TBI Medicaid Waiver Options and Issues

Monday January 31st from 2:00 to 3:30 ET

National Health Law Program Q&A on TBI Waivers

Question: My client has disabilities resulting from a traumatic brain injury (TBI) and is living in a nursing facility. Are there home and community-based waivers to serve people with TBI? Has there been litigation on access to such home and community-based services?

Answer: Yes, states may choose to offer home and community based waiver services to people with TBI or spinal cord injuries. More than half of the states have such a waiver.

Discussion

Background

Traumatic brain injury (TBI) is defined as an injury to the head caused by trauma that results in decreased level of consciousness, amnesia, other neurologic or neuropsychologic abnormalities, skull fracture, or lesions on the brain. TBI is the number one killer and cause of disability for young people in the United States. According to the Centers for Disease Control and Prevention, approximately 5.3 million Americans live with the effects of TBI. Of the 1.9 million Americans who have a TBI each year, nearly half experience at least short-term disability and more than 90,000 people have sufficiently severe injuries that they are significantly dehabilitated. Medical costs for treating TBI have been estimated at more than $4 billion annually.¹ Long term effects of these injuries can include mental and emotional problems as well as physical ones. TBI survivors may have their ability to live independently diminished by these problems. Spinal cord injuries affect an estimated 11,000 people each year.²

¹State Grants for Traumatic Brain Injury, 66 Fed. Reg. 30937 (June 8, 2001), from the Health Resources and Services Administration (HRSA), Department of Health and Human Services.

In 1998, it was estimated that nearly 200,000 people were living with spinal cord injuries in the U.S. \(^3\) In addition to affecting an individual’s mobility, SCI can result in many secondary health problems. The most common are pressure sores, respiratory complications, urinary tract infections, spasticity, and scoliosis.\(^4\)

Under the Medicaid Act, home and community-based (HCB) services may be offered through waivers. Such waivers may cover certain groups of individuals who would be eligible for Medicaid if institutionalized in a hospital, nursing facility or intermediate care facility for the mentally retarded (ICF-MR) and who, without the provision of waiver services, would require the level of care provided in one of those settings.\(^5\) The Secretary of the Department of Health and Human Services (HHS) is authorized to grant waivers of otherwise applicable Medicaid requirements of comparability and statewideness. Because financial eligibility rules can also be waived, waiver services may be offered to individuals who would not otherwise be eligible for Medicaid. Services may be offered that Medicaid cannot otherwise cover, such as respite, habilitation and home modifications.\(^6\) In addition, individuals may receive optional services that a state has not chosen to cover for other individuals over age 21, such as personal care or case management services.\(^7\) States are required to assure the Secretary that the waiver will be cost-neutral and that providing waiver services will cost no more than it would cost to provide institutional services to the same population over the period of the waiver. These waivers are often referred to as “1915(c)” waivers, after the section of the Social Security Act that authorizes them. States may choose to design such waivers to serve individuals with TBI or spinal cord injury who require a level of care comparable to that provided in a hospital or nursing facility.\(^8\)

\(^3\)Id.

\(^4\)Id.

\(^5\)42 U.S.C. § 1396n(c). Other types of home and community based waivers may be provided to individuals 65 years and older who would be likely to require institutional care, 42 U.S.C. § 1396n(d), and children under age five who have been infected with AIDS or are drug dependent at birth, 42 U.S.C. § 1396n(e).

\(^6\)42 U.S.C. § 1396n(c)(4)(B). For a detailed discussion of Medicaid mandatory and optional service categories, see Jane Perkins and Sarah Somers, AN ADVOCATE’S GUIDE TO THE MEDICAID PROGRAM, (June 2001), ch. 4.

\(^7\)Other optional Medicaid services can also be offered under a waiver, e.g., personal care services, private duty nursing, adult home health and home health services, which includes durable medical equipment and “other medical and social services . . . which will contribute to the health and well-being of individuals and their ability to live in the community.” 42 C.F.R. § 440.180.

\(^8\)For more information about 1915(c) waivers, see National Health Law Program,
Waivers are approved for an initial period of three years and renewed for five year periods.  

