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Report to Congressional Requesters

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TRAUMATIC BRAIN INJURY

Programs Supporting Long-Term Services in Selected States

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The Honorable Thomas J. Bliley, Jr.
Chairman, Committee on Commerce
House of Representatives

The Honorable James Greenwood
House of Representatives

Research has shown that traumatic brain injury (TBI) is the leading cause of death and disability in young American adults.[1] Faster emergency response and improved medical techniques have resulted in more persons surviving their injuries, but many survive with a substantial long-term neurological disability. There are no comprehensive data describing the incidence of TBI-related disability, making it difficult to estimate the costs of providing adequate services to adults with TBI.[2] Reliable estimates of the total number of individuals living with residual effects of TBI or those currently requiring services are not now available. However, it has been estimated that 1.5 to 2 million individuals sustain a TBI each year.[3]

Both the private and public sectors finance acute care services to adults with TBI. Federal and state governments, however, pay for a large part of post-acute services received by adults with TBI, since private insurance generally limits post-acute services and does not pay for long-term care and individuals may quickly exhaust personal resources. In addition, individuals' longevity may be unaffected by the injury and adults with TBI may require post-acute services for an extended period of time—some for the remainder of their lives. As a result, the costs of caring for a person with TBI can be substantial.

Because of your concern about the substantial governmental costs for services to persons with TBI, you asked us to review federal-state efforts to provide services to these individuals. Specifically, we examined (1) the primary federal and state programs that provide adults with TBI services to

[1]The Traumatic Brain Injury Act of 1996 (P.L. 104-166) defines TBI as an acquired injury to the brain that does not include brain dysfunction caused by congenital or degenerative disorders or birth trauma but may include injuries caused by anoxia due to near drowning. (See app. I for a brief description of the act.)

[2]Incidence is a measure of the number of new injury cases in a specified period; prevalence measures all existing cases of a condition at a point in time.

[3]D. M. Sosin, J. E. Sniezek, and D. J. Thurman, "Incidence of Mild and Moderate Brain Injury in the United States, 1991," Brain Injury, Vol. 10, No. 1 (1996), pp. 47-54; J. F. Kraus and D. L. McArthur, "Epidemiologic Aspects of Brain Injury," Neuroepidemiology, Vol. 14, No. 2 (1996), pp. 435-49 (estimates are for 1992).

help them function more independently, (2) the strategies that states have developed to enhance access to TBI-related services, and (3) the circumstances believed to be most frequently associated with difficulty in obtaining services. As agreed with your office, we focused our study on post-acute services for civilians injured as adults with an emphasis on services that help reintegrate these individuals into the community.[4]

To conduct our study, we visited two states, Arizona and Pennsylvania, and interviewed representatives from seven other states—Colorado, Florida, Massachusetts, Minnesota, Missouri, New Hampshire, and New Jersey—generally considered leaders in providing services to adults with TBI. We interviewed national experts in TBI; representatives from state TBI advocacy groups, Medicaid, and state vocational rehabilitation (VR) agencies; Medicaid providers; and case managers. We also reviewed documents from these states. We did not evaluate the effectiveness of any of the Medicaid or state programs. We conducted our work from November 1996 to January 1998 in accordance with generally accepted government auditing standards. (See app. II for more information on our scope and methodology.)

Results in Brief

Adults with TBI receive services to facilitate their reintegration into the community primarily from three federal-state programs: Medicaid, VR, and Independent Living Services (ILS). Medicaid provides medical, rehabilitation, and social support services to poor individuals with disabilities. VR agencies provide services to individuals with disabilities to prepare them for and support them during the transition to employment. ILS programs provide skills training to individuals with disabilities to facilitate their independence in the community.[5] All three programs are financed by a combination of federal and state funds and serve a range of individuals with disabilities, only a small number of whom have a TBI. Although comprehensive data on TBI-related expenditures are not available for these programs, in three of the five states with small targeted Medicaid programs for adults with TBI, Medicaid expenditures for the targeted programs were greater than the combination of VR expenditures for adults with TBI and ILS expenditures for all individuals with disabilities.

