

# FUNDING STATE BRAIN INJURY PROGRAMS

*A Primer on State  
Brain Injury  
Trust Fund and  
Medicaid HCBS  
Programs*

This document was prepared for the  
Administration for Community Living  
Traumatic Brain Injury State Partnership Workgroup on Waiver  
and Trust Fund Programs by the  
National Association of State Head Injury Administrators.



# **Funding State Traumatic Brain Injury Programs:**

## **A Primer on State Brain Injury Trust Fund and Medicaid Home and Community-Based Services (HCBS) Programs**

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**For the Administration for Community Living TBI State Partnership Grant  
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In 2018, the U.S. Department of Health and Human Services' (HHS) Administration for Community Living's (ACL) Traumatic Brain Injury (TBI) State Partnership Program awarded grants to states in two categories: Mentor State Grants and Partner State Grants. These grantees were then assigned to workgroups established in accordance with topics relating to each state's goals. Colorado and Iowa were awarded Mentor State Grants and designated to lead the workgroup on Medicaid TBI Home and Community-based Services (HCBS) Waiver and State Trust Fund programs, working with Arkansas, Idaho, Kansas and Ohio, which received Partner State Grants.

The workgroup first met in 2018 to identify needs and products that would help further the work of states interested in developing, implementing, and expanding TBI HCBS Waiver and Trust Fund programs. To help with this work, Colorado and Iowa contracted with the National Association of State Head Injury Administrators (NASHIA). NASHIA arranged for the on-site workgroup meeting held to coincide with the 2018, as well as the 2019, Annual State of the States Meeting and provided information on each state's Medicaid TBI HCBS Waiver and Trust Fund program. The mentor grantees arranged conference calls in the interim.

The second year, 2019, the workgroup expanded on that work by addressing information regarding all Medicaid HCBS State Plan options, state general revenue, in addition to revenue generated for trust fund programs. This is in recognition that states use several funding streams to pay for an array of services and supports, recognizing that some states use all of these revenue streams, while other states may find that one or two funding streams is more in keeping of how their states may fund service delivery. This document was subsequently prepared to help states understand how to pursue these funding options. In addition, the workgroup asked that NASHIA prepare a handout that would help grantees to educate state executive branch leadership about funding options and the importance of providing services and resources to individuals with TBI.

To further assist the workgroup, NASHIA arranged for Mary Sowers, Executive Director, National Association of State Directors of Developmental Disabilities Services (NASDDDS), to participate in a call to discuss opportunities for collaboration with state intellectual and developmental disabilities (I/DD) systems; trends in long-term services and supports (LTSS); and opportunities for Medicaid funded LTSS. The plan going forward is for NASHIA to prepare a PowerPoint presentation as an additional resource to assist states in educating their advisory councils, state agencies and other policymakers about options for funding services, supports and resources.

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## Introduction

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As states administer several funding streams for programs and services targeted specifically to individuals with traumatic brain injury (TBI)/acquired brain injury (ABI) to pay for an array of rehabilitation and community services and supports, this primer has been developed to provide information about:

- 1) funding streams specifically authorized for services and resources for individuals with TBI and their families;
- 2) tips on how to pursue funding, and
- 3) examples of how these programs and services are administered in selected states.

States may administer just one funding stream, such as general revenue, revenue derived from a trust fund or Medicaid, often in coordination with other state and federal resources. Other states may have access to multiple funding streams dedicated for individuals with brain injury, meaning legislators appropriate general revenue, trust fund revenue, and specialized Medicaid services to support the needs of individuals with TBI. About half of the states administer a brain injury home and community-based services (HCBS) Medicaid waiver program and about half of the states administer a trust fund program, but not necessarily the same states. Individuals with brain injury may also receive services through the following:

- 1) Medicaid State Plan benefits; including 1915(k), Community First Choice, 1915(i), HCBS State Plan, and 1915(j), Self-Directed Personal Assistance Services;
- 2) State programs or Medicaid HCBS waiver programs designed for other populations, such as physical disabilities, intellectual/developmental disabilities, and mental/behavioral health; and/or
- 3) Other state and federal programs offering assistance to individuals with special health care needs, such as Title V Maternal and Child Health (MCH) Block Grant Program, and programs that provide assistance based on a disability eligibility, such as Vocational Rehabilitation.

States are increasingly looking to managed care organizations to deliver services to Medicaid beneficiaries and many states are now including long-term services and supports in these arrangements. In some states, brain injury HCBS waivers have collapsed with other population specific waivers into one HCBS waiver program. A few states offer HCBS through State Plan benefits, including 1915(j), 1915(k), and 1915(i). More recently, a few states have expanded their waiver, or trust fund and/or general revenue funded program to cover individuals with non-traumatic brain injury. With regard to children's services, children with TBI may be eligible for Medicaid Early and Periodic Screening, Diagnostic, and Treatment (EPSDT), a mandatory Medicaid benefit; Katie Beckett or TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) programs designed for children with complex medical needs, or through waiver programs that offer private duty nursing or other needed care that may waive parent income.

There are states, however, that have not had success with obtaining funding designated specifically for individuals with brain injury or expanding existing services to target the needs of individuals with brain injury

## Pursuing Funding for Services

States that have been successful in developing and expanding services and programs have usually had active consumer state organizations associated with the Brain Injury Association of America (BIAA); U.S. Brain Injury Alliance (USBIA); or other consumer organizations, such as the Alabama Head Injury Foundation. These organizations and their members bring awareness to the need through public education (e.g., news articles, television/radio, governor's proclamations); advocacy (Capitol Hill day, legislation); and participation in conferences or state task forces with other disability groups, such as the Olmstead committee or Governor's Council on Disabilities.

These organizations have often been the impetus for getting support from the state executive branch, including the governor, and the legislative branch. Governors have issued Executive Orders calling for a report and legislators have convened interim committees to study the needs. In some instances, a state agency head has been the one leading the charge.

Federal TBI grants have also helped states to develop advisory boards, needs and resource assessments, and state plans. At least one state used the federal grant to develop a policy program, similar to the Partners in Policymaking developed by the Minnesota Governor's Council Developmental Disabilities, to teach consumers how to be effective advocates and involved in decision making. States may also include people with brain injury in their Partners in Policymaking organized by their state council on developmental disabilities to help them be effective advocates of change at the community and state level.

Other strategies for promoting the needs of people with brain injury is to attend and participate in the various disability and health related conferences in the state and to hold local, regional or state forums for purposes of soliciting input and generating awareness with regard to the needs. Coalitions of disability, healthcare, traffic safety, insurance, veterans, military or other interested groups to promote and advocate for the services can help to broaden the support and marshal support for addressing the needs. Organizations which may be helpful include the state developmental disabilities council,

### Considerations for Pursuing Services and Programs for Individuals with Brain Injury:

- *Is there an active organization(s) outside of government that would advocate for services?*
- *Is data available to help educate policymakers about the extent of TBI?*
- *Are there other organizations which would coalesce to help push for services and supports?*
- *Is there a state agency which would be amenable to developing and administering services and programs for brain injury? Is there infrastructure to support new programs?*
- *Are there existing state and community programs that would be willing to expand to accommodate individuals with brain injury?*
- *Is there a brain injury advisory body that has responsibility for planning and coordinating policies?*
- *Are there state legislators who may have a personal interest or willingness to pursue funding, policies, legislation resulting in services and supports for individuals with brain injury?*
- *Are there state efforts to change or expand Medicaid LTSS which could provide the opportunity to ensure that TBI is included?*

state independent living council, hospital and medical associations, Governor's Council on Disabilities, state association of rehabilitation facilities/programs, state emergency medical services (EMS) association, physician's associations, insurance, and veterans organizations.

It is also helpful to obtain buy-in from a state agency that is willing to receive the funding to administer services. Otherwise, legislators could appropriate funding or legislation only to find resistance from the state agency. In instances of state hiring freezes, are there other ways to deliver the services, such as through existing case management or service coordination systems or offices; or through contracts with associations, universities or providers who would be willing to take on the responsibility. In one state, the agency contracted with local community health agencies, as they were able to do so through sole source contracts and the staff are able to have access to state data systems, state emails, and so forth. Other states have contracted with their state association or alliance for some of the service delivery functions.

Another consideration is the availability of community providers. Many states contract or work closely with their intellectual/developmental disabilities (I/DD) providers, vocational rehabilitation (VR) community, mental health, and other disability providers to provide the necessary services. Training is generally provided to ensure that staff understand how to work with individuals with brain injury and have the resources to do so.



## State Trust Fund Programs

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Beginning in the 1980s, states began responding to families requesting services and assistance to address the unique cognitive and behavioral needs of individuals with TBI. Often, these individuals found that their insurance coverage was insufficient to cover the array of short-term and long-term rehabilitation care and community supports. Through consumer and family advocacy, state legislators in Pennsylvania enacted legislation establishing the Catastrophic Medical and Rehabilitation Fund from traffic fines dedicated to address these concerns, the first state to pass what is referred to as a trust fund program.

