Medicaid Balancing Incentive Program: Recommendations for Core Assessment Tools for Individuals with Brain Injury

June 2015

Introduction
The Centers for Disease Control and Prevention’s (CDC) National Center for Injury Prevention and Control (NCIPC) reports that brain injury is a “serious public health problem” contributing to a substantial number of deaths and permanent disability in the United States. In 2010, CDC reported that 2.5 million Americans sought treatment for a brain injury as the result of a car crash; fall; recreational and sporting injury; violence, such as gunshot wounds, domestic violence or child abuse; or other contributing events. The effects of these injuries result in problems with thinking, memory, emotions, language, physical, mobility and sensory, which impact a person’s ability to return to school, work, home and community.

Approximately 5.3 million Americans are living with a brain injury-related disability impacting relationships with family and friends, as well as their ability to be employed, do household tasks, drive, and participate in other activities of daily living. Individuals may also have co-occurring problems associated with substance abuse or mental health conditions. Lack of insight and awareness of problems may contribute to the individual’s ability to self-assess, report issues, making decisions, make adjustments and understand the need to participate in rehabilitation or tasks designed to assist with living more independently in the community.

Over the years, States have designed systems, services and supports to address the cognitive and behavioral issues associated with brain injury. Many States expanded services through Medicaid home and community-based services (HCBS) programs, such as brain injury waivers or waiver programs designed for persons with other disabilities. The Affordable Care Act (ACA) created the Balancing Incentives Program (BIP) to authorize grants to States to increase access to non-institutional long-term services and supports (LTSS). Several States which administer brain injury waiver programs are also participating in the BIP, which may impact brain injury HCBS programs as States look to redesign or coordinate waiver programs for all populations served.

The BIP requires States to adopt a standardized core assessment tool(s) for all individuals served in Medicaid HCBS programs to determine eligibility, to identify support needs, and to inform service planning for home and community-based services. To assist States with identifying a core standardized assessment tool and supplemental tools to better assess the HCBS needs of individuals with brain injury, the National Association of State Head Injury Administrators (NASHIA) created a national workgroup of participating BIP States with brain injury HCBS waiver programs. The members reviewed tools under consideration and behavioral and cognitive issues related to brain injury which may make assessment difficult. It is acknowledged that this was a short-term project that did not involve scientific research, but rather the workgroup relied on members’ knowledge and experience with regard to assessing needs and developing and administering service plans for individuals with brain injury.
LTSS for Individuals with Brain Injury: Assessment Considerations

About Brain Injury-related Disabilities and Impact on LTSS
The most common problems associated with individuals with brain injury are deficits in cognition and behavior. Cognitive functioning encompasses thinking, understanding, reasoning, and memory leading to the attainment of information and knowledge. Issues related to memory affect attention, concentration, storing and retrieving information and understanding communication. Executive functioning refers to a set of cognitive abilities that control and regulate other abilities and behaviors. Executive dysfunction often occurs due to injury to the frontal lobes of the brain which affects a person’s ability to plan and organize, and impacts flexible thinking, multi-tasking, solving problems, self-awareness, decision making, motivation, controlling or regulating emotions, concentrating and taking in information, impulse control (e.g. curbing inappropriate language or behavior), and integrating past experience with present action.

These cognitive issues affect a person’s ability to initiate, organize, and carry out the most basic functions of activities of daily living (ADLs). While a person may be able to make a sandwich, he or she may not remember the order to make a sandwich (bread on top and bottom) or to even remember to make the sandwich to eat. Accommodations, including cueing, are critical to assist people to remember to take their medications, which medications to take; to buy groceries; to eat; to bath; and so forth.

Brain injury may also affect motor functions, such as impaired coordination and balance; sensory, such as hearing, vision, impaired perception and touch; emotions, such as depression, anxiety, aggression, impulse control, and personality changes; and other physical problems such as fatigue. Seizures may also occur after a brain injury. Individuals with brain injury may also have co-occurring problems associated with substance use disorders or mental health conditions. Staff assessing persons with brain injury should take all these issues into account in determining how they impact the person’s ability to live independently without supports and how without supports, they may be faced with few other alternatives than institutional levels of care, even correctional facilities or being homeless.

