



Rutgers Center for
State Health Policy

The Institute for Health, Health Care Policy and Aging Research

Issue Brief:

A Survey of Medicaid Brain Injury Programs

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March 2008

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Rutgers Center for
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The Community Living Exchange at Rutgers/NASHP provides technical assistance to the Real Choice Systems Change grantees funded by the Centers for Medicare & Medicaid Services.

We collaborate with multiple technical assistance partners, including ILRU, Muskie School of Public Service, National Disability Institute, Auerbach Consulting Inc., and many others around the nation.

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This document was developed under Grant No. 11-P-92015/2-01 from the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services. However, these contents do not necessarily represent the policy of the U.S. Department of Health and Human Services, and you should not assume endorsement by the Federal government. Please include this disclaimer whenever copying or using all or any of this document in dissemination activities.

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Summary

In late 2007, the Center for State Health Policy surveyed 23 states that operate Medicaid waivers targeted to individuals with brain injuries. Data was obtained about the cost and number of individuals served by these waivers for the waiver years 2002 through 2006. Three states began waivers for individuals with brain injuries in 2002 or later, and three other states discontinued waivers in 2006. Every state except Arizona has multiple Medicaid 1915(c) home and community-based services (HCBS) waivers. Arizona operates its long-term care system as an 1115 Waiver.

Conversations with state staff about why brain injury waivers were established indicate two frequently mentioned reasons: lobbying by advocates and the desire to end expensive out-of-state placements. Federal funding was invariably mentioned in discussions with states about why a waiver was established; however, only one state responded that the motivation to begin the waiver was primarily fiscal.

Data developed for the Kaiser Commission on Medicaid and the Uninsured show that in 2004 there were 263 waivers nationally, providing services to over one million individuals at a cost of \$20.5 billion.¹ These data also show that for a 5-year period, from 2000 through 2004, the total number of participants in all Medicaid 1915(c) HCBS waivers increased 31% and expenditures increased 62%. The Rutgers data indicate that waivers for individuals with brain injury grew more rapidly over the 5-year period than waivers in general.

The waivers for individuals with brain injury are small in comparison to other waivers, providing services to approximately 11,214 unduplicated persons in 2006. According to the national data for 2004, 9,393 persons were served on brain injury and spinal corded waivers, only the waivers targeted to individuals with mental health needs were smaller, having 2,089 participants. Only slightly larger were the waivers for children with special needs, 11,982 participants, and for individuals with HIV/AIDS, 14,254 participants. All of these waivers combined account for only 10% of the individuals served in 2004 and comprise 7% of the total expenditures.

Although small, waivers for individuals with brain injuries have grown significantly in recent years, doubling from 5,400 individuals served in 2002 to 11,214 in 2006, at a cost of \$155 million in 2002 to \$327 million in 2006. Three states with the largest waivers account for most of this growth. If these three states are excluded, the percentage increase reported by the remaining states is similar to the national data. The per capita cost remained relatively constant in this period although there was a dramatic variation in per capita costs in 2006, ranging from almost \$12,000 to over \$82,000. Providing HCBS to individuals with brain injury is less expensive than providing services

¹Kaiser Commission on Medicaid and the Uninsured (2007, December); *Medicaid Home and Community-Based Service Programs: Data Update*, The Henry J. Kaiser Family Foundation, Washington D.C. Table 4 Retrieved on 2-28-08 from <http://www.kff.org/medicaid/upload/7720.pdf>

in nursing homes, hospitals, and similar institutions. Data from 17 of the surveyed states indicate that when compared to institutional costs, a total of almost \$273 million was saved by Medicaid through the use of these brain injury waivers. On average \$30,000 per person was saved

As reported by Kaiser, in 2006 waiting lists for traumatic brain injury (TBI) waiver services were reported in eight states and totaled 1,658 persons. In late 2007, the Rutgers survey found that nine states had waiting lists for services, with a total of 1,228 individuals.

Services provided under the brain injury waivers vary considerably from a single waiver service to extensive arrays of services. The size of the waivers also varies from 19 individuals to over 3,600 individuals served in a year.

Introduction

This paper addresses waivers targeted to individuals with a brain injury, a specific type of disability. States that had such waivers were identified and contacted to obtain information about how the state decided to create a waiver program, what the eligibility requirements were to obtain services, how many persons were served, what the services were, and what the cost of the services were.

Background on Waiver Development

Waiver services granted under the authority of section 1915(c) of the Social Security Act are designed to help Medicaid-eligible individuals who might otherwise be admitted to a hospital or nursing facility to live independently in the community and to permit a state to provide services that are not typically covered under the state's regular Medicaid program. This paper addresses waivers targeted to individuals with a brain injury.

In order for a state to receive approval for a waiver, in its waiver request the state's Medicaid agency must:

- Provide assurances that the waiver will protect the health and welfare of participants.
- Specify how many people will be served during each year of the waiver's operation. Unlike its regular Medicaid program, a state can limit the number of individuals it will serve. This allows a state to control the costs of a waiver and have a waiting list when that number is reached.
- Identify what services are in the waiver. A waiver allows a state to cover services that are not permitted in the regular Medicaid program and provides a

waiver participant with “optional” Medicaid services that a state has chosen not to include in its regular Medicaid program. A state may also provide a waiver participant with more of a service than it will provide to an individual through its regular Medicaid program.

- Finally, the state must show that the cost of waiver services will not exceed what the state would have spent in the absence of the waiver; this is also referred to as cost neutrality.

The Social Security Act lists seven specific services that may be provided under a HCBS waiver. In addition, states may apply for permission to provide other optional services as the state defines them, which are above and beyond the services provided in the Medicaid State plan. The services that each of the states covers in its brain injury waiver are categorized, for the most part, according to categories and definitions used in a report examining waiver services targeted to support individuals with intellectual and developmental disabilities.²

A waiver is also required to be cost neutral: “under such waiver the average per capita expenditure estimated by the State in any fiscal year for medical assistance provided with respect to such individuals does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for such individuals if the waiver had not been granted.”³

Following federal policy, state Medicaid programs have medical requirements an individual must meet in order to be eligible for a waiver. The federal requirement for “level of care” assessment calls for the state to determine “that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or intermediate care facility for the mentally retarded, the cost of which could be reimbursed under the State plan.”⁴ The “such services” referred to in this section are the services provided to individuals under a state’s Medicaid waiver.

When the brain injury is a result of either birth trauma or a degenerative disease, an individual is, in almost all states, not eligible for waiver services. Medicaid waivers providing home and community-based services are generally considered part of the long-term care service system. The services provided under these brain injury waivers vary considerably from a single waiver service to extensive arrays of services. In most states, the waiver for individuals with brain injury can also be characterized in this fashion. Individuals are provided with services that support them in a community-based living arrangement, and they continue to receive services for as long as they are needed.

² Smith, G.; Agosta, J.; Fortune, J. and O’Keeffe, J., Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Final Project Report, April 2007 available at: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>. Using the same service categories make it easier to compare the descriptions of services in the different reports.

³ Social Security Act, Section 1915(c) (2) (D)

⁴ Social Security Act, Section 1915(c) (1), found at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm

Five states have structured waiver services in another way; they focus primarily on rehabilitation. Rather than provide supports designed to meet the long-term care needs of those individuals in the waiver, services are designed to provide rehabilitation and community reintegration, as well as to provide the other supports needed to reside in a community-based living arrangement. These “rehabilitation” waivers may have level of care requirements that are more stringent than nursing facility requirements.

Table 1: States Surveyed

State	Individuals Served in 2006	Year Waiver Established
Colorado	293	1995
Connecticut	344	1997
Florida*	283	1999
Idaho**	19	2001
Illinois	3,601	1999
Indiana	131	2000
Iowa	825	1996
Kansas	269	1991
Kentucky	98	1999
Maryland	23	2003
Massachusetts	90	2001
Minnesota	1,372	1992
Nebraska	26	2000
New Hampshire	140	1992
New Jersey	276	1993
New York	1,953	1995
North Dakota**	29	1994
Pennsylvania	324	2002
South Carolina*	497	1995
Utah	91	1995
Vermont**	59	1994
Wisconsin	334	1995
Wyoming	137	2002
Total	11,214	

Source: Center for State Health Policy, Rutgers University

Note: Mississippi also operates a waiver; requested information was not received.

Kentucky and Vermont based on 2005 data

* Serves individuals with spinal cord injuries as well

** Waiver no longer in operation

National Waiver Data

Every state except Arizona has multiple Medicaid 1915(c) HCBS waivers. Arizona operates its long-term care system as an 1115 Waiver. In 2004, there were 263 waivers nationally, providing services to over one million individuals at a cost of \$20.5 billion. Data presented in a report produced by the Kaiser Commission on Medicaid and the Uninsured show that for a five-year period, from 2000 through 2004, the total number of participants in all Medicaid 1915(c) HCBS waivers increased 31% from 770,000 to 1,015,000, and expenditures increased 62% from \$12.6 billion to \$20.5 billion.⁵

Table 2: National Data – All Waivers

Year	Total # Participants (000)	Total Expenditures (billion)
2000	770,000	\$12.60
2001	841,000	\$14.30
2002	924,000	\$16.90
2003	982,000	\$18.90
2004	1,015,000	\$20.50

Source: Medicaid Home and Community-Based Service Programs: Data Update

The information from the Rutgers Center for State Health Policy survey is based on interviews with state staff in 23 states that operate Medicaid waivers for individuals with brain injury, as well as on participant and expenditure data from these states. Whenever it was available from the state, data from the federal reporting form called the CMS 372 was used. When CMS 372 data was not available, expenditure or participant data reported by a state from other sources was used.

The Rutgers survey indicates that waivers for individuals with brain injury grew at a higher rate over five years than all waivers. Both the number of participants and the total expenditures doubled, while the per capita cost remained relatively constant in this period.

The three states with the largest waivers account for most of this growth. If these three states are excluded, the percentage increase reported by the remaining states is quite similar to the Kaiser data, which shows a 31% increase in individuals served and a 62% increase in expenditures.

⁵ Kaiser Commission on Medicaid and the Uninsured (2007, December); *Medicaid Home and Community-Based Service Programs: Data Update*, The Henry J. Kaiser Family Foundation, Washington D.C. Retrieved on 2-28-08 from <http://www.kff.org/medicaid/upload/7720.pdf>

Table 3: Increases Over Time in Brain Injury Waivers

Individuals Served			
	Three Largest Waivers	Remaining Waivers	Total
2002	2,501	2,908	5,409
2006	6926	3807	10,733*
Growth	185%	24%	98%
Expenditures (Million)			
	Three Largest Waivers	Remaining Waivers	Total
2002	\$71.5	\$85.0	\$157
2006	\$190.4	\$138.6	\$329
Growth	166%	63%	110%

*Represents only those states that provided 2006 expenditure data
Source: Center for State Health Policy, Rutgers University

Table 4: Annual Changes in Brain Injury Waivers

	Number of states	Number of Participants	Expenditures	Per Capita Expenditures
2002	21	5,409	\$156,719,621	\$28,974
2003	22*	6,901	\$204,951,815	\$29,699
% Change from prior year		28%	31%	3%
2004	23*	8,446	\$255,978,429	\$30,308
% Change from prior year		22%	25%	2%
2005	23*	9,920	\$317,809,438	\$32,037
% Change from prior year		17%	24%	6%
2006	20**	10,733	\$328,983,064	\$30,652
% Change from prior year		8%	4%	-4%

* States began new waivers

** Data not available from all states

Source: Center for State Health Policy, Rutgers University

The waivers for individuals with brain injury are small in comparison to other waivers. According to the Kaiser data for 2004, only the waivers targeted to individuals with mental health needs are smaller with 2,089 participants. Only slightly larger are the waivers for children with special needs with 11,982 participants, and individuals with

HIV/AIDS with 14,254 participants. When combined, all of these waivers account for only 10% of the individuals served and 7% of the total expenditures.⁶

In conversations with state staffs, the Center for Health Policy was told that three states began waivers for individuals with brain injuries in 2002 or later.⁷ In addition, three states discontinued their small waivers in 2006 and individuals enrolled in these waivers continued to receive services through another of the state's waivers.⁸

Rationale for Establishing a Brain Injury Waiver

Conversations with state staff about why brain injury waivers were established indicate two frequently mentioned reasons: lobbying by advocates and the desire to end out of state placements. Seven states reported that lobbying efforts of advocates and advocacy groups, such as the brain injury association in the state, were major factors in the decision to establish the waiver.⁹ In one state, the waiver resulted from a citizen-based initiative.¹⁰ In another, the legislature created an advisory board charged with conducting a needs assessment; the needs assessment ultimately led to the waiver.¹¹ A third state's legislature required a plan to address the needs of individuals with brain injuries; this plan led to the waiver.¹² The remaining four states reported their waivers were established because advocates very actively lobbied the legislature and executive. In one other state, the waiver began as a response to litigation.¹³ The organizations involved in the litigation, the state's Office of Protection and Advocacy and the legal services organization, participated in the planning and development of the waiver, as did the state brain injury association. Two states reported beginning their waiver, as a proactive response to the unmet service needs of individuals with brain injuries.¹⁴

Six states reported that prior to their waiver, Medicaid eligible individuals with brain injuries were frequently placed in specialized, high cost facilities outside the state.¹⁵ The decision to establish waivers in these states was an effort on the state's part to return its citizens to the community. In one state, families and advocates petitioned to "repatriate" its citizens.¹⁶ These states indicated that the high cost of the out of state facilities was a principal driver of the decision to establish the waiver. Three of these states also indicated that a waiver was established because the state lacked the capacity to provide specialized services to individuals with brain injuries and that the waiver was a

⁶ The data reported by Kaiser show that waivers targeted to individuals who are aged and disabled account for 50% of the participants and 19% of the expenditures, and waivers targeted to individuals with developmental disabilities account for 40% of the participants and 74% of the expenditures.

⁷ Maryland, Massachusetts and Pennsylvania

⁸ Idaho, North Dakota and Vermont

⁹ Colorado, Illinois, Iowa, Kansas, Kentucky, Minnesota and Wyoming

¹⁰ Colorado

¹¹ Illinois

¹² Minnesota

¹³ Connecticut

¹⁴ New York and Pennsylvania

¹⁵ Indiana, Maryland, New Hampshire, New Jersey, Vermont and Wisconsin

¹⁶ New Hampshire

key element in building this capacity.¹⁷ Two additional states cited building their service capacity as a primary reason for their waiver, without linking it to returning citizens to the state.¹⁸

Medicaid waivers provide a mechanism for states to obtain federal reimbursement for covered services provided to Medicaid eligible individuals. During discussions with states about why a waiver was established, federal funding was invariably mentioned as part of the rationale. However, only one state responded that the motivation to begin the waiver was primarily fiscal.¹⁹ This state was already operating a large state-funded program for individuals with brain injuries and state administrators viewed a waiver as a mechanism to maximize revenues. This state's waiver is one of the smaller waivers among those states surveyed, serving 90 individuals in 2006 with expenditures of just under \$5 million. By comparison, its state-funded program serves approximately 1,200 individuals with expenditures of approximately \$15 million. Both programs provide identical services and operate in the same manner; waiver enrollment does not require any specific action on the part of the participant; and, enrollment decisions for Medicaid eligible individuals are made based upon revenue maximization and cost neutrality considerations. The state noted that waiver approval entailed a five-year process before approval was received in 2001.

Eligibility

Waiver services granted under the authority of section 1915(c) of the Social Security Act are designed to help Medicaid-eligible individuals who might otherwise be admitted to a hospital or nursing facility live independently in the community.²⁰ Federal regulations permit a state to provide services that are not typically covered under the state's regular Medicaid program. This permission is called a waiver and the use of waivers is regulated by the Social Security Act and the Code of Federal Regulations. Under these waiver rules, states are permitted to limit services to specific geographical regions of a State and to target services to certain groups, such as persons over the age of 65 and individuals with a general or a specific disability. Normally, such limitations are not allowed under the regular Medicaid program.²¹

For an individual to be eligible for Medicaid, and specifically for one of the waivers for people with brain injury, the individual must meet financial criteria (i.e.,

¹⁷ Indiana, New Jersey and Vermont

¹⁸ Colorado and South Carolina

¹⁹ Massachusetts

²⁰ There are two types of waivers based on two provisions of the Social Security Act, sections 1115 and 1915. This paper discusses 1915(c) waivers regarding the provision of home and community-based services for persons who have brain injuries. See HCBS.org for reports on waivers. For a list of waivers by state see <http://www.hcbs.org/files/122/6068/HCBSWaivers2006--Table1.xls> and <http://www.hcbs.org/files/122/6065/HCBSWaivers2006--Table2.xls> retrieved 2-27-08

²¹ The Northeast Center for Special Care has an excellent collection of articles about Medicaid waivers and readers are referred to their collection at http://www.northeastcenter.com/links_hcbs_medicaid_waivers.htm

income and resources) and non-financial criteria. States have flexibility, within limits defined by the federal requirements to determine the specific eligibility criteria for a waiver.

Financial Eligibility

To be eligible for home and community-based waiver services a person must meet the financial requirements of a state's Medicaid program for services in a hospital, nursing home, or intermediate care facility for the mentally retarded.²² In an institution, an individual can have an income up to 300% of the federal Supplemental Security Income, (SSI) benefit. The federal SSI benefit is \$637 a month in 2008, and 300% equals \$1,911 a month.²³

Waivers allow states to cover individuals who "over income" for Medicaid while living in the community if their income would allow them to be eligible in an institution such as a hospital or nursing facility. Federal rules allow states to set higher income limits for people in institutions or in a waiver, up to 300% of the federal Supplemental Security Income (SSI) benefits or higher if a state has a medically needy program. A state is not required to cover individuals with incomes up to this limit; each state can determine the income level it will cover.

Typically, the maximum amount of resources (savings and other assets) that an individual may have and still be eligible for Medicaid is \$2,000; this amount is the SSI resource limit. Fifteen of the states use this amount for waiver eligibility: three have a lower resource limit, either \$1,500 or \$1,600; and, five states a higher resource limit, ranging from \$3,000 to \$8,000.