When children and youths under age 21 are covered by HCB waivers, special Medicaid requirements govern their services and may necessitate different policies than those that apply to adults. Medicaid’s Early and Periodic Screening, Diagnostic and Treatment (EPSDT) provisions require that all Medicaid beneficiaries under age 21 receive screening, diagnostic and treatment services. Treatment services consist of all services listed in the Medicaid Act necessary to “correct or ameliorate” physical and mental conditions and illnesses, regardless of whether those services are covered for adults. All children and youth receiving HCB services are eligible for full EPSDT benefits. This applies equally to children receiving services under an HCB waiver, even if that child would not be eligible in the absence of the waiver. Moreover, while states may place limits on services offered under an HCB waiver, they may not place limitations on necessary services covered by EPSDT. However, the Medicaid Act allows states to limit waiver participants to individuals that the state reasonably believes would cost more to serve under the waiver than they would at the comparable level of institutional care.


10. 42 U.S.C. § 1396a(a)(43), 1396d(r)(5) (referring to services listed in 1396d(a)). For more detail about EPSDT, see Jane Perkins and Sarah Somers, TOWARD A HEALTH FUTURE: MEDICAID EARLY AND PERIODIC SCREENING, DIAGNOSTIC AND TREATMENT SERVICES FOR POOR CHILDREN AND YOUTH, (April 2003); Jane Perkins and Sarah Somers, REPRESENTING CLIENTS WHO NEED MEDICAID EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT: A PRACTICE MANUAL FOR THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS (Sept. 2001).

11. Dept. of Health and Human Services, Dear State Medicaid Director, (Jan. 10, 2001) (re: Olmstead No. 4, attachment 4-B) (“Olmstead No. 4”) available at http://www.cms.hhs.gov/olmstead/smdltrs.asp. For a detailed discussion of the interplay between service requirements applicable to Medicaid HCB waivers and those governing EPSDT, see Sarah Somers, “Fact Sheet: Cost-Related Community Integration Barriers in Medicaid,” March 2002 (available from NAPAS).

12. Olmstead No. 4, supra note 11. See also Dear Ohio State Medicaid Director, (July 6, 1992) (Stating that a state Medicaid program must make EPSDT available for all Medicaid eligible individuals under age 21, regardless of whether the individual is eligible under the state’s HCB waiver) (available from NHELP).

13. 42 U.S.C. § 1396n(c)(4)(A), see also Somers, supra note 1; CMS, “Section 1915(c) Home and Community Based Services Waiver Application,” p. 8 (allowing states to elect to
Thus, if a child is eligible for Medicaid only because of special income eligibility rules that apply under the waiver and her services exceed a designated cost, the child may no longer be eligible for the waiver.

**TBI Waivers**

As of September 2004, 27 states were operating 1915(c) waivers targeted to individuals with TBI or spinal cord injuries: Colorado, Connecticut, Delaware, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maryland, Massachusetts, Minnesota, Mississippi, Montana, Nebraska, New Hampshire, New Jersey, New York, North Dakota, Pennsylvania, South Carolina, Utah, Vermont, Wisconsin, and Wyoming. Most of these waivers were originally designed to provide services to a small number of individuals. For example, in 2001, Idaho’s waiver served 12 individuals, North Dakota’s, 21 and Vermont’s, 50. Most are targeted to adults over 18 or over 21, with a few exceptions. For example, South Carolina’s head and spinal cord injury waiver is targeted to individuals from birth to 60 and Vermont’s TBI waiver serves individuals aged 16 and older.

Services offered under these waivers generally include personal care, case management, respite, and medical equipment. Some states specifically offer less typical services such as personal emergency response systems (Delaware), crisis management (Idaho), sleep cycle support (Kansas), and vehicle modifications (Minnesota).

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refuse services to anyone for whom the state has a reasonable expectation that the cost of providing HCB services to that individual would cost more than the corresponding level of institutional care.) available at [http://www.cms.hhs.gov/medicaid/1915c/cwaiverapp.pdf](http://www.cms.hhs.gov/medicaid/1915c/cwaiverapp.pdf).