[4]For the purposes of this study, we defined post-acute services as those provided after hospital discharge. Veterans and active military with TBI may receive services from the Department of Veterans Affairs or the Department of Defense; these services are not discussed in this report. Most of the states we contacted use age 22 and older to define the adult TBI population.

[5]We use ILS to refer to both Independent Living Services programs and Centers for Independent Living programs.

Because most of the services covered by standard Medicaid programs are medical, all states have expanded Medicaid services through home and community-based waivers, which permit them to offer additional services—such as homemaker services, adult day care, and nonmedical transportation—to persons at risk of institutionalization. These Medicaid waivers generally target long-term community-based services to a broad population, such as the physically disabled or disabled elderly. Although Medicaid broad-based home and community-based waivers cover many services that adults with TBI may require to remain in the community, these programs' eligibility criteria are often strict and based on certain physical limitations, such as difficulty in bathing, dressing, or eating.

Recognizing the difficulties adults with TBI experience in accessing services, each of the states that we contacted have developed various strategies to target services to adults with TBI. Five target Medicaid services specifically to limited numbers of adults with TBI. Colorado, Minnesota, New Hampshire, and New Jersey use TBI home and community-based waivers to target Medicaid services to less than 500 adults overall. Missouri has developed a package of services for adults with TBI in its standard Medicaid program, which an average of 19 adults with TBI accessed monthly in 1996. Five states—Arizona, Florida, Massachusetts, Missouri, and Pennsylvania—have established state-financed programs specifically targeted to persons with TBI. These programs are intended to fill funding gaps and are used as a last resort. With the exception of Florida, which provided services to over 3,000 individuals in 1996, these state-financed programs together covered a small number of adults with TBI—about 1,300—in 1996.[6]

Despite these strategies, service gaps are likely—the number of adults with TBI who are provided services remains small relative to estimates of the total number. For example, in 1996, Colorado provided services under its TBI Medicaid waiver to 36 adults and Missouri served 223 in its state-funded program; GAO analysis shows that Colorado and Missouri have, respectively, about 4,000 and 5,600 individuals who sustain a TBI each year. According to program representatives and experts, those most likely to have difficulty accessing services are (1) individuals with cognitive impairment but who lack physical disabilities; (2) individuals without an effective advocate to negotiate the social service system or without a social support system; and (3) individuals with problematic or unmanageable behaviors, such as aggression, destructiveness, or participation in illegal behaviors. Without treatment, individuals with

[6]Numbers of individuals served for Florida include both children and adults.

problematic or unmanageable behaviors are the most likely to become homeless, institutionalized in a mental facility, or imprisoned.

Background

TBI is the injury most likely to result in death or permanent disability. Recent Centers for Disease Control and Prevention (CDC) data indicate that each year approximately 50,000 people die, 210,000 are hospitalized and survive, and 70,000 to 90,000 individuals are disabled due to a TBI.[7] CDC cautions that these numbers underestimate the numbers of individuals sustaining a TBI because they exclude individuals seen in emergency departments or other outpatient settings but not admitted to the hospital. Other researchers estimate that for each person who dies of TBI, 5 people are hospitalized and 27 are examined in emergency rooms without overnight hospitalization.[8]

Almost one-half of all TBIs result from transportation-related incidents. Most of the remainder result from falls, assaults, sports and recreation, and firearm-related injuries. Younger adults generally are more likely to be injured than older adults. Adult males sustain a TBI more than twice as frequently as women, and blacks are more likely than whites or Hispanics to sustain a TBI and to die from their injury.[9] People at the lowest income levels are at the greatest risk of sustaining a TBI.