Brain Injury Medicaid HCBS Waiver Programs
The 1915(c) Medicaid Home and Community-based Services (HCBS) waiver program is one of many options available to States to allow the provision of long-term services and supports (LTSS) in home and community based settings. States can offer a variety of services under an HCBS Waiver program through a combination of standard medical services and non-medical services. States can also propose “other” types of services that may assist in diverting and/or transitioning individuals from institutional settings into their home and community. The brain injury waiver programs vary considerably across the country in numbers served and services offered. The level of care criteria also differs from State to State. Most States use nursing facility level of care as the criteria for institutional care, while a few use a rehabilitation hospital or specialized nursing facility as the level of care criteria.

There are currently twenty-seven brain injury 1915(c) waiver programs designed for individuals with brain injury: Colorado, Connecticut (2), Florida, Illinois, Indiana, Iowa, Kansas, Kentucky (2), Maine, Maryland, Massachusetts (3), Minnesota, Mississippi, Nebraska, New Jersey, New Hampshire, New York, Pennsylvania, South Carolina, Utah, West Virginia, Wisconsin and Wyoming. A few States which previously administered brain injury waiver programs have incorporated their brain injury waivers into other waiver programs for individuals with disabilities.
Balancing Incentives Program (BIP) and Core Standardized Assessment (CSA)

The Balancing Incentives Program (BIP) was created through the Affordable Care Act and authorizes grants (in the form of a federal enhanced match on HCBS services) to participating States to help transform their long-term care systems by:

- Lowering costs through improved systems performance & efficiency
- Creating tools to help consumers with care planning & assessment
- Improving quality measurement & oversight

States are required to achieve the following benchmark- 50% of LTSS spending on home and community based services and implement three structural changes within the State’s community based long-term services and support systems:

- No wrong door/Single Entry Point network
- Conflict Free Case Management
- Core Standardized Assessment Instruments

BIP requires that the standardized assessment(s) be used across the State and across populations to (1) determine eligibility, (2) identify support needs, and (3) inform service planning for home and community-based services. States have the option to use their existing assessment tool(s); adapt or supplement their existing assessment tool(s) with new question sets; or completely replace their existing processes for collecting assessment information and develop new CSA instruments. The Centers for Medicare and Medicaid Services (CMS) mandated five data domains and topics to be included:

1. Activities of Daily Living (ADLs), which are basic self-care tasks
2. Instrumental Activities of Daily Living (IADLs), which are complex skills needed to successfully live independently
3. Medical Conditions
4. Cognitive Function and Memory/Learning Difficulties
5. Behavior Difficulties

The following States which also administer 1915(c) brain injury waiver programs are participating in the Balancing Incentives Program: Connecticut, Illinois, Indiana, Iowa, Kentucky, Maryland, Massachusetts, Mississippi, Nebraska, New Hampshire, New York, Pennsylvania. As such, these States are required to implement a core standardized assessment tool, which will impact the State’s brain injury waiver program.

Assessment Tools
Workgroup members reviewed and reported to the workgroup on the multiple assessment tools that are being considered by their States participating in BIP and/or operating a Brain Injury Waiver program and how well the tools assess information with regard to individuals with brain injury. Below is a summary of those tools.

BIP Assessment Tools Considered by States

interRAI Home Care Assessment System (HC)
The interRAI Home Care Assessment System (HC) is a proprietary tool designed to assess a person’s functioning and quality of life by assessing needs, strengths, and preferences, and facilitating referrals when appropriate. When used over time, it provides the basis for an outcome-based assessment of the person’s response to care or services. The interRAI HC was first developed in 1994. Initially it was designed to be compatible with the Long-Term Care Facilities system that was implemented in U.S. nursing homes. It was revised in 1999 (Version 2.0), at which time items were dropped, modified, or added, and the period of observation (time frame) for
most assessment items was decreased from 7 to 3 days. It was further revised in 2007 to be compatible with the other assessment systems in the interRAI suite. The interRAI HC was developed for use with adults in home and community-based settings. The instrument is generally used with the frail elderly or persons with disabilities who are seeking or receiving formal health care and supportive services. Go to their website for more information: http://www.interrai.org/home-care.html