18Sleep cycle support is a type of specialized personal care services consisting of "non-nursing physical assistance and supervision during the consumer's normal sleeping hours" and includes "physical assistance or supervision with toileting, transferring and mobility, prompting and reminding of medication." Kansas Department of Social and Rehabilitation Services, “HCBS/TBI Waiver: Policies and Procedures,” Services, p. 10, (Sept. 1, 2004)
Illustration: Florida’s TBI/Spinal Cord Injury Waiver

Florida’s Agency for Health Care Administration (AHCA) and its Department of Health (DOH) operate a 1915(c) home and community-based waiver (HCBW) program for adults with traumatic brain injury (“BSCI Waiver”). The waiver was initially approved in July 1999 and was renewed for an additional five years in 2002. As with all 1915(c) waivers, the program is designed to provide individuals who would otherwise need an institutional level of care with the services that will enable them to live in the community. 42 U.S.C. § 1396n(c).

The original waiver was approved for 200 slots and was expanded to 300 slots for the five-year waiver renewal period. To be eligible for the waiver, individuals must be medically stable and meet the state’s definition for spinal cord and/or moderate to severe brain injury. Adults who are already categorically eligible for Medicaid are eligible, as are aged or disabled individuals with income of 90 percent or less of the federal poverty level and individuals with incomes of 300 percent or less of the SSI federal benefit level.19

Services offered under the waiver include:

• Assistive Technologies
• Attendant Care
• Companion Services
• Community Support Coordination
• Consumable Medicaid Supplies
• Environmental Accessibility Adaptions
• Life Skills Training
• Personal Adjustment Counseling
• Personal Care Services
• Adaptive Health and Wellness


19Florida, Agency for Health Care Administration, Home and Community Based Waiver for Traumatic Brain and Spinal Cord Injury, Renewal Request, June 7, 2002. For a detailed discussion of Medicaid eligibility categories, see Perkins, AN ADVOCATE’S GUIDE, ch. 4, supra note 6.
• Rehabilitation Engineering Evaluation

A few of these services deserve particular mention. Adaptive Health and Wellness services include membership in a “Health Studio” to participate in a workout regimen to improve coordination, strength, stamina and other attributes that would enhance the individual’s ability to perform activities of daily living. The regimen is designed by a physical therapist. Behavioral Programming consists of individually-designed strategies to decrease an individual’s maladaptive behaviors that interfere with his ability to remain in the community. The service includes a complete behavioral assessment and development of a behavior intervention plan. Community Support Coordination can assist waiver recipients in gaining access to waiver services and other needed services, regardless of the funding source. This service is distinct from case management and is provided after the state closes an individual’s case with the separate BSCIP program (see discussion below). Individuals may also receive a Rehabilitation Engineering Evaluation, which is an assessment of the need for technologies to address barriers encountered by the individual. It may include assistance in obtaining or maintaining assistive technology devices. The service is intended for beneficiaries who need more extensive evaluation than that which is usually required by an individual receiving assistive technology services. In addition, all waiver participants who are aged 18-21 are entitled to all of the benefits covered under EPSDT.

Florida also operates an 1115 “Independence Plus” demonstration waiver to expand consumer-directed care. This waiver allows participants the opportunity to exchange traditional waiver services for a cash option to purchase services from a service provider of their choice. The waiver provides that up to 39 BSCI waiver participants may also participate in the consumer-directed care waiver.

In addition, Florida’s Brain and Spinal Cord Injury Program (BSCIP) provides services to children and adults who have sustained moderate to severe brain or spinal cord injuries. In contrast to the BSCI waiver, which provides longer term services to more severely injured individuals, the BSCIP provides short-term, post-injury rehabilitation services including acute care services, inpatient and outpatient rehabilitation, community-based living services and

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20 Florida, AHCA, Renewal Request supra note 19.
21 Id. p. 21.
22 Id. p. 22.
23 Id. p. 23.
adaptive modifications.\textsuperscript{25}

**Litigation**

As has been the case with other types of home and community based waivers, advocates have identified problems with TBI waivers. Long waits for services for individuals in institutions and in the community, as well as failure to provide due process protections are the most common problems. Cases have been filed to address these problems.