Adults with TBI frequently have difficulty with executive skills, such as managing time, money, and transportation. They also have difficulty with short-term memory, concentration, judgment, and organization, which are necessary to function independently in the community. Adults with TBI often have normal intelligence but are unable to transfer learning from one environment to another.

Both the private and public sectors finance acute care services to adults with TBI. When the individual progresses past the acute phase, private health insurance typically limits coverage of rehabilitation therapies and does not cover long-term care or community-based support services. As families exhaust their financial resources, the public sector pays for a greater share of the services received.[10]

[7]CDC unpublished data, Dec. 3, 1997.

[8]J. F. Kraus and D. L. McArthur, "Epidemiologic Aspects of Brain Injury," p. 439.

[9]J. F. Kraus and D. L. McArthur, "Epidemiologic Aspects of Brain Injury," p. 441.

[10]The exceptions are those individuals injured on the job and thus covered by workers' compensation.

Medicaid, Vocational Rehabilitation, and ILS Programs Provide Services to Adults With TBI

Federal funding is available for medical and social support services under Medicaid, vocational rehabilitation services provided through state VR agencies, and for independent living services.[11] (See app. III for a summary of the broad categories of services provided through these programs by at least one of the states we contacted.)

Medicaid provides health care for about 37 million disabled, blind, or elderly people and low-income families.[12] At the state level, Medicaid operates as a health insurance program under a state plan covering both required and state-selected optional health care services.[13] Generally, state plan benefits must be provided in the same amount, duration, and scope to all Medicaid beneficiaries. With the exception of nursing facility care, most services provided under the standard Medicaid program are medically oriented. Standard Medicaid programs generally do not provide many of the long-term community-based support services needed by many adults with TBI.

To provide long-term home and community-based services for broad groups of Medicaid beneficiaries—such as the elderly disabled or physically disabled, including adults with TBI—states generally have used 1915(c) waivers.[14] There are currently over 200 home and community-based waiver programs serving more than 250,000 individuals nationwide. Under these waivers, states, with HCFA approval, can waive one or more of the requirements for statewideness, income and resource standards, comparability of services, and equal provision of services, as long as the average per capita cost of providing these services will not exceed the cost of institutional care. States select the services, the service definition, the target population, and the number of individuals included under each HCFA-approved home and community-based waiver. Examples of services that can be provided under these waivers are personal care, homemaker, and nonmedical transportation services.

[11]Adults with TBI may receive services from community mental health centers.

[12]Medicaid, a $160 billion joint federal-state health financing program, is authorized under title XIX of the Social Security Act and is administered by the states under the general oversight of the Health Care Financing Administration (HCFA), Department of Health and Human Services. The federal share of a state's total Medicaid expenditures can range from 50 to 83 percent.

[13]Examples of required services are inpatient and outpatient hospital care, physician services, and nursing facility care. Examples of optional services are rehabilitative services and prescriptions.

[14]Forty-nine of the 50 states have at least one home and community-based waiver. Arizona, the 50th state, has a program that functions like a waiver program.

Adults with TBI might benefit from some home and community-based services covered under broad-based waivers. However, these individuals often are unable to qualify for such services because the preadmission screening process may be oriented to physical rather than cognitive disabilities. For example, Colorado Medicaid reports that most adults with TBI are unlikely to qualify for the broad-based waiver for elderly and physically disabled individuals because the assessment weighs physical factors more heavily than cognitive factors. Pennsylvania has a home and community-based waiver for personal attendant services, but beneficiaries with cognitive impairment are excluded. In addition, home and community-based waivers targeted to individuals who are aged or physically disabled generally do not cover services needed by cognitively impaired individuals, such as cognitive rehabilitation.

States Target Medicaid Services to Small Groups of Adults With TBI

States generally use Medicaid home and community-based waivers to target Medicaid services to small groups of adults with TBI.[15] Missouri, however, narrowly targets services from its standard Medicaid program to persons with TBI.