**Mayo Portland Adaptability Inventory (MPAI)**
The Mayo-Portland Adaptability Inventory (MPAI) is primarily designed: (1) to assist in the clinical evaluation of people during the post acute (post hospital) period following acquired brain injury (ABI), and (2) to assist in the evaluation of rehabilitation programs designed to serve these people. Evaluation and rating of each of the areas designated by MPAI-4 items assures that the most frequent sequelae of ABI are considered for rehabilitation planning or other clinical interventions. MPAI-4 items represent the range of physical, cognitive, emotional, behavioral, and social problems that people may encounter after ABI. MPAI-4 items also provide an assessment of major obstacles to community integration which may result directly from ABI as well as features of the social and physical environment. Now in its fourth revision, the MPAI-4 and its three subscales (Ability Index, Adjustment Index, Participation Index) offer measures with highly developed and well documented psychometric properties.
http://tbims.org/combi/mpai/mpai4.pdf

**Minimum Data Set – Home Care (MDS-HC)**
The Minimum Data Set (MDS) was designed in the 1980s as a tool for use in Medicaid–Medicare certified nursing homes. Its aim was to help physicians to identify their elderly patients’ needs and to provide standardized health care plans. A Home Care (HC) version of MDS was developed in order to assess the needs and direct health care planning for community-dwelling elderly. The inventoried items cover cognitive functions, communication, vision and hearing, mood, social functioning, situation of the informal caregiver, ADL and IADL, continence, inventory of comorbidity, situation of feeding, skin and mouth problems, housing conditions and medication use.

**Minnesota Choices Assessment (MnChoices)**
The Minnesota Choices Assessment (MnCHOICES) is a single, comprehensive assessment and support planning web-based application for long-term services and supports used in Minnesota. MnCHOICES uses a person-centered planning approach to: allow for timely consideration of support options beyond what is reimbursed through Medical Assistance long-term care programs; combine long-term care assessment processes; provide additional data to evaluate outcomes; and simplifies and standardizes face-to-face assessments. http://mn.gov/dhs/partners-and-providers/continuing-care/reform-initiatives/mnchoices/

**Continuity Assessment Record and Evaluation (CARE) Item Set CARE**
The Continuity Assessment Record and Evaluation (CARE) Item Set is designed to standardize assessment of patients’ medical, functional, cognitive, and social support status across acute and post-acute settings, including long-term care hospitals (LTCHs), inpatient rehabilitation facilities (IRFs), skilled nursing facilities (SNFs), and home health agencies (HHAs). The CARE Item Set targets a range of measures that document variations in a patient’s level of care needs including factors related to treatment and staffing patterns such as predictors of physician, nursing, and therapy intensity.

**Kentucky Medicaid Waiver Assessment**
The Kentucky MAP 351 tool is proprietary and was designed by the Kentucky Medicaid program specifically to determine the level of care for Medicaid waiver admittance; to establish baseline information with regard to functional abilities; and to identify chronic and acute health conditions

Other

St. Louis University Mental Status Exam (SLUMS)
The St. Louis University Mental Status Exam (SLUMS) is a screening tool for trained healthcare professionals to use to detect mild cognitive impairment and dementia. It consists of eleven items and measures cognition, orientation, short-term memory, calculations, naming of animals, clock drawing, and recognition of geometric figures. The SLUMS looks at present cognitive deficits and can be used to identify changes in cognition over time. http://medschool.slu.edu/agingsuccessfully/pdfsurveys/slumsexam_05.pdf

Brain Injury Assessment Tools
The workgroup also reviewed assessment instruments available through the Traumatic Brain Injury (TBI) Model Systems Center for Outcome Measurement in Brain Injury (COMBI) website to determine if they would meet the BIP criteria or could be used for supplemental information. COMBI is an online resource for measures commonly used in the field of brain injury rehabilitation and assessment. The tools listed below are not necessarily recommended for usage, but rather included for informational purposes.