**New Hampshire’s TBI Waiver Litigation: Bryson v. Shumway**

In December 1999, two individuals living in nursing facilities who were on a waiting list for the state’s Acquired Brain Disorder (ABD) HCB waiver filed suit in the U.S. District Court for New Hampshire.\textsuperscript{26} Plaintiffs claimed that the state was violating the Medicaid Act and regulations and the due process clause of the 14\textsuperscript{th} Amendment to the U.S. Constitution. They also raised claims under the integration mandate of the Americans with Disabilities Act (“ADA”) and Section 504 of the Rehabilitation Act of 1973 (“Rehab Act”). The parties made cross-motions for summary judgment. The state also moved to dismiss the case on the grounds that the Eleventh Amendment protected them from suits under the Medicaid Act.

In October 2001, the court entered a ruling granting summary judgment for defendants on plaintiffs’ claims for “effective Medicaid services.”\textsuperscript{27} The court also ruled in plaintiffs’ favor on their claim that the Medicaid Act’s due process provision had been violated.\textsuperscript{28} Though the court recognized that plaintiff had the right to receive service with reasonable promptness, it did not grant summary judgment to them on that claim. It allowed the case to proceed to trial on it, as well as plaintiff’s claims under the ADA and Rehab Act.\textsuperscript{29} The court also dismissed the


\textsuperscript{27}This claim was based on 42 U.S.C. § 1396a(17), the requirement that the Medicaid program operate pursuant to “reasonable standards” for determining eligibility and the extent of services; § 1396a(a)(19), the requirement that the program be administered in the best interests of the recipients; and 42 C.F.R. § 430.230(b), the requirement that services be sufficient in amount, duration and scope to achieve their purpose. Bryson v. Shumway, 177 F. Supp. 2d 78, 86-92 (D. N.H. 2001).

\textsuperscript{28}177 F. Supp.2d at 98.

\textsuperscript{29}177 F. Supp.2d at 96, 101. 42 U.S.C. § 1396a(a)(8) provides that assistance shall be provided with reasonable promptness.
defendants’ Eleventh Amendment argument.\textsuperscript{30}

After submission of stipulated facts, in December, the court held that defendants had failed to provide reasonably prompt services.\textsuperscript{31} Holding that the Medicaid Act required the state to serve at least 200 individuals under a 1915(c) waiver, the court ordered it to request enough slots to serve plaintiffs.\textsuperscript{32}

On appeal, the First Circuit Court of Appeals partially reversed this ruling, holding that the district court had misinterpreted 1915(c) and that states were allowed to serve fewer than 200 individuals in HCB waivers.\textsuperscript{33} The court did accept, however, the principle that the state was obligated to furnish waiver services with reasonable promptness up to the limit of the waiver cap.\textsuperscript{34} The court remanded the case for a determination of whether the state had violated the ADA and other issues. The parties renewed their motions for summary judgment and the district court, on remand, determined that neither motion could be granted. The court held that it could not determine whether the ADA’s integration mandate had been violated because too many issues of fact still existed, including whether New Hampshire’s waiting list was moving at a reasonable pace, and whether the plaintiffs were requesting a fundamental alteration.\textsuperscript{35} Counsel for the case is the Disabilities Rights Center of New Hampshire. Trial is currently expected in May 2005.

**Florida’s TBI/Spinal Cord Injury Waiver Litigation: DuBois v. Medows**

\textsuperscript{30}Id. at 87. For more information about state sovereign immunity, the Eleventh Amendment and HCB waiver litigation, see Jane Perkins, “Sovereign Immunity Claims in Medicaid Cases,” (December 31, 2001) and NHELP’s Court Watch website, at http://www.healthlaw.org/courtwatch/index.shtml.


\textsuperscript{33}Bryson v. Shumway, 308 F.3d 79 (1st Cir. 2003).

\textsuperscript{34}308 F.3d at 89. The Court of Appeals also held that the plaintiffs had an enforceable right under 42 U.S.C. § 1983 to enforce the provisions of the Medicaid Act at issue. For more information about private rights of action and § 1983, see NHELP’s Court Watch website, at http://www.healthlaw.org/courtwatch/index.shtml.