Home and community-based waivers can be used by states to target select services to smaller, more specific groups of individuals, such as adults with TBI. HCFA reports that, as of June 1997, a total of 15 states have applied for and received TBI waivers.[16] These programs are small, covering an estimated 2,478 individuals and $118 million in expenditures in 1996.

Four of the states we contacted—Colorado, Minnesota, New Hampshire, and New Jersey—have TBI home and community-based waivers to compensate for the difficulty some adults with TBI experience in accessing services. In addition to services covered, the four waivers vary in terms of the target population, the number of individuals served, expenditures per individual, and the services covered. (See table 1.)

[15]HCFA has developed a prototype TBI waiver application to expedite the approval process for states.

[16]These states are Colorado, Connecticut, Iowa, Kansas, Louisiana, Minnesota, New Hampshire, New Jersey, New York, North Dakota, South Carolina, Utah, Vermont, Washington, and Wisconsin. As of January 1, 1998, Louisiana and Washington dropped their TBI waivers, while Illinois and Maine received approval for their TBI waivers.

Table 1: Characteristics of Medicaid TBI Home and Community-Based Waivers in Four States, 1996

Waiver characteristic	Colorado	Minnesota	New Hampshire	New Jersey
Target population	Hospital patients to facilitate earlier discharge into post-acute settings	Individuals with cognitive and behavioral deficits; persons with problematic behaviors[a]	Individuals who have been placed in or are at risk of placement in nursing homes	Individuals who are at risk of placement in nursing homes
Actual number of individuals served	36	231	74[b]	137
Average cost per person	$9,281	$27,258[c]	$78,864	$47,936
Maximum allowed individuals	97	290	74	240
Maximum allowed cost per person	$13,969	$63,793	$88,524	$55,454

[a]Problematic behaviors include aggression to self or others, property destruction, sexual inappropriateness, illegal activities, and drug and alcohol abuse. Minnesota's waiver describes this problematic behavior as occurring with such frequency, duration, or intensity that the individual cannot be managed in another, less structured environment.

[b]New Hampshire's waiver is for individuals with acquired brain injury and includes individuals not generally included in TBI waivers (for example, individuals with Huntington's disease). The state reports that of 85 individuals on this waiver since its inception, less than one-half have had a TBI.

[c]Actual cost per person in Minnesota is an average of costs for two main levels of care with a total of 11 case mix classifications.

Source: HCFA.

The TBI waivers for three of the four states—Minnesota, New Hampshire, and New Jersey—target people in nursing facilities and similar institutions or at risk of institutional placement. Many of these individuals will likely require home and community-based services like those covered by the waiver for the remainder of their lives. In contrast, Colorado's waiver targets adults with TBI in the hospital who receive post-hospital waiver services so that they can be discharged more quickly. Colorado estimates that individuals will receive services under the TBI waiver for 2 years; after that time, they will receive, if necessary, services under the home and community-based waiver for the elderly, blind, and disabled, which covers a less intense level of services. Minnesota's TBI waiver covers two levels of home and community-based care: (1) for individuals at risk of nursing

home placement and (2) for individuals at risk of placement in neurobehavioral units in hospitals.[17]

Some waiver services are covered by all four states: case management, personal care, respite care, environmental modifications, transportation, behavior modification programs, and day treatment or day care programs.[18] Some type of alternative residential setting, cognitive rehabilitation, assistive technology, independent living training, specialized medical equipment and supplies, and mental health services are covered by three of the four states. Many of the services covered under the TBI waivers are similar to services required by other people with physical disabilities or chronic illnesses, such as personal care services or extended physical, occupational, and speech therapies. Some, however, are particularly useful to adults with TBI, such as cognitive rehabilitation or behavioral programming.[19] (See app. IV for a comprehensive list of services covered under Colorado's, Minnesota's, New Hampshire's, and New Jersey's TBI waivers.)