Twenty-five (25) states have enacted similar legislation designating funding, usually associated with traffic fines and/or surcharges to vehicle registration and motor vehicle licenses, for an array of programs and services for individuals with TBI and their families. Five states, however, do not have a designated funding stream with two states (MT, UT) relying on volunteer donations. The Maryland Department of Health (MDH), in partnership with the Maryland Department of Transportation (MDOT), announced a dedicated funding source through MDOT for the Maryland Brain Injury Trust Fund, which was created in 2013 without a funding mechanism. The Nebraska Brain Injury Trust Fund, created in 2019, is funded from a transfer of \$500,000 from the Healthcare Cash Fund, to be administered by the University of Nebraska Medical Center. Delaware, which has not enacted legislation establishing a trust fund, as such, has established a TBI Fund through general revenue funds appropriated to the State Council for Persons with Disabilities (SCPD) which has administered the fund since 2013. A few states do not refer to the designated program as a “trust fund.”

Associated fines are usually collected by county clerks who forward the money to the state treasurer to be placed in a non-reverting account. These funds are generally carried across state fiscal years in order for the fund to accrue – meaning, the fund is not erased at the end of a fiscal year and then, must start collecting/accruing the beginning of the next fiscal year.

Legislation usually designates a state agency to administer the funds. Most state statutes established an advisory body to provide input and oversee the fund expenditures. There is variability with regard to the amount generated across the states and how the funds are used. States may use funding to support a registry; research; public education and awareness; prevention; rehabilitation; case management or service coordination; family education; durable medical equipment or other goods requested by consumer; and/or for an array of rehabilitation and community services and supports. States may pay for services and supports through community grants, provider agreements, contracts, Request for Proposals (RFP), or a simple application submitted by the individuals with a TBI or a family member. States may use funds to pay for state administrative costs and associated expenses, such as travel for the advisory board, and for staff for service or care coordination.

The state may contract for services such as service coordination, resource facilitation, information & referral (I&R) services and supports. The state may place caps annually or lifetime expenditures on what consumers may receive and/or have financial requirements to access the funds. Trust fund programs may be administered by health, Vocational Rehabilitation, Medicaid, education, social services agencies in partnership with community organizations, providers and professionals. As such, the program may mirror how services are organized and delivered by the state agency in which it is



housed. In many states, the state BIAA association or USBIA affiliation is the primary recipient of the funds and may be responsible for resource facilities I&R, public awareness and other activities.

## Considerations/Tips for Pursuing a Trust Fund

### **Is a Trust Fund Constitutional in Your State?**

Some states have been hampered in pursuing a trust fund from designated traffic fines due to unconstitutionality, as fines may be earmarked for education. Another consideration is to determine if there are fines or surcharges supporting other programs which may deter lawmakers from increasing the fines, as they may view the additional fine as being a hardship to constituents.

### **Why is a State Brain Injury Trust Fund Needed?**

A needs and resources assessment will help to determine needs, amount of funds needed, and number of persons who could benefit, should the funds be used to support services, and other gaps in service delivery. If other funds are currently available, such as general revenue or Medicaid, perhaps identifying how the program will differ or augment may help to avoid the temptation to supplant existing resources.

### **What is the Purpose?**

Defining the purpose is critical. It will help to determine how much revenue is needed; how it should be administered; and which state agency should be the primary agency to receive the appropriation from the trust fund revenue to administer the program. Often, the trust fund program will take on the culture of the administering service agency in terms of mission, eligibility requirements, and how the funds will be dispersed.

### **Are There Competing Interests or Opponents?**

State and county programs facing budget short falls may desire similar funding sources to support their priorities. For example, collecting fees or fines may involve the county court and judges who determine traffic fines. There have been instances when county courts needed funding to upgrade their information technology (IT) and looked to the trust fund as a means. There have also been instances when the state general services administration agency (e.g., accounting, budget) proposed taking a percentage across all state dedicated accounts to meet state budget demands.

### **Does the Executive Branch Support the Program?**

Since a state agency will be responsible for receiving the funding from the revenue generated and for dispersing funding in accordance with the law, the agency will probably be asked for support and may be tasked with completing a fiscal note for the legislation. The agency head may not take a position, unless he or she knows that the governor will support it. It may also be helpful to know if other agencies, such as the agency that collects fees/fines and maintains the accounts, will support the fund.

### **What is the Source of Revenue?**

Most states have imposed fines for traffic related offenses and/or boating offenses (boating while drinking), while other states have added a surcharge to a driver's license or reinstatement fee or other similar approach. The agencies involved in collecting these fees or surcharges will be helpful in determining how much could be generated from different approaches. Some states have found local authorities not as willing to collect fines.

### **Will the Trust Fund Support Administration?**

Some states have authority to use funding for staff and other administrative purposes. Many state laws require an annual report to policymakers with regard to expenditures. Some trust fund laws support an advisory body to oversee the fund and provide input into priorities. States may use the funds to support state staff, but outsource for services, public awareness, Information & Referral, resource facilitation, registries, prevention and other non-direct services through provider agreements, contracts or grants.

### **Will the Trust Fund Duplicate Existing Services?**

No, on the contrary, this will provide funding for those who are ineligible for a Medicaid or other state programs or provide funding for other functions necessary for service delivery. The beauty of a trust fund is that it can be tailored and flexible to meet the needs.

As a trust fund may not solve all the gaps in service delivery, policymakers should be made aware of the limitations, so they are not surprised if advocates want to increase or add to the revenue source or advocate for state general revenue in future years.

### **Are There Legislative Champions?**

Identifying lawmakers who can carry the water is critical for successful legislation. You may want to consider lawmakers who are on appropriations committees or a committee that will have jurisdiction for the legislation.

### **Is There Grassroots Support?**

Identifying organizations and individuals who will help advocate is key. The brain injury alliance or association is a natural advocate. But, there may be other interested groups, such as the state independent living council, developmental disabilities council, medical association, rehabilitation association, hospital association, protection & advocacy (P&A) agency, injury prevention, insurance, veterans organizations and any organization that may be impacted. These organizations may be useful for overall planning and to advocate as a coalition.

In summary, trust fund legislation usually, identifies or specifies:

- ✓ A fund generator (fine or surcharge or fee assessment)
- ✓ A state agency responsible for administering the funds (in some states, it is a pass through)
- ✓ The purpose
- ✓ How funds can be used
- ✓ Who is eligible to receive the funds
- ✓ An advisory body to oversee the use of the funds
- ✓ Revenue is placed in an interest-bearing, non-reverting account
- ✓ A report to the governor and/or state lawmakers as to how the funders were used

Some state legislation is quite detailed, while other state laws basically establish the fund, how funds are generated, purpose and how funds can be used, in general. Most state laws require an annual report. And, state legislators may appropriate the funds as part of the annual appropriations process.

# Medicaid: Title XIX of the Social Security Act of 1965

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## Overview

Title XIX of the Social Security Act of 1965 established the Medicaid program, which is a joint federal-State health care program to provide health and related medical services to individuals with low income. State participation is voluntary, although all states and the District of Columbia participate in the federal program. The state must name a state Medicaid agency to administer the program. The federal government determines annually the match rate that each state receives for the Medicaid program, known as the Federal Medical Assistance Percentage (FMAP). It is determined by a formula that compares the state's average per capita income level with the national average. The Affordable Care Act (ACA) allowed states to enact Medicaid Expansion program to cover people with income up to 133% of the poverty line qualify for coverage, including working adults without dependent children. The federal government pays 100% of costs for three years.

Traditionally, states have administered the program as a “fee-for-service” model reimbursing providers according to an established rate. However, states are moving to a capitated coordinate care model or managed care model for long-term care, in part to constrain costs. States are adopting a value-based payment (VBP) models to reward high quality and cost-effective care to beneficiaries.

## Medicaid Eligibility

States must cover “categorically needy” individuals, including children, aged, blind or disabled individuals, and pregnant women, and families or caretakers with dependents who meet certain criteria, such as receiving cash assistance. States also have the option of providing Medicaid coverage for certain other “categorically related” groups of persons. Most State cover recipients of SSI, *but not all states use SSI criteria* and use more restrictive requirements than those of the SSI program. States may cover:

- Individuals who would be eligible if institutionalized, but who are receiving care under home and community based services waivers.
- individuals eligible under a special income level (the amount is set by each State—up to 300% of the SSI federal benefits rate).
- Certain aged, blind, or disabled adults who have incomes above those requiring mandatory coverage, but below the federal poverty level.
- “Medically needy” persons.

In order to be eligible for Medicaid, individuals need to satisfy federal and state requirements regarding residency, immigration status, and documentation of U.S. citizenship. As low income adults without dependent children were ineligible for Medicaid coverage, the 2010 Affordable Care Act (ACA) gave states the option to expand Medicaid eligibility to include adults with incomes of up to 133 percent of the federal poverty level in order to provide health care coverage (Medicaid expansion) to uninsured individuals. However, individuals who may be covered under ACA Medicaid expansion will not necessarily receive the same services as offered in the State Plan or waiver programs.