Nationally, financial eligibility is 300% of SSI in 77% of all HCBS waivers according to the Kaiser data. It is set at SSI in 20% of the waivers and is between these amounts in only 3% of the waivers.²⁴ Of the 23 states Rutgers Center for State Health Policy surveyed, 15 set the income level at 300% of the federal SSI payment²⁵. In the remaining eight states, the income eligibility criteria are set at a lesser amount: three at the SSI income level and five at between 300% of SSI and the SSI income level. Three states set eligibility at the SSI income level²⁶. States are permitted, and some choose, to supplement the Federal SSI benefit with additional payments based on income, living

²² There is a substantial literature on Medicaid financial eligibility. For short fact sheet on financial eligibility see Mollica, R. (2005, October), *Medicaid Financial Eligibility*, Center for State Health Policy, Rutgers University, New Brunswick, NJ Retrieved on 2-28-08 from <http://www.cshp.rutgers.edu/cle/Products/MedicaidFinancialEligibilityWEB.pdf>
See also, Mollica, R. (2005, October), *Medically Needy Individuals*, Center for State Health Policy, Rutgers University, New Brunswick, NJ Retrieved on 2-28-08 from <http://www.cshp.rutgers.edu/cle/Products/MedicaidEligibilityMedicallyNeedyWeb.pdf>

²³ The Supplemental Security Income program is described at <http://www.ssa.gov/ssi/>

²⁴ Kaiser, *ibid.* Table 8

²⁵ Colorado, Connecticut, Florida, Iowa, Idaho, Kansas, Kentucky, Maryland, New Jersey, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin, and Wyoming

²⁶ Illinois, Indiana and North Dakota

arrangements, and other factors.²⁷ As a result, the actual income for Medicaid waiver eligibility in a state may be higher than the federal SSI payment (\$637 per month).

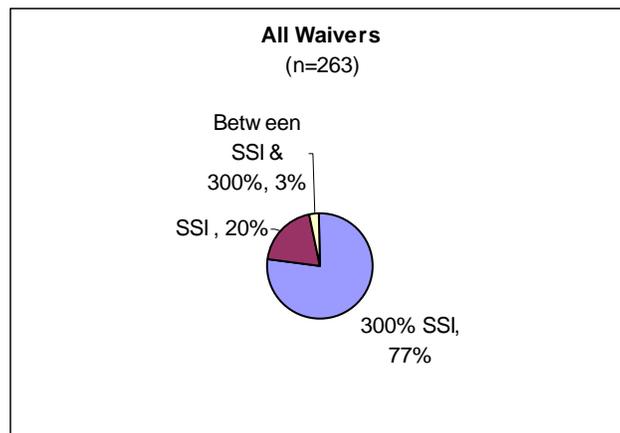
Table 5: Eligibility – Income Limits

Income Eligibility Standard	SSI Income Limit	Federal Poverty Guideline	\$1,250	300% SSI (\$1,911 in 2008)
All states	3 states	4 states	1 state	15 states

Source: Rutgers University, Center for State Health Policy, 2008

The following figures show the comparison of income eligibility standards between all waivers nationally and the states with waivers for individuals with brain injuries. The data for all waivers represent all states except Arizona. Data for Brain Injury Waivers represent 23 states. Typically, states use the same eligibility criteria for all waivers that they operate. Therefore, the differences in eligibility criteria observed may be attributable to differences in state’s eligibility policies.

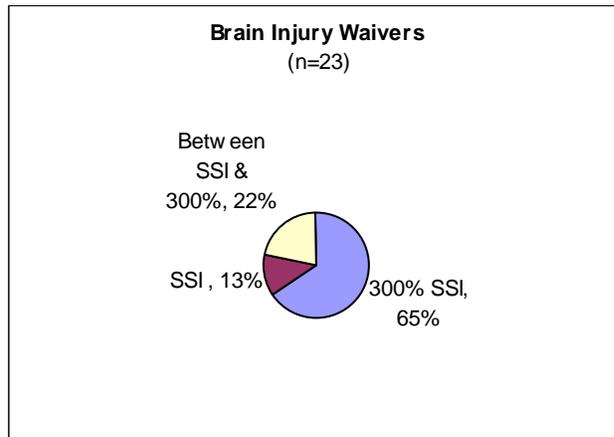
Figure 1: Income Eligibility: All Waivers



Source: Medicaid Home and Community-Based Service Programs: Data Update

²⁷ Understanding Supplemental Security Income SSI Benefits, found at <http://www.ssa.gov/ssi/text-benefits-ussi.htm>

Figure 2: Income Eligibility – Brain Injury Waivers



Source: Rutgers University, Center for State Health Policy, 2008

This resource amount is used by 15 of the states for Medicaid eligibility.²⁸ Three have a lower resource limit for Medicaid than the SSI limit, either \$1,500 or \$1,600.²⁹ Five states utilize a higher limit for Medicaid, ranging from \$3,000 to \$8,000.³⁰

Table 6: Eligibility – Resource Limits

Resource Limit for Eligibility	Less than SSI resource limit	Uses SSI resource limit	More than SSI resource limit
All states	3 states	15 states	5 states

Source: Rutgers University, Center for State Health Policy, 2008

²⁸ Colorado, Florida, Iowa, Idaho, Illinois, Kansas, Kentucky, Maryland, Massachusetts, New Jersey, South Carolina, Utah, Vermont, Wisconsin and Wyoming

²⁹ Connecticut, Indiana and New Hampshire

³⁰ Minnesota, Nebraska, New York, North Dakota and Pennsylvania

Non-Financial Eligibility

The non-financial eligibility requirements for Medicaid waivers can be characterized as “Level of Care” and “other criteria.” Individuals seeking services on a brain injury waiver must also meet the state’s non-financial criteria for admission to a nursing home or other institution. These criteria are often referred to as “medical,” “functional,” or “Level of Care,” and these have been developed to assure that only individuals needing institutional service are admitted to one of those settings. Waivers are intended to substitute for institutional care and, therefore, are limited to serving only individuals who could be admitted to a nursing home or institution if they applied, or individuals who live in one of these institutions and want to move to the community. States also set additional requirements that individuals must meet in order to be enrolled in one of these waivers. These criteria vary from state to state and are discussed later; the specific requirements are also listed in each state’s summary (see Appendices).

Waivers for aged and disabled persons invariably use a nursing home level of care, and waivers for persons with intellectual and developmental disabilities invariably use a ICFs/MR institutional level.

The level of care that a state specifies has a significant effect on the cost neutrality calculation for a waiver. A non-specialized nursing facility is, in all likelihood, the least expensive of the institutional options potentially available to an individual. To the extent that a state has other higher cost facilities and there are individuals enrolled in the waiver that meet the level of care for those facilities, there is the potential to provide a more expensive service package and still meet the federal cost neutrality test. States can and do include more than one level of care in brain injury waivers.

In evaluating eligibility, states also consider the causation of the individual’s brain injury, the age of onset of the disability, and the current age of the individual as criteria for waiver eligibility. Within these broad categories, states use these specific criteria to structure eligibility for these waivers. Rather than try to compare states’ specific criteria, we used broader, more easily comparable criteria.

Individuals with a traumatic brain injury may be eligible for the waiver in all of the surveyed states. Six³¹ of the surveyed states limit their waiver to individuals who have a traumatic brain injury, an additional three states specify that the individual must have a traumatic brain injury, but have a broad definition of “traumatic” that may include stroke.³² The remaining 14 states have broader eligibility criteria to include individuals with an acquired brain injury.³³ Three states list specific ICD-9 codes that are required in

³¹ Florida, Indiana, Kansas, Maryland, Nebraska and Pennsylvania

³² New Jersey, New York and Vermont

³³ Colorado, Connecticut, Idaho, Iowa, Illinois, Kentucky, Massachusetts, Minnesota, New Hampshire, North Dakota, South Carolina, Utah, Wisconsin and Wyoming

order for an individual to be eligible.³⁴ In addition, the waiver in Florida and South Carolina is designed to serve individuals with a spinal cord injury in addition to individuals with a brain injury.

When the brain injury is a result of either birth trauma or a degenerative disease, an individual is, in almost all states, not eligible for waiver services. New Hampshire does include individuals with a degenerative disease if it occurred between the ages of 22 and 60. Three³⁵ states specifically require that the brain injury occur after adulthood (age 21) and one state requires in its waiver that participants be age 16 or older with a “recent” brain injury.³⁶ Most of the other states indicated that a child with a brain injury would, in all likelihood, be considered developmentally disabled and, therefore, would be enrolled in the DD/MR waiver; however, they did not specify an age of onset/acquisition of the brain injury.

Regardless of the cause, brain injuries result in a range of effects. Some may be subtle and difficult to initially diagnose; others may be obvious and serious. Some individuals who have experienced a minor brain injury may recover completely in a relatively short time, while others may experience life-long disability.³⁷ The effects of a brain injury may be physical (e.g., ambulation problems, speech difficulties, seizure or fatigue), cognitive (e.g., memory loss, difficulty concentrating, or poor judgment), and/or behavioral (e.g., impulsiveness or the need to be reminded to begin or finish tasks). Services needed by individuals with brain injury are specialized, such as substance abuse or cognitive therapy, and are not normally included in the waivers for individuals with physical disabilities such as those that suffer a loss of limbs in a car accident.

The level of care that a state specifies has a significant effect on the cost neutrality calculation for a waiver. A non-specialized nursing facility is, in all likelihood, the least expensive of the facility/institutional options potentially available to a state.³⁸ To the extent that a state has other higher cost facilities and individuals enrolled on the waiver meet the level of care, there is the potential to provide for the persons who require more resources than others require and still meet the federal cost neutrality test. Persons in states that seek to establish a brain injury waiver, such advocates in West Virginia and Alaska, should take this consideration into account.

³⁴ International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), is the official system of assigning codes to diagnoses in the United States and is used by Colorado, Idaho and Iowa.

³⁵ Idaho, Maryland and New Jersey

³⁶ Vermont

³⁷ Of the 1.4 million who sustain a TBI each year in the United States: 50,000 die; 235,000 are hospitalized; and 1.1 million are treated and released from an emergency department. The number of people with TBI who are not seen in an emergency department or who receive no care is unknown.

³⁸ One of the states surveyed reported a per capita cost of a specialized facility almost 700% of the per capita nursing facility cost.

The cost neutrality calculations for brain injury waivers are markedly different than the cost neutrality of other waivers that use a uniform level of care comparison.

Of the states surveyed, six reported using more than one level of care in their waiver; accordingly, the figures below add up to more than 23. Nineteen of the states use a nursing facility as the level of care. Five of the states require the nursing facility to be a specialized facility.³⁹ Six states utilize a hospital, generally a specialized hospital, as the ‘Level of Care.’⁴⁰ Four states use an intermediate care facility for the mentally retarded as the “Level of Care.”⁴¹

Table 7: Level of Care: Institution

Level of Care Used	Nursing Facility (NF)	Specialized NF	Hospital	Intermediate Care Facility for the Mentally Retarded
All states	19 states	5 states	6 states	4 states

Source: Rutgers University, Center for State Health Policy, 2008.

“Other criteria” for Medicaid waiver eligibility include the causation of the individual’s disability, the age of onset of the disability, and the current age of the individual. Within these broad categories, states use these specific criteria to structure eligibility for these waivers.⁴² Rather than try to compare states’ specific criteria, broader, more easily compared criteria were used.

States vary considerably in the designation of the age of individuals who may be eligible for the waiver. Fourteen of the states provide services only to adults. However, the definition of “adult” varies slightly, with a range of 18, 21 or 22.⁴³ Three states provide services to individuals as young as 16.⁴⁴ The remaining six states include individuals “any age”.⁴⁵ Twelve of the states have an upper age limit, most typically 64,

³⁹ Colorado*, Connecticut, Florida, Idaho, Illinois, Indiana, Kentucky, Maryland, Massachusetts*, Minnesota, Nebraska, New Hampshire*, New Jersey, New York, North Dakota, Pennsylvania*, South Carolina, Utah and Vermont*

* must be specialized

⁴⁰ Colorado, Connecticut, Kansas, Maryland, Minnesota and Wisconsin

⁴¹ Connecticut, Iowa, South Carolina and Wyoming

⁴² These criteria are more specific than the criteria for mandatory eligibility groups such as aged, blind and disabled individuals who receive benefits under the federal SSI program.

⁴³ Connecticut, Florida, Idaho, Kentucky, Maryland, Massachusetts, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Pennsylvania, Utah and Wyoming

⁴⁴ Colorado, Kansas and Vermont

⁴⁵ Illinois, Indiana, Iowa, Minnesota, South Carolina and Wisconsin

with one state using 62 and two states using 65 years old.⁴⁶ Those states that have a lower age limit generally report that younger persons are potentially covered by the waiver for individuals with developmental disabilities/mental retardation. States with an upper age limit similarly report that those individuals who “age out” are provided services through the waiver for the aged and/or the disabled.

Two states responded that an individual must be assessed and attain “scores” in a defined range, using a specific, standardized measure of neuropsychological or cognitive functioning.⁴⁷ Other states may include one or more of these measures in the assessment process, but do not require that the results of the measure be within a specified range.

Waiting Lists

In 2006, waiting lists for TBI waiver services were reported in eight states and totaled 1,658 individuals, as reported by Kaiser. In late 2007, the Rutgers Center for State Health Policy survey found that nine states had waiting lists for services, with a total of 1,228 individuals. The different states included in the Center’s survey and Kaiser’s *Medicaid Home and Community-Based Service Programs: Data Update* do not appear to have any bearing on the decrease in the number of persons on the waiting list from one year to another. The preponderance of the change is a result of one state that reported that it uses waiting lists kept by local agencies and that it has been working over time to establish greater consistency in waiting list practices.

⁴⁶ Colorado, Connecticut, Iowa, Kansas, Kentucky, Massachusetts, Minnesota, Nebraska, New Jersey, New York, South Carolina and Wyoming.

⁴⁷ New Jersey and Wyoming

Table 8: Eligibility for Waiver Services

State	Level of Care	Income	Resources	Other
CO	Specialized Nursing Facility Hospital	300% of federal SSI	\$2,000	Age 16 to 64 with a condition in a specified group of ICD-9 codes.
CT	Nursing Facility Intermediate Care Facility- Mental Retardation (ICF- MR) Chronic Disease Hospital Acquired Brain Injury Facility	300% of federal SSI	\$1,600	Age 18 and to 64 with an acquired brain injury not from a degenerative or a developmental disorder.
FL	Skilled Nursing Facility	300% of federal SSI	\$2,000	Age 18 or older with a brain injury caused by external trauma and/or a spinal cord injury; must be medically stable.
IA	ICF-MR Intermediate Care Facility	300% of federal SSI	\$2,000	Age one month to 64 with a traumatic or non-traumatic injury to the brain that occurred since birth in a specified set of ICD-9 codes.
ID	Skilled Nursing Facility	300% of federal SSI	\$2,000	Have a brain injury attained after the age of 21 in one of a specified set of ICD-9 codes
IL	Skilled Nursing Facility	SSI MN, spend down to FPL	\$2,000	Any age with an acquired brain injury not including degenerative, congenital, or neurological disorders related to aging.
IN	Skilled Nursing Facility	SSI	\$1,500	Any age and have experienced an external insult resulting in a traumatic brain injury.
KS	Traumatic Brain Injury Rehabilitation Hospital	300% of federal SSI MN spend down to \$716	\$2,000	Age 16 to 64 and have a traumatic injury to the brain.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
KY	Skilled Nursing Facility	300% of federal SSI	\$2,000	Age 21 to 65 with a post-birth acquired brain injury excluding a stroke treatable in a nursing facility providing routine rehabilitation services, spinal cord injury with no brain injury, progressive dementia of a chronic degenerative nature (including alcoholism or another addiction),
MD	Skilled Nursing Facility Chronic Hospital	300% of federal SSI	\$2,000	Have a traumatic brain injury that occurred after age 21 and inpatient in a state Mental Hygiene Administration facility, a state owned and operated nursing facility, or placed by Medicaid in an out-of state facility.
MA	Specialized NF	100% FPL	\$2,000	Age 21 to 62 with a traumatic or non-traumatic brain injury that has occurred since birth.
MN	Skilled Nursing Facility Neurobehavioral Hospital	FPL MN spend down to 75% of FPL	\$3,000	Under age 65 at the time of application with a traumatic or acquired brain injury, or a degenerative disease (not congenital) with a cognitive impairment.
NE	Skilled Nursing Facility	FPL	\$4,000	Ages 21 to 64 and have a traumatic brain injury.
NH	Specialized NF	\$1,250	\$1,500	Age 22 or older with an acquired brain disorder (including degenerative conditions such as Multiple Sclerosis and Huntington's Disease) acquired between age 22 and 60.
NJ	Skilled Nursing Facility	300% of federal SSI	\$2,000	Ages 21 to 65 with a traumatic or acquired brain injury with an age of onset of 21 and a minimum score of 4 on the Rancho Los Amigos Levels of Cognitive Functioning Scale.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
NY	Skilled Nursing Facility	FPL	\$4,200	Age 21 to 64 with traumatic brain injury: individuals with deficits similar to traumatic brain injury because of anoxia, toxic poisoning, stroke or other neurological conditions may also be eligible. Gestational or birth difficulties or degenerative diseases are not eligible.
ND	Skilled Nursing Facility	SSI	\$3,000	Age 18 and older, determined disabled according to Social Security criteria. (See profile as this Waiver is now merged into the state's Aged and Disabled waiver
PA	Specialized Rehabilitation Nursing Facility	300% of federal SSI	\$2,000 after a \$6,000 disregard	Age 21 and older with a diagnosis of traumatic brain injury not of a degenerative, congenital or post-operative nature and requiring a service plan designed specifically to meet the needs of individuals with traumatic brain injury.
SC	Skilled Nursing Facility ICF-MR	300% of federal SSI	\$2,000	Under 65 with a brain injury that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder and is not congenital or induced by birth trauma. "Similar disabilities" are included if not progressive; degenerative; a result of chronic disease or alcohol/drug use; or not a neurological disorder related to aging.
UT	Skilled Nursing Facility	300% of federal SSI	\$2,000	Age 18 or older with an acquired brain injury that occurred after birth.
VT	Specialized Nursing Facility	300% of federal SSI	\$2,000	Age 16 or older with a recent traumatic brain injury that is not degenerative but that may include stroke.