\textsuperscript{35}Bryson v. Shumway, (Order, Mar. 26, 2004).
At the beginning of 2003, only about 176 participants were enrolled in Florida’s BSCI waiver, leaving at least 124 slots unfilled. Many people with TBI and spinal cord injury were waiting for services - one quarter of those individuals who were waiting had been on the list for more than two years and another quarter had been waiting for 1-2 years. In addition, the state was not providing written determinations on applications, updates on their wait for services or notification of the right to appeal adverse determinations. Accordingly, in April 2003, Florida residents with TBI brought an action in the U.S. District Court for Northern Florida on behalf of more than 226 people with brain or spinal cord injuries who were waiting for services under the BSCI waiver. \(^{36}\)

The plaintiffs brought claims under the ADA and Rehab Act. In addition, they alleged that the defendants had violated the Medicaid Act by failing to provide services with reasonable promptness, failing to provide a choice between institutional and HCB services and by failing to provide notice and hearing rights. \(^{37}\) They also alleged that their due process rights under the 14th Amendment had been denied. \(^{38}\)

The state moved to dismiss the lawsuit, arguing that the law did not require them to fill all of the empty waiver slots and that the ADA integration mandate did not apply to individuals who were not living in institutions. \(^{39}\) The court denied the motion to dismiss and certified a class of individuals with TBI or SCI who the state has already determined or will determine to be eligible to receive BSCI Waiver Program Services and have not received such services. The parties are currently in mediation. NHELP is co-counsel, along with lead counsel Southern Legal Counsel in Gainesville, FL.

Maryland’s TBI/DD Waiver Litigation: Williams v. Wasserman

In 1994, institutionalized individuals with TBIs or developmental disabilities filed suit in Federal District Court in Maryland to obtain community services. \(^{40}\) In 1996, the court denied both parties’ motion for summary judgment. In September 2001, the court dismissed the lawsuit, finding that Maryland had made sufficient efforts to meet the needs of plaintiffs and other


\(^{37}\)42 U.S.C. § 1396a(a)(8) (reasonable promptness), § 1396n(c)(2)©) (home and community based waiver services) and § 1396a(a)(3) (right to notice and hearing)

\(^{38}\)DuBois v. Medows, (Complaint).

\(^{39}\)Defendants’ Motion to Dismiss, DuBois v. Medows, 03-CV-107 (May 27, 2003).

\(^{40}\)(CCB-94-880) (D. Md.).
individuals with mental health needs. The court based its decision in part on its view that requiring Maryland to make greater efforts to support individuals in the community would cause a fundamental alteration in its programs for individuals with disabilities. Counsel in the case was the Maryland Disability Law Center.

**Tennessee’s Litigation: Tennessee P & A v. Wells**

The Tennessee Protection and Advocacy sought access to the medical and financial records of a man with TBI living in a nursing home. The man was a truck driver who acquired his TBI when he was age 20. Suit was filed, based upon the argument that the Developmental Disabilities Act ("DD Act") authorized the P & A to obtain records to investigate possible abuse. The district court denied access, holding that the DD Act did not cover individuals with "acquired" disabilities. The Sixth Circuit reversed, holding that a TBI that occurred before age 21 qualified as a developmental disability within the meaning of the DD Act.

**Conclusion**

States have the option of creating HCB waivers specifically for people with TBI and spinal cord injuries. Many states already operate these waivers, though they usually serve small numbers of people. Advocates in states without waivers may want to encourage their state policy makers and Medicaid agency to consider operating such a waiver. Advocates in states where waivers already exist should find out about their waivers and whether individuals with TBI are receiving appropriate services. Policy advocacy for expanded waiver slots may be desirable. Before filing litigation, however, advocates should determine whether open waiver slots exist - when all slots are filled, succeeding in Medicaid or ADA claims is very difficult. Even if slots are available, advocates should carefully tailor their complaints to include the claims with the best track record. Finally, advocates should stay abreast of case developments in the enforceability of Medicaid claims and on the fundamental alteration defense to claims under the ADA.

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42 *Id.* p. 638.

43 No. 2:01-0078 (M.D. Tenn. Sept. 6, 2002).

44 371 F.3d 342 (6th Cir. 2004).