Brain Injury Screening Questionnaire (BISQ)
The Brain Injury Research Center of Mount Sinai (BIRC-MS) developed the Brain Injury Screening Questionnaire (BISQ) to address unidentified TBI in individuals. The format for the BISQ is based on the "HELPS" instrument, developed by Picard, Scarisbrick, and Paluck (1991) at Mount Sinai's TBI Rehabilitation and Prevention Center. The list of symptoms in the BISQ was adapted from the TBI Symptom Checklist (Medical College of Virginia, undated) and the TIRR Symptom Checklist, created by Don Lehmkuhl (1988). Those interested in developing a screening program can obtain the BISQ, with technical assistance to insure appropriate use in the variety of settings in which screening may be undertaken. Costs include training, the questionnaire itself, and scoring.

Brief Test of Adult Cognition by Telephone (BTAC)
The Brief Test of Adult Cognition by Telephone (BTACT) was developed in response to the need for a brief, but reliable test that covers important areas of adult cognition. It can be administered easily over the telephone to adults from a broad range of ages and educational backgrounds.

Functional Assessment Measure (FAM)
The Functional Assessment Measure (FAM) items were developed by clinicians representing each of the disciplines in an inpatient rehabilitation program. The FAM was developed as an adjunct to the FIM (below) to specifically address the major functional areas that are relatively less emphasized in the FIM, including cognitive, behavioral, communication and community functioning measures. The FAM consists of 12 items. These items do not stand alone, but are intended to be added to the 18 items of the FIM. The total 30 item scale combination is referred to as the FIM+FAM. The time required to administer the FIM+FAM is approximately 35 minutes. http://www.tbims.org/combi/FAM/index.html

Functional Independence Measure (FIM)
The Functional Independence Measure (FIM) is an 18-item, seven level ordinal scale to address uniform measurement and data on disability and rehabilitation outcomes. The FIM was intended to be sensitive to change in an individual over the course of a comprehensive inpatient medical rehabilitation program. The FIM can be completed in approximately 20-30 minutes in conference, by observation, or by telephone interview. http://www.tbims.org/combi/FAM/index.html
The Cognitive Log (Cog-Log)
The Cognitive Log (Cog-Log) provides a measure of general cognitive abilities that can be obtained at bedside. It is a brief measure of cognition that can document progress during rehabilitation and provide an estimate of skills as assessed by more lengthy evaluations. The Cog-Log can be considered a companion measure to the Orientation-Log. Clinical experience suggests that people with brain disorders can be oriented (and perform well on the Orientation-Log), but still exhibit significant cognitive limitations, such as with respect to memory functioning and executive skills. The Cog-Log assists in evaluating this group. Typically, the Orientation-Log is administered initially. The Cog-Log is added to or replaces the O-Log when orientation is achieved.

http://www.tbims.org/combi/coglog/index.html

The Montreal Cognitive Assessment
The Montreal Cognitive Assessment is a screening tool for healthcare professionals to detect mild cognitive impairment. It was designed as a rapid screening instrument and assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. The time to administer the MoCA is approximately 10 minutes. http://www.mocatest.org/

Considerations Regarding Assessment of Individuals with Brain Injury
As a reminder to States, the Balancing Incentives Program does not require States to use the same tool for all waiver populations and programs. States have the flexibility to use different tools for different populations. All tools, however, must address the five BIP domains included in the CMS guidance. Since many individuals with brain injury access services through aging and disability waivers and/or an intellectual disability waiver programs, these considerations need to be applied to individuals with brain injury, regardless of the waiver program providing the services and supports. To help States with determining appropriate assessment tools, the workgroup offers the following observations and considerations:

- Brain injury waivers may have multiple levels of care. This may impact the selection of an assessment tool.

- Assessment tools used for individuals with brain injury must adequately address cognition and executive dysfunction, which are common after brain injury.

- If a State identifies an assessment instrument that accurately measures and accommodates the behavioral and cognitive executive function of an individual with a brain injury, but the tool may not meet the BIP requirements, the State may need to consider using a combination of instruments or creating an instrument that covers all of the domains.

