some sort that has a relationship with all these entities. I don’t think that exists and is clear in every state. This varies tremendously by state. If it’s the ADRC the state Department of Aging would be the lead agency. But if it’s a MFP or BIP state the lead agency may be the state’s Medicaid agency. It is not clear whether the NBIP team is assuming that there is a lead agency that “owns” the development of the “No Wrong Door” system in a state.”

It was suggested that a No Wrong Door system may not necessarily mean that a state has a formal partnership with every entity. It may be more important to examine if within each entity there are people who can function as a navigator to the system.

One TEP member reported that data and literature indicate that collaboration is preferable and with more collaboration the greater the likelihood the state is going to be able to solve issues and provide LTSS.

Shawn Terrell also reported, “One of the things a ‘No Wrong Door’ system has to deal with is people who are not eligible and enrolled in any particular public program (i.e., private pay) so you have to deal with that group. One of the things we are trying to think through is how to be supportive in a person-centered way – sort of navigation/coordination activity that you would want to have as part of the system to try to keep people out of the public system. I don’t think we have hit this on the care coordination side so far.”

TEP members reported that all of this information is available from state waivers and other state documents. It was suggested that the NBIP team review other sources rather than ask states for this information, or utilize secondary data to compare to states’ responses.

What refinements were made and how were they made?

Overall, the refinements and/or expansions that the team made for Indicator CT1 included the following:

1. Updated terminology and revised language used.
 - Language was revised for the indicator descriptions to make the purpose of the indicator clearer and more concise.
 - Language was revised or deleted in the tip boxes to make the instructions to make clearer for respondents.

- Language was revised throughout the indicator to make questions clearer for respondents (e.g. Question 1, Sub-Indicator CT1a)

Specific Changes Made to Sub-Indicator CT1a

None made.

Specific Changes Made to Sub-Indicator CT1b

None made.

Specific Changes Made to Sub-Indicator CT1c

1. Deleted Table in Sub-Indicator CT1c.
 - The table in Sub-Indicator CT1c was deleted and the questions were reorganized.

Indicator CT2. Service Coordination

The Service Coordination Indicator examines the variety of service coordination options that a state may provide. The indicator examines whether service coordination exists and the quality of the service provided.

Why were refinements necessary?

TEP member did not have comments on Sub-Indicator CT2a.

It was reported that the table is from the NCIs for IDD and should be indicated as such. TEP members suggested that the NBIP team collect the data from the state as well. Chas Moseley, a TEP member from the National Association of State Directors of Developmental Disability Services (NASDDDS), commented, "Some states can answer this question without using the National Core Indicators (NCIs). They might use the HCBS Participant Experience Survey (PES) or other tools to get at this question. Use the NCIs for what you can get but don't close yourself off to just that source of information."

What refinements were made and how were they made?

Overall, refinements and/or expansions made for Indicator CT2 included the following:

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to make options more clear (e.g., Medicaid was added to § 1915(c) HCBS Waivers and § 1115 Waivers.

Specific Changes Made to Sub-Indicator CT2a

1. Options for Questions were added/expanded.

- Options for Questions in the table in Sub-Indicator CT2a were expanded to include Medicaid State Plan Amendment (SPA) services.

Specific Changes Made to Sub-Indicator CT2b

None made.

Indicator CT3. LTSS Care Transition

This indicator examines the promotion of continuity of care and seamless transitions from setting to setting across major developmental stages throughout an individual's lifespan.

Why were refinements necessary?

TEP member Chris Murtaugh from the Visiting Nurse Association of NYC asked, "In regards to Question 6, do states typically have these transition programs? The ones noted in the document are specific acute to community-based care and the models are for the aged and adult populations and not other populations. Are they implementing these programs more broadly?" Another TEP member asked if the questions were limited to the care transition programs listed, and, if so, they should be expanded to include other care transition programs.

What refinements were made and how were they made?

Overall, refinements and/or expansions made for Indicator CT3 included the following:

1. Updated terminology and revised language used.

Specific Changes Made to Indicator CT3.