Table 8 Eligibility for Waiver Services (continued)

	Level of Care	Income	Resources	Other
WI	Inpatient Traumatic Brain Injury Rehabilitation	300% of federal SSI	\$2,000	Any age and have a mechanical or infectious brain injury including one vascular in origin that is sustained by the person prior to attaining age 22. Not including alcoholism, Alzheimer’s disease or a like irreversible dementia.
WY	ICF-MR	300% of federal SSI	\$2,000	Age 21 to 64 with a traumatic or non-traumatic brain injury that has occurred since birth caused by an external physical force or by a metabolic disorder; not including congenital or birth trauma related injury and a specified score range on one or more standard assessments.

Source: Rutgers University, Center for State Health Policy, 2008.

Abbreviations used

300% of federal SSI – Is three times the amount of Supplemental Security Income paid by the federal government to eligible individuals. In 2008, this is \$1,911 (federal SSI is \$637).

SSI – the actual amount of SSI varies from state to state because the state may make supplemental payment in addition to the federal portion. There may also be variations within a state as the supplemental payment may differ with the type of setting of the individual.

FPL – In 2008, it is \$866.66/month for a single person in all states except Hawaii and Alaska. 75% of the Federal Poverty Level (FPL) is \$650.

MN – Medically Needy is an optional eligibility group that a state may elect to cover in its Medicaid State plan. However, even if a state covers this group for some services, they are eligible for waiver services in a state if specified in the state’s waiver. Medically Needy individual’s have incomes too high to qualify for Medicaid. This option allows them to “spend

down” to Medicaid eligibility limits by paying for medical care. The exact amount to which they need to spend down varies by state.

Waiver Services

The Social Security Act lists seven specific services that may be provided under a home and community-based services waiver: case management, homemaker services, home health aid services, personal care services, adult day health, habilitation, and respite care. In addition, states may apply for permission to provide other optional services above and beyond the services provided in the Medicaid state plan.⁴⁸ The state requests and defines the services it plans to provide on its waiver application.

The services that each of the states covers in its brain injury waiver were categorized, for the most part, according to a set of categories and definitions used in a report examining waiver services targeted to support individuals with intellectual and developmental disabilities.⁴⁹ These service categories are:

- Case Management/Service Coordination
- Supports of Participant Direction (Support Broker)
- In-Home Services
- Person-Directed Goods and Services
- Equipment/Supplies
- Vehicle Repair/Modification
- Respite
- Clinical Services
- Day Supports
- Environmental Accessibility Adaptations
- Health Related
- Financial Management Services
- Supported Employment
- Family and Caregiver Training
- Transportation
- Other

In order to not to over use the “other” category for the services developed and targeted to the needs of individuals with brain injuries, four additional categories were created for this report, in order to better quantify and describe offered services and they included:

- Residential

⁴⁸ Section 1915 of the Social Security Act available at http://www.ssa.gov/OP_Home/ssact/title19/1915.htm

⁴⁹ Smith, G.; Agosta, J.; Fortune, J. and O’Keeffe, J., Gauging the Use of HCBS Supports Waivers for People with Intellectual and Developmental Disabilities: Final Project Report, April 2007 available at: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>

Using the same service categories make it easier to compare the descriptions of services in the different reports.

- Night Supervision
- Substance Abuse
- Behavioral Services

Table 10 (see page 31) indicates the specific categories of services included in each state’s waiver. The Appendix “States Profiles,” contains more detailed information about the specific services that are included in the each state’s waiver.

Case Management is intake, assessment, service planning, and on going monitoring of individuals applying for, or enrolled in, the waiver.⁵⁰ All of the states surveyed provide case management. In all but four of the states, it is a waiver service. In these four states, it is a service available either through the State plan⁵¹ or included as a specified component part of the waiver service⁵².

Supports of Participant Direction is assistance to individuals/families that use consumer-directed services. Such assistance may include the development of the person-centered plan, managing individual budgets, recruiting workers, and accessing generic services and supports.⁵³ This service was reported available in only three states. It is a waiver service in only one of the three states, where it replaces case management if the individual chooses to utilize consumer-directed services.⁵⁴ The other two states reported that this service is required if the waiver participant chooses to use consumer-directed services.⁵⁵

In-Home Services include personal care/assistance, chore services, companion services, and homemaker services.⁵⁶ These services are available in all states except for two.⁵⁷ We have chosen to expand the definition of this category to include other waiver services that may be provided in an individual’s home and other settings, for example a workplace or a provider’s office. Examples of these services are:

- Behavioral programming
- Community Integration Counseling Service and Personal Adjustment Counseling and Training, a counseling service provided to a waiver participant who is coping with altered abilities and skills, the need to revise long term expectations, and changed roles in relation to significant others.
- Crisis Response Services which may also include training to staff related to the needs of the individual and/or emergency back-up staff to assist during the crisis.

⁵⁰ Smith et al.

⁵¹ Illinois, Kansas, and Massachusetts.

⁵² Nebraska offers one Waiver service, Assisted Living.

⁵³ Smith et al.

⁵⁴ Kentucky

⁵⁵ Iowa and Utah.

⁵⁶ Smith et al.

⁵⁷ Nebraska offers one Waiver service (Assisted Living) which specifically includes personal care and other services related to homemaker or chore services. North Dakota, which no longer operates a separate brain injury Waiver, included a service (Residential Care) that provided the essential elements of In-Home Services as major components.

- Family Counseling and Training as well as Family Assistance and Supports
- Home delivered meals
- Independent Living Skills Training and Transitional Living Skills
- Interim Medical Monitoring and Treatment
- Residential habilitation
- Respite care
- Supported living, individual support services, community support services, and home and community support services. These services are provided to waiver participants able to live independently or semi-independently in the community if provided services and supports to meet their needs. These include assistance in daily living skills, instrumental activities of daily living, use of community resources, community safety, and social skills. These may also include coaching/cueing services for consumers needing minimal or no “hands on” assistance.
- Therapy such as: occupational therapy, physical therapy, speech-language therapy, behavioral therapy, cognitive therapy, and drug and alcohol therapy

Person-Directed Goods and Services permit waiver participants to purchase goods and services that are not specifically covered in a waiver but contribute to meeting the person’s needs for assistance.⁵⁸ Services provided in this manner may also be referred to as “Cash and Counseling.”⁵⁹ Fourteen states provide at least one element of this service for participants in their brain injury waiver. Eleven provide this as a waiver service⁶⁰ and three permit participants to use consumer-directed options as included in the state plan.⁶¹ These last three states were among the initial participants in the Cash and Counseling Demonstration and Evaluation.⁶² As such, they may be expected to have more robust options available in their service system for all Medicaid beneficiaries, not just waiver participants. Six more of the states that cover these services in their brain injury waiver are expansion states in Cash and Counseling.⁶³

Equipment/Supplies including but not limited to adaptive equipment, augmentative communication devices, control switches, chairs and other mobility aids, and personal emergency response systems (PERS).⁶⁴ Nineteen states have specific waiver services that meet this definition. Two states cover items that meet this definition as part of Environmental Accessibility Adaptations but do not specifically include one or more waiver services, such as adaptive equipment or PERS that are clearly in this category.⁶⁵ The two remaining states⁶⁶ that do not provide this service cover a very

⁵⁸ Smith et al.

⁵⁹ <http://www.cashandcounseling.org/about>

⁶⁰ Connecticut, Iowa, Illinois, Kansas, Kentucky, Minnesota, New Hampshire, Pennsylvania, South Carolina, Utah and Wisconsin

⁶¹ Florida, New Jersey and New York (which did not complete the demonstration)

⁶² Florida, New Jersey and New York (which did not complete the demonstration)

<http://www.cashandcounseling.org/resources/20051205-134040/CDocumentsandSettingsVITALEBDesktopclibDeterminingPreferenceSurveyResults.pdf>

⁶³ http://www.cashandcounseling.org/about/participating_states

⁶⁴ Smith et al.

⁶⁵ Kentucky and New Jersey

limited number of services, primarily in a residential setting, to a small number of individuals.

Executive function deficits are common and associated with damage to the frontal lobes of the brain. These impairments can have marked impact on a person's ability to initiate, plan, organize, and complete everyday and higher-level tasks related to activities of daily living and to work tasks. They may hinder the person's ability to follow-through with suggestions and to use compensatory strategies.⁶⁷ Providing flexibility in the types of equipment that can be purchased can be beneficial in assisting an individual to compensate for these functional deficits and at the same time help the persons to be self-reliant. A wide variety of "off the shelf" electronic equipment, specialized equipment, adaptive aids, as well as web-based applications and computer software, is available to assist individuals.

Vehicle Repair/Modification provides for alterations to a vehicle to accommodate a person with a physical disability.⁶⁸ Either eleven states cover this as a waiver service either explicitly or as an option that can be covered through Environmental Modifications.⁶⁹

Respite is relief to a person's primary caregiver and is provided in 18 states as a distinct service.⁷⁰ As noted above, three states, the two previously noted,⁷¹ and a third⁷² provide a very limited number of services, primarily in residential settings staffed by paid shift workers, where respite would not be an expected or appropriate service. Another state's waiver has a strong rehabilitation focus and provides the supportive services an individual needs to become independent;⁷³ the focus of respite is on the caregiver, so it is not surprising that it is not a covered service in this waiver. One state that offers a wide array of waiver services and does not offer respite as a distinct service does provide "companion care" for up to 6 hours/day of supervision and assistance as relief for caregivers.⁷⁴

Clinical Services include physical therapy, occupational therapy, behavioral interventions, speech and language services, and similar services performed by credentialed professionals.⁷⁵ These services are included in 18 states as a waiver service. Of the five states not offering clinical services, one state provides these services through the state plan with few limitations, as long as the individual is making progress towards

⁶⁶ Maryland and Nebraska

⁶⁷ <http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact>

⁶⁸ Smith et al.

⁶⁹ Connecticut, Iowa, Indiana, Minnesota, New Hampshire, New Jersey, New York, Pennsylvania, South Carolina, Wisconsin and Wyoming

⁷⁰ Smith et al.

⁷¹ Maryland and Nebraska

⁷² North Dakota

⁷³ Kansas

⁷⁴ Florida

⁷⁵ Smith et al.

goals.⁷⁶ Another also uses its state plan for these services despite there being issues with the state plan limits on scope and duration of services.⁷⁷ Finally, three states provide residential service as a component the primary waiver service but do not consider residential services as a distinct waiver service.⁷⁸

For the purposes of this report, we also included additional therapies provided by professional specialists. Cognitive, physical, emotional, and behavioral impairments may follow brain injury. Physical, motor, and basic sensory functions can be affected. Individuals with brain injury may also have subtle to significant impairments in their perception, language, attention, concentration, information processing, learning, and/or memory.⁷⁹ In addition to the basic clinical services noted above, we expanded the definition to include additional specialized services (cognitive therapy, psychological and other counseling, other specialty services and crisis response) that are needed to rehabilitate and provide on-going support to many individuals with a brain injury.

Thirteen states provide one or more of these services as a defined waiver service: cognitive therapy is provided by eight states⁸⁰, psychological and other counseling is provided by six states,⁸¹ other specialty therapy is provided by two states,⁸² and crisis response is offered by one state.⁸³ The individual state profiles provide information about the specific services covered and whether they are unique waiver services or extended state plan services.

Day Supports are services furnished outside the person's residence in facility-based settings such as day habilitation centers or in the community to promote community inclusion (e.g., community participation).⁸⁴ Eighteen states provide this service,⁸⁵ and one state includes day service in its definition of specialized assisted living.⁸⁶ Supported employment is a separate category and was, therefore excluded from this category. Pre-vocational service is, however, included in this category and is provided by seven states.⁸⁷ One state provides day supports as a component of crisis service.⁸⁸

Environmental Accessibility Adaptations are home modifications to accommodate physical disabilities (e.g., ramps, bathroom modifications, and others). Nineteen states provide this service. The three states that provide residential service as

⁷⁶ Iowa

⁷⁷ Utah

⁷⁸ Maryland, Nebraska and North Dakota provide primarily residential service.

⁷⁹ <http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact>

⁸⁰ Colorado, Connecticut, Illinois, Kansas, Minnesota, New Jersey, Pennsylvania and Wyoming

⁸¹ Florida, New Jersey, New York, Pennsylvania, South Carolina and Wisconsin

⁸² New Hampshire and Vermont

⁸³ New Hampshire

⁸⁴ Smith et al.

⁸⁵ the exceptions being Connecticut, Florida and North Dakota

⁸⁶ Nebraska

⁸⁷ Iowa, Illinois, Minnesota, Pennsylvania, South Carolina, Wisconsin and Wyoming

⁸⁸ Vermont

the sole or primary waiver service⁸⁹ do not provide these modifications because the residential setting is expected to be accessible. Only one state provides a broad array of waiver services does not cover this service.⁹⁰

Health-Related Services are “typically skilled nursing services.”⁹¹ These services are provided as waiver services in seven states.⁹² These services are also included by one additional state in its definition of specialized assisted living.⁹³

For the purposes of this report, the definition of health-related services was expanded to reflect additional ways states are meeting the specialized needs of individuals with brain injury. One state that provides nursing services also provides health education for individuals using consumer-directed care as a waiver service.⁹⁴ Another state provides Interim Medical Monitoring and Treatment, which it defines as monitoring and treatment of a medical nature, requiring specially trained caregivers beyond those normally available in a day care setting for persons age 20 and under.⁹⁵ One state provides limited oral health services not available through its state plan.⁹⁶ One state provides both crisis response services and specialty services for participants whose medical, behavioral, therapeutic, health and personal well being require these specialized services for the unique conditions and aspects of acquired brain disorders.⁹⁷

Financial Management Services are those that support individuals who directly hire their own workers and/or manage an individual budget.⁹⁸ These services include payroll, accounting, hiring, training in employer skills, and similar activities that individuals exercising the consumer-directed services option need to perform. Only three states provide these services as part of waiver services.⁹⁹ Four additional states make these services available to individuals who choose consumer direction, but it is not considered a waiver service.¹⁰⁰ One of these latter four states requires that financial management service be used if an individual elects to use consumer-directed services.¹⁰¹

Supported Employment is a service to assist individuals to secure regular community jobs and support their on-going employment. It is offered by waivers in 16 states.¹⁰²

⁸⁹ Maryland, Nebraska and North Dakota

⁹⁰ Utah

⁹¹ Smith et al.

⁹² Idaho, Illinois, Indiana, Pennsylvania, South Carolina, Wisconsin and Wyoming

⁹³ Nebraska

⁹⁴ South Carolina

⁹⁵ Iowa

⁹⁶ Kansas

⁹⁷ New Hampshire

⁹⁸ Smith et al.

⁹⁹ Connecticut, New Hampshire and Wisconsin

¹⁰⁰ Iowa, Kansas, New Jersey and Utah

¹⁰¹ Iowa

¹⁰² Connecticut, Idaho, Illinois, Indiana, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, New Hampshire, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin and Wyoming

Family and Caregiver Training includes services that teach family members and/or caregivers to perform activities that address one or more dimensions of a person's disability.¹⁰³ Rather than limit the definition to training, we have expanded it to include counseling, therapy, and treatment involving the family and/or caregiver as well as the individual. Twelve states provide one or more services that have at least one of these elements.¹⁰⁴ One of these states specifically includes substance abuse treatment services,¹⁰⁵ two of these states specifically include services of a dietician,¹⁰⁶ and three of these states specifically include family training as part of the behavioral programming service.¹⁰⁷

Transportation to community activities and/or other waiver services is a service offered by 12 states,¹⁰⁸ and another state specifically includes transportation in the single broadly defined waiver service that it provides.¹⁰⁹

The following service categories were created for this report:

Residential Services are services that provide the individual with a place to live as well as some, or all, of the supports needed by the individual. This is one additional category developed for this paper. Fifteen states make some type of residential service available to waiver participants.¹¹⁰ Federal matching funds may only be used to make deposits on residences and for services within the living setting, but not for room and board. These services include 24-hour support and assistance from a licensed or otherwise approved, provider. Examples of residential services are:

- Assisted Living, Assisted Living Plus and Specialized Assisted Living
- Habilitation and Support as well as Residential Habilitation
- Residential Care Facility, Residential Care Services, Residential Care
- Supportive Living, Supported Community Living, Community Residential Services, Personal Care Services and Community Living Supports
- Transitional Living – designed to be a short-term service to prepare an individual for more independent living.

Note: In some cases, these services may also be provided to individuals living with family or in a home of their own.

These services are provided in several different settings as detailed below.

¹⁰³ Smith et al.

¹⁰⁴ Colorado, Connecticut, Florida, Idaho, Iowa, Kentucky, Massachusetts, Minnesota, New York, Pennsylvania, Utah and Wyoming

¹⁰⁵ Colorado

¹⁰⁶ Pennsylvania and Wyoming

¹⁰⁷ Connecticut, Florida and New York

¹⁰⁸ Colorado, Connecticut, Idaho, Iowa, Massachusetts, Minnesota, New Jersey, New York, Pennsylvania, South Carolina, Utah and Wisconsin

¹⁰⁹ Nebraska

¹¹⁰ Colorado, Connecticut, Iowa, Kentucky, Maryland, Massachusetts, Minnesota, Nebraska, New Hampshire, New Jersey, North Dakota, Pennsylvania, Utah, Wisconsin, Wyoming

Table 9: Residential Service Settings

Type of Setting	Number of States
Residential Care Facility	3
Assisted Living Facility (may be specialized for individuals with a brain injury)	2
Group Home, or other small home with paid staff	5
Foster Care	4
Unspecified Congregate Facility	6

Note: Totals to more than 15 because some states offer services in more than one type of setting

Source: Rutgers University, Center for State Health Policy, 2008.