The ACA established a new methodology for determining income eligibility for Medicaid, which is based on Modified Adjusted Gross Income (MAGI). MAGI is used to determine financial eligibility for Medicaid, Children's Health Insurance Program (CHIP), and premium tax credits and cost sharing reductions available through the health insurance marketplace. The purpose is to make it easier for a single application across programs. Some individuals are exempt from the MAGI-based income counting rules, including those whose eligibility is based on blindness, disability, or age (65 and older). Medicaid eligibility for individuals 65 and older or who have blindness or a disability is generally determined using the income methodologies of the SSI program administered by the Social Security Administration, except states known as 209(b) which use more restrictive eligibility criteria than SSI.

## Medicaid State Plan

Each state designs and administers its own program with regard to (1) eligibility standards; (2) type, amount, duration, and scope of services; and (3) the rate for payment for services. The designated state Medicaid agency submits a State Plan to the federal agency, Centers for Medicare and Medicaid Services (CMS), to approve. The State Plan describes how the state administers its Medicaid program, including groups of individuals to be covered, services to be provided, methodologies for providers to be reimbursed and the administrative requirements that states must meet to participate.

States frequently send a State Plan Amendment, referred to as a SPA, to CMS for review and approval as they change the program. Missouri added post-acute rehabilitation for TBI under the State Plan, until a later Governor repealed all optional services for adults, of which some optional services have since been re-instated. Missouri does have a memorandum of understanding (MOU) with the state Medicaid agency to reimburse for administrative case management for TBI service coordination provided to Medicaid eligible program participants in the Department of Health and Senior Services' Adult Brain Injury Program. This additional income allowed the program to add service coordinators.

The federal Medicaid program mandates certain benefits that have to be offered, including, inpatient hospital services; outpatient hospital services; Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT); nursing facility services; home health services; physician services; rural health clinic services; laboratory and X-ray services; and transportation to medical care. States may offer additional services or benefits, known as optional services, and these include diagnostic services; case management; prescription drugs and prosthetic devices; clinic services; intermediate care facilities for individuals with intellectual disabilities (ICF-I/DD), optometrist services and eyeglasses; rehabilitation; therapy services, transportation services; inpatient psychiatric hospital services for individuals under the age of 21; home and community-based services (HCBS) waiver programs; and personal care services.

HCBS services that are available through the State Plan include:

- 1905(a) Home Health (mandatory: skilled nursing, home health aide, medical supplies & equipment & appliances; optional: PT/OT/Speech/Audiology)
- 1905(a) Personal Care (including self-directed)
- 1905(a) Rehabilitative Services
- 1915(i) State Plan HCBS
- 1915(k) Community First Choice

- 1915(c) HCBS waiver services complement and/or supplement (above and beyond) the services that are available through:
  - The Medicaid State plan;
  - Other federal, state and local public programs; and
  - Supports from families and communities.
- 1915(j) Self-Directed Personal Assistant Services

Some states require legislative approval before making changes to their State Plan affecting services and eligibility criteria.

## Health Home Services State Plan Option

The Affordable Care Act (ACA) provided states with a new State Plan option to provide health home services, such as care coordination and case management, for Medicaid beneficiaries with chronic conditions. States receive a temporary 90 percent enhanced FMAP for participation. This approach is for persons who are Medicaid eligible who have two or more chronic conditions; have one chronic condition and are at risk for a second; or have one serious and persistent mental health condition. States can target health home services geographically. Services include comprehensive care management; care coordination; health promotion; comprehensive transitional care/follow-up; patient & family support; and referral to community & social support services.

## LTSS Eligibility: Level of Care Assessments

Eligibility for Medicaid long-term services and supports (LTSS) depends on financial eligibility (income and assets) and status, referred to as level of care. States use functional assessment tools, which are sets of questions that states collect with regard to an applicant's health conditions and functional needs. Such tools may also be used to develop a care plan of specific services that an individual will receive upon being determined eligible for coverage.

States have autonomy in how they determine level of care, also referred to as nursing level of care. There are four areas which are commonly considered when a state determines a person's level of care need: Physical functional ability (ability to complete activities of daily living); health/medical needs; cognitive (mental) impairment; and behavior problems. States may use a proprietary tool for all or partial populations. "Home grown tools" may be developed for specific populations and states may use a combination of tools to assess functioning abilities.

### Considerations Regarding Assessment of Individuals with Brain Injury

(from NASHIA's Medicaid Balancing Incentive Program: Recommendations for Core Assessment Tools for Individuals with Brain Injury, 2015)

- Assessment tools used for individuals with brain injury must adequately address cognition and executive dysfunction, which are common after brain injury.
- A state may need to consider using a combination of instruments or creating an instrument that covers all of the domains.

- 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 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 also 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.
- 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, particularly if the participant has significant fatigue or attention issues.

## Long-term Services and Supports (LTSS) Options

Medicaid is the primary payer of long-term services and supports (LTSS). State Medicaid programs have to pay for LTSS provided in nursing homes, while most home and community-based services (HCBS) are optional. The U.S. Supreme Court's 1999 landmark decision in *Olmstead v. L.C.* resulted in increased Medicaid options to assist states in offering community-based services in lieu of institutional services. These options and incentives includes the Money Follows the Person (MFP) Demonstration program, has been extended until November 30, 2020, as well as the spousal impoverishment protections for people receiving HCBS, also through November 30, 2020. The states of Iowa, Massachusetts, Missouri, and Vermont use the MFP program to transition individuals with brain injury from nursing facilities to community programs. The Affordable Care Act of 2010 (ACA) authorized the Balancing Incentive Program (BIP) to provide financial incentives to increase non-institutional LTSS, which has since ended. Advocates are considering legislation to resurrect this program.

National per enrollee spending varies among the HCBS authorities, ranges from under \$8,000 for Section 1915(i) state plan services to nearly \$30,000 for Section 1915(c) waivers, depending on the range of services provided (Kaiser Family Foundation 2020).

### 1915(c) Home and Community-Based Services Waivers

The Home and Community-Based Services (HCBS) waiver program was established under section 1915(c) of the Social Security Act of 1981. The purpose of this provision is to offer a broad range of home- and community-based services to people who may otherwise be institutionalized. This option allows states to waive certain Medicaid program requirements, including:

- **Statewideness:** Allows states to target waivers to areas of the state where the need is greatest, or where certain types of providers are available.
- **Comparability of services:** Allows states to offer waiver services to only certain groups of people who are at risk of institutionalization, such as brain injury.
- **Income and resource rules applicable in the community:** Allows states to provide Medicaid to people who would otherwise be eligible only in an institutional setting, often due to the income and resources of a spouse or parent. States can also use spousal impoverishment rules to determine financial eligibility for waiver services.

States must demonstrate cost neutrality. This may be determined by the aggregate numbers served by the program or by individual costs. State HCBS Waiver programs must:

- Demonstrate that waiver services won't cost more than providing these services in an institution.
- Ensure the protection of people's health and welfare.



- Provide adequate and reasonable provider standards to meet the needs of the target population.
- Ensure that services follow an individualized and person-centered plan of care.

To be eligible for a waiver program, a person must meet the state's Medicaid and waiver eligibility criteria and require an institutional level of care (nursing level of care) as assessed by the state. Services provided by the waiver are to be above and beyond the services otherwise offered by the State Medicaid Plan.

### TBI/ABI HCBS 1915(c) Waiver Programs

TBI/ABI HCBS waiver programs vary considerably across the country in terms of numbers served and how the state has defined the level of care requirement. Twenty-two states administer TBI/ABI waiver programs with three states administering more than one TBI/ABI waiver (CT, KY, MA). Most states have designed their waiver programs around typical long-term services and supports (LTSS) services. However, a handful of states have designed their waiver services to focus primarily on short-term rehabilitation and community reintegration.

Most states base their level of care waiver requirements and project cost savings based on care provided in a nursing facility. Some states define the level of care based on Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID), neurobehavioral hospital, rehabilitation hospital, or specialized nursing facility as the type of institution for which the person would need if not for the HCBS waiver. In many states which do not offer a waiver program, the nursing facility rate is much lower than other settings, which makes it difficult for the state to demonstrate costs savings by providing the array services needed within a community setting.

As states are responsible for assessing level of care, functional assessment tools and evaluation varies with each state and even with regard to each waiver program that the state administers (i.e. IDD, physical disabilities, aging, or autism). Understanding how functional assessments are performed is critical in determining needs and eligibility for HCBS waiver programs. These assessments may be performed by personnel from a State agency or through contracted agencies. Once a person is assessed and determined to be eligible, a comprehensive service plan (personal care plan) will be developed generally by an interdisciplinary team, service coordinator/case manager, other support programs/resources/providers, the individuals with a TBI, and any others that the individual with a TBI may choose.

Most services covered under TBI/ABI HCBS Waiver programs include adult day care, personal assistant, case management, cognitive rehabilitation, homemaker, home and vehicle modifications, durable medical equipment, therapies, behavioral programming, family counseling, respite, prevocational services, supported employment, and personal emergency response systems. Waiver participants must have full access to State Plan services. Waivers cannot cover room and board, however. In many states, a non-Medicaid agency may be responsible for administering the program aspects of the waiver program, while the Medicaid agency is responsible for submitting the waiver and general oversight.