Fewer than 500 individuals are covered by these waivers in the four states, with large variation among the states in the number covered, ranging from 36 served in Colorado to 231 served in Minnesota. The actual cost per person also varies widely, ranging from less than $10,000 per person in Colorado to almost $80,000 in New Hampshire. The differences in actual cost per person reflect differences in the target population. For example, according to Colorado Medicaid, the lower cost per person reflects the fact that the waiver targets individuals who, although they receive costly treatment following discharge from the hospital, receive these services for only a short period of time. In contrast, New Hampshire reports that their higher cost per person reflects their target population, who are more disabled than TBI waiver recipients in other states and whom other states generally do not place in the community.

In its standard Medicaid program, Missouri includes a package of services targeted specifically to adults with TBI, including neuropsychological, psychological, vocational, and recreational services, as well as physical, occupational, and speech therapies. Adults with TBI receive this service

[17]Minnesota reports that some adults with TBI who require fewer services are included in their Community Alternative for Disabled Individuals (CADI) waiver, but the state is unable to estimate their number.

[18]Under Colorado's Medicaid state plan, case management is an administrative function and as such is provided to adults with TBI covered by the waiver.

[19]Behavioral programming aims to decrease an individual's severe maladaptive behaviors that interfere with the ability to remain in the community.

package for 6 to 12 months. In state fiscal year 1996, Missouri Medicaid provided its TBI service package to an average of 19 persons each month at a cost totaling almost $614,000. Missouri Medicaid officials chose to narrowly target these services to adults with TBI under the standard Medicaid program because this was administratively simpler than a home and community-based waiver.

VR and ILS Provide Services to Reintegrate Adults With TBI Into the Community

VR and ILS—Department of Education programs administered by the states—provide services to disabled adults, including adults with TBI, to support their reentry into the community.[20] VR programs provide vocational rehabilitation services to help disabled individuals prepare for and obtain employment. ILS provides training, peer support, advocacy, and referral through a decentralized system of federally funded ILS programs to help people with disabilities live independently.[21] Both programs are financed by a combination of federal and state funds—totaling roughly $2.5 billion in 1996—and receive referrals from a variety of sources.[22]

VR provides vocational rehabilitation services to individuals with disabilities, including adults with TBI, to prepare them for and support them during their transition to employment. To be eligible, individuals must have a documentable disability that impedes employment but does not preclude the ability to work and must demonstrate a need for vocational rehabilitation services. Eligible individuals and VR counselors develop an individualized plan that includes an employment objective and services needed to reach that objective. These services can include rehabilitative therapies and supported employment services, which provide individuals who are integrated into a work setting post-employment support—such as job coaching or on-the-job training—to help facilitate their transition to employment. VR generally can provide supported employment services, for a maximum of 18 months; after this time, states must either find additional funds to pay for

[20]VR and ILS are authorized under the Rehabilitation Act of 1973 and are administered by the states under the general oversight of the Rehabilitation Services Administration, Department of Education.

[21]The Rehabilitation Services Administration reports that there are about 260 federally funded ILS centers nationally, with a minimum of one in each state. There also are about 420 state-funded ILS centers.

[22]The federal portion of VR expenditures is 78.7 percent. The federal government pays 90 percent of the ILS program funded under title VII, chapter 1, part B of the Rehabilitation Act of 1973 and 90 percent of title VII, chapter 2 of the act for special projects for the blind elderly. Federally funded ILS centers also receive direct funding under title VII, chapter 1, part C of the act, which makes up from 0 to 100 percent of their total funding.

continuing services or discontinue the services.[23] Adults with TBI, however, may still need these services to continue working.

All federally funded ILS centers are required to provide four core services—independent living skills training, peer support, advocacy, and referral—to individuals with disabilities, including adults with TBI, on a continuing basis. Whether a center purchases additional services for consumers is determined locally. As a result, there is likely to be variation in whether ILS offers other services, such as personal assistant services or home modification, from state to state and within a state.[24] ILS emphasizes peer support and consumer-directed action. The adult with TBI is provided information and peer support to determine his or her specific needs as well as referrals and advocacy from an ILS specialist. Trainers—generally individuals with similar disabilities—help the consumer identify barriers and ways to get around them. In some of the states we contacted, TBI experts expressed concern about the ILS model of consumer-directed needs assessment. Adults with TBI often do not recognize their own limitations and lack executive skills to coordinate services.