Night Supervision services provide physical assistance and/or supervision during normal sleeping hours in the individual's place of residence. Typically, this service includes: physical assistance or supervision with toileting, transferring, turning, feeding of liquids, mobility; and prompting and reminding of medication when the individual's mobility, memory and cognition is affected by the brain injury. These services are provided in eight states. In four of these states, the service is referred to as either night supervision or sleep cycle support.¹¹¹ In the other four states, the service is part of a broader community living support service.¹¹²

Other states that did not specifically report providing this service provide similar in-home supports for waiver participants. Additionally, one state reported that night supervision was not billable by providers of residential service because it was expected that providers would deliver essentially the same service whenever it was required by the resident(s).¹¹³ We believe it is reasonable to consider it likely that this service is more widely available than reported.

Substance Abuse Services assist the individual in building skills to resist alcohol and drug use, to replace alcohol and/or drug-using activities with constructive and rewarding non-alcohol and non-drug-using activities, and to address associated problems. The incidence of substance abuse among individuals who survived a traumatic brain injury is high. It is estimated that over half of the individuals who sustained a traumatic brain injury were substance abusers prior to the injury, and that from 25% to 50% continue to abuse alcohol after their injury.¹¹⁴

¹¹¹ Kansas, Minnesota, New Jersey and Pennsylvania

¹¹² Connecticut, Iowa, Utah and Vermont

¹¹³ New Jersey

¹¹⁴ Katz, R., "Substance Abuse In TBI Survivors" available at http://www.tbihelp.org/substance_abuse_in_tbi.htm

These services are available as waiver services in seven states¹¹⁵ and are either a stand-alone service specifically for substance abuse or part of a broader counseling service. One state reported that substance abuse services are available to waiver participants through its mental health system.¹¹⁶

Behavioral Services assist the individual to change behavior, replacing maladaptive, badly adjusted, or self-destructing behaviors by learning new, more appropriate behaviors. A brain injury can modify an individual's emotional behavior and behavior patterns. Emotional changes may include depression, anxiety, and problems with substance abuse. Behavioral problems include difficulties with emotional control and problems with controlling anger and aggression.¹¹⁷ Behavioral issues often are the greatest challenge faced by family and other persons involved with an individual sustaining a brain injury. Individuals with brain injury are effectively served by providers that are aware of or sensitive to the unique issues faced by the individual with a brain injury. If the provider is not aware of the unique issues, there is an increased chance that the relation between the brain injury and the behavior will become blurred, disregarded, or sometimes completely lost.¹¹⁸

Sixteen states provide behavioral services as a distinct waiver service, and two states¹¹⁹ provide behavior services as a defined part of their residential service. Although five states do not provide a discrete service labeled “behavioral,” they each offer broad services such as residential care, habilitation, or support services that may be expected to provide behavioral interventions.¹²⁰

Other - Eleven states offer one or more of the services described briefly below.

- Adaptive Health and Wellness - membership in a “health studio” to follow an exercise regimen ordered by a physician and designed by a physical therapist.¹²¹
- Community Integration Services and related training enable the consumer to plan for and engage in meaningful adult activities.¹²²
- Community Transition – one-time costs to relocate from an institution to the community or to obtain the individual’s first community home is offered in four states.¹²³
- Home delivered meals are available to waiver participants in four states.¹²⁴
- Independent Living Skills Therapies – art, music and recreation therapies¹²⁵
- Interpreter service¹²⁶

¹¹⁵ Colorado, Florida, Kansas, Kentucky, Massachusetts, New Jersey, and New York

¹¹⁶ Connecticut

¹¹⁷ <http://vesid33.nysed.gov/publications/briefs/braininjury/#What%20is%20the%20Impact>

¹¹⁸ <http://www.nashia.org/issues/neurobehavioral.html>

¹¹⁹ Maryland and Nebraska

¹²⁰ Massachusetts, North Dakota, Utah, Wisconsin and Wyoming

¹²¹ Florida

¹²² Pennsylvania

¹²³ Minnesota, New York Pennsylvania and Wisconsin

¹²⁴ Illinois, Indiana, Minnesota and Wisconsin

¹²⁵ Minnesota

- Mental Health, including Psychological Testing¹²⁷
- Prescribed drugs beyond state plan limits.¹²⁸
- Specialized Assisted Living – with service components of: adult day care, escort services, essential shopping, health maintenance activities, housekeeping activities, laundry services, meal service, medication assistance, personal care services, transportation services, behavioral services.¹²⁹
- Training or education services that help the waiver participant re-learn or regain skills and knowledge that were lost due to the brain injury, or assist in acquiring new skills to compensate for lost skill(s), are available in three states.¹³⁰
- Transitional living designed to assist an individual move from a congregate or institutional setting to his/her own home.¹³¹

¹²⁶ Massachusetts

¹²⁷ Minnesota

¹²⁸ South Carolina

¹²⁹ Nebraska

¹³⁰ Florida, Pennsylvania and Wisconsin

¹³¹ North Dakota

Table 10: Services Covered as Waiver Services

Services Offered by States	CO	CT	FL	IA	ID	IL	IN	KS	KY	MD	MA	MN	NE	NH	NJ	NY	ND	PA	SC	UT	VT	WI	WY
Case Management	X	X	X	X	X	X	X	1	X	X	1	X	4	X	X	X	X	X	X	X	X	X	X
Supports of Participant Direction (Support Broker)				1,2					X3											2			
In-Home Services	X	X	X	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X
Person-Directed Goods and Services		X	1	X		X		X	X			X		X	1	1		X	X	X		X	
Equipment/Supplies	X	X	X	X	X	X	X	X			X			X		X	X	X	X	X	X	X	X
Vehicle Repair/Modification		X		X			X					X		X	X	X		X	X			X	X
Respite	X	X		X	X	X	X		X		X	X		X	X	X		X	X	X	X	X	X
Clinical Services	X	X	X	1	X	X	X	X	X		X	X		X	X	X		X	X		X	X	X
Day Supports	X			X	X	X		X	X	X	X	X	4	X	X	X		X	X	X	X	X	X
Environmental Accessibility Adaptations	X	X	X	X	X	X	X	X	X		X	X		X	X	X		X	X			X	X
Health Related				X	X	X	X	X					4	X				X	X			X	X
Financial Management Services		X		1,2				1						1	1					2		X	
Supported Employment		X		X	X	X	X		X	X	X	X		X				X	X	X	X	X	X
Family and Caregiver Training	X	X	X	X	X				X		X	X				X		X		X			X
Transportation	X	X		X	X						X	X	4		X	X		X	X	X		X	
Residential	X	X		X					X	X	X	X	4	1	X		X	X		X		X	X
Night Supervision		X		X				X				X			X			X		X	X		
Substance Abuse	X	1	X					X	X		X				X	X							
Behavioral Services	X	X	X	X	X	X	X	X	X			X	4	X	X	X		X	X		X		
Other			X			X	X				X	X	X			X	X	X	X			X	

Note: See State profile for specific services. State plan services may provide a service not specifically indicated.

- 1 – Service is available to Waiver participants, but not as a specific Waiver service.
- 2 – Service is required if the individual is using consumer-directed services.
- 3 – Replaces case management if the individual is using consumer-directed services.
- 4 – The service is specifically delineated in the definition of Assisted Living.

Source: Rutgers University, Center for State Health Policy, 2008.

Other Considerations

Focus of the Waiver

Medicaid waivers providing Home and Community-Based Services are generally considered part of the long-term care service system. In most states, the waiver for individuals with brain injury can also be characterized in this fashion. Individuals are provided with services that support them in a community-based living arrangement, and they continue to receive services for as long as they are needed.

Five states have structured their waiver services in another way: they focus primarily on rehabilitation.¹³² Rather than provide supports designed to meet the long-term care needs of those individuals in the waiver, the services provided are designed to provide rehabilitation and community reintegration, as well as to provide the other supports needed to reside in a community-based living arrangement.

These “rehabilitation” waivers may have level of care requirements that are more stringent than nursing facility, including specialized nursing facility, hospital, rehabilitation hospital, or intermediate care facility. There may also be additional requirements that:

- the brain injury be relatively recent;
- the individual requires goal-oriented therapy with medical management;
- the individual requires and benefits from specialized rehabilitation services;
- significant supervision and structure is necessary to manage the individual;
- there is a prognosis for continued functional improvement;
- there is potential for rehabilitation and reintegration into the community;
- progress must be demonstrated in the annual review;
- an administrative review be conducted when an individual is in the waiver for a specified number of years; and,
- the individual demonstrates benefit from the program from which he/she is referred.

Kentucky submitted a long-term care waiver to CMS for individuals with brain injury. CMS approval had not been received at the time of contact with the state. Vermont’s waiver had a very strong rehabilitation focus, but not all of the individuals initially enrolled had made the progress that they needed to be successfully discharged from the waiver. Accordingly, there was a long-term services option for these individuals.

Cost Effectiveness

¹³² Colorado, Iowa, Kansas, Kentucky and Vermont

Providing home and community-based services (HCBS) to individuals with brain injury is less expensive than providing services in nursing homes, hospitals, and similar institutions. Data including institutional costs were available from 17 of the surveyed states; only waiver data were available from the remaining states. In these 17 states alone, a total of almost \$273 million was saved annually by providing home and community-based services when compared to the institutional cost of services for the same number of individuals. On average, \$30,000 per person was saved.

Table 11 shows the state data for home and community-based services and institutional services costs, as well as the number of individuals who received services in that year. Data from the most recent waiver year available was used. Typically, this was 2006, but in a few cases it was an earlier year (indicated with a note). Institutional cost data was not available for every state.

In waiver applications, a state must demonstrate that the estimated cost of HCBS under the waiver will not exceed the estimated cost of providing institutional services. Two terms are used in the waiver application that states must submit, as well as in annual reports that are required for waivers. “Factor D” is the total cost of waiver services provided during the year, divided by the number of individuals who received waiver services in that year. “Factor G” is the average per person cost of services in the institution(s) used for the waiver’s level of care.

As indicated in Table 11, states experience cost savings with HCBS, as these costs are lower than the cost of institutional services.

Table 11: Cost-Effectiveness of Brain Injury Waivers

State	Factor D Per Capita Cost HCBS	Factor G Per Capita Cost Institution	Difference Factor G & Factor D	Unduplicated Participants	Total Savings
Colorado	\$30,811	\$58,556	\$27,745	293	\$8,129,172
Connecticut (1)	\$74,683	\$117,588	\$42,905	344	\$14,759,261
Florida	\$20,860	\$32,521	\$11,661	283	\$3,300,033
Idaho	\$59,660	nr		19	
Illinois	\$11,814	\$20,008	\$8,194	3,601	\$29,507,582
Indiana	\$25,884	\$39,322	\$13,438	131	\$1,760,424
Iowa	\$13,192	nr		825	
Kansas	\$23,379	\$61,603	\$38,224	269	\$10,282,136
Kentucky (2)	\$66,659	nr		98	
Maryland (1)	\$64,753	\$171,710	\$106,957	23	\$2,460,009
Massachusetts	\$54,265	nr		90	
Minnesota (1)	\$50,266	\$105,052	\$54,786	1372	\$75,166,045
Nebraska	\$28,202	\$67,058	\$38,856	26	\$1,010,261
New Hampshire (3)	\$82,223	\$118,346	\$36,123	119	\$4,298,637
New Jersey	\$66,575	\$83,727	\$17,152	276	\$4,733,855
New York	\$40,465	\$71,297	\$30,832	1953	\$60,213,921
North Dakota	\$27,496	nr		29	
Pennsylvania (2)	\$45,380	\$125,587	\$80,207	285	\$22,858,995
South Carolina (1)	\$24,642	\$40,586	\$15,944	497	\$7,924,114
Utah	\$22,848	\$29,916	\$7,068	91	\$643,215
Vermont (3)	\$53,719	\$160,600	\$106,881	51	\$5,450,931
Wisconsin	\$60,165	nr		334	
Wyoming	\$28,766	\$175,715	\$146,949	137	\$20,132,077
Total Savings					\$272,630,668

Notes:

(1) state uses 2 or more institutions

(2) 2005 data

(3) 2004 data

“nr” indicates no response. Factor G data not reported, state data provided was in a form other than a complete CMS 372 report

.nr

Source: Rutgers University, Center for State Health Policy, 2008

Conclusions

Medicaid waivers targeted to individuals with brain injuries operate in half of the states and are small when compared to waivers targeting other groups. These waivers provide significant cost savings, on average \$30,000 annually per person, when compared to institutional facility-based services.

A state's experience and policies for its other waivers, especially financial eligibility, will set the parameters within which a waiver for individuals with brain injuries will operate. State officials, advocates, and others considering whether to pursue a new waiver or modifying an existing waiver may benefit from the experiences of other states by examining and considering the waivers described in this paper in order to make decisions about four key areas:

- What age range and how many persons will be included in the waiver?
- What services will be included and what costs may be expected? Will the waiver have a long-term care focus, a rehabilitation focus, or both? Will the cause of the brain injury (e.g. traumatic or acquired) be a determining factor in an individual's eligibility for the waiver?
- What institution will be used to determine the level of care? Will more than one be used?
- What providers will be enrolled and how will case management be done?

These waivers have been successful both programmatically and financially. In addition to cost savings, these waivers have provided other significant benefits. The existence of these waivers supports the growth of community non-profit brain injury agencies. There is clear evidence of the desirability of home and community-based services among those directly affected by brain injury: there has been growth of these waivers that has resulted in a doubling of the number of persons served over five years; and, there is a visible role played by advocates in encouraging states to develop these waivers. These waivers, over time, have contributed to states' efforts to create and grow an in-state service capacity to provide services to individuals with brain injuries.

Terminology/Glossary

The following frequently used terms in this report may not be familiar to every reader.

Acquired Brain Injury - According to The Brain Injury Association of America (BIAA), acquired brain injury is an injury to the brain which is not hereditary, congenital, degenerative, or induced prior to birth or by birth trauma.¹³³ An acquired brain injury may result in mild, moderate, or severe impairments in one or more areas, including cognition; speech-language communication; memory; attention and concentration; reasoning; abstract thinking; physical functions; psychosocial behavior; and information processing.¹³⁴

This definition does not exclude traumatic brain injuries.

Birth trauma - refers to a physical injury to the infant that occurred during the birth process.

Centers for Medicare and Medicaid Services (CMS) - The federal agency, within the Department of Health and Human services, that administers the Medicare and Medicaid programs; it also administers the State Children's Health Insurance Program. It was initially established as the Health Care Financing Administration.¹³⁵

Cost neutral (or cost neutrality) - When the average per capita expenditure by the State in any fiscal year for medical assistance provided under a Waiver to Waiver participants does not exceed 100 percent of the average per capita expenditure that the State reasonably estimates would have been made in that fiscal year for expenditures under the State plan for these individuals if the Waiver had not been granted.¹³⁶ A state uses estimates of these service costs when applying for a Waiver. Once a state is operating a federally approved Waiver, actual costs are used.

Developmental Disability - according to the Developmental Disabilities Assistance and Bill of Rights Act of 2000, the term "developmental disability" means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency; and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or

¹³³ <http://www.biausa.org/education.htm#causes>

¹³⁴ http://www.biausa.org/Pages/types_of_brain_injury.html#aquired

¹³⁵ <http://www.hhs.gov/about/whatwedo.html/>

¹³⁶ Social Security Act, Section 1915(c) (2) (D)

other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.¹³⁷

Federal Poverty Level - The commonly used term for the federal Health and Human Services Poverty Guideline. The poverty guidelines are a federal poverty measure issued each year by the Department of Health and Human Services (HHS). The guidelines derived from more detailed “poverty thresholds.” The guidelines are used for administrative purposes, for instance, determining financial eligibility for certain federal programs.

The poverty guidelines are designated by the year in which they are issued; the guidelines issued in January 2008 are designated the 2008 poverty guidelines. However, the 2008 HHS poverty guidelines only reflect price changes through calendar year 2007 as measured by the Consumer Price Index.¹³⁸ The 2008 poverty guideline for a one-member household is \$10,400 in all states except Alaska and Hawaii where it is higher.¹³⁹

Medicaid 1915(c) Home and Community-Based Services (HCBS) Waiver - these are frequently referred to as an HCBS Waiver, a Medicaid Waiver, or just Waiver. According to the federal Department of Health and Human Services,¹⁴⁰ states may offer a variety of services to consumers under an HCBS Waiver program with no limit on the number of services that can be provided. A combination of traditional medical services as well as non-medical services (i.e. respite, case management, environmental modifications) is permitted. Similarly, states may determine the maximum number of individuals that will be served in a HCBS Waiver program.

Spinal Cord Injury - According to the National Spinal Cord Injury Association, spinal cord injury (SCI) is damage to the spinal cord that results in a loss of function such as mobility or feeling. In addition, individuals with SCI also experience other changes such as: bowel and bladder dysfunction; in the case of very high neck injuries, loss of many involuntary functions including the ability to breathe, necessitating breathing aids such as mechanical ventilators or diaphragmatic pacemakers; low blood pressure; inability to regulate blood pressure effectively; reduced control of body temperature; inability to sweat below the level of injury; and chronic pain.

The spinal cord is the major bundle of nerves that carries nerve impulses to and from the brain to the rest of the body. It is surrounded by rings of bone called vertebra. These bones constitute the spinal column (back bones) and neck. In general, the higher in the spinal column the injury occurs, the more dysfunction a person will experience.

Frequent causes of damage are trauma (car accident, gunshot, falls, etc.) or disease (polio, spina bifida, Friedreich's Ataxia, etc.). The spinal cord does not have to be severed in order for an individual to experience loss of functioning; most of the time

¹³⁷ 114 STAT. 1684 Public Law 106-402

¹³⁸ <http://aspe.hhs.gov/poverty/08poverty.shtml>

¹³⁹ *Federal Register*, Vol. 73, No. 15, January 23, 2008, pp. 3971–3972

¹⁴⁰ [http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915\(c\).asp](http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp)

the spinal cord is intact, but damaged. SCI is very different from back injuries such as ruptured disks, spinal stenosis or pinched nerves.

It is possible for an individual to "break their back or neck" yet not sustain a spinal cord injury. This would occur when only the bones around the spinal cord (the vertebrae) are damaged, but the spinal cord is not affected. In these situations, the individual may not experience paralysis after the bones are stabilized.¹⁴¹

Stroke (also referred to as cerebrovascular accident or CVA) – According to the National Stroke Organization,¹⁴² there are two types of stroke:

- Ischemic stroke – blocked arteries resulting from blood clots or by the gradual build-up of plaque and other fatty deposits and
- Hemorrhagic stroke - a blood vessel in the brain breaks, leaking blood into the brain.