1915(c) waivers are approved for a period of 3 years with the possibility of a 5 year extension.

- States may request amendments to their waiver.
- States may request that waivers be renewed; CMS considers whether the state has met statutory/regulatory assurances in determining whether to renew.
- Renewals are granted for a period of 5 years.

## Considerations for Pursuing a TBI/ABI Waiver

The first step in pursuing a waiver is to understand your State's Medicaid Program – eligibility and State Plan services, including current waiver programs. Medicaid waivers are exceptions to the State's Plan Medicaid services and must provide benefits above and beyond what is currently provided. Other areas to consider include:

- Current facilities where individuals with brain injury are receiving LTSS and to what extent. A state may want to conduct a survey to determine how many people are residing in institutional settings and the associated costs for that care.
- Purpose of the waiver.
- Which of the Medicaid requirements will be waived (i.e. statewideness, comparability of services, freedom of choice).
- How will the waiver be administered and operated and by whom. Who will provide oversight to ensure quality of care -- systems to effectively monitor the adequacy of service plans, the qualifications of providers, and the health and welfare of beneficiaries. In some states, it rests with the Medicaid agency and in other states, responsibilities are split with another agency responsible for service delivery for the population to be served.
- Participant access and eligibility.
- Functional assessment tools used by the state to determine level of care -- does the level of care assessment tool distinguish between being able to perform tasks independently with or without cues or prompting in order to perform activities of daily living (ACLs) and Instrumental Activities of Daily Living (IADLs).
- What is the scope of services or limitations, delivery methods and rate.
- What additional services are needed beyond the State Medicaid Plan to provide the level of supports to enable an individual to live in the community (e.g., housing).
- Who are the providers that will be needed to carry out the community services -- what type of providers, their qualifications (credentials/licensure), and expertise.
- Financial information to demonstrate cost neutrality.
- Obtaining state match needed for the waiver. Will the state match require a new state appropriation or will funds from an existing state TBI program be used for the state match requirement.
- Can services be covered under an existing waiver that may be amended.
- Does your state require legislative approval to submit a waiver application.

### **1915(k) Community First Choice Option State Plan**

Section 2401 of the Affordable Care Act (ACA) established a new state option to provide home and community-based attendant services and supports, known as Community First Choice Option (CFC), at a 6 percentage point increase in the Federal Medical Assistance Percentages (FMAP) – federal match.

To be eligible, individuals must be in need of an institutional level of care. The state cannot target populations or disabilities, areas of the state or cap the number served.

States electing this option must make available home and community-based attendant services and supports to assist in accomplishing ADLs, IADLs, and health related tasks through hands-on assistance, supervision, and/or cueing. States may also provide transition costs such as rent and utility deposits, first month's rent and utilities, purchasing bedding, basic kitchen supplies, and other necessities required for transition from an institution; and the provision of services that increase independence or substitute for human assistance to the extent that expenditures would have been made for the human assistance, such as nonmedical transportation services or purchasing a microwave.

States are required to use a person centered service plan that is based on an assessment of functional need and allows for the provision of services to be self-directed under either an agency provider model, a self-directed model with service budget, or other service delivery model defined by the state and approved by the Secretary. States may offer more than one service delivery model. States which have been approved are: California, Connecticut, Maryland, Montana, New York, Oregon, and Texas, and Washington (KFF 2020).

Half of states choose to offer additional services beyond the minimum benefit package, which must include assistance with self-care, household activities, and health-related tasks, self-direction opportunities, and back-up systems. Although Oregon Aging and People with Disabilities does not provide K plan services based on diagnosis, the agency does provide HCBS to individuals with brain injury with complex needs.

### **1915(i) HCBS State Plan Option**

The ACA expanded financial eligibility for 1915(i) services, first established by the Deficit Reduction Act of 2005 (DRA), and created as a new optional Medicaid eligibility group that allows people not otherwise eligible to access full Medicaid benefits in addition to State Plan HCBS. This provision allows states to target 1915(i) services to specific populations (i.e., based on diagnosis, age, disability or coverage group), and expand services that states may cover under this option. This option does not require cost neutrality to the federal government nor require individuals to meet an institutional level of care in order to qualify for HCBS. It allows states to offer services and supports to individuals before they need institutional care. Many states have used this option to cover behavioral health services for individuals with substance use or mental health conditions. North Dakota, however, has included individuals with brain injury and is in the process of implementing this program.

States that have this option include: Iowa (habilitation services); Colorado; Nevada; Oregon; Idaho (elderly and disabled; developmental therapy and community crisis supports); Connecticut; California; Indiana; Mississippi; Maryland; Delaware; District of Columbia; Texas; Ohio (severe and persistent mental illness; chronic conditions); Michigan, and New Hampshire. Arkansas elected the Section 1915 (i) HCBS state plan option, effective March 2019.

Benefits generally include, depending on the population, home-based services, day services, and supported employment (I/DD); case management, home-based, and other mental/behavioral health

services (mental illness); and home-based services, day services, case management, and round-the-clock services are the most frequently covered Sections for seniors/people with physical disabilities (KFF 2020).

### **1915(j) Self-directed Personal Assistance Services (PAS)**

PAS are personal care and related services provided under the Medicaid State plan and/or section 1915(c) waivers that a State may already have in place. Under the 1915(j) State Options, states can:

- Target people already getting section 1915(c) waiver services
- Limit the number of people who will self-direct their PAS
- Limit the self-direction option to certain areas of the State, or offer it Statewide

People enrolled in 1915(j) can:

- Hire legally liable relatives (such as parents or spouses)
- Manage a cash disbursement
- Purchase goods, supports, services, or supplies that increase their independence or substitute for human help (to the extent they'd otherwise have to pay for human help)
- Use a discretionary amount of their budget to purchase items not otherwise listed in the budget or reserved for permissible purchases

## **CMS HCBS Rules, Regulations and Guidance**

### **Program Settings**

CMS issued a final rule on January 14, 2014, to enhance quality in HCBS programs and to add protections for individuals receiving services. The rule establishes requirements for HCBS program settings operated in accordance with 1915(c) HCBS Waiver programs, 1915(i) HCBS State Plan Option, and 1915(k) Community First Choice State Plan Option, and:

- defines person-centered planning requirements;
- provides states with the option to combine multiple target populations into one waiver to facilitate and streamline administration of HCBS waivers;
- clarifies the timing of amendments and public input requirements when states propose modifications to HCBS waiver programs and service rates, and
- provides CMS with additional compliance options for HCBS programs.

The rule addresses an outcome-oriented definition of HCBS settings, rather than one based solely on a setting's location, geography, or physical characteristics. In accordance with the rule, states will need to evaluate the settings currently in their 1915(c) waivers and 1915(i) State plan programs and, if there are settings that do not meet the final regulation's HCBS requirements, work with CMS to develop a plan to bring their program into compliance. The rule called for the public to have an opportunity to provide input on a state's transition plan developed to ensure that the HCBS settings are in compliance.

In this final rule, CMS specifies that service planning must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. In summary, CMS supports LTSS that are:

- **Person-driven:** The system affords older people, people with disabilities and/or chronic illness the opportunity to decide where and with whom they live, to have control over the services they receive and who provides the services, to work and earn money, and to include friends and supports to help them participate in community life.
- **Inclusive:** The system encourages and supports people to live where they want to live with access to a full array of quality services and supports in the community.
- **Effective and accountable:** The system offers high quality services that improve quality of life. Accountability and responsibility is shared between public and private partners and includes personal accountability and planning for long-term care needs, including greater use and awareness of private sources of funding.
- **Sustainable and efficient:** The system achieves economy and efficiency by coordinating and managing a package of services paid that are appropriate for the beneficiary and paid for by the appropriate party.
- **Coordinated and transparent:** The system coordinates services from various funding streams to provide a coordinated, seamless package of supports, and makes effective use of health information technology to provide transparent information to consumers, providers and payers.
- **Culturally competent:** The system provides accessible information and services that take into account people's cultural and linguistic needs.
- **Conflict-free case management:** The rule calls for conflict-free case management that must be independent of service provision. An agency or provider cannot provide both case management activities and direct services.

Existing 1915(c) HCBS Waiver and 1915(i) and (k) State Plan options have until March 17, 2022, to transition their HCBS systems with regard to the settings rule. New 1915(c), 1915(i), and 1915(k) settings must be compliant prior to approval.

