



Characteristics of Medicaid HCBS Services for Individuals with Brain Injury: *A Policy Brief and Recommendations*

Background

Since the 1980s, States have funded an array of rehabilitation, short-term and long-term community services and supports for individuals with traumatic brain injury (TBI) or acquired brain injury (ABI) and their families. These programs and services have been funded primarily through State revenue, trust funds (designated funding primarily through fines assessed to traffic offenses) or other designated funds, and Medicaid. In 1991, Kansas became the first State to develop and implement a Medicaid Home and Community Based Services (HCBS) Waiver specifically for individuals with brain injury. Since then, almost half of the States have implemented Waiver services for individuals with brain injury. These waivers vary significantly in size and scope and are generally much smaller than MR-DD and elderly waivers. States also serve individuals with brain injury under other waivers, such as developmental disabilities, physical disabilities and self-directed care waivers.

On June 22, 2009, CMS published in the Federal Register and advanced notice of proposed rulemaking two major changes to the HCBS Waiver program. One is to offer States the option to develop waivers based on need as opposed to waivers based on categorical or diagnostic conditions. CMS noted that many States have used a HCBS waiver as a component of their Olmstead Plan compliance to provide options for community services and supports in lieu of institutionalization. CMS has proposed this rule to remove barriers so that services and supports are based on needs, rather than diagnosis or existing dedicated funding streams. The National Association of State Head Injury Administrators (NASHIA) supports this change.

Also, as part of the notice, CMS stated its intention to propose rule requirements related to identifying the characteristics of HCBS settings. However, since then, CMS has been meeting with national organizations of State directors representing the array of HCBS waivers, including NASHIA, to develop criteria or characteristics, instead of issuing a rule, that would apply to all waiver programs to ensure that these programs reflect community alternatives to institutional care or nursing facility levels of care.

As the goal of the CMS Waiver program is to offer a person a choice of community living services in lieu of more expensive institutional services, which Medicaid does pay for (i.e.

nursing home, ICF-MR), the purpose of this paper is to offer guidance as to how to define or characterize home and community based services for individuals with brain injury (TBI/ABI).

HCBS Waiver Characteristics for Brain Injury

Brain injury can occur to any one at any age and the resulting disabilities vary widely. Individuals who have a brain injury at a younger age will have challenges with new learning, while individuals at an older age have challenges in re-learning skills previously achieved. Individuals who are injured as an adult are likely to have completed their education, obtained a drivers license, worked and may have married. These individuals have already experienced their independence, and find that their brain injury has limited their ability to return to their previous lives as they knew it. Providing supports that are in keeping with their goals and desires may be challenging, as anything less than returning to their previous lives may not be viewed as desirous.

Defining what community living should look like is tricky. A person living in an apartment with supports may not find that to be desirous, if he or she previously owned his or her home independently. Yet a person who has never lived independently may find living with roommates as a worthy goal. So, how does one assign characteristics of home and community support services to reflect community integration, that reflect the wishes of the participant, that provide continued opportunities for the participant to self-direct or be able to make choices of how they want to live with regard to type of housing, employment, socialization and other activities of daily living. To achieve these goals NASHIA supports person centered planning as a process to address individual needs, goals and desires. Where a person lives and whether the person is employed or seeking employment or involved in volunteer activities, as well as opportunities for socialization and other community activities are indicative of community integration.

Housing

While Medicaid does not pay for housing (room and board) for an individual served by a Waiver program, where a person lives is generally indicative of whether the person is integrated into the community. Disability advocates have historically argued these issues may be indicators of community integration:

- the number of residents living together
- location of the residence (located on grounds of an institution/nursing home vs. in a neighborhood)
- separation of day services and supports from the residential setting and provider
- age appropriateness
- having choice as to where to live
- individual lease or rental agreement in place with tenant rights

These indicators may be somewhat contradictory for different populations. Individuals who are seniors often live in assisted living or retirement settings. These settings may be beneficial for seniors with disabilities. Similarly, students in college generally live with several other students, whether in dorm or apartment settings. A person with a brain injury in this age group may find living with others similar in age to be satisfactory.

Some individuals with brain injury may exhibit such inappropriate behaviors that will require a structured living environment in order to live in the community as independently as possible. Generally, behavioral treatment/rehabilitation will be a component of the residential setting, just

as behavioral supports will need to accompany the individual in other settings in order to ensure consistency of treatment. One provider may provide all of these services.

Person Centered Planning -- Person Directed

The key to understanding whether HCBS waivers support community integration of one's choice is through the person centered planning process. Who decides when to eat, when to sleep, what to eat, what to watch on TV? That is how control impacts quality of life. To help ensure that individuals do have choice as to where and how they want to live many State and community disability/brain injury service agencies have adopted a person-centered planning approach. This approach places the person in charge of planning and establishing short-term and long-term goals to meet his/her needs and desires.