When an individual has a stroke, brain cells begin to die and brain damage occurs. Where the stroke occurs in the brain and how serious the brain damage is determine what abilities (such as speech, movement and memory) are lost and how serious the loss is.

Supplemental Security Income (SSI) - a federal program that gives monthly cash payments to people who are age 65 or older or are blind or have a disability and who also have low income and few resources. The Social Security Administration runs the SSI program deciding who is eligible, making payments and keeping a master record of recipients. Even though Social Security runs the program, SSI is not Social Security; it is not financed by Social Security trust funds.

In 2008, the highest federal SSI payment is \$637 a month for a person and \$956 a month for a couple. States may add money to the federal SSI payments and may change the payment amounts based on where and with whom people live. States can let the federal government manage the state supplement and pay the costs. In these states, individuals apply at a Social Security office. Or, a state may manage its own supplement. In states that manage the supplement, individuals must apply to the state for the supplement. States managing their own supplement are: Alabama, Alaska, Arizona, Colorado, Connecticut, Florida, Idaho, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Minnesota, Missouri, Nebraska, New Hampshire, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, South Carolina, South Dakota, Texas, Virginia, Washington, Wisconsin and Wyoming.¹⁴³

Traumatic Brain Injury - According to the Centers for Disease Control, a traumatic brain injury is an injury to the head that is documented in a medical record, with one or more of the following conditions attributed to head injury:

- observed or self-reported decreased level of consciousness,
- amnesia,

¹⁴¹<http://www.spinalcord.org/news.php?dep=17&page=94&list=1190>

¹⁴² http://www.stroke.org/site/DocServer/STROKE_101_Fact_Sheet.pdf?docID=4541

¹⁴³ <http://www.socialsecurity.gov/pubs/11015.html> and *Federal Register*, Vol. 73, No. 15, January 23, 2008, pp. 3971–3972

- skull fracture,
- objective neurological or neuropsychological abnormality,
- diagnosed intracranial lesion¹⁴⁴

The BIAA defines a traumatic brain injury (TBI) as an insult to the brain, not of a degenerative or congenital nature but caused by an external physical force, that may produce a diminished or altered state of consciousness, which results in an impairment of cognitive abilities or physical functioning. It can also result in the disturbance of behavioral or emotional functioning. These impairments may be either temporary or permanent and cause partial or total functional disability or psychosocial maladjustment.¹⁴⁵

Typically, the cause is a blow or jolt to the head or a penetrating head injury that disrupts the function of the brain. Not all blows or jolts to the head result in a TBI. The severity of such an injury may range from "mild," i.e., a brief change in mental status or consciousness, to "severe," i.e., an extended period of unconsciousness or amnesia after the injury. A TBI can result in short or long-term problems with independent function.¹⁴⁶

¹⁴⁴ Thurman DJ, Sniezek JE, Johnson D, et al. Guidelines for Surveillance of Central Nervous System Injury. Atlanta: Centers for Disease Control and Prevention, 1995

¹⁴⁵ http://www.biausa.org/Pages/types_of_brain_injury.html#tbi

¹⁴⁶ <http://www.biausa.org/aboutbi.htm>

APPENDIX: STATE PROFILES

Service Category	Y/N	Specific Service
In-Home Services	Y	Independent Living Skills Training Personal Care Supported Living
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Assistive Equipment
Vehicle Repair/Modification	N	
Respite	Y	Respite Care
Clinical Services	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Day Support	Y	Adult Day Services Day Treatment
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Transportation	Y	Non-medical Transportation
Residential	Y	Supported Living Transitional Living
Night Supervision	N	
Substance Abuse	Y	Counseling and Training Including Substance Abuse Treatment and Family Counseling
Behavioral Services	Y	Behavioral Programming

Monthly cost limit: \$22,500.

Background:

Colorado began this Medicaid Waiver in 1995 as a result of legislation stemming from a citizen based initiative calling for the development of a comprehensive community-based rehabilitation program for Medicaid funded people who had sustained acquired or traumatic brain injuries.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	384	\$6,462,081	\$16,828	235	\$72
2003	404	\$8,337,702	\$20,638	267	\$77
2004	368	\$8,945,382	\$24,308	278	\$87
2005	328	\$9,002,955	\$27,448	255	\$108
2006	293	\$9,027,736	\$30,811	247	\$125

Waiver year is July 1, to June 30

Waiting List: None.

Connecticut

Waiver Name: Acquired Brain Injury Waiver

Operated by the Department of Social Services, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$1,600 or less.

Levels of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)
Chronic Disease Hospital
Acquired Brain Injury Facility
Nursing Facility

Must be between the ages 18 and 64 with an acquired brain injury; it does not include degenerative disorders or developmental disorders. An individual with cognitive impairment who does not qualify for the state's mental retardation services may qualify for the waiver; the state defines the developmental period as ending at 18.

After an initial screening of records, the individual is assessed by a social worker in person to determine the level of care.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal Care Assistance Homemaker Services Chore Services Respite Care Companion Services Home Delivered Meals Independent Living Skill Training – development and implementation of a plan to assist the individual to meet ADL and IADL needs. Individuals are expected to require this service for a limited duration and then transition to companion services.
Person Directed Goods and Services	Y	Personal Care Assistance Homemaker Services Chore Services Companion Services
Equipment/Supplies	Y	Specialized Medical Equipment and Supplies Personal Emergency Response Systems
Vehicle Repair/Modification	Y	Vehicle Modification Services
Respite	Y	Respite Care
Clinical Services	Y	Cognitive/Behavioral Programs
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Accessibility Adaptations
Health Related	N	
Financial Management Services	Y	One has been selected by the state to be available to participants.
Supported Employment	Y	Supported Employment
Family and Caregiver Training	Y	Cognitive/Behavioral Programs
Transportation	Y	Transportation
Residential	Y	Transitional Living Services – time limited and also limited to individuals requiring increased supports when relocating from an institution.
Night Supervision	Y	Community Living Support Systems – scheduled one to one supervision, typically overnight. May be shared among roommates in an apartment or among several apartments if there is a cluster.

Service Category	Y/N	Specific Service
Substance Abuse	N	This service is available, through the state's mental health system
Behavioral Services	Y	Cognitive/Behavioral Programs

Monthly cost limits are defined by policy as 200% of the level of care cost. The waiver is managed in aggregate.

Nursing facility - \$10,260

Acquired Brain Injury Facility - \$19,600

ICFs/MR – \$25,867

Chronic Disease Hospital - \$57,200

Background:

Connecticut began this waiver in 1997, in part because of litigation. Advocates, including the state's brain injury association, protection and advocacy, and legal services participated in developing the waiver. Among the reasons for developing the waiver were: service maximization, provision of long-term care supports in the community and an effort to move away from a model of "intrusive" staff support.

The waiver has remained generally stable since its inception. In the most recent renewal, the waiver was changed to allow individuals already enrolled to remain in this waiver after they are 65. Application still must be made before age 65.

One unique aspect of the waiver administration is that the state uses a separate entity to process all bills for waiver services. Case managers submit service authorizations to this entity, which then enters them into a claims management system. Waiver providers submit their bill(s) to this entity and the bill is reviewed to assure that it is based on an authorized service. The entity then submits the appropriate claim to the state's Medicaid fiscal intermediary for payment.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	157	\$9,072,381	\$57,786	293	\$197
2003	193	\$12,278,239	\$63,618	292	\$218
2004	232	\$15,750,722	\$67,891	242	\$281
2005	304	\$21,949,671	\$72,203	301	\$240
2006	344	\$25,691,011	\$74,683	305	\$245

Waiver year is January 1 to December 31

Waiting List: None at this time, but close to maximum number of individuals of 369.

Florida

Waiver Name: Traumatic Brain Injury and Spinal Cord Injury HCBS Waiver

Operated by the Department of Health, a separate department from the single State agency (Agency for Health Care Administration).

Target Population: Traumatic Brain Injury (and/or Spinal Cord Injury)

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Skilled Nursing Facility

Be age 18 or older, have a brain injury caused by an external trauma and/or a spinal cord injury and be medically stable. The Department of Elder Affairs determines the level of care based upon an assessment instrument and administrative process designated by the single State agency.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Community Support Coordination – every individual enrolled in the waiver must receive this service
Support Broker	N	
In-Home Services	Y	Attendant Care (may also be provided in the workplace) Behavioral Programming Companion Services Personal Adjustment Counseling and Training - ongoing therapeutic services to resolve interpsychic or interpersonal conflict resulting from the traumatic injury. Counseling may be provided as an adjunct to behavioral programming, and may include services for substance abuse. Personal Care Services

Service Category	Y/N	Specific Service
Person Directed Goods and Services	N	Available through a separate waiver. Some waiver services may be provided by independent vendors, not affiliated with an agency, who are enrolled Medicaid providers
Equipment/Supplies	Y	Assistive technologies Consumable Medical Supplies as an expanded State plan service Rehabilitative Engineering Evaluation
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	Y	Personal Adjustment Counseling and Training
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Accessibility Adaptations
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	Behavioral Programming Personal Adjustment Counseling and Training
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	Y	If needed provided as either Personal Adjustment Counseling or Behavioral Programming
Behavioral Services	Y	Behavioral Programming

Service Category	Y/N	Specific Service
Other	Y	Adaptive Health and Wellness – membership in a “health studio” to follow an exercise regimen ordered by a physician and designed by a physical therapist. Life Skills Training - includes assistance and training: with financial resource management; utilization of community resources; management of personal assistance services; activities of daily living such as grooming and personal hygiene; household management, cooking and nutrition; family and child support activities; health and disability self-management; and social integration skills and interpersonal relationships.

Background:

Florida began this waiver in 1999; almost half of the individuals enrolled have sustained a brain injury. Most live in their own homes or with family; about 20-25 are estimated to be assisted living residents. The focus is on community reintegration.

In addition to the waiver, Florida has a very similar state funded program, a trust fund (based on motor vehicle surcharges). The state has a TBI/SCI registry with mandatory reporting and once reported, staffs of the registry are required to have a face-to-face meeting with the injured individual. Most referrals for the waiver come through this the registry.

The waiver was initially approved for 100 individuals; this has increased to 375.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	152	\$1,835,909	\$12,078	249	\$49
2003	200	\$2,918,408	\$14,592	274	\$53
2004	230	\$3,938,491	\$17,124	311	\$55
2005	265	\$5,282,840	\$19,935	321	\$62
2006	283	\$5,903,410	\$20,860	316	\$66

Waiting List: 450 as of October 2007, prioritized based on a needs assessment.

Idaho

Idaho no longer has a brain injury waiver. Because of the small number of individuals served, when it expired in 2006, it was combined with the state's aged and disabled waiver. The information that follows reflects the operation of the waiver up until its expiration.

Operated by the single State agency (Department of Health).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing Facility

Have a diagnosis of brain injury attained after the age of 21 in one of a specified set of ICD-9-CM codes. Staff of the Regional Medicaid Unit develop the initial comprehensive assessment including: A Uniform Assessment Instrument, a written narrative, medical, physical, and social history and, as necessary, specialized assessments, e.g. medical, behavioral, mobility, etc.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	
Support Broker	N	
In-Home Services	Y	Personal care services as an extension of State plan services. Residential habilitation Chore services
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized medical equipment and supplies Personal emergency response system
Vehicle Repair/Modification	N	
Respite	Y	Respite care
Clinical Services	Y	As extended State plan services: Physical therapy Occupational therapy Speech, hearing and language services

Service Category	Y/N	Specific Service
Day Support	Y	Day Rehabilitation: assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that takes place in a non-residential setting, separate from the home or facility in which the individual resides.
Environmental Accessibility Adaptations	Y	Environmental accessibility adaptations
Health Related	Y	Skilled nursing
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Residential habilitation includes family and caregiver training.
Transportation	Y	Transportation services
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Residential Habilitation includes behavior shaping. Behavior consultation/crisis management.

Background:

Idaho's brain injury waiver was incorporated into the state's aged and disabled Waiver as noted previously. Most of the services were already contained in the aged and disabled waiver. However, the following services were added and restricted to individuals with traumatic brain injury:

- Residential habilitation
- Day rehabilitation
- Supported employment
- Behavioral consultation/crisis management

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	20	\$741,856	\$37,093	318	\$117
2003	19	\$1,175,119	\$61,848	301	\$205
2004	19	\$965,435	\$50,812	297	\$171
2005	20	\$1,037,525	\$51,876	318	\$163
2006	19	\$1,133,542	\$59,660	354	\$169

Illinois

Waiver Name: HCBS Waiver for Persons with Brain Injury

Operated by the Department of Human Service, Division of Rehabilitation Services under an agreement with the single State agency (Department of Healthcare and Family Services).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: SSI recipients, Medically Needy at 100% of FPL, TWWIA Basic Coverage Group: countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing facility

May be of any age, with an acquired brain injury; does not include degenerative, congenital or neurological disorders related to aging. The state utilizes a “Determination of Need” instrument, administered by case managers to determine eligibility for nursing facility and this, and other, waivers. A minimum score is required for waiver eligibility, and the score is used to establish a maximum service cost.

Focus: Long-Term Care.

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	Y	Personal Assistant Homemaker Respite Home health Care (as an extended State plan service)
Person Directed Goods and Services	Y	Personal Assistant Individual may also hire Certified Nursing Assistant or Nurse (LPN or RN)

Service Category	Y/N	Specific Service
Equipment/Supplies	Y	Assistive Equipment Specialized Medical Equipment and Supplies Personal Emergency Response System
Vehicle Repair/Modification	N	
Respite	Y	Respite
Clinical Services	Y	Cognitive/Behavioral Services As extended State plan services: Speech, hearing, and language Physical Therapy Occupational Therapy
Day Support	Y	Adult Day Care Day Habilitation Pre-vocational Services
Environmental Accessibility Adaptations	Y	Environmental Modifications
Health Related	Y	Skilled Nursing through Home health Care (as extended State plan service)
Financial Management Services	N	See Background
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Cognitive/Behavioral Services
Other	Y	Home Delivered Meals

Monthly service cost limits vary from \$1,659 to \$3,349 depending upon the individuals score from the “Determination of Need” instrument. The limit may be exceeded on a monthly basis to meet a temporary increase in need for services if the average monthly cost for services during the twelve-month period does not exceed the limit.

Background:

Illinois began the waiver in 1999 after a needs assessment conducted by the Head and Spinal Cord Injury Advisory Board in partnership with the state. A waiver advisory committee (whose membership includes persons with brain injury, family members, advocates, services providers and state government representatives) developed the waiver program. The waiver is growing more rapidly than other waivers in the state. This growth is attributed to older individuals who have had strokes accessing the waiver in order to get services.

The consumer directed services were developed even before this waiver was implemented. Personal assistants, while hired and fired by the waiver participant, are covered under a collective bargaining agreement, and their wages are set. The rates for certified nursing assistants and nurses can be negotiated up to an established cap. A state operated payroll system is used for these employees.

A comprehensive assessment tool was developed to address all services needs and assist in planning. The waiver was amended to include the TWWIA eligibility group.

The brain injury waiver is part of a larger program called the Home Service Program (HSP) that also includes the HIV or AIDS program and the persons with disabilities program; both these programs have corresponding waivers. HSP is operated identically to the HCBS Waiver programs, with the exception of the financial eligibility requirements; these are more generous than Medicaid. Approximately 75% of the HSP participants are Medicaid eligible. All applicants for HSP services must also apply for Medicaid. If found eligible for Medicaid, they become part of the waiver. If they do not meet the Medicaid eligibility requirements, they are not included in the waiver, but receive all of the same services.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	955	\$7,959,572	\$8,335	213	\$39
2003	1,641	\$15,884,602	\$9,680	230	\$42
2004	2,404	\$25,933,490	\$10,788	246	\$44
2005	3,085	\$36,885,093	\$11,956	260	\$46
2006	3,601	\$42,541,226	\$11,814	264	\$45
2007	3,619	\$41,641,308	\$11,506	255	\$45

Waiver year is July 1 to June 30

Waiting List: None

Indiana

Waiver Name: Traumatic Brain Injury Waiver

Operated by the Division of Aging, a separate division within the single State agency (Family and Social Services Administration).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: SSI income eligibility countable resources of \$1,500 or less.

Level of Care in approved waiver: Nursing facility

No age criteria and have experienced an external insult resulting in a traumatic brain injury. The Area Agency on Aging determines level of care based upon review of an assessment by an independent case manager.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	Y	Attendant Care Homemaker Home Health Aide Residential Based Habilitation
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Special Medical Equipment and Supplies Personal Emergency Response System
Vehicle Repair/Modification	Y	Vehicle Modification
Respite	Y	Respite
Clinical Services	Y	Extended State Plan Services: Physical Therapy Occupational Therapy Speech Therapy
Day Support	N	
Environmental Accessibility Adaptations	Y	Environmental Modifications
Health Related	Y	Nursing Health Care Coordination

Service Category	Y/N	Specific Service
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Behavior Management
Other	Y	Home Delivered Meals

Background:

Indiana began this Medicaid Waiver in 2000 and has an approved renewal that is effective January 1, 2008. The waiver was developed to increase the state's capacity to provide services to individuals with brain injury and to decrease the number of out of state placements.

The state has authority to serve 200 individuals but is serving far fewer, in large part because there is a lack of providers. In addition, a slot stays with an individual for a full year, so there is no mechanism to add someone to the waiver when a slot is vacated.

There is consideration to changing the income level for eligibility to 300% of SSI, the eligibility level for the state's aged and disabled waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	139	\$3,193,875	\$22,978	342	\$67
2003	170	\$3,210,380	\$18,885	285	\$66
2004	164	\$3,751,083	\$22,872	326	\$70
2005	139	\$3,424,024	\$24,633	351	\$70
2006	131	\$3,390,758	\$25,884	355	\$73

Waiver year is January 1 to December 31

Waiting List: Yes, 173 reported as of November 2007. However, each Area Agency on Aging maintains its own waiting list with inconsistent criteria. Individuals listed on the waiting list may be receiving services through the state's aged and disabled waiver (which has a higher income eligibility threshold), not have been assessed for level of care, or not have had financial eligibility determined.