Medicaid Outspends Both VR and ILS for Adults With TBI in Three of Four States With TBI Waivers

Medicaid, VR, and ILS expenditures for adults with TBI are small relative to total program expenditures. Total Medicaid expenditures for adults with TBI are unknown, but the expenditures for TBI home and community-based waiver services alone in three of the four states with these waivers are greater than the combination of VR expenditures for adults with TBI and all ILS expenditures.

States with small Medicaid programs targeted specifically to adults with TBI are able to identify the costs of these programs. VR agencies are able to identify the costs of services to adults with TBI. However, the costs of adults with TBI served by ILS or the entire Medicaid program cannot be determined. Medicaid waiver expenditures for 1996 vary widely, from $300,000 in Colorado to $6.6 million in New Jersey; VR and ILS expenditures vary less. (See table 2 for federal and state expenditures in these programs.)

[23]In certain circumstances, supported employment services can be provided after 18 months; however, this is rare.

[24]The Department of Education indicates that the vast majority of ILS resources are used to hire staff and to provide core services.

Table 2: Federal-State Program Expenditures in States With Targeted Medicaid Programs for Adults With TBI (in Millions), 1996

State	Medicaid expenditures targeted to small groups of adults with TBI	VR expenditures for all adults with TBI[a]	Federal-state ILS expenditures for all disabled adults[b]
Colorado	$0.3[c]	$0.8	$1.8
Minnesota	$6.3[c]	$1.6	$4.3
Missouri	$0.6[d]	$1.8[e]	$3.2
New Hampshire	$5.8[c]	$0.1	$1.7
New Jersey	$6.6[c]	$1.4	$2.5

[a]Reports by state VRs.

[b]Report by ILS program, Rehabilitation Services Administration.

[c]GAO estimates of 1996 expenditures for TBI-specific waivers.

[d]Report by Missouri Medicaid.

[e]VR expenditures for Missouri, a non-TBI waiver state, are for closed cases only.

State-Financed Programs Provide Services to Adults With TBI

Five states that we contacted—Arizona, Florida, Massachusetts, Missouri, and Pennsylvania—have developed programs funded exclusively by the state to provide services to a generally small number of adults with TBI.[25] These programs—which obtain services from other programs and pay only for services that cannot be financed otherwise—are more flexible than Medicaid waiver programs. For example, Massachusetts' program has a sliding fee scale for services, which would not be permitted under Medicaid. Florida and Missouri have no income requirement for case management services, although Missouri restricts other services to those whose income is at or below 185 percent of poverty.

While case management is a key component of each of these programs,[26] the funds available to purchase services vary widely, as do the number of people served. (See table 3.)

[25]The Arizona and Florida programs also provide services to individuals with a spinal cord injury.

[26]Case managers identify, obtain, and manage a set of services tailored to individual needs from available programs and funding sources.

Table 3: Number of Adults Served and Service Dollars Available for State-Funded TBI Programs, 1996

	Ariz.	Fla.	Mass.	Mo.[a]	Pa.
Persons served	169	3,108[b]	400	223	531
Service dollars[c] (in millions)	$0.2	$12.3[d]	$6.0	$0.6	$5.0

[a]Individuals served and expenditures reflected in Missouri's state-funded program are financed by the state's Department of Health, not by Medicaid.

[b]Includes children and adults.

[c]Case management services are purchased with these funds in Massachusetts and Pennsylvania but not in Arizona, Florida, and Missouri.

[d]Includes inpatient expenditures for persons with TBI and/or spinal cord injury.

Source: State programs.