### **Guidance on Employment and Employment Related Services**

CMS sent Medicaid State Directors an Informational Bulletin CMS guidance September 16, 2011, on development and implementation of §1915 (c) Waivers regarding employment and employment related services. While the guidance does not constitute new policy, it does highlight the opportunities available to use waiver supports to increase employment opportunities for individuals with disabilities within current policy. Further, it underscores CMS's commitment to the importance of work for waiver participants and provides further clarification of CMS guidance regarding several core service definitions. CMS updated some of the core service definitions, as well as added several new core service definitions, to better reflect best and promising practices that it will support states' efforts to

increase employment opportunities and meaningful community integration for waiver participants. The guidance:

- Highlighted the importance of competitive work for people with and without disabilities and CMS's goal to promote integrated employment options through the waiver program.
- Acknowledged best and promising practices in employment support, including self direction and peer support options for employment support.
- Clarified that Ticket to Work Outcome and Milestone payments are not in conflict with payment for Medicaid services rendered because both Ticket to Work and Milestone payments are made for an outcome, not service delivery.
- Added a new core service definition- by splitting what had previously been supported employment into two definitions -- individual and small group supported employment.
- Included a new service definition for career planning, that may be separate or rolled into the other employment related service definitions.
- Emphasizes the critical role of person centered planning in achieving employment outcomes
- Modifies both the prevocational services and supported employment definitions to clarify that volunteer work and other activities that are not paid, integrated community employment are appropriately described in pre-vocational, not supported employment services.
- Explained that pre-vocational services are not an end point, but a time limited (although no specific limit is given) service for the purpose of helping someone obtain competitive employment

## **Electronic Visit Verification**

Section 12006(a) of the 21<sup>st</sup> Century Cures Act (Cures Act) mandates that states implement electronic visit verification (EVV) for all Medicaid personal care services by January 1, 2020, and for all Medicaid home health care services by January 1, 2023, or otherwise be subject to incremental federal medical assistance percentage (FMAP) reductions. The Cures Act included a provision that allowed states to delay implementation of EVV for up to one year, if they could demonstrate they have made a good faith effort to comply and have encountered unavoidable delays. The process to request a good faith effort exemption was as follows:

- CMS accepted requests for good faith effort exemptions for personal care services beginning July 1, 2019. CMS strongly encouraged states to submit good faith effort exemption request by November 30, 2019.
- States were required to use the form titled "Good Faith Effort Request Form – Personal Care Services" when submitting their requests.
- Only the State Medicaid Agency Director or his/her designee can submit this form.

However, the coronavirus delayed the requirement for EVV for personal care services.

## **Managed Care for Long-term Services and Supports**

State may offer benefits on a fee-for-service basis whereby the state pays providers directly for services covered. States are increasingly looking to capitated Medicaid Managed care programs for long-term services and supports (MLTSS), where the state pays a fee to a managed care organization



for each person enrolled in the managed care plan. In turn, the plan pays providers for all of the Medicaid services a beneficiary may require that are included in the plan's contract with the state. Medicaid MLTSS programs can be operated under multiple federal Medicaid managed care authorities as determined by the state and as approved by CMS, including 1915a, 1915b, and 1115. There are requirements and limitations related to each authority, and managed care authority can be combined with other home and community based authorities to operate the MLTSS program (as with a concurrent 1915(b)/1915(c), for example). Some states have integrated behavioral health, primary, acute, and behavioral health services, and the capitation payment is more comprehensive. These arrangements are also to adhere to the CMS settings rule and requirements for person centered planning and conflict free case management. Providers which may have delivered services previously under a separate brain injury waiver program, based on fee-for service, may need to insure they are included under a managed care network of providers should the state shift waiver services to a managed care organization in order to continue to provide services once reimbursed through a waiver program.

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## Selected State Examples

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This section features states which administer Medicaid, Trust Fund, General Revenue funding programs, often in combination, to show the various ways services and supports are delivered. In some instances, a history is provided to show how services and supports can change over time due to a lawsuit or due to budget cuts or change in how services are delivered – the ebb and flow of service delivery.

### General Revenue, Trust Fund and Medicaid

Both Missouri and Massachusetts started their programs with general revenue appropriated by their state lawmakers in 1985. Over time, both states have also received funding through a trust fund and through Medicaid. Missouri was just approved in October 2019 for a Medicaid HCBS waiver, while Massachusetts administers three waiver programs for TBI and for ABI. Missouri Department of Health and Senior Services (DHHS) also has a Memorandum of Understanding (MOU) with the state Medicaid agency for administrative case management, whereby DHSS, which administers the State Adult Brain



Injury Program, bills the Medicaid agency for service coordination for individuals with TBI who are also Medicaid eligible. This funding arrangement allowed DHHS to add service coordinators so that there are now eleven service coordinators assigned to geographic areas in order to cover the state.

In both of these states, one state agency and program administers all TBI designated funds, which includes general revenue, trust fund, Medicaid State Plan and Medicaid HCBS waiver services.

**Massachusetts** – Massachusetts lawmakers appropriated state general revenue to establish the Statewide Head Injury Program (SHIP) in 1985, which is housed in the Massachusetts Rehabilitation Commission (MRC). The program provides the following services to eligible people with external traumatic brain injuries.

- **Skills Training:** Helping you to learn the skills you need to live in the community.
- **Adult Companion:** Provides companionship and social activities. This aide can also be used so a caregiving family can take a break.
- **Residential Services:** Provided in a home setting for more than one individual. Supervision and support is provided around the clock. Availability is very limited due to funding.
- **Shared Living:** Living in a paid caregiver's home. The caregiver helps you with everyday needs. Availability is limited due to funding.
- **SHIP – Regional Service Centers:** The centers help you to improve your skills. Staff will work with you by yourself and in groups. The Centers can also help you find and use other services in your community.

The Head Injury Treatment Services (HITS) Trust Fund was passed as an outside section of the State budget in 1991. The legislation levied a surcharge on fines for Driving Under the Influence (DUI). In 2000 legislation passed to levy a surcharge on speeding fines to increase collections. The trust fund language references the use of these monies for nonrecurring services. The intent was to serve SHIP eligible consumers whose needs are short-term or are totally unanticipated. SHIP Service Coordinators work with individuals and their families to identify the supports they need to maintain or increase their level of functioning and independence in the community. This may include, but is not limited to, day services, respite, recreation, assistive technology, home modifications, substance abuse treatment, transitional living programs for the homeless, extended rehabilitation, dental care, life skills training, and case management. The need is brought to the attention of supervisors and, ultimately, the program administrator, who authorizes use of trust fund monies.

Massachusetts was sued under Olmstead (*Hutchinson v. Patrick* Settlement) by the Brain Injury Association of Massachusetts. On June 2, 2008, a settlement was reached that enables individuals with brain injuries to move out of nursing facilities and into the community. A similar lawsuit, *Rolland V. Patrick*, was settled in 2013, after 15 years of litigation. The lead plaintiff in the Rolland lawsuit was a women with cerebral palsy.

Following these lawsuits, the state implemented two brain injury Medicaid HCBS Waiver programs. In 2013, the Hutchinson Settlement was revisited, and a Money Follows the Person Demonstration project and two additional HCBS waivers were written, approved, and linked to the settlement. An enhanced

education and outreach program to ensure class members are aware of opportunities to leave institutional settings and reside in the community was also implemented.

Today, under the umbrella of the Community Based Services, MRC brain injury programs include: Statewide Head Injury Program (SHIP); Traumatic Brain Injury HCBS Waiver, Post-transition Rolland Services; ABI/Money Follows the Person (MFP) Demonstration Program (Acquired Brain Injury Non-Residential Waiver and Moving Forward Plan Community Living Waiver) and Elder Services (TBI) Implementation Grant.

**Missouri Adult Brain Injury Program** – In 1985, Missouri state legislators also appropriated state general revenue to the then Department of Health (now, the Department of Health and Senior Services) for community services and a separate state appropriation to the Missouri Office of Administration for the Missouri Head Injury Advisory Council staff and associated expenses. Missouri legislators also changed the name and mission of a state chest hospital to the Missouri Rehabilitation Center that offered short-term outpatient rehabilitation and transition services, and eventually expanded to offer a substance abuse program for individuals with cognitive disabilities who were Medicaid eligible and vocational rehabilitation and job training services for individuals with TBI. Legislation passed to include post-acute rehabilitation as a Medicaid State Plan Service.

After two years, the health department transferred the state money and program to the council staff to administer, which staff did for five years until legislators passed legislation establishing a TBI program within the health department. The Missouri Rehabilitation Center was transferred to the University of Missouri Hospitals and Clinics, then closed, when cuts were made to Medicaid.

The health department's Adult Brain Injury Program expanded as legislators appropriated funding for service coordinators. The department obtained a Centers for Disease Control and Prevention Primary and Secondary Injury Prevention grant which was used to establish a central office person to set up and evaluate the service coordination program. The department entered into a MOU with the Medicaid agency to be reimbursed for services that the program offered to individuals who were Medicaid eligible. These services included post-acute rehabilitation, administrative case management, day program, and non-emergency medical transportation (NEMT) services. In 2002, the legislature passed the Missouri Head Injury Trust Fund to generate funding for the council and for supports not otherwise available to individuals served by the health department's program.

In 2005, the governor transferred the council and the trust fund program to the Missouri Department of Health and Senior Services and cut all Medicaid optional services for adults, which included post-acute rehabilitation and other services, with the exception of case management. The Missouri Rehabilitation Center also closed, since the program also received Medicaid reimbursement for post-acute rehabilitation services and substance abuse rehabilitation.