1. Table was deleted.
 - The table in Indicator CT3 was deleted and the questions were reorganized to simplify them to facilitate respondents completing them.
2. Questions were refined.
 - Question 7 was refined to more broadly examine care transitions. A tip box was added to include the Naylor and Coleman care transitions models as examples of community-based care transitions models.

Prevention Principle

Overview

The Prevention Principle examines states' efforts to encourage and support health and wellness programs that promote healthy living, slow functional decline, and ensure the optimal health, well-being, safety, and functioning of people with disabilities.

The objective of this principle has not changed over time. However, the TEP members consistently have questioned the appropriateness of using this principle, and its two related indicators, to examine whether a state has a balanced, person-driven LTSS system. As a result, the NBIP team further expanded the background of the Prevention Principle to substantiate its place as an NBI principle by conducting a thorough review of the literature and including that information in the background of the principle. In addition, at the request of Jennifer Burnett and Annette Shea at CMS, the team refined the background language for the indicator to reduce biased statements.

Principle Features

The team developed the following two Principle Features for the Prevention Principle:

- *Universal Availability and Utilization of Community, Clinical and Preventive Services*
- *State and Local Communities are Free from Preventable Illnesses and Injury*

No additional changes were made to either Principle Feature.

Indicators and Refinements and/or Expansions Made

There are two indicators for the Prevention Principle:

- Indicator P1. *Health Promotion and Prevention*
- Indicator P2. *Disaster/Emergency Preparedness*

The following section discusses these indicators and why refinements and/or expansions were necessary, and what refinements and/or expansions the team made and how.

Indicator P1. Health Promotion and Prevention

This indicator examines whether a state provides health promotion and prevention programs that target individuals of all ages who have disabilities. In addition, the indicator examines the availability of programs supported by a full array of state funding sources.

Why were refinements necessary?

Overall, TEP members felt that this indicator did not capture differences in health promotion and preventive supports and services among types of disabilities because, “Prevention-related programs for one population may not be the same as for another. Vaccination Programs for kids are different than Thai Chi Programs for adults and elders. The questions are too generic.” As a result, the NBIP team felt that the most effective way to address this concern was to include additional sub questions throughout that require respondents to identify which population was being targeted for services and supports.

In addition to TEP feedback, the NBIP team felt that it was necessary to revise language throughout the indicator to reflect the most current terminology and to make questions clear and easy to understand.

What refinements were made and how were they made?

Overall refinements and/or expansions made for Indicator P1 include the following:

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to reflect more current terminology (e.g., “Duals” is now Medicare-Medicaid Enrollee “MME”) (e.g., Question 4) as well as to make questions clearer.
2. Simplified survey questions.
 - Questions that formerly had multiple sub questions (two questions counting as one question) were separated into two separate questions with separate response options (e.g., Question 10).

Specific Changes Made to Indicator P1

1. Made questions related to the health promotion and preventive supports and services for persons with disabilities more specific to capture information by disability type and where applicable by age and disability type (e.g., Question 9).
 - This was accomplished by adding a new subquestion to many of the questions that asks the respondent to identify which disability and/or age group the service or support in question applies to or targets (e.g., Question 1a).
2. Included options to capture additional information.
 - Options were added to capture additional funding sources for programs supporting health promotion and preventive services and supports (e.g., Question 9).

Indicator P2. Disaster/Emergency Preparedness

This indicator examines whether or not a state includes individuals with disabilities and other at-risk groups in its statewide disaster/emergency planning efforts and policies. In addition, it examines states' approaches to planning for potential disasters and emergencies for individuals with disabilities. Evidence of the importance of the states' having disaster/emergency preparedness systems is evident in the research and recommendations from several LTSS and public health organizations, and special volumes in top journals.

Why were refinements necessary?

TEP members suggested that the NBIP team explore ways in which contacts are identified and reached in an emergency for LTSS users living in the community. States are required to have a disaster/emergency preparedness plan in place. Awareness of and compliance with this requirement became the basis for the first question of this Indicator. This was followed by a question that addresses whether or not the state has addressed the unique needs of people with disabilities in the state's Disaster/Emergency Preparedness Plan, and, if so, which populations were addressed and in which settings.