The states' administration of their programs varies somewhat with regard to program referral, restrictions, and oversight. Four programs receive referrals from individuals, families, providers, advocates, and other state agencies. Florida's program, however, receives notification from a central registry—to which admitting hospitals are mandated to report—of all individuals with a TBI who are hospitalized overnight. Individuals reported to the central registry are assigned to case managers, who provide the individual and his or her family with information on all available resources. The Florida program tries to refer as many individuals as possible to the vocational rehabilitation program with the objective of returning them to work.

Four of the five states—Arizona, Florida, Massachusetts, and Missouri—do not place limits on the length of time services can be provided. In contrast, Pennsylvania places time—and cost—limits on services provided. In Pennsylvania, adults with TBI are limited to 36 months for case management services and 2 years for rehabilitation services. To date, however, Pennsylvania has only enforced its cost limit, which is $125,000 per year per person for rehabilitation.[27]

Four of the five states—Pennsylvania is the exception—have legislatively mandated that their state-funded programs have an advisory council to provide guidance and oversight. These advisory councils are generally composed of representatives of persons with TBI, state agencies concerned with TBI, and experts in the field.

[27]Pennsylvania's Head Injury Program reports that no new clients have received rehabilitation services since early 1995 due to insufficient funds.

Despite State Efforts to Provide Services, Certain Individuals Are Likely to Confront Substantial Barriers

Some adults with TBI encounter substantial barriers in accessing services that will support their reintegration into the community. Although the states we contacted have developed strategies to expand such services, a small number of individuals relative to the number of adults with TBI are generally served by these programs. For example, in 1996, Colorado provided services under its TBI Medicaid waiver to 36 adults and Missouri served 223 in its state-funded program; GAO analysis shows that Colorado and Missouri have 4,006 and 5,578 individuals, respectively, who sustain a TBI each year.[28] Florida is the exception. In 1996, Florida served more than 3,100 individuals with TBI, and the state estimates that 1,829 residents sustain a TBI each year.

We asked program representatives and experts to describe individuals who have the greatest difficulty in accessing services from these and other programs and the consequences of being unable to access services. These experts most frequently identified three groups: individuals who are cognitively impaired but lack physical impairments, individuals without personal advocates, and individuals with problematic behaviors. They reported that many of these people ultimately end up homeless or in nursing homes, institutions for mental illness, prisons, and other institutions.

Individuals Lacking Physical Impairments

Individuals who are cognitively impaired but lack physical disabilities are less likely than those with more visible impairments to obtain services. Experts repeatedly told us that adults with TBI who walk, talk, and look "normal" are refused services, even though they cannot maintain themselves in the community without help. Cognitively impaired people frequently lack executive skills—such as managing time, money, and other aspects of daily living—and have difficulty functioning independently. This difficulty will most likely last throughout their lifetime.

These individuals frequently do not qualify for Medicaid waiver services under programs for the physically disabled because they have little to no difficulty in bathing, dressing, eating, or other activities of daily living used to assess disability. The services needed by these adults with TBI—which may include someone to remind them to pay the bills or provide assistance in figuring out their bank balance—are relatively low-cost but crucial to their ability to live in the community.

[28]Colorado officials recently reported that they are currently serving 162 people.

Individuals Without Personal Advocates

The lack of executive skills also complicates the ability of adults with TBI to negotiate the various service delivery systems. People without someone to act as their personal advocate have difficulty obtaining services from multiple programs. We repeatedly heard that an adult with TBI without an effective and knowledgeable advocate would probably not receive services.

People without social support systems or whose social support systems fail also fall into this category. Adults with TBI often return to their parents' home following hospital discharge. Even those married at injury may be cared for by their parents, since many married adults with TBI divorce post-injury. TBI advocates report that parents who have been the primary caregiver frequently are unable to continue to provide care due to exhaustion, aging, or death. As a result, individuals cared for by their parents for years suddenly appear, trying to obtain services to remain in the community.