Iowa

Waiver Name: HCBS Brain Injury Waiver

Operated by the Department of Human Services, which is also the single State agency.

Target Population: Traumatic and Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)
Intermediate Care facility
Skilled Nursing Facility

Must be between the ages one month and 64, have a traumatic or non-traumatic injury to the brain that has occurred since birth and that falls into a specified set of ICD-9 codes. The individual is assessed by a case manager or facility discharge planner who collects information using a state developed tool and forwards it to a nurse reviewer employed by Iowa Foundation for Medical Care (IFMC). The IFMC nurse will confirm the brain injury diagnosis and determine the level of care.

Focus: The goal of the waiver is rehabilitation to the maximum extent possible. An individual must, at a minimum, receive case management services each quarter and use at least one BI waiver service each quarter.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	Although not a waiver service, must be used if participating in the Consumer Choice Option
In-Home Services	Y	Consumer Directed Attendant Care Supported Community Living Family Counseling and Training Interim Medical Monitoring and Treatment Respite Behavioral Programming

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Consumer Directed Attendant Care (in home or community) Note: the Consumer Choice Option is available to participants. It also includes self-directed supported community living and individually directed goods and services.
Equipment/Supplies	Y	Personal Emergency Response System Specialized Medical Equipment
Vehicle Repair/Modification	Y	Home and vehicle Modification
Respite	Y	Respite
Clinical Services	N	Physical therapy, occupational therapy and speech services available as regular State plan services.
Day Support	Y	Adult Day Care Pre-vocational Services
Environmental Accessibility Adaptations Health Related	Y	Home and vehicle Modification
Financial Management Services	Y	Interim Medical Monitoring and Treatment - Monitoring and treatment of a medical nature requiring specially trained caregivers beyond what is normally available in a day care setting for persons age 20 and under
Supported Employment	N	Although not a waiver service, must be used if participating in the Consumer Choice Option.
Family and Caregiver Training	Y	Supported Employment
	Y	Family Counseling and Training
Transportation	Y	Transportation

Service Category	Y/N	Specific Service
Residential	Y	Supported Community Living - one to twenty-four hours of support per day based on the individual's needs. This service is designed to assist the consumer with daily living needs. Assistance may include, but is not limited to: Personal and home skills, community skills, personal needs, and transportation and treatment services. SCL may be provided in the family home, the guardian home or other typical community settings (i.e., houses, apartments, condominiums, townhouses, trailers, etc.) All living arrangements must be integrated into the community. If not the individual's own home, the living unit may include a "waiver home," one to four persons sharing a home and living with staff or a Residential Care Facility, up to 20 persons with 24-hour supports.
Night Supervision	Y	Supported Community Living
Substance Abuse	N	
Behavioral Services	Y	Behavioral Programming (in home or community)

Monthly cost limits: \$2,730 (an exception is possible).

Background:

Iowa's waiver was approved and implemented in October 1996 based upon legislation influenced by a strong advocacy group. These advocates were active participants in developing the waiver. Initially, the waiver could serve 150 individuals and this grew gradually over time.

Waiver services are provided to children, and their care plans are required to be coordinated with the child's individual education plan (IEP) and EPSDT (Care For Kids) plan(s).

In 2006, the state started a new, state funded program, offering the same services and using the same providers as the waiver. It is operated by a different department (the Department of Health) than the waiver. Individuals on the waiting list for the waiver, as well as those determined ineligible for Medicaid, are referred to this program.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	473	\$3,637,669	\$7,691	233	\$33
2003	526	\$6,354,695	\$12,081	299	\$40
2004	569	\$7,511,880	\$13,202	313	\$42
2005	662	\$8,638,048	\$13,048	286	\$46
2006	825	\$10,883,459	\$13,192	296	\$45

Waiting List: 35 as of September 2007. It is ‘first come, first served’ based on date of application. Eligibility is evaluated when admission can be offered.

Kansas

Waiver Name: Traumatic Brain Injury Waiver (formerly known as the Head Injury Waiver).

Operated by the Department of Social and Rehabilitative Services separate agency from the single State agency (Kansas Health Policy Authority).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI or Medically Needy spending down to \$716, countable resources of \$2,000 or less.

Level of Care in approved waiver: Traumatic Brain Injury Rehabilitation Hospital

Must be between the ages 16 and 64 and have a traumatic injury to the brain. Assessments are conducted by a private “enrolled case management agency” (Center for Independent Living, Home Health Agency) using the state’s TBI Uniform Assessment Instrument and the TBI Assessment Addendum.

Focus: Rehabilitation – no limit on the length of time an individual may be enrolled in the waiver if progress is demonstrated.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	Targeted Case Management (a State plan service) is required.
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal Services – may include health maintenance activities when delegated by a physician or nurse. Transitional Living Skills – comprehensive home and community training and support services designed to prevent and/or minimize chronic disabilities while restoring the individual to optimal levels of functioning. This service is required of all waiver participants. Occupational Therapy, Physical Therapy and Speech Language Therapy as extended State plan services Behavioral Therapy Cognitive Therapy Drug and Alcohol Therapy
Person Directed Goods and Services	Y	Personal Services Sleep Cycle Support
Equipment/Supplies	Y	Assistive Services – provides adaptive equipment and assistive technology as well as durable medical equipment. Personal Emergency Response Systems.
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	Y	Occupational Therapy, Physical Therapy and Speech Language Therapy as extended State plan services. (State plan covers six months post injury, and then it becomes a waiver service.) Cognitive Rehabilitation
Day Support	Y	Transitional Living Skills – comprehensive home and community training and support services designed to prevent and/or minimize chronic disabilities while restoring the individual to optimal levels of functioning. This service is required of all waiver participants.
Environmental Accessibility Adaptations	Y	Assistive Services

Service Category	Y/N	Specific Service
Health Related	Y	Oral Health Services not covered through the State plan dental services and limited to \$600 per year.
Financial Management Services	N	Consumers partner with Centers for Independent Living and Home Health Agencies as co-employers of the individuals who provide the self-directed service(s). Consumer selects and may fire employee.
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	Y	Sleep Cycle Support
Substance Abuse	Y	Drug and Alcohol Therapy
Behavioral Services	Y	Behavior Therapy

Monthly cost limits: NA aggregate used; there are limits on utilization of each service.

Background:

Kansas began the waiver in 1991 as a Model Waiver; in 2004 it was changed to a regular 1915(c) Waiver and; in 2006, it was amended to: modify service limits, add oral health service, modify provider qualifications, expand the age group served to allow individuals who demonstrate progress in rehabilitation to remain on the waiver and reduce the maximum number served.

There is no limit on the length of time an individual may be enrolled in the waiver. However, progress must be demonstrated in the annual review, and an administrative review is conducted when an individual is in the waiver for four years. All plans of care are reviewed and approved at the program management office for the operating agency.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	156	\$3,596,736	\$23,056	226	\$102
2003	178	\$4,835,317	\$27,165	279	\$97
2004	190	\$5,255,859	\$27,662	264	\$105
2005	240	\$5,427,857	\$22,616	245	\$92
2006	269	\$6,289,071	\$23,379	242	\$97

Waiver year is July 1 to June 30

Waiting List: None at this time. The state has a waiting list policy that is “first come first served” based on the date of assessment. This can be superseded for 1) individuals transferring from the HCBS/PD waiver; 2) those exiting a Kansas Medicaid approved TBI Rehabilitation Facility or state hospital; or 3) those approved by the TBI Program Manager.

Kentucky

Waiver Name: Acquired Brain Injury Waiver Program

Operated by the Department of Medicaid, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 65 and have a post birth acquired brain injury. The following conditions excluded: stroke treatable in a nursing facility providing routine rehabilitation services, spinal cord injury in which there is no known or obvious injury to the intracranial central nervous system, progressive dementia of a chronic degenerative nature (including alcoholism or another addiction), depression or a psychiatric disorder in which there is no known or obvious central nervous system damage, birth defect, mental retardation without an etiology to an acquired brain injury or a condition which causes an individual to pose a level of danger or an aggression which is unable to be managed and treated in a community. Additionally, must have the potential for rehabilitation and reintegration into the community. The determination is made by Kentucky Health Services, the state's QRO.

Focus: Rehabilitative

Waiver Services

Service Category	Y/N	..Specific Service
Case Management	Y	Case Management
Support Broker	Y	Only for those utilizing the "consumer directed option." It is then required and replaces case management.
In-Home Services	Y	Personal Care Companion Respite
Person Directed Goods and Services	Y	The option includes personal care, residential services and companion.
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	Y	Respite

Service Category	Y/N	Specific Service
Clinical Services	Y	Occupational Therapy Speech and language services Counseling and Training (Physical therapy is a State plan service)
Day Support	Y	Structured Day Program - previously supported employment was a stand alone service; now it is incorporated into Structured Day Program
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	Y	Counseling and Training
Transportation	N	
Residential	Y	Community Residential Services
Night Supervision	N	
Substance Abuse	Y	Counseling and Training
Behavioral Services	Y	Behavioral Programming

Background:

Kentucky began this waiver in 1999 with strong support and significant input from advocates, particularly the state's Brain Injury Association. Originally, the service package did not include residential services. After about two years of waiver operation, the need for these services became apparent, and they were added. As of October 2007, 73% of the waiver participants utilize these services.

The present waiver is considered rehabilitative; the state has recently submitted a similar, but long-term care, waiver for CMS approval. Additional services (physical therapy, nursing and transitional housing), not in the present waiver, would be provided to the individuals served under this new.

In a recent reorganization, the office operating the waiver was moved to the state Medicaid agency.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	104	\$2,617,877	\$25,172	270	\$93
2003	96	\$3,841,498	\$40,016	259	\$154
2004	92	\$5,244,346	\$57,004	287	\$199
2005	98	\$6,532,587	\$66,659	285	\$234
2006			Data not available		

Waiver year is January 1 to December 31

Waiting List: Over 100 individuals are on a first come first served waiting list. The state has a review panel and a process to allow individuals with urgent needs to be prioritized on the waiting list

Maryland

Waiver Name: Waiver for Adults with Traumatic Brain Injury

Operated by the Mental Hygiene Administration, a separate agency within the single State agency (Department of Health/Mental Hygiene).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Chronic Hospital
Nursing Facility

Individuals with a traumatic brain injury that occurred after the age of 21 and who are inpatients in State Mental Hygiene Administration facility, inpatients in a state owned and operated nursing facility, or individuals who have been placed by Medicaid in an out-of state facility.

Information is provided by medical staff at the facility and reviewed by a nurse at the state's utilization control unit.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	..Specific Service
Case Management	Y	Case management
Support Broker	N	
In-Home Services	Y	Individual Support Services
Person Directed Goods and Services	N	
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	Y	Day habilitation
Environmental Accessibility	N	
Adaptations		
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	N	
Transportation	N	

Service Category	Y/N	Specific Service
Residential	Y	Residential habilitation – all Waiver participants receive this service as of October 2007.
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Background:

Maryland began this waiver in 2003; it was designed to provide community-based residential services to individuals who require extensive supports and were living in institutional settings.

It initially was restricted to residents of state operated facilities with the expanding to other settings, including out of state neuro-behavioral facilities, at renewal. Individual support services were added as a “step down” from residential habilitation; it is designed for individuals who reside in their own home or with family. As of October 2007, this service has not been used.

The waiver was initially approved for 10 individuals, growing at 10 additional per year for the initial waiver; it was renewed for 30.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2004	5	\$196,272	\$39,254	106	\$370
2005	12	\$1,033,886	\$86,159	296	\$219
2006	23	\$1,489,321	\$64,753	255	\$254

The difference in the annual per capita cost between 2005 and 2006 can be explained by the significantly different costs between the two levels of care and the small number of individuals in the much more expensive chronic hospital level of care.

Waiver Year	# served	Expenditures	Annual per capita cost
2005	CH – 2	\$280,691	\$140,346
	NF – 12	\$793,195	\$79,320
2006	CH – 3	\$281,487	\$93,829
	NF – 20	\$1,207,835	\$60,392

Waiver year is July 1 to June 30

Waiting List: As of October 2007, this waiver is closed to enrollments and there is a waiting list of eight.

Massachusetts

Waiver Name: Traumatic Brain Injury Home and Community-Based Services Waiver

Operated by the Brain Injury and Special Community Services Department, Mass Rehabilitation Commission, a separate organization within the same Secretariat as the single State agency.

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income at or below 100% of federal poverty level, countable resources of \$2,000 or less.

Level of Care in approved waiver: Specialized Nursing facility

Be between the ages 21 and 62 and have a traumatic or non-traumatic injury to the brain that has occurred since birth. MDS Homecare and supplemental information are completed by Case Manager, and a neuron-psychologist on staff makes the determination of eligibility.

Focus: Long-Term Care

Waiver Services

Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	Y	Personal Care Assistance Chore Service Homemaker Service Companion Services
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized Medical Equipment
Vehicle Repair/Modification	N	
Respite	Y	Respite Care
Clinical Services	Y	Occupational Therapy Physical Therapy Speech and Language Services
Day Support	Y	Day Services
Environmental Accessibility Adaptations	Y	Environmental Adaptation
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment

Family and Caregiver Training Y Family Training

Service Category	Y/N	Specific Service
Transportation	Y	Non-medical Transportation
Residential	Y	Residential Habilitation – approximately half of the individuals in the waiver receive this service.
Night Supervision	N	
Substance Abuse	Y	Substance Abuse Services
Behavioral Services	N	
Other	Y	Interpreter Services

Monthly Cost Limits: NA aggregate used.

Background:

Massachusetts began this waiver in 2001 after many years of negotiation with CMS. The state views this waiver as a revenue maximization effort coordinated with its large, state funded program. The waiver is authorized to provide services for approximately 100 individuals and is a mirror of the state funded program that provides services to approximately 1200 individuals.

Initially, the waiver was authorized to serve 200 individuals and provided therapeutic recreation. When the waiver was renewed, the number of persons served was decreased and therapeutic recreation service was discontinued.

As of November 2007, the state is negotiating with CMS for an 1115 Waiver that will subsume this waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	28	\$1,043,710	\$37,275	240	\$240
2003	32	\$1,304,919	\$40,779	189	\$216
2004	33	\$1,107,087	\$33,548	118	\$284
2005	88	\$5,042,421	\$57,300	304	\$188
2006	90	\$4,883,813	\$54,265	315	\$172

Waiver year is July 1 to June 30

Waiting List: None at this time.

Service Category	Y/N	Specific Service
In-Home Services	Y	Adult Companion Service Chore services Extended Home Care Services – home health aide, personal care aide, private duty nursing and therapies (physical, occupational, speech language/pathology and respiratory) beyond what is provided by the State plan. Homemaker Independent Living Skills Respite
Person Directed Goods and Services	Y	Consumer Directed Community Supports - includes both goods and services
Equipment/Supplies	Y	Specialized Supplies and Equipment – including durable medical equipment not provided or denied by the State plan
Vehicle Repair/Modification	Y	Modifications and Adaptations
Respite	Y	Respite
Clinical Services	Y	Cognitive Remediation Training - Services and interventions specifically designed to improve cognitive functions, including: Attention and concentration, information processing skills, learning and memory, planning, problem solving, executive functions (processes by which a person plans, prioritizes, organizes, sets goals, executes strategies and monitors personal behavior), self-control and Visual-spatial deficits
Day Support	Y	Adult Day Care Adult Day Care Bath Pre-vocational Services Structured Day Program – that includes physical, occupation, speech language and cognitive therapies if required in the care plan

Service Category	Y/N	Specific Service
Environmental Accessibility Adaptations	Y	Modifications and Adaptations
Health Related	N	
Financial Management Services	N	
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	Y	Family Training, Education and Counseling
Transportation	Y	Transportation
Residential	Y	Assisted Living Assisted Living Plus - includes 24-hour on-site supervision in addition to services provided by home care aides, home health aides or residential staff. Foster Care Residential Care Services - supportive and health supervision services provided in a licensed residential setting
Night Supervision	Y	Night Supervision Services
Substance Abuse	N	
Behavioral Services	Y	Behavioral Programming
Other	Y	Independent Living Skills Therapies – specifically art, music and recreation therapies Home Delivered Meals Mental Health Mental Health Psychological Testing Transitional Services – needed to relocate from an institution or licensed setting to the individuals own home

Monthly cost limits do not apply as the waiver is managed in aggregate.

Background:

Minnesota began this waiver in 1992; in 1995, the waiver was amended to remove the “Model” status. Advocacy groups, particularly the state’s brain injury association, were instrumental in obtaining legislative approval for the waiver. Initially, the waiver provided for only nursing facility level of care with an amendment to permit neurobehavioral hospital level of care approved in 1993. In addition, eligibility criteria were changed substantially in 1993, expanding waiver coverage to include individuals with acquired as well as traumatic brain injuries that are not caused by a congenital

condition. In 2003, the waiver was amended to manage funding in aggregate rather than by individual.

The state lead agency for brain injury services, the Department of Human Services, formed an ad hoc Advisory Committee to facilitate communications and coordination of policy and service development. There is also a TBI Interagency Leadership Council that works through a formal Interagency Cooperative Agreement between the departments of: Human Services, Economic Development, Health, and Corrections as well as, the Brain Injury Association, the Minneapolis Veterans Affairs Medical Center and the state Disability Law Center. The state anticipates that the Mayo Clinic will join in 2008. The formal purpose of this interagency group is "To coordinate, support, evaluate and improve the effective and efficient provision of services for Minnesotan's with brain injury. Neither of these groups has direct, formal decision-making powers concerning the waiver; they do have great influence.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	574	\$22,376,846	\$38,984	307	\$127
2003	895	\$33,964,408	\$37,949	274	\$139
2004	1196	\$49,599,230	\$41,471	308	\$135
2005	1311	\$60,575,581	\$46,206	315	\$147
2006	1372	\$68,965,299	\$50,266	320	\$157

Note: there are two levels of care in the waiver. For the most recent year, approximately 25% of the individuals were neurobehavioral hospital level of care and accounted for approximately half of the expenditures.

Waiver year is April 1 to March 31

Waiting List: No.