Today, the Missouri Department of Health and Senior Services' Adult Brain Injury Program still offers rehabilitation and community services and service coordination as a separate service through the use of state general revenue and revenue generated by the trust fund. All individuals receiving rehabilitation and community services is assigned a service coordinator, which are the entry point in terms of determining eligibility and facilitating a person-centered plan. However, individuals may have service coordination as a service without any other health department's state program services. All individuals

served, of course, may receive services and supports from other state agencies, such as Vocational Rehabilitation. The program still bills the Medicaid agency for administrative case management and as of October 2019, has been approved to administer a HCBS Medicaid waiver program for adults with TBI. The program also partners with the state Medicaid agency on Money Follows the Person program, whereby the Medicaid agency refers individuals with TBI in nursing facilities to the brain injury program.

## **1915(c) HCBS Brain Injury Medicaid Waiver and Trust Fund**

**Minnesota** -- The Minnesota HCBS Brain Injury (BI) Medicaid Waiver and the Trust Fund program are administered by two separate state agencies, which is not uncommon. The Department of Human Services' (DHS) Disability Services Division administers the BI waiver. Individuals apply for the BI waiver at the local county public health or social service agency.

The Brain Injury Waiver provides funding for home and community-based services for children and adults who have an acquired or traumatic brain injury. People may receive BI Waiver services in their home, in a biological or adoptive family's home, a relative's home (e.g. sibling, aunt, grandparent etc.), a family foster care home, a corporate foster care home, a board and lodging facility or in an assisted living facility. If married, a person may receive brain injury Waiver services while living at home with his or her spouse.

A screening process determines eligibility and individuals are eligible if they meet the following criteria:

- Are assessed at Level IV or above on the Rancho Los Amigos Levels of Cognitive Functioning Scale
- Are certified as disabled by the State Medical Review Team or by the Social Security Administration
- Are eligible for Medical Assistance
- Are under the age of 65 years when the waiver is opened
- Are determined to need the level of care available in a nursing facility or neurobehavioral hospital
- Choose services in the community instead of services in a nursing facility or neurobehavioral hospital
- Have a documented diagnosis of traumatic or acquired brain injury or degenerative disease diagnosis where cognitive impairment is present, provided the diagnosis is not congenital
- Experience significant/severe behavioral and cognitive problems related to the injury or disease

Once eligibility is determined for participation in the BI Waiver, certain questions must be asked about services including:

- Are the services necessary to ensure your recipient's health, welfare and safety?
- Have all options been assessed and does this option meet your needs and preferences?
- Is the cost of the service considered reasonable and customary?
- Is the service covered by any other funding source, for example, Medical Assistance state plan services, private health care coverage, Medicare, education or Vocational Rehabilitation?

In addition to services covered by Medical Assistance (Medicaid State Plan), these services are available through the BI waiver.

- 24-hour emergency assistance
- Adult companion
- Adult day service/Adult day service bath
- Caregiver living expenses
- Case management and case management aide
- Chore
- Consumer-directed community supports, a service option giving the person flexibility and responsibility to direct his or her own services and supports
- Crisis respite
- Customized living
- Employment development
- Employment exploration
- Employment support
- Environmental accessibility adaptations
- Extended home care nursing
- Extended home health care services, including extended home health aide, nursing, and occupational, physical, speech and respiratory therapies
- Extended personal care assistance
- Family training and counseling
- Foster care
- Home-delivered meals
- Homemaker • Housing access coordination • Independent living skills therapies • Independent living skills training
- Individualized home support
- In-home family support
- Night supervision
- Personal support services
- Positive support services
- Prevocational services
- Respite
- Specialist services
- Specialized equipment and supplies
- Structured day program
- Supported employment services
- Transitional services
- Transportation

**Minnesota Trust Fund Program** – The Minnesota TBI and Spinal Cord Injury Trust Fund was created and funded with a DWI license reinstatement fee and administered by the Minnesota Department of Health. The department contracts with the Minnesota Brain Injury Alliance, which serves as a starting point for receiving services and supports for people affected by brain injury, and those who support them. The Minnesota Brain Injury Alliance provides information, help finding resources, advocacy, family and peer support, case management, and education.

**Colorado Trust Fund Program** -- The Colorado Brain Injury (BI) Trust Fund was created by Title 26, Article 1, Part 3 of the Colorado Revised Statutes, to improve the lives of Colorado residents who have survived brain injuries (BI). The statute was created to finance program activities, along with a Board of Directors to advise the program on Trust Fund operations. The Board is administered by MINDSOURCE – Brain Injury Network within the Colorado Department of Human Services (CDHS).

The Trust Fund receives revenue from surcharges assessed for convictions of driving under the influence of drugs or alcohol (DUI), driving while ability is impaired (DWAI), speeding, and riding a motorcycle or motorized bicycle without a helmet (for youth under the age of 18). The surcharges are \$20 for drinking and driving related convictions, and \$15 for speeding convictions and helmet convictions. Funds are divided across the following program activities:

Client Services, Brain Injury Research and Education. A minimum of 55 percent for client services, a minimum of 25 percent for brain injury research, and a minimum of 5 percent for education. This leaves 15 percent of funds available and flexible so that MINDSOURCE Director and Board of Directors can determine program activities that are in need of an increase in funds during the year. The board creates an annual legislative report that is made available to the public upon CDHS approval.

**Colorado Brain Injury HCBS Waiver** – The Colorado Department of Health Care and Financing administers the Brain Injury Waiver, which covers individuals age 16-65, who are Medicaid eligible and meet the level of care requirements. Benefits and services include:

- |  |  |
|--|--|
| Adult day services                           | Non-medical transportation                                   |
| Behavioral management and education          | Peer mentorship  |
| Buy-in for working adults with disabilities  | Personal care  |
| Consumer directed attendant support services | Personal emergency response systems                          |
| Day treatment                                | Respite care   |
| Home delivered meals                         | Specialized medical equipment and supplies/assistive devices |
| Home modification                            | Substance use counseling                                     |
| Independent living skills training           | Supported living program                                     |
| Mental health counseling                     | Transition services  |
|  | Transition set up  |
|  | Transitional living program                                  |

### **1915(c) HCBS Brain Injury Medicaid Waiver and State Revenue: Managed Care**

**North Carolina** – The North Carolina Department of Health and Human Services receives a state appropriation that is allocated to Local Management Entity Managed Care Organizations (LME-MCO) to provide TBI specific services and supports to individuals with TBI living in their respective catchment area. In 2018, the department was approved to pilot a TBI Medicaid HCBS and is now operational in Alliance’s four-county service area. In accordance with the waiver, life-advancing services as occupational, speech and physical therapy; cognitive rehabilitation; supported employment and assistive equipment may be provided.

### **Trust Fund Program Only**

**Georgia** – The Georgia Brain and Spinal Injury Trust Fund Commission provides grants to Georgians for their post-acute care and rehabilitation for traumatic brain and spinal cord injury. In November 1998, Georgia voters overwhelmingly approved (by 73%) a constitutional amendment to create a Trust Fund for brain and spinal injuries, paid for by a surcharge on drunk driving fines. The program awards grants directly to individuals with brain injury for many categories of assistance such services as

- Transportation
- Assistive technology

- Medical and rehabilitative care
- Home access modifications
- Personal support services
- Durable medical equipment

Individuals complete an application, and confirm they have a brain injury, a Georgia resident, and provide a costs quote from vendor the person anticipates to use, thus determining eligibility.

### **1915(i) HCBS State Plan**

**North Dakota** -- During the 2019 legislative session, North Dakota lawmakers passed S.B. 2012, which authorized the North Dakota Department of Human Services to create a Medicaid 1915(i) State Plan amendment to allow North Dakota Medicaid to pay for additional home and community-based services to support individuals with behavioral health conditions, including individuals with brain injury. Medicaid enrollees age 18 and older who have a behavioral health condition and/or brain injury and currently are experiencing one or more of the following needs-based criteria are eligible: housing instability, intensive service utilization such as frequent emergency room (ER) visits, and/or criminal justice involvement.

Persons who qualify, services proposed under this 1915(i) Medicaid State Plan amendment include supports for housing, employment, education, transitions out of homelessness or institutional living, and peer support. Housing supports include tenancy support services to help individuals access and maintain stable housing in the community; employment supports include individualized services to assist individuals to obtain and keep competitive employment at or above the minimum wage. Educational supports assist persons who want to continue their education or formal training with a goal of achieving skills necessary to obtain employment.

Transition supports include coverage for goods and services specified in an individual's person-centered plan to address barriers to recovery and to support community integration and may include: security deposits, furniture and transportation. Peer supports include services delivered by trained and certified individuals who have experience as recipients of behavioral health services and share personal, practical experience, knowledge and first-hand insight to benefit service users. Funding these community-based services and supports through Medicaid has the advantage of leveraging existing payor infrastructure while securing over 50% federal match for services.