Individuals With Problematic Behaviors

People with problematic behaviors—such as aggression, destructiveness, or participation in illegal activities—generally do not have the skills required to return to the community and usually require expensive treatment in residential environments with a great deal of structure. Without treatment, these individuals are the most likely to become homeless, be committed to a mental institution, or be sentenced to prison.

A number of providers, such as day treatment or outpatient rehabilitation programs and nursing homes, often will not accept people with behavioral problems, either because of potential disruption to their programs or because they claim that Medicaid reimbursement rates do not compensate them for the resources needed to care for these individuals. For example, we were told about one person who had been discharged from 14 nursing homes in 6 months due to behavioral problems. Some of the states we contacted do not have programs for adults with TBI who have behavioral problems. Minnesota funds treatment for limited numbers of individuals with the most severe behaviors, but funding at a lower level may be inadequate to provide services for those less severely affected.

Conclusion

With faster emergency response and advances in technology and treatment, the number of persons surviving a TBI has increased. A substantial number of adults with TBI are cognitively impaired and some have physical disabilities; however, their longevity is usually not affected.

As a result, individuals with permanent disability require long-term supportive services to remain in the community.

The nine states we contacted deliver long-term community-based services to adults with TBI through Medicaid or state-funded programs. As shown by our analysis of Medicaid programs targeted specifically to adults with TBI and state-financed programs, few adults with TBI are being served by these programs. Based on state reports of the number of individuals who sustain a TBI in a year, the gap between the number receiving long-term services and the estimated number of disabled adults with TBI remains wide.

Agency Comments

We provided a draft of this report to the Administrator of HCFA. We also provided draft reports to officials at the Department of Education, CDC, National Institutes of Health, the Health Resources and Services Administration, and the Brain Injury Association; Medicaid officials; vocational rehabilitation officials in each of five states with Medicaid programs specifically targeting adults with TBI; and officials of the five state-funded programs for persons with TBI. A number of these officials provided technical or clarifying comments, which we incorporated as appropriate.

In addition, CDC pointed out the need for data and referral systems by which persons with TBI-related disability are identified and referred for services. CDC suggested that components of such systems might include, for example, population-based registries of persons sustaining acute TBI (developed in conjunction with state TBI surveillance systems) and guidelines for acute care providers and hospitals pertaining to follow-up service referral for patients with TBI. In many or most jurisdictions, such systems do not exist, with the result that many persons with TBI-related disabilities—especially those who have sustained less severe injuries—may be unaware of the availability of services. CDC's comments reinforce our conclusions that the need for services among people with TBI appears to greatly exceed the services delivered.

We will send copies of this report to the Secretaries of the Departments of Health and Human Services and Education, the Administrator of HCFA, state officials in the nine states we interviewed, appropriate congressional committees, and other interested parties. We will also make copies available to others upon request.

Please contact me on (202) 512-7114 or Phyllis Thorburn on (202) 512-7012 if you or your staff have any questions. Major contributors to this report are Sally Kaplan and Mary Ann Curran.

William J. Scanlon
Director, Health Financing and
Systems Issues

Contents

Abbreviations

CADI	Community Alternative for Disabled Individuals
CDC	Centers for Disease Control and Prevention
HCFA	Health Care Financing Administration
HRSA	Health Resources and Services Administration
ILS	Independent Living Services
NIH	National Institutes of Health
TBI	traumatic brain injury
VR	vocational rehabilitation

Traumatic Brain Injury Act of 1996

The Congress passed the Traumatic Brain Injury Act of 1996 (P.L. 104-166) to expand efforts to identify methods of preventing TBI, expand biomedical research efforts to prevent or minimize the severity of dysfunction as a result of TBI, and to improve the delivery and quality of services through state demonstration projects. The legislation authorizes CDC to carry out projects to reduce the incidence of TBI, the National Institutes of Health (NIH) to grant awards for basic and applied TBI research, and the