- As brain injury waiver programs are typically smaller in size (i.e. numbers served, costs) than other waiver programs, they may have resource limitations related to administration of assessment instruments.

- Considerations must be given to participant choice, preference, fatigue issues, and cognitive accessibility when selecting assessment tools.

- Individuals with brain injury often have limited awareness of deficits; therefore, assessment cannot solely be based on self reporting. Information must be gathered or validated by other sources or observation. Assessors must have the training to be able to identify the need for additional information.

- Length of assessment should be considered as accommodations for the administration of the assessment may be needed (e.g. giving adequate breaks, speaking clearly and slowly, repeating questions, reducing environmental distractions, and offering information in alternative formats). This is to accommodate individuals with cognitive issues related to
attention, fatigue, lack of insight, awareness, and other limitations that can impact their ability to participate in an assessment process that is too long or requires the individual to self-report (e.g. yes/no type of questions).

- It is also recommended that assessments be given in the person’s environment. Assessment tools that incorporate narrative descriptions of a person’s function and narrative justification for services may work best.

- As behavioral issues after brain injury can become more frequent or more severe under certain conditions or with certain triggers, an assessment tool may need to track and assess behaviors over a period of weeks or months to identify antecedents and needs in this area.

- Assessment tools utilized for individuals with brain injury must address issues related to mental health and substance use.

- Assessment tools must gather information about a participant’s need for cueing or supervision to complete ADLs and IADLs, not just the level of physical assistance with the task. It is common for an individual with a brain injury to be physically capable of completing a task, yet may not have the cognitive ability to initiate or complete the task without cueing and supervision.

**Recommendations:**
To help States adequately assess individuals with brain injury seeking HCBS, the workgroup is making these recommendations to be addressed at both the federal and State levels:

**Federal**
- The Centers for Medicare and Medicaid Services (CMS) and/or other federal agencies, such as NIDRR, should initiate research on the validity/reliability of State assessment tools for individuals with brain injury with regard to assessing activities of daily living, behavior difficulties and executive/cognitive functioning. The federal agencies should help States to identify appropriate tool(s) or supplemental tools.

- CMS should review the five areas of domain to be assessed and incorporate issues relating to brain injury for assessment tools to consider, such as brain injury related medical conditions (i.e. seizures, substance abuse, chronic diseases/conditions, sleep disorders, neurodegenerative diseases, and depression).

- CMS should capture data related to the provision of LTSS to individuals with brain injury to determine effectiveness of current programs and initiatives for these individuals. Brain injury data is currently lumped in to data sets related to persons with physical disabilities and/or intellectual disabilities.

- CMS should provide information on brain injury assessment to State Medicaid agencies to consider when adopting assessment tool(s) for any Medicaid waiver program which may also serve individuals with brain injury.

**State**
- Training and qualifications of assessors is important. Assessors must understand how to administer the selected tool; must be trained to recognize common brain injury related deficits; and understand how to accommodate those issues during the assessment process (e.g. gather information from additional sources, give breaks, reduce environmental distractions and repeat questions).
Tools must be sensitive to cognitive and behavioral issues related to brain injury. They should specifically take into consideration executive functioning deficits and, their impact on information processing/organization and the behavioral responses to environmental stimulus.

ADL questions must recognize that an individual with brain injury may know how to perform an ADL, but due to short term memory issues or other cognitive problems, will not remember to execute the activity appropriately without prompting and cueing, thus putting the person at risk for institutionalization.

Screening should include questions with regard to a history of brain injury.

Accommodations may be needed during assessment process if the participant has significant fatigue or attention issues.

Summary
The workgroup noted that some of the assessment tools that are being considered by BIP States for use with HCBS aging and disability programs are heavily focused on activities of daily living (ADLs), which are basic self-care tasks, and instrumental activities of daily living (IADLs), which are the complex skills needed to successfully live independently. The ability to carry out these tasks should not solely be assessed in terms of medical or nursing needs (hands on care). The need for verbal assistance, cueing and other accommodations to help the person to initiate and carry out the task should also be assessed.