Like Indicator P1 above, in addition to TEP member feedback, the NBIP team felt that it was necessary to revise language throughout the questions to reflect the most current terminology and to make questions clearer and easier to understand.

What refinements were made and how were they made?

Overall refinements and/or expansions made for Indicator P2 include the following:

1. Updated terminology and revised language, as appropriate.
2. The flow of questions was revised.

Specific Changes Made to Indicator P2

1. Indicator P2 went through a number of refinements to expand the examination of disaster/emergency preparedness.
2. Questions 4a and 4b were formerly Questions 4 and 5. As such they would have been answered by all respondents, rather than those respondents who checked an appropriate response that would require additional information.
3. A question was added to capture the awareness of and compliance with a requirement to have a disaster/emergency preparedness plan in place.
 - This was done by opening the questions with whether the state has a disaster/emergency preparedness plan in place (Question 1).

4. A question was added to examine if the disaster/emergency preparedness plan requires back-up contacts for vulnerable populations, such as people with disabilities, and, if so, in which settings (Question 2c).

Cultural and Linguistic Competency Principle

Overview

The Cultural and Linguistic Competency (CLC) Principle examines the infrastructure that states have in place to provide services and supports to diverse populations. This objective has remained consistent over time. At the request of Jennifer Burnett and Annette Shea at CMS, the NBIP team made minor edits to the background of the CLC Principle to reduce biased statements. The NBIP team also refined the principle based on a separate discussion that it had with TEP member Dr. Susanne Bronheim, a CLC expert from Georgetown University's National Center for Cultural Competence. Dr. Bronheim did not attend the scheduled TEP meeting at which the Cultural and Linguistic Competency Principle was discussed by TEP members.

Principle Features

The NBIP team developed the following three Principle Features for the Cultural and Linguistic Competency Principle:

- *Services are Offered to Diverse Populations* (related to Indicators CLC1 and CLC2)
- *Users of Services and their Families and Community Members are Engaged in Planning, Implementing, and Evaluating Services*
- *State Program Staff, LTSS Provider Organizations, and DSW Receive Cultural and Linguistic Competency Education and Training on an Ongoing Basis* (related to Indicator CLC3)

The team slightly changed the Principle Feature *Services are Offered to Diverse Populations*. It was originally entitled *Service Offerings to a Diverse Population*. The team also changed the Principle Feature *State Program Staff, LTSS Provider Organizations, and DSW Receive Cultural and Linguistic Competency Education and Training on an Ongoing Basis*. The Principle Feature was formerly entitled *State and Local Organizations Provide Ongoing Education, Training, and Awareness Activities in Cultural and Linguistic Competence for Providers and Others*.

The team initially developed two additional Principle Features for this Principle:

- Consumers of services and their families and community members are engaged in planning and evaluating services; support is provided for their engagement, including language and disability access, accommodation for literacy levels, and financial supports when needed

- Procedures are in place to address prejudice and prevent discrimination in the workplace or living and community space

The NBIP team did not implement these Principle Features because either the team was unable to develop an indicator or the Federal Partners did not develop an indicator that was related to them.

Indicators and Refinements and/or Expansions Made

There are three indicators for the Cultural and Linguistic Competency Principle:

- Indicator CLC1. *Needs Assessment and Target Population*
- Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups*
- Indicator CLC3. *Cultural and Linguistic Training Requirements*

The following section discusses these indicators, why refinements to and/or expansions of them were necessary, and what refinements and/or expansions the team made and how.

Indicator CLC1. Needs Assessment and Target Population

This indicator examines whether diverse groups of users receive LTSS and if states are mandated to provide services to these users. The indicator also assesses if a state collects and reports data on the diverse groups served by its LTSS programs.

Why were refinements necessary?