Nebraska

Waiver Name: Traumatic Brain Injury Waiver

Operated by the Department of Health and Human Services, Medicaid & Long-Term Care Division, the single State agency.

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 100% of federal poverty level, resources of \$4,000 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 64 and have a traumatic brain injury. A functional assessment tool is utilized by a service coordinator to gather information about activities of daily living, risk (physical such as falls and behavioral) and cognition that are needed to determine the level of care.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	N	
Support Broker	N	
In-Home Services	N	
Person Directed Goods and Services	N	
Equipment/Supplies	N	
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	N	
Environmental Accessibility	N	
Adaptations		
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	N	

Transportation	N
Residential	N

Service Category	Y/N	Specific Service
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	
Other	Y	Specialized Assisted Living – With service components of: adult day care, escort services, essential shopping, health maintenance activities, housekeeping activities, laundry services, meal service, medication assistance, personal care services, transportation services, behavioral services.

Monthly Service cost cap: NA as aggregate used.

Background:

Nebraska developed this waiver in 2000 to transition individuals from acute rehabilitation setting. In addition to the service components noted above, there is a community focus for supported employment and volunteer activities. There is one provider of waiver service.

A Quality Council, begun through a Quality Assurance/Quality Improvement grant from CMS, is in place and acts in an advisory capacity for all the state's HCBS Waivers.

The state was approved to serve 40 individuals and has consistently served about 20 to 25. There are a limited number of discharges and enrollments; a few individuals have transitioned into more independent settings.

Individuals with brain injury are one of the groups targeted in the state's Money Follows the Person grant. It is anticipated that this will lead to an increase in the number of persons served and an expansion of services. The state's aged and disabled waiver provides services to many individuals with acquired brain injury.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	22	\$682,455	\$31,021	358	\$87
2003	24	\$705,374	\$29,391	332	\$89
2004	25	\$772,133	\$30,885	335	\$92
2005	25	\$840,975	\$33,639	356	\$94
2006	26	\$733,247	\$28,202	335	\$84

Waiver year is May 1 to April 30

Waiting List: No

New Hampshire

Waiver Name: Acquired Brain Disorder Waiver

Operated by The Bureau of Developmental Services, an agency within the single State Medicaid agency (Department of Health and Human Services).

Target Population: Acquired Brain Disorder

Eligibility:

Financial eligibility:

Level of Care in approved waiver: Skilled Nursing Facility (a specialized facility).

Must be over 22 years of age and have an Acquired Brain Disorder, this includes individuals with degenerative conditions such as Multiple Sclerosis and Huntington's disease. In order to be eligible, the brain disorder must be acquired between the ages of 22 and 60; the age of the person at the time of application is not considered. If an individual is over 60 and has had more than one incident, the incident that led to the level of care being met must have occurred prior to 60. An individual who acquired a brain disorder prior to age 22 may be eligible for this waiver if he/she is ineligible for the state's developmental disability waiver.

The level of care determination is a two-step process. Staff of an Area Agency, the state contracts with 10 agencies in distinct areas, conducts an assessment to determine whether the individual has an acquired brain disorder and obtain other pertinent information. If the individual has an acquired brain disorder, then the information is sent to the Bureau of Development Services where an eligibility committee meets to determine whether the individual meets the level of care criteria.

Focus: Long-Term Care –

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Service Coordination
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	<p>Personal Care Services</p> <p>Community Support Services – services provided to individuals who have skills to live independently in the community if provided continuous availability of, and access to, services and supports, to assure that needs are met. Community support services include assistance in areas such as: daily living skills, money management, shopping skills, food preparation, laundry, household maintenance, use of community resources, community safety, and social skills. This service may begin while the individual is still residing with his/her family.</p> <p>Crisis Response Services - may also include training to staff related to the needs of the individual, and or emergency back-up staff for the direct support of the individual in crisis.</p>
Person Directed Goods and Services	Y	Consolidated Acquired Brain Disorder Services – provides participants with full freedom and control in choosing provider(s) for each aspect of their services.
Equipment/Supplies	Y	Assistive Technology Support Services
Vehicle Repair/Modification	Y	Environmental Modification Services
Respite	Y	Respite Services
Clinical Services	Y	<p>Specialty Services - services intended for participants whose medical, behavioral, therapeutic, health and personal well being require services which are specialized pertaining to unique conditions and aspects of acquired brain disorders</p> <p>Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.</p>
Day Support	Y	Day Services
Environmental Accessibility Adaptations	Y	Environmental Modification Services

Service Category	Y/N	Specific Service
Health Related	Y	Specialty Services - services intended for participants whose medical, behavioral, therapeutic, health and personal well being require services which are specialized pertaining to unique conditions and aspects of acquired brain disorders Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.
Financial Management Services	Y	Included as a part of Consolidated Acquired Brain Disorder Services.
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	N	
Transportation	N	
Residential	N	Personal Care Services - may be provided to an individual residing in a setting that is not independent in the community, such as a group home or in Enhanced Family Care (adult foster care).
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Crisis Response Services – includes direct consultation and clinical evaluation for individuals who are experiencing a behavioral, emotional or medical crisis.

Monthly cost limits: None, as the waiver is managed in the aggregate.

Background:

New Hampshire began this waiver in 1992 because of efforts by families and advocacy groups to return individuals placed in out-of-state facilities to the state. The waiver has grown substantially over time. The waiver is unique because individuals with neuro-degenerative disorders may be enrolled in the waiver if they meet the other eligibility criteria.

The state has a Brain and Spinal Cord Injury Council that provides advice on service needs and related matters. While not dedicated to this waiver, they may advise on issues related to the waiver.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	103	\$7,386,833	\$71,717	304	\$236
2003	109	\$8,965,150	\$82,249	342	\$240
2004	119	\$9,784,562	\$82,223	332	\$248
2005	129	\$10,283,470	\$79,717	nr	na
2006	140	\$11,487,626	\$82,054	332	\$247

Waiver year is November 1 through October 31.

Waiting List: Yes, 16 as of December 2007. In order to be placed on the waiting list the individual must meet the level of care criteria. Medicaid eligibility determination need not be finalized if it is clear that financial eligibility criteria are met.

New Jersey

Waiver Name: HCBS Waiver for Persons with Acquired Traumatic Brain Injuries

Operated by the Division of Disability Services (DDS), an agency within the single State Medicaid agency, the Department of Human Services.

Target Population: Brain Injury – “acquired traumatic”

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing facility

Be between the ages 21 and 65 for enrollment; individuals already enrolled may remain in the waiver after reaching 65. Additionally, professional staff of the DDS verifies that a traumatic or acquired brain injury occurred with an age of onset of 21 or older and meet in person with the applicant.

In addition to the routine NF level of care determination, the Rancho Los Amigos Levels of Cognitive Functioning Scale is administered with a minimum score of 4 being required.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Case Management – acceptance of case management is required of all enrollees.
Support Broker	N	
In-Home Services	Y	Personal Care Assistant Chore Services Companion Services
Person Directed Goods and Services	N	Personal assistant services (PAS) may be consumer directed
Equipment/Supplies	N	
Vehicle Repair/Modification	Y	Environmental Modification
Respite	Y	Respite Care – in home and out of home (not available to individuals residing in a community residential service setting).

Service Category	Y/N	Specific Service
Clinical Services	Y	Therapy services which include: physical and occupational therapy, speech-language pathology Cognitive Therapy services. Counseling services
Day Support	Y	Structured day program - Supported day program - independent activities (in-home or out of home) requiring initial and periodic support from a professional to sustain the program; it is a step-down alternative to structured day program.
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	N	
Financial Management Services	N	Available if using PAS
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	Y	Transportation – to access services in the individual plan; in addition to, but not replacing, State plan service; family members are not reimbursed
Residential	Y	Community residential services (CRS) is a package of services provided to a beneficiary living in a community residence owned, rented or supervised by a licensed community residential services provider and includes personal care, companion services, chore services, transportation, night supervision and therapeutic activities. Approximately 2/3's of the waiver participants reside in these settings.
Night Supervision	Y	Night Supervision services (not available to individuals receiving CRS)
Substance Abuse	Y	Counseling services (indicated in “clinical services”) specifically include substance abuse counseling.

Service Category	Y/N	Specific Service
Behavioral Services	Y	Behavioral program services - a daily program provided by and under the supervision of a licensed psychologist and by aides (specialists) trained by a licensed psychologist; designed to serve individuals who display severe maladaptive or aggressive behavior; provided in or out of the home; time limited and designed to treat the individual and caregivers, if appropriate.

Monthly cost limits are \$8,178 for individuals receiving day services and living in the community and \$10,032 for persons placed in CRS settings.

Background:

New Jersey began this waiver in 1993 as a way to return individuals with brain injury to New Jersey from expensive out of state placements. It initially was approved to serve 150 individuals and is now approved to serve 350. Age of onset of the brain injury was changed from 16 to 21.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	236	\$13,563,248	\$57,471	330	\$174
2003	231	\$14,577,348	\$63,105	343	\$184
2004	232	\$14,626,416	\$63,045	343	\$184
2005	264	\$17,378,970	\$65,829	334	\$197
2006	276	\$18,374,797	\$66,575	329	\$202

Waiver year is July 1 to June 30

Waiting List: In October 2007, 44 individuals were on the “referral list” of individuals waiting for enrollment. A referral form, which can be submitted by anyone, is used to apply for the waiver. Upon receipt of this form, professional staff of DDS reviews medical and other pertinent records, meet with the individual to explain the waiver and assess the likelihood of eligibility and appropriateness for the waiver. Arrangements are also made for one or more providers to meet with the individual to determine whether there is a willing, appropriate provider. Then, when a vacancy occurs, the next appropriate person on the “referral list” is offered waiver enrollment.

New York

Waiver Name: Adult HCBS Medicaid Waiver for Individuals with Traumatic Brain Injury

Operated by the single State agency (Department of Health).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 100% of federal poverty level or medically needy and spend down to this level with countable resources of \$4,200 or less.

Level of Care in approved waiver: Nursing Facility

Be between the ages 21 and 64 and have a brain injury. Have a diagnosis of traumatic brain injury; individuals who experience deficits similar to a traumatic brain injury because of anoxia, toxic poisoning, stroke or other neurological conditions may also be eligible. Individuals with gestational or birth difficulties such as cerebral palsy or autism or who have a degenerative disease are not eligible for the waiver. Be assessed by a nurse or licensed social worker using the state's Hospital and Community Patient Review Instrument and SCREEN tool as needing nursing facility level of care.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Service Coordination is a required service
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	<p>Independent Living Skills Training and Development Services – not intended as a long-term support. Services may include assessment, training, and supervision of, or assistance to, an individual with issues related to self-care, medication management, task completion, communication skills, interpersonal skills, socialization, sensory/motor skills, mobility, community transportation skills, reduction/elimination of maladaptive behaviors, problem solving skills, money management, pre-vocational skills and skills to maintain a household.</p> <p>Respite</p> <p>Community Integration Counseling Service – as described below.</p> <p>Home and Community Support Services - individually designed support services essential for the participant's health and welfare. These services include cueing, prompting and supervision with activities of daily living (ADLs) and Independent Activities of Daily Living (IADLs) as well as supporting integration into the community. It is not intended as a “hands-on” service and cannot assist with the administration of medication, dress open wounds, assist with tube feedings, or perform any other activities that are within the scope of practice of a nurse, PCS or HHA under any circumstance.</p>
Person Directed Goods and Services	N	Available for State plan services of personal care assistance, home health and nursing.
Equipment/Supplies	Y	Assistive Technology Services
Vehicle Repair/Modification	Y	Environmental Modifications Service
Respite	Y	Respite

Service Category	Y/N	Specific Service
Clinical Services	Y	Community Integration Counseling Service - a counseling service provided to a participant coping with altered abilities and skills, the need to revise long term expectations, and changed roles in relation to significant others. It is available to participants and/or anyone involved in an ongoing significant relationship with the participant when the issues to be discussed relate directly to the participant.
Day Support	Y	Structured Day Program Services
Environmental Accessibility	Y	Environmental Modifications Service
Adaptations		
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	Y	An element of an Intensive Behavioral Program as described below
		Community Integration Counseling Service as described above
Transportation	Y	Waiver Transportation
Residential	N	
Night Supervision	N	
Substance Abuse	Y	Substance Abuse Program Services
Behavioral Services	Y	Intensive Behavioral Program - include but are not limited to: comprehensive assessment of the individual's behavior, a detailed behavioral treatment plan, arrangements for training informal supports and waiver and non-waiver service providers to effectively use the basic principles of the behavioral plan, regular reassessments of the plan and modifying the plan as needed, and an emergency intervention plan when there is the possibility of the participant becoming a threat to himself, herself or others.

Service Category	Y/N	Specific Service
Other	Y	Community Transitional Services - funding for the reasonable costs of one-time set-up expenses for individuals transitioning from a nursing home to their own home or apartment in the community.

Monthly cost limits are not applicable as the waiver is managed in aggregate.

Background:

New York began this waiver in 1995. The State Department of Health administers the waiver through the Regional Resource Development Centers and Specialists who serve specific counties throughout the State.

Initially, the age of onset of the brain injury was 18; this requirement has been eliminated. Individuals have to be no more than 64 years old to apply for the waiver; they may remain enrolled in the waiver after turning 65.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	972	\$41,350,022	\$42,541	335	\$127
2003	1157	\$49,434,784	\$42,727	314	\$136
2004	1446	\$61,124,741	\$42,272	320	\$132
2005	1684	\$76,654,494	\$45,519	326	\$140
2006	1953	\$79,029,120	\$40,465	310	\$131

Waiver year is April 1 to March 31

Waiting List: None statewide at this time, but in the Metropolitan New York City area there is one due to a shortage of providers.

North Dakota

Waiver Name: Traumatic Brain Injury

North Dakota no longer has a brain injury waiver; in 2006, it was merged with the state's aged and disabled waiver at the urging of CMS. The information that follows reflects the operation of the waiver up until its expiration.

Operated by the Developmental Disabilities Division, a separate division within the single State agency (Department of Health).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income, SSI eligible and countable resources of \$3,000 or less.

Level of Care in approved waiver: Nursing Facility

Individuals over 18 and determined disabled according to Social Security criteria.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	N	
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Emergency Response
Vehicle Repair/Modification	N	
Respite	N	
Clinical Services	N	
Day Support	N	
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services	N	
Supported Employment	N	
Family and Caregiver Training	N	
Transportation	N	
Residential	Y	Residential Care
Night Supervision	N	
Substance Abuse	N	

Behavioral Services N
 Other Y Transitional living

Background:

North Dakota began this waiver in 1994; in 2006 it was merged with the state's aged and disabled waiver at the urging of CMS. Residential Care was the primary service used in this waiver; only one or two individuals used emergency response or transitional living.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	31	\$781,645	\$25,214	296	31
2003	30	\$817,096	\$27,237	330	30
2004	31	\$841,110	\$27,133	326	31
2005	29	\$826,438	\$28,498	337	29
2006	29	\$797,371	\$27,496	315	29

Waiver year is July 1 to June 30

Waiting List: NA

Pennsylvania

Waiver Name: COMMCARE – Community Care

Operated by the Office of Long-Term Care, a separate office within the single State agency (Department of Public Welfare).

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less after a \$6,000 disregard.

Level of Care in approved waiver: Specialized Rehabilitation Nursing Facility. This is a facility where more than 70 percent of the residents have a neurological-muscular diagnosis and severe functional limitations.

Determining level of care is a two-step process for this waiver. First, as is routine for all long-term care applicants, the Area Agency on Aging determines eligibility for nursing facility level of care for individuals 21 years of age and older using the state's Options Assessment Tool. Then, if the applicant demonstrates a medically determinable diagnosis of traumatic brain injury not of a degenerative, congenital or post-operative nature, the specialized facility assessment is conducted. This second step assessment determines whether the applicant will require overall management of a service plan designed specifically to meet the needs of individuals with traumatic brain injury involving technical and professional personnel to meet the needs of the individual to promote recovery.

Focus: Long-Term Care, although residential services in group homes are considered short term to lead to an individual moving to another setting.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Service coordination
Support Broker	N	

Service Category	Y/N	Specific Service
In-Home Services	Y	Personal care services Chore services Habilitation and support services - up to a full day of services and/or supports designed to ensure the health and welfare of the individual, and to assist in the acquisition, retention and/or improvement in skills necessary to support individuals to live successfully in their homes. Expressly included is the provision of personal care services as well as chore type services and household maintenance Coaching/Cueing Services (Behavioral Therapy Coach) are provided to consumers needing minimal or no “hands on” assistance. Provides prompting and cueing to carry out the routines and tasks of daily living. Coaching/cueing can be provided in or out of the home
Person Directed Goods and Services	Y	Personal Care Services Coaching/Cueing Services (Behavioral Therapy Coach) Night Supervision Respite Care
Equipment/Supplies	Y	Assistive technology/specialized medical equipment and supplies. Personal Emergency Response Systems.
Vehicle Repair/Modification	Y	Environmental modifications
Respite	Y	Respite Care –
Clinical Services	Y	Cognitive Therapy Counseling services Extended State plan services to include: Physical Therapy Occupational Therapy Speech Therapy

Service Category	Y/N	Specific Service
Day Support	Y	Pre-vocational services Structured Day Program: services may include social skills training, sensory/motor development, and reduction/elimination of maladaptive behavior, and preparation for community reintegration (teaching concepts such as compliance, attending to a task, task completion, problem solving, safety, money management, etc.). Cognitive rehabilitation therapy will also be provided as part of the structured day program if needed.
Environmental Accessibility Adaptations	Y	Environmental modifications
Health Related	Y	Extended State plan services: Part time nursing
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Cognitive Retraining Services Dietician Services Counseling services
Transportation	Y	Non-medical transportation
Residential	Y	Habilitation and support services as described above may be offered in a licensed or certified setting, group homes with less than six residents.
Night Supervision	Y	Night supervision services Habilitation and support services may be provided around the clock.
Substance Abuse	N	
Behavioral Services	Y	Coaching/Cueing Services (Behavioral Therapy Coach) are provided to consumers needing minimal or no “hands on” assistance. Provides prompting and cueing to carry out the routines and tasks of daily living. Coaching/cueing can be provided in or out of the home Behavioral Specialist Consultant

Service Category	Y/N	Specific Service
Other	Y	Educational services Community transition services limited to \$4,000 per person. Community Integration Services and related training enable the consumer to plan for and engage in meaningful adult activities including domestic and leisure activities. Community integration can include cues, on-site modeling of behavior, and/or supervision to assist the consumer in maintaining maximum independent functioning. Community integration is limited to: money management, interpersonal communication, development of relationships, development of decision-making skills, civil rights and protections, and volunteer work.