The group agreed that the assessment tools were weaker in the areas of behavior and cognition as related to brain injury, which also impact ADLs and IADLs. The assessments with regard to medical conditions generally did not include common brain injury related conditions, such as seizures, chronic pain, headaches, sleep disturbance, substance use disorders, and mental health conditions. However, the workgroup was unable to identify any tools that are valid and reliable that would address the five domains required by BIP requirements for individuals with brain injury and also adequately assess the areas of cognition and behavior to accurately reflect the functional abilities of an individual with a brain injury and accurately drive service planning. Several of the assessment tools found on the COMBI website adequately assess behavior and cognition, but do not address the other three BIP domains: ADLs, IADLs and medical conditions. They could be used by States to supplement a tool that lacks detail related to behavior or cognition.

References

- Medicaid Waiver Programs: http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/waivers_faceted.html
- The TBI Model Systems Center for Outcome Measurement in Brain Injury (COMBI): http://www.tbims.org/combi/
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The mission of the National Association of State Head Injury Administrators (NASHIA) is to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families. For more information about the National Association of State Head Injury Administrators (NASHIA) go to www.nashia.org.

February 27, 2015
Updated June 3, 2015
## Addendum

### Summary of States’ Core Standardized Assessment (CSA) Instruments

March 2015

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<td>For children: MED Kids-KB assessment; MED Kids-PDN Assessment; SIS</td>
<td>For children: MED Kids-KB assessment; MED Kids-PDN Assessment; SIS</td>
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<td>For adults: LOCUS; ANSA; ISP; PASRR I and II</td>
<td>For adults: DS Comprehensive/Support HCB Waiver Assessment (BMS-99); PASRR II Psychosocial/Function Evaluation #3; PASRR I</td>
<td>MED assessment</td>
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<td>Brain Injury Assessment Tool for Section 97 Eligibility for Residential Services</td>
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<td>State</td>
<td>Mental Health</td>
<td>Developmental/Intellectual Disability</td>
<td>Elderly</td>
<td>Physical Disability</td>
<td>Traumatic Brain Injury</td>
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<td>SIS</td>
<td>interRAI HC</td>
<td>MO HealthNet Application/ Eligibility Statement</td>
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<td>Prioritization of Need for DD Services</td>
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<td>MS</td>
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<td>ANSA</td>
<td>SIB-R</td>
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<td>SIB-R</td>
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<td>interRAI Assessment Tool or other comparable assessment tool</td>
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<td>NJ CHOICE (interRAI Assessment)</td>
<td>NJ CHOICE (interRAI Assessment)</td>
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<td>Trigger questions for MI population on Level 1 Screen INDA</td>
<td>Trigger questions for DD population on Level 1 Screen DDRT</td>
<td>Screen for Community Services</td>
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<td>NY</td>
<td>For adults: interRAI CMH; interRAI CHA</td>
<td>interRAI DD Tool; CAS interRAI CHA UAS-NY Community Assessment</td>
<td>For adults: interRAI CHA; UAS-NY Community Assessment</td>
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<td>For children: CANS-NY</td>
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<td>PA</td>
<td>Community Support Plan</td>
<td>SIS, PA Plus, Adult Autism Waiver (AAW) &amp; Adult Community Autism Program (ACAP), Eligibility Worksheet, SIB-R, MA-51</td>
<td>CMI, LCD</td>
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<td>TX</td>
<td>ANSA, CANS</td>
<td>New tool being researched, Current tools are: ICAP and SIB-R, Form 8662: Related Conditions, Form 8578: ID</td>
<td>Form 2060, Needs Assessment, Form 2060b</td>
<td>Form 2060, Needs Assessment</td>
<td>Form 2060b</td>
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* MA provides much of its community LTSS through state plan services; therefore, assessments to develop plans of care are often based on type of service and not population type.

** As of 12/31/2014, state is no longer participating in the Program.

For more information, please see Work Plans posted on Medicaid.gov: [http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html](http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Balancing/Balancing-Incentive-Program.html). This chart was taken from that website.