TEP members suggested that the team remove the table in Question 8 (population table) to simplify the survey and avoid the possibility of missing one or more population groups. They suggested that it is more important to examine data collection and use than examine the populations on which data are reported.

As mentioned above, the NBIP team discussed the indicator separately with TEP member Dr. Suzanne Bronheim, a CLC expert from Georgetown University's National Center for Cultural Competence. Dr. Bronheim recommended that the team make the following refinements:

- Revise the terms "clear" and "effective" in Question 1. She suggested that Question 1 be revised to ask simply if a state has a written policy. Dr. Bronheim also said that often states do not have any written policy related to offering providing cultural and linguistic competent LTSS.
- Dr. Bronheim recommended that Question 3 be a more general question about how states include users, representatives, and advocates in developing and implementing state's CLC policies for LTSS.

- Dr. Bronheim asked how Question 3 differs from Question 2. To differentiate the two questions, Dr. Bronheim suggested deleting both questions and creating a new question that asks “Does the State involve culturally and linguistically diverse users, representatives, and/or advocates in Cultural and Linguistic Competency-related LTSS policy development? If ‘Yes,’ how?” Dr. Bronheim also asked, “How does the state formalize their participation in order to obtain their feedback?”
- Dr. Bronheim stated that the NBIP team needed to determine how to examine and ask states questions about how they examine Cultural and Linguistic Competency by diversity group and disability type.
- Dr. Bronheim was concerned about the term “allows” in Question 5. “I believe Title VI requires this [policy on language service access]. What is a state’s policy for ensuring that people who need it get language access? What does the ADA say? Does a state provide language access and if so how do they do it and pay for it?” Dr. Bronheim suggested adding a follow-up question to Question 5 regarding how language access services are paid for.
- Dr. Bronheim suggested that Question 7 be combined with Question 8 to create a new Question 4. She suggested that the NBIP make the following changes to improve the table under Question 8:
 - Add Native Americans;
 - Add a column to the table that asks whether data collected were used to evaluate and monitor quality of LTSS by race, ethnicity, language spoken, etc.;
 - Add “refugee group” that can be filled in by a state to capture variations across states about large refugee groups (i.e., Russian refugees).

What refinements were made and how were they made?

Overall, the team made the following refinements to and/or expansions of Indicator CLC1:

1. Updated terminology and revised language used.
 - Language was revised throughout the indicator to make questions clearer (e.g., Question 1 removed the words “clear” and “effective”).

Specific Changes Made to Sub-Indicator CLC1

1. Questions were added.
 - Questions 2 to 4 were added to capture information on how and in what phase of policy the state includes users, families, and advocates.
 - Question 6 was added to examine how a state ensures that language services are available to those who need them and how those services are funded.
2. Simplified questions when possible.

- Question 8 was refined to allow respondents to describe the state’s data collection efforts in order to better understand the needs and characteristics of LTSS users in the state. The table in the previous version of Question 8 was removed and replaced by multiple open-ended questions.

Indicator CLC2. Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups

This indicator examines whether a state designs its LTSS system to address the needs of diverse groups of users based on mandates and evidence-based practices. In addition to the design, this indicator examines whether the state agency provides staff that can support the diverse groups of users that are targeted.

Why were refinements necessary?

TEP members suggested that Indicator CLC2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups* examine more closely how a state integrates cultural and linguistic competency into everything that it does and whether training is provided on how to integrate CLC into everything that it does.

Dr. Bronheim (TEP member) recommended that the team make the following refinements to this indicator:

- Related to Question 1, Dr. Bronheim asked, “Does the state provide a list of Cultural and Linguistic Competency-related items that are to be covered in a person’s needs assessment and included in his person-centered plan? How does the state monitor if the Cultural and Linguistic Competency-related items identified in the person’s needs assessment and included in a person’s person-centered plan are being addressed and how frequently does the monitoring occur? The state should tell us.”
- Dr. Bronheim suggested that the team add a follow-up question to examine how often a person’s needs assessment is updated to reflect any changes in cultural and/or linguistic needs. In addition, she suggested that Question 1b be revised to find out if the person’s documented cultural and/or linguistic needs included in his/her service/care plan are monitored, how they are monitored, and how frequently.
- Dr. Bronheim suggested that Question 1b regarding person-centered planning be asked in another section of the survey (i.e., in a section that addresses person-centered planning and all relevant applications). Currently these questions are included in Indicator S2. *Availability and Use of Self-directed Services*.
- Dr. Bronheim had an issue with the term “allows” in Question 2. She also asked if the question was duplicative. “I think it would be more interesting to ask about who is paying for language access services.”
- For Question 3, Dr. Bronheim suggested that the evidence-based practices should be culturally adapted and this question might be too much detail.

- Dr. Bronheim suggested Question 4 be deleted and the information be covered in Question 1b.
- Dr. Bronheim suggested that Questions 5 to 6 be moved to a section on DSW [possibly to the Sustainability Principle and the creation of a Sub-Indicator S3c] and referred to here for scoring. She thought that Questions 7 and 8 should remain in this indicator. She also mentioned that LTSS providers need to be able to address the cultural and linguistic needs of diverse groups.

What refinements were made and how were they made?

Overall, refinements and/or expansions made for Indicator CLC2 included the following:

1. Updated terminology and revised language used throughout the indicator to make questions clearer.

Specific Changes Made to Indicator CLC2

1. Revised flow of questions.
 - Questions 1 and 2 were formerly Question 1.
2. Questions were deleted.
 - Question 2 was deleted because it was duplicative of question 1 in CLC1.
 - Question 3 was deleted.
3. Questions were relocated.
 - Questions related to DSW and staff training were relocated to Sub-Indicator S3d. *DSW Training* and Indicator CLC3. *Training Requirements*.

Indicator CLC3. Cultural and Linguistic Training Requirements

The Cultural and Linguistic Competency Training indicator examines training requirements for LTSS and vocational rehabilitation providers that address cultural and linguistic competency.

Why were refinements necessary?

The TEP members suggested that questions related to LTSS and vocational rehabilitation provider training be added to the NBIs and that Cultural and Linguistic Competency training-related questions for LTSS and vocational rehabilitations providers be included within that set of questions. In addition, during the NBIP team’s discussion Dr. Bronheim regarding Indicator CLC3, she recommended that all direct service worker (DSW) training and education-related questions be placed in the survey with other similar questions (not related to Cultural and Linguistic Competency, but DSW-related training and education). This approach would simplify the survey tool and make it easier for states to complete the survey. Also, she said it would be helpful to ensure that good data are collected from states. As a result, Dr. Bronheim suggested that Questions 5 and 6 from Indicator CLC2 and Question 1 from Indicator CLC3 be moved to

the Indicator S3 in the Sustainability Principle under Sub-Indicator S3d. *Direct Service Workforce Training*.

What refinements were made and how were they made?

Overall, the team made the following refinements and/or expansions to Indicator CLC2:

1. Updated terminology and revised language used throughout the indicator to make questions clearer.

Specific Changes Made to Indicator CLC3.

1. Simplified and revised questions capturing staff Cultural and Linguistic Competency training requirements.
 - Questions from Indicator CLC 2. *Efforts to Design Services and Supports for Culturally and Linguistically Diverse Groups* related to state staff training were relocated to Indicator CLC3. *Training Requirements*.
 - Sub-questions were added to Questions 1 and 2 to allow respondents to provide additional detail to describe training curricula used and training frequency.
 - Questions related to training for direct service workers were relocated to Sub-indicator S3d. *Direct Service Workforce Training*.

APPENDIX J. APRIL 2014 DRAFT TECHNICAL ASSISTANCE GUIDE

Please see the following attachment:

Howard, J., Zuckerman, I., Woodcock, C., Flanagan, S., Urdapilleta, O., Poey, J., Waterman, G., Ruiz, S., Clark-Shirley, L., (2014). *The National Balancing Indicators Technical Assistance Guide*. Centers for Medicare and Medicaid Services.