Obviously, waiver services should be tailored to meet the individual needs and accommodating to each individual's disability, and person-centered planning may be the vehicle for ensuring needs are met of ones choosing. However, adopting the principles of person centered planning does not necessarily mean that a service delivery system or its provider agencies has implemented the process effectively. All levels of the system must be engaged in the principles, and carry out these principles accordingly. On-going training and coaching in the planning process should be a part of the delivery system, not only in terms of the process, but in understanding cognitive and behavioral issues unique to brain injury.

A caveat with regard to brain injury is that individuals with brain injury may have had a great deal of independence prior to their injury. They may have been in high school, college, been a professional or engaged in manual labor or other employment prior to their injury. They may have been the sole provider of their family, a spouse and/or a parent. Goals that may be seem suitable to their present level of functioning to others, may not be suitable to them. This stresses the need for expertise in facilitating and engaging them and their supports in the planning processes, otherwise they may perceive the plan goals and objectives as falling short, if their goal is to return to life as they knew it prior to injury and in a short time frame. Helping them to define appropriate short-term goals to achieve their overall goal may take some finesse. It also needs to balance preferences and desires with individual needs as defined by a larger circle of supports.

Employment

Whether it is return to work or working for the first time, employment is viewed as a successful outcome for individuals with brain injury. Successful employment often results in decreased depression, decreased substance abuse, improved self-esteem, and perceived status within the family and community. It gives people a reason to get up of a morning, connect with people, as well as earn some money.

Although HCBS waivers do not pay for vocational rehabilitation services, the waivers should support vocational and employment goals by providing such services as long-term supports and counseling. Supported employment has been cited to be beneficial in assisting individuals with brain injury in obtaining and retaining a job. Where a person resides should also support this goal with regard to transportation or access to employment and job training venues. These activities combined with housing support community integration.

(Wehman, P; Targett, P.; West, M. and Kregel, John. Productive work and employment for persons with traumatic brain injury: what have we learned after 20 years? *J of Head Trauma Rehabil.* 2005;Vol. 20, No. 2, pp. 115-127.)

Recommendations

NASHIA believes that HCBS waivers should support the goals of the Olmstead Decision in offering and providing community services and supports in lieu of institutional services and that these services reflect:

- Person-centered planning (PCP)/person directed as an integral part of the delivery process;
- PCP that supports individuals to be as independent as possible based on comprehensive assessments by professionals with experience in brain injury, and conducted as much as possible in real life settings;
- Age appropriate services and supports;
- Freedom to move about in the community;
- A residential setting with privacy and, wherever possible, a lease or rental agreement;
- Services that are integrated and accessible to other public services such as transportation and recreational venues (i.e. parks, YMCA, walking trails), church/synagogues, shopping, adult learning classes; and that these opportunities should be reflected in the person centered plan; and
- Person centered planning that involves vocational and integrated employment goals, including volunteer work, when appropriate, or other meaningful day time activities.

While desirous to separate therapies and day services from housing, these services may need to be integrated for individuals with brain injury in order for cognitive and behavioral compensatory strategies to be affective. However, these instances and desired outcomes should be documented in the planning process.

In addition, individuals with brain injuries should be accorded the same choices and rights in selecting and approving their living arrangements and providers as individuals who have not sustained brain injuries. A person's living arrangement that is connected with services may experience interference with service and provider choices. For example, a provider may resist a client's wishes to receive a service, currently provided by that provider, from a "competing provider" – this has happened. Unless it is absolutely therapeutically indicated, living arrangements should be independent of services.

NASHIA believes that HCBS waiver services should **not** be provided in a hospital, nursing facility or on the grounds of an institutional setting. While some group settings may be appropriate for certain age groups for people without disabilities, such as retirement communities or dormitory living, these settings should only be used if documented in a person centered plan. If the setting meets the individual's needs, but does not reflect community integration, then perhaps the state needs to use other funding streams to support the individual. That is, HCBS Waiver funding should truly be used for intended community inclusion and integration.

In closing, NASHIA supports the State of Washington's service guidelines that described the desired benefits from residential and day services. These person centered benefits are:

1. Health and Safety
2. Power and Choice
3. Status and Respect
4. Integration into Community
5. Relationships
6. Competence

Washington uses these six benefits as measures of whether or not services delivered are accomplishing what they need to accomplish on behalf of people with disabilities:

- What is the most straightforward and cost-effective way to provide opportunities to realize all of the Benefits at once?
- What "Individual Budget" program offers the recipient maximum flexibility, choice, and self-determination over expenditures?
- What is among the top three questions that people ask when they are getting to know you?
- What expands your choices about the bank you use, the stores where you shop, the activities you pursue, the places you go?
- What gives you access to a range of relationships outside your family and allows you to participate on an equal footing?
- What is the proof that you are learning new skills and practicing old ones?

These questions help to ensure that individuals are living and working in community settings of choice and desired outcomes.

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*The National Association of State Head Injury Administrators assists State government
in promoting partnerships and building systems to meet the needs
of individuals with brain injuries and their families.*