Background:

Pennsylvania began this waiver in 2002, and the service package has remained stable. The unduplicated number of persons served in the waiver year ending 2007 was 324.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2003	14	\$545,038	\$38,931	124	\$314
2004	68	\$2,542,810	\$37,394	219	\$171
2005	152	\$6,897,762	\$45,380	285	\$159
2006	324		Data not available		

Waiver year is July 1 to June 30.

Waiting List: None at this time. Some advocates may refer to the “pending application list,” a list maintained to track individuals going through the application process, as a waiting list. As of October 2007, all eligible individuals have been enrolled.

South Carolina

Waiver Name: Head and Spinal Cord Injury (HASCI) Waiver Services

Operated by the Department of Disabilities and Special Needs (DDSN), Head and Spinal Cord Injury (HASCI) Division. The single State agency is the Department of Health and Human Services.

Target Population: Traumatic Brain Injury and/or Spinal Cord Injuries
(Acquired brain injuries are effectively included as “similar disabilities” which are included by law.)

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing Facility
Intermediate care facility for mentally retarded persons (ICFs/MR)

Be between the ages 0 and 65, have a medically documented injury to the brain that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder; it does not include brain injuries that are congenital or brain injuries induced by birth trauma. “Similar disabilities” are included; however they are not defined except that: there is no limit by early age of onset, it is not progressive or degenerative, it is not dementia resulting from chronic disease or alcohol/drug use and it is not a neurological disorder related to aging.

A service coordinator conducts a functional assessment to determine level of care. The assessment focuses on functional/ADL deficits and the need for skilled nursing service(s); this results in it being weighted towards individuals with spinal cord injuries and therefore approving fewer individuals with brain injuries.

Focus: Long-Term Care.

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	
Support Broker	N	
In-Home Services	Y	Attendant care Private Duty Nursing Behavior Support Non-institutional Respite Care Residential Habilitation

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Personal care Assistant Attendant care Health Education for Consumer Directed Care Peer Guidance for Consumer Directed Care
Equipment/Supplies	Y	Specialized Equipment Specialized Supplies Personal Emergency Response System
Vehicle Repair/Modification	Y	Private Vehicle Modification
Respite	Y	Institutional Respite Care Non-institutional Respite Care
Clinical Services	Y	Psychological Services Speech Therapy Physical Therapy Occupational Therapy Audiological services (Extended beyond age 21, the limits of State plan services)
Day Support	Y	Day Habilitation Pre-vocational Habilitation
Environmental Accessibility Adaptations	Y	Environmental Modification
Health Related	Y	Private Duty Nursing Health Education for Consumer Directed Care
Financial Management Services	N	
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	N	
Residential	N	
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	Y	Behavior Support
Other	Y	Prescribed drugs – State plan limits beneficiaries to 4 prescriptions, waiver participants are allowed up to seven prescriptions.

Background:

South Carolina began this waiver in 1995; with the exception of adding consumer directed services, it has remained relatively consistent.

Estimates are that 5-10% of participants have had a brain injury, 60-70% have had a spinal cord injury and 20-25% have had injury to both brain and spinal cord.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	478	\$9,847,528	\$20,602	326	\$63
2003	478	\$11,181,049	\$23,391	343	\$68
2004	489	\$10,741,579	\$21,966	341	\$64
2005	489	\$12,146,034	\$24,839	346	\$72
2006	497	\$12,247,128	\$24,642	338	\$73

Waiver year is July 1 to June 30

Waiting List: 218 individuals are on the waiting list as of October 2007. The waiting list has two categories, urgent and routine. 25 individuals are classified as urgent, and waits are typically three to four months. Individuals may be reassessed and reclassified.

Utah

Waiver Name: HCBS Section 1915(c) Acquired Brain Injury Waiver

Operated by the Department of Human Services, Division of Services for People with Disabilities (DSPD), a separate agency of the State,

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI and medically needy spending down to 100% of federal Poverty Level. Countable resources of \$2,000 or less.

Level of Care in approved waiver: Nursing Facility

Be 18 or older and have an acquired brain injury that occurred after birth and be assessed as meeting the level of care by a Division of Services for People with Disabilities' ABI support coordinator. Oversight of the level of care determination process is the responsibility of the single State agency. The State Medicaid Agency retains authority to review level of care determinations made by the Division of Services for People with Disabilities and to make necessary modifications to the determinations.

A specialized form and assessment are used by the ABI Support Coordinators for the waiver's level of care determination; the assessment is scored and eligibility is determined by the score falling within a specific range.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	ABI Support Coordination
Support Broker	N	
In-Home Services	Y	Chore Services Community Living Supports Companion Services (if not receiving Community Living Supports) Family Assistance and Supports Homemaker Services Respite Care Services (Unskilled)

Service Category	Y/N	Specific Service
Person Directed Goods and Services	Y	Chore Services Community Living Supports Family Assistance and Supports Homemaker Services Respite Care Services (Unskilled)
Equipment/Supplies	Y	Personal Emergency Response System Specialized Medical Equipment and Supplies (includes both purchase and ongoing service fee)
Vehicle Repair/Modification	N	
Respite	Y	Respite Care Services (Unskilled)
Clinical Services	N	
Day Support	Y	Day Habilitation (Structured Day Program)
Environmental Accessibility Adaptations	N	
Health Related	N	
Financial Management Services		See note
Supported Employment	Y	Supported Employment Services
Family and Caregiver Training	Y	Family Assistance and Supports
Transportation	Y	Transportation Services (Non-medical)
Residential	Y	Community Living Supports (provided in a congregate setting or "host home")
Night Supervision	Y	Community Living Supports
Substance Abuse	N	
Behavioral Services	N	

Note: The self-directed employee model requires the enrollee to use a Waiver Personal Services Agent as an integral component of the waiver service to assist with managing the employer-related financial responsibilities associated with the self-directed employee model. The Waiver Personal Services Agent is a person or organization that assists waiver enrollees and their representatives, when appropriate, in performing a number of employer-related tasks, without being considered the common law employer of the enrollees' service workers. Tasks performed by the Waiver Personal Services Agent include documenting service workers' qualifications, collecting service worker time records, preparing payroll for enrollees' service workers, and withholding, filing and depositing federal, state, and local employment taxes.

Enrollee-employed service workers complete a time sheet for work performed. The enrollee confirms the accuracy of the time sheet, signs it, and forwards it to the Waiver Personal Services Agent for processing. The Waiver Personal Services Agent files a claim for reimbursement through the Medicaid MMIS system and

upon receipt of payment completes the employer-related responsibilities, deducts the established administrative fee, and forwards payment directly to the service worker for the services documented on the time sheet.

Background:

Utah began this waiver in 1995 as a traumatic brain injury waiver. In 2004 it was changed to provide services to individuals with acquired brain injury. The number of individuals served grew gradually over time.

An amendment to unbundled services is pending. In addition to unbundling services, a new service, “behavioral consultation” is being proposed.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	85	\$1,813,437	\$21,335	292	\$73
2003	83	\$2,192,061	\$26,410	336	\$79
2004	78	\$2,393,342	\$30,684	346	\$89
2005	101	\$1,980,338	\$19,607	291	\$67
2006	91	\$2,079,141	\$22,848	333	\$69

Waiver year is July 1 to June 30

Waiting List: Yes, 93 individuals. A standardized statewide assessment is used to prioritize individuals’ placement on the waiting list. An individual may request a reassessment if needs change.

Vermont

Vermont no longer has a separate brain injury waiver. It was discontinued in 2006 when services to individuals with traumatic brain injury were included in the state's consolidated waiver. The information that follows reflects the operation of the waiver up until the consolidation.

Target Population: Traumatic Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Specialized Nursing Facility (out of state)

Be age 16 or older and have a recent traumatic injury to the brain that is not degenerative and that may include stroke. The individual must have the potential to benefit from rehabilitation and demonstrate benefit from the program in which he participates at the time of referral. Additionally, the individual must agree to participate in a substance abuse treatment program if there is a history of such abuse.

Focus: Primarily rehabilitation with a long-term care option.

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Case Management
Support Broker	N	
In-Home Services	Y	Respite Community Supports
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Environmental and Assistive Technology
Vehicle Repair/Modification	N	
Respite	Y	Respite
Clinical Services	Y	Habilitation Services
Day Support	Y	Crisis Supports
Environmental Accessibility Adaptations	Y	Environmental and Assistive Technology
Health Related	N	
Financial Management Services	N	

Supported Employment	Y	Employment Supports
Family and Caregiver Training	N	

Service Category	Y/N	Specific Service
Transportation	N	
Residential	N	
Night Supervision	Y	Community Supports
Substance Abuse	N	
Behavioral Services	Y	Crisis Supports

Monthly cost limits

Background:

Vermont's separate brain injury waiver, which began in 1994, was discontinued in 2006 when services to individuals with traumatic brain injury were included in the state's Global Commitment to Health 1115 Waiver.

Vermont began the waiver in 1994 in order to be able to provide in-state services to its residents who experienced a traumatic brain injury. There were no specialized nursing facilities in Vermont: all individuals were sent out of state. Recently, the number of Vermonters sent out of state has been one per year. As noted above the separate 1915(c) waiver was ended and combined into the state's 1115 Waiver.

The waiver had a very strong rehabilitation focus but not all individuals initially enrolled made the progress needed to be successfully discharged from the waiver. Accordingly, there was a long-term services option for these individuals.

Advocates were very involved in the waiver development and ongoing operation.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	47	\$2,168,528	\$46,139	271	\$170
2003	48	\$2,401,808	\$50,038	294	\$170
2004	51	\$2,739,681	\$53,719	309	\$174
2005	59	\$2,566,906	\$43,507	No data	
2006	68		\$5,500/month	No data	

Waiver year is October 1 to September 30

Wisconsin

Waiver Name: Adult Brain Injury Waiver

Operated by the Division of Long-Term Care, Developmental Disabilities Services Section, a separate division within the single State agency (Department of Health and Family Services)

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI and countable resources of \$2,000 or less.

Level of Care in approved waiver: inpatient traumatic brain injury rehabilitation

Be any age and have brain injury, occurring at any age, whether mechanical or infectious, the result of which constitutes a substantial impairment to the individual and is expected to continue indefinitely. Brain injury includes any injury to the brain that is vascular in origin that is sustained by the person prior to attaining age twenty-two. Brain injury does not include alcoholism, Alzheimer's disease or a like irreversible dementia.

A nurse determines level of care based upon review of a functional assessment conducted by a case manager as well as a review of the individual's care plan.

Focus: Long-Term Care

Waiver Services		
Service Category	Y/N	Specific Service
Case Management	Y	Support and Service Coordination
Support Broker	N	
In-Home Services	Y	Supportive Home Care - support and supervision and household services in the home Daily Living Skills Training Skilled Nursing Services; when not covered by the State plan Respite Care
Person Directed Goods and Services	Y	Consumer-Directed Supports

Service Category	Y/N	Specific Service
Equipment/Supplies	Y	Specialized Medical and Therapeutic Supplies when not covered by the State plan Communication Aids Adaptive Aids Personal Emergency Response Systems
Vehicle Repair/Modification	Y	Adaptive Aids
Respite	Y	Respite Care
Clinical Services	Y	Counseling and Therapeutic Services
Day Support	Y	Adult Day Services Children's Day Services Adult Day Care – for older adults Pre-Vocational Services
Environmental Accessibility Adaptations	Y	Home Modifications
Health Related	Y	Skilled Nursing Services when not covered by the State plan
Financial Management Services	Y	Financial Management/Fiscal Intermediary Services
Supported Employment	Y	Supported Employment
Family and Caregiver Training	N	
Transportation	Y	Specialized Transportation
Residential	Y	Residential Support Services - support and supervision in the following settings: Adult Family Home (County certified or state licensed), Children's Foster Homes, (including treatment Foster Homes), and Community-Based Residential Facilities of 5-8 residents
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Service Category	Y/N	Specific Service
Other	Y	Daily Living Skills Training - teaching skills to function in the home and community; Housing counseling - assists individuals find or buy homes in the community Housing Start-up - assistance with furniture & start-up costs of first home in the community Home-Delivered Meals

Monthly cost limits: \$5,400 for state matched funds; additional available if the county provides funding to be used in the match.

Background:

Wisconsin began this waiver in 1995 in order to provide home and community-based alternatives for people with traumatic brain injuries who were then currently being served in high cost rehabilitation and treatment facilities both in state and out of state. One of the waiver's purposes was to address the high cost of out of state facilities. The provision of Wisconsin-based, community alternatives was perceived as beneficial for the people served and the state's financial position.

The state's brain injury association was involved in developing training and advising on waiver issues.

The counties are very involved in the waiver and county funds may be used for waiver services, and federal match, over and above the state funding.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	268	\$15,966,889	\$59,578	337	\$177
2003	303	\$17,756,141	\$58,601	340	\$172
2004	322	\$19,194,295	\$59,610	350	\$170
2005	334	\$20,032,784	\$59,978	348	\$172
2006	334	\$20,095,110	\$60,165	351	\$171

Waiver year is January 1 to December 31.

Waiting List: Yes, as of November 2007, 121 are on wait list, managed on a first come first served basis.

Wyoming

Waiver Name: Adult Acquired Brain Injury HCBS Waiver

Operated by the Developmental Disabilities Division, a separate division within the single State agency (Department of Health).

Target Population: Acquired Brain Injury

Eligibility:

Financial eligibility: income of 300% of federal SSI countable resources of \$2,000 or less.

Level of Care in approved waiver: Intermediate care facility for mentally retarded persons (ICFs/MR)

Be between the ages 21 and 64, have an traumatic or non traumatic injury to the brain that has occurred since birth that may have been caused by an external physical force or by a metabolic disorder; it does not include brain injuries that are congenital or brain injuries induced by birth trauma. Additionally, a medical team will review the medical documentation from the time of the injury/incident.

A team with a physician and a registered nurse will engage in a collaborative evaluation process with a neuropsychological examination by a licensed psychologist with one year of post-doctoral work in ABI. Initial assessments include: a neuropsychological evaluation that includes a standard battery of tests used to determine the Individual Budget Amount using DOORS.¹⁴⁷ In addition, any of the following tests from the neuropsychological and other evaluations:

- Mayo Portland Adaptability Inventory (MPAI) score of 42 or more
- California Verbal Learning Test II, Trials 1-5, T Score or 40 or less
- Supervision Rating Scale of 4 or more Inventory for Client and Agency Planning (ICAP) Service Score of 70 or less

Focus: Long-Term Care – since its inception, only 36 individuals have disenrolled from the waiver.

¹⁴⁷ DOORS is the financial model used for using an individual budgeted amount based on the characteristics for each person served. This model considers the characteristics of the adults with ABI, and the services and settings they may choose. The primary purpose of this is to match ABI Waiver service dollars to individual consumer's needs and to allow for fiscal accountability. (Wyoming Waiver application at <http://wdh.state.wy.us/Media.aspx?mediaId=942>) More information about DOORS may be found at <http://ddd.state.wy.us/Documents/architec.htm>.

Waiver Services

Service Category	Y/N	Specific Service
Case Management	Y	Case Management – acceptance of case management is required of all enrollees.
Support Broker	N	
In-Home Services	Y	<p>Personal Care Services</p> <p>In-Home Support Services: provision of habilitation services to individuals who reside with their family or independently. In-home support services included conducting a designed program to allow the individual with acquired brain injury to acquire, retain, and improve the self-help, socialization, and adaptive skills necessary to reside successfully in the community.</p>
Person Directed Goods and Services	N	
Equipment/Supplies	Y	Specialized medical equipment and supplies to include devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live and are in addition to any medical equipment and supplies furnished under the State plan.
Vehicle Repair/Modification	Y	
Respite	Y	Respite Care –

Service Category	Y/N	Specific Service
Clinical Services	Y	Extended State Plan Services: Physical Therapy and Occupational Therapy. Waiver Services: Speech, Hearing, and Language Services Cognitive Retraining Services: Training provided to the person served or family members that will assist the compensation or restoring cognitive function (e.g. ability/skills for learning, analysis, memory, attention, concentration, orientation, and information processing) Dietician Services include menu planning, consultation with and training for care givers, and education for the individual served.
Day Support	Y	Day Habilitation Pre-vocational services.
Environmental Accessibility Adaptations	Y	Environmental accessibility adaptations
Health Related	Y	Skilled nursing services - provided to clients who have been ordered by an attending physician to receive specific skilled nursing treatments and care.
Financial Management Services	N	
Supported Employment	Y	Supported employment
Family and Caregiver Training	Y	Cognitive Retraining Services Dietician Services
Transportation	N	
Residential	Y	Residential Habilitation – approximately 45% of waiver participants live in a congregate setting.
Night Supervision	N	
Substance Abuse	N	
Behavioral Services	N	

Background:

Wyoming began this waiver in 2002 because of legislation influenced by a strong advocacy group. Several services initially covered (vision, psychological) were deleted from the waiver as they were not significantly different from State plan Services.

The waiver was initially approved for 100 individuals with no more than 85 to be served at any one time. This has been increased by amendments.

Waiver Year ending	# served	Expenditures	Annual per capita cost	Average length of stay	Per diem cost
2002	25	\$620,525	\$24,821	164	\$151
2003	70	\$2,270,680	\$32,438	256	\$127
2004	83	\$3,018,483	\$36,367	311	\$117
2005	102	\$3,368,779	\$33,027	301	\$110
2006	137	\$3,940,878	\$28,766	297	\$97

Waiver year is July 1 to June 30

Waiting List: None at this time, but close to maximum enrollment. However, waiting lists have existed at times in the past; placement on waiting list was based on a priority, need assessment.