Specifically, services include:

1. Care Coordination
2. Training and Supports for Unpaid Caregivers
3. Peer Support
4. Respite
5. Non-Medical Transportation
6. Community Transition Services



7. Benefits Planning Services
8. Supported Education
9. Pre-Vocational Training
10. Supported Employment
11. Housing Supports

### **North Dakota 1915(i) – Children and Youth**

Youth under age 21 and diagnosed with a mental health condition and/or a substance use disorder and/or brain injury who do not qualify for developmental disabilities case management and meet one or more of the following home and community-based services (HCBS) eligibility criteria are eligible:

1. Intensive service needs as demonstrated by at least one of the following risk factors:
  - a. at least one admission to a psychiatric residential treatment facility (PRTF) in the past 12 months
  - b. at least one admission to a local community inpatient hospital related to behavioral health needs in the past 24 months
  - c. more than one behavioral health-related emergency department visit in the past 12 months
  - d. at least one admission to a residential child care facility in the past 24 months
  - e. at least one placement in treatment foster care in the past 24 months
  - f. at least one institutional placement related to behavioral health needs in the past 24 months
  - g. at least one group-like supervised living placement related to a behavioral health issue in the past 24 months
  - h. at risk of placement in a PRTF per assessment of referral information;
2. Intensive forensic service needs identified by criminal justice system involvement (l – k):
  - i. more than two law enforcement contacts in the past 12 months
  - j. involvement in the juvenile justice system in the past 12 months
  - k. involvement in jail or prison in the past 12 months
3. Any other significant functional limitations expected to result in homelessness, intensive service need, or justice involvement

Anticipated services:

- Service coordination
- Respite
- Customized goods and services (supplemental supportive services)
- Transitional supports
- Peer services
- Supported employment
- Supported education
- Housing supports
- Non-medical transportation
- Family training and supports



- Crisis stabilization
- In-home therapy

Implementation is expected to begin at the start of State Fiscal Year 2021. Accompanying this implementation, DHS also expects that increased costs for community-based services will be partially offset by decreases in the costs of treatment and other health-care expenditures such as emergency department utilization and inpatient psychiatric treatment.

**North Dakota Brain Injury Network** -- In addition to this new program, the North Dakota Department of Human Services contracts with the Center for Rural Health, University of North Dakota School of Medicine & Health Sciences in Grand Forks for the North Dakota Brain Injury Network (NDBIN). NDBIN staff provides personalized assistance in finding support groups, referrals to pre-employment training, and help identifying and accessing appropriate benefits and programs. Eligible individuals must be a legal resident of North Dakota and have experienced a brain injury. Since 2013, NDBIN has been working throughout North Dakota toward raising awareness of brain injury prevention. NDBIN staff provide information through outreach and education, referral services, peer support, and more. NDBIN website: <https://www.ndbin.org/>

## **1915(k) Community First Choice**

**Oregon** was the second state to implement the Community First Choice (CFC) Option under Section 2401 of the Affordable Care Act (ACA) and Section 1915(k) of the Social Security Act. The Oregon Department of Human Services, Aging and People with Disabilities administers the program for people who are aging or with disabilities. Although the 1915(k) program is not allowed to target services to a specific population group, nor put a limit on the number served, the Oregon program does provide home and community-based services and supports to Medicaid eligible individuals with TBI with complex needs. The k-plan allows the state to cover a range of home and community-based services under the Medicaid State Plan, rather than through 1915(c) waivers.

As specified in the ACA and regulations, Oregon's program covers home and community-based attendant services and supports to assist individuals with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and health-related related tasks, which are provided through hands-on assistance, supervision and/or cueing.

Medicaid beneficiaries must be eligible for medical assistance in an eligibility group whose benefits include nursing facility services, or have countable income below 150 percent of the federal poverty level if their eligibility group does not cover nursing facility services. All individuals must meet an institutional level of care to qualify for CFC services.

Services include behavioral support services; relief care; voluntary training on how to select, manage and dismiss attendants; support system activities; environmental modification, with limits; assistive devices; community transportation; home delivered meals for those unable to prepare meals; and expenditures for transition costs, such as rent and utility deposits, first

month's rent and utilities, bedding, basic kitchen supplies, and other necessities required for an individual to make the transition from institutions to residence in community settings. Oregon will not make direct cash payments prospectively to CFC participants.

### **In Summary**

As demonstrated by the states highlighted above, states have pursued funding options to provide services and supports, often pursuing more than one funding stream to fund individuals who are Medicaid eligible and those who may not be Medicaid eligible. Individuals with TBI may also receive services and supports through Medicaid waiver programs designed for I/DD, persons with physical disabilities, self-directed care, and children with chronic or complex needs. As states have moved towards managed care organizations to manage long-term services and supports, some states have ensured that individuals with brain injury are covered under these contracts. Most of these initiatives have been supported by advocates and organizations in their states who have urged policymakers to provide supports to individuals in order to return to community and live as independently as possible. In addition, state service coordination and resource facilitation systems also coordinate resources and assist with accessing Vocational Rehabilitation services, education, substance use programs, behavioral health, natural supports, and other resources that may be identified in their person centered plans to help them achieve and maintain their goals. The ACL TBI State Grant Partnership Program has been an impetus for states to identify and assess resources and needs in the state to assist in pursuing funding for service delivery.

## Appendix

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### Acronyms

**ABI** – Acquired Brain Injury  
**ACA** – Affordable Care Act  
**ACL** – Administration for Community Living  
**ADLs** – Activities of Daily Living  
**CFC** -- Community First Choice  
**FMAP** – Federal Medical Assistance Percentages  
**HCBS** -- Home and community-based Services  
**IADLS** -- Instrumental Activities of Daily Living  
**LTSS** – Long-term services and supports  
**VR** – Vocational rehabilitation

### State Contacts

- **Colorado Mindsource Brain Injury Network:** <https://mindsourcecolorado.org/trust-fund-and-board/>
- **Colorado Brain Injury Waiver:** <https://www.colorado.gov/pacific/hcpf/brain-injury-waiver-bi>
- **Georgia Brain and Spinal Injury Commission:** <https://bsitf.georgia.gov/>
- **Massachusetts ABI HCBS Waiver Program:** <https://www.mass.gov/info-details/acquired-brain-injury-abi-waivers>
- **Massachusetts Statewide Head Injury Program:** <https://www.mass.gov/service-details/statewide-head-injury-program-ship>
- **Minnesota Brain Injury Waiver:** <https://mn.gov/dhs/people-we-serve/people-with-disabilities/services/home-community/programs-and-services/bi-waiver.jsp>
- **Minnesota TBI Trust Fund:** <https://www.health.state.mn.us/communities/tbi/>
- **Missouri Adult Brain Injury Program:** <https://health.mo.gov/living/families/shcn/ahi.php>
- **North Carolina TBI Program:** <https://www.ncdhhs.gov/assistance/disability-services/traumatic-brain-injury>
- **North Dakota Brain Injury Network:** <https://www.ndbin.org/>
- **Oregon Aging and People with Disabilities:** <https://www.oregon.gov/DHS/APD/Pages/default.aspx>

### Sample Trust Fund Legislation

#### NEW MEXICO

*Establishment & Administration: N.M. Stat. Ann. § 24-1-24 (2005)  
24-1-24. Brain injury services fund created.*

A. There is created in the state treasury the "brain injury services fund." The fund shall be invested in accordance with the provisions of Section 6-10-10 NMSA 1978, and all income earned on the fund shall be credited to the fund.

B. The brain injury services fund shall be used to institute and maintain a statewide brain injury services program designed to increase the independence of persons with traumatic brain injuries.

C. The department of health shall adopt all rules, regulations and policies necessary to administer a statewide brain injury services program. The department of health shall coordinate with and seek advice from the brain injury advisory council to ensure that the statewide brain injury services program is appropriate for persons with traumatic brain injuries.

D. All money credited to the brain injury services fund shall be appropriated to the department of health for the purpose of carrying out the provisions of this section and shall not revert to the general fund.

**Revenue Source: N.M. Stat. Ann. § 66-8-116.3(E) (2005)**

*66-8-116.3. Penalty assessment misdemeanors; additional fees.*

In addition to the penalty assessment established for each penalty assessment misdemeanor, there shall be assessed:

E. a brain injury services fee of five dollars (\$5.00), which shall be credited to the brain injury services fund.

**Revenue Source: N.M. Stat. Ann. § 66-8-119(B)(5) (2005)**

*66-8-119. Penalty assessment revenue; disposition.*

B. The division shall remit all penalty assessment fee receipts collected pursuant to (5) Subsection E of Section 66-8-116.3 NMSA 1978 to the state treasurer for credit to the brain injury services fund.

## **Missouri**

### **MO Brain injury fund created, moneys in fund, uses--surcharge imposed, when.**

304.028. 1. There is hereby created in the state treasury for use by the department of health and senior services a fund to be known as the "Brain Injury Fund". All judgments collected pursuant to this section, federal grants, private donations and any other moneys designated for the brain injury fund shall be deposited in the fund. Moneys deposited in the fund shall, upon appropriation by the general assembly to the department of health and senior services, be received and expended by the department for the purpose of transition and integration of medical, social and educational services or activities for purposes of outreach and supports to enable individuals with traumatic brain injury and their families to live in the community. Notwithstanding the provisions of section 33.080 to the contrary, any unexpended balance in the brain injury fund at the end of any biennium shall not be transferred to the general revenue fund.

2. In all criminal cases including violations of any county ordinance or any violation of criminal or traffic laws of this state, including an infraction, there shall be assessed as costs a surcharge in the amount of two dollars. No such surcharge shall be collected in any proceeding involving a violation of an ordinance or state law when the proceeding or defendant has been dismissed by the court or when costs are to be paid by the state, county or municipality.

3. Such surcharge shall be collected and distributed by the clerk of the court as provided in sections 488.010 to 488.020. The surcharge collected pursuant to this section shall be paid to the state treasury to the credit of the brain injury fund established in this section.

(L. 2002 H.B. 1270 and H.B. 2032, A.L. 2011 H.B. 464)

## Legislation Authorizing 1915(i) – North Dakota

### Sixty-sixth Legislative Assembly of North Dakota In Regular Session Commencing Thursday, January 3, 2019

SENATE BILL NO. 2012  
(Appropriations Committee)

AN ACT to provide an appropriation for defraying the expenses of the department of human services; to create and enact two new sections to chapter 50-06 of the North Dakota Century Code, relating to peer support specialist certification and the establishment of a community behavioral health program; to amend and reenact subsection 9 of section 50-06.4-10 and sections 50-24.1-31, 50-24.1-37, and 54-27-25 of the North Dakota Century Code, relating to the brain injury advisory council, optional medical assistance for children, the Medicaid expansion program, and tobacco settlement trust fund allocations; to provide a statement of legislative intent; to provide for transfers; to provide for a legislative management report; to provide for a legislative management study; to provide an exemption; to provide an effective date; to provide an expiration date; and to declare an emergency.

#### **(Note: Selected Sections Pertaining to 1915(i) and brain injury)**

##### **Peer support certification.**

The behavioral health division shall establish and implement a program for the certification of peer support specialists. In developing the program, the division shall:

1. Define a peer support specialist;
2. Establish eligibility requirements for certification;
3. Establish application procedures and standards for the approval or disapproval of applications for certification;
4. Enter reciprocity agreements with other states as deemed appropriate to certify nonresident applicants registered under the laws of other states having requirements for peer support specialists; and
5. Establish continuing education and certification renewal requirements.

**SECTION 4.** A new section to chapter 50-06 of the North Dakota Century Code is created and enacted as follows:

##### **Community behavioral health program.**

1. The department of human services shall establish and implement a community behavioral health program to provide comprehensive community-based services for individuals who have serious behavioral health conditions.
2. In developing the program, the department shall:
  - a. Establish a referral and evaluation process for access to the program.
  - b. Establish eligibility criteria that includes consideration of behavioral health condition severity.
  - c. Establish discharge criteria and processes.
  - d. Develop program oversight and evaluation processes that include outcome and provider reporting metrics.

e. Establish a system through which the department:

- (1) Contracts with and pays behavioral health service providers.
- (2) Supervises, supports, and monitors referral caseloads and the provision of services by contract behavioral health service providers.
- (3) Requires contract behavioral health service providers to accept eligible referrals and to provide individualized care delivered through integrated multidisciplinary care teams.
- (4) Provides payments to contract behavioral health service providers on a per – month per-referral basis based on a pay-for-performance model that includes consideration of identified outcomes and the level of services required.

**SECTION 5. AMENDMENT.** Subsection 9 of section 50-06.4-10 of the North Dakota Century Code is amended and reenacted as follows:

9. The department shall provide the council with administrative contract with a private, nonprofit agency that does not provide brain injury services, to facilitate and provide support services to the council.

**SECTION 6. AMENDMENT.** Section 50-24.1-31 of the North Dakota Century Code is amended and reenacted as follows:

**50-24.1-31. Optional medical assistance for families of children with disabilities.**

The department of human services shall establish and implement a buy in program under the federal Family Opportunity Act enacted as part of the Deficit Reduction Act of 2005 [Pub. L. 109-171; 120 Stat. 4; 42 U.S.C. 1396] to provide medical assistance and other health coverage options to families of children with disabilities and whose net income does not exceed two hundred fifty percent of the federal poverty line.

**SECTION 7. AMENDMENT.** Section 50-24.1-37 of the North Dakota Century Code is amended and reenacted as follows:

**50-24.1-37. Medicaid expansion - Legislative management report. (Effective January 1, 2014, through July 31, 20192021 - Contingent repeal - See note)**

1. The department of human services shall expand medical assistance coverage as authorized by the federal Patient Protection and Affordable Care Act [Pub. L. 111-148], as amended by the Health Care and Education Reconciliation Act of 2010 [Pub. L. 111-152] to individuals under sixty-five years of age with income below one hundred thirty-eight percent of the federal poverty level, based on modified adjusted gross income line published by the federal office of management and budget applicable to the household size.

2. The department of human services shall inform new enrollees in the medical assistance expansion program that benefits may be reduced or eliminated if federal participation decreases or is eliminated.

3. The department shall implement the expansion by bidding through private carriers or utilizing the health insurance exchange.
4. The contract between the department and the private carrier must:
  - a. Provide a reimbursement methodology for all medications and dispensing fees which identifies the minimum amount paid to pharmacy providers for each medication. The reimbursement methodology, at a minimum, must:
    - (1) Be available on the department's website; and
    - (2) Encompass all types of pharmacy providers regardless of whether the pharmacy benefits are being paid through the private carrier or contractor or subcontractor of the private carrier under this section.
  - b. Provide full transparency of all costs and all rebates in aggregate.
  - c. Allow an individual to obtain medication from a pharmacy that provides mail order service; however, the contract may not require mail order to be the sole method of service and must allow for all contracted pharmacy providers to dispense any and all drugs included in the benefit plan and allowed under the pharmacy provider's license.
  - d. Ensure that pharmacy services obtained in jurisdictions other than this state and its three contiguous states are subject to prior authorization and reporting to the department for eligibility verification.
  - e. Ensure the payments to pharmacy providers do not include a required payback amount to the private carrier or one of the private carrier's contractors or subcontractors which is not representative of the amounts allowed under the reimbursement methodology provided in subdivision a.
5. The contract between the department and the private carrier must provide the department with full access to provider reimbursement rates. The department shall consider provider reimbursement rate information in selecting a private carrier under this section. Before August first of each even-numbered year, the department shall submit a report to the legislative management regarding provider reimbursement rates under the medical assistance expansion program. This report may provide cumulative data and trend data but may not disclose identifiable provider reimbursement rates.
6. Provider reimbursement rate information received by the department under this section and any information provided to the department of human services or any audit firm by a pharmacy benefit manager under this section is confidential, except the department may use the reimbursement rate information to prepare the report to the legislative management as required under this section.

**SECTION 8. AMENDMENT.** Section 50-24.1-37 of the North Dakota Century Code is amended and reenacted as follows:

**50-24.1-37. Medicaid expansion - Legislative management report. (Effective January 1, 2014, through July 31, 20192021 - Contingent repeal - See note)**

1. The department of human services shall expand medical assistance coverage as authorized by the federal Patient Protection and Affordable Care Act [Pub. L. 111-148], as amended by the Health Care and Education Reconciliation Act of 2010 [Pub. L. 111-152] to individuals\ under



sixty-five years of age with income below one hundred thirty-eight percent of the federal poverty level, based on modified adjusted gross income line published by the federal office of management and budget applicable to the household size.

2. The department of human services shall inform new enrollees in the medical assistance expansion program that benefits may be reduced or eliminated if federal participation decreases or is eliminated.

3. Except for pharmacy services, the department shall implement the expansion by bidding through private carriers or utilizing the health insurance exchange.

4. The contract between the department and the private carrier must:

a. Provide a reimbursement methodology for all medications and dispensing fees which identifies the minimum amount paid to pharmacy providers for each medication. The reimbursement methodology, at a minimum, must:

(1) Be available on the department's website; and

(2) Encompass all types of pharmacy providers regardless of whether the pharmacy benefits are being paid through the private carrier or contractor or subcontractor of the private carrier under this section.

b. Provide full transparency of all costs and all rebates in aggregate.

c. Allow an individual to obtain medication from a pharmacy that provides mail order service; however, the contract may not require mail order to be the sole method of service and must allow for all contracted pharmacy providers to dispense any and all drugs included in the benefit plan and allowed under the pharmacy provider's license.

d. Ensure that pharmacy services obtained in jurisdictions other than this state and its three contiguous states are subject to prior authorization and reporting to the department for eligibility verification.

e. Ensure the payments to pharmacy providers do not include a required payback amount to the private carrier or one of the private carrier's contractors or subcontractors which is not representative of the amounts allowed under the reimbursement methodology provided in subdivision a.

5. The contract between the department and the private carrier must provide the department with full access to provider reimbursement rates. The department shall consider provider reimbursement rate information in selecting a private carrier under this section. Before August first of each even-numbered year, the department shall submit a report to the legislative management regarding provider reimbursement rates under the medical assistance expansion program. This report may provide cumulative data and trend data but may not disclose identifiable provider reimbursement rates.

6.5. Provider reimbursement rate information received by the department under this section and any information provided to the department of human services or any audit firm by a pharmacy benefit manager under this section is confidential, except the department may use the reimbursement rate information to prepare the report to the legislative management as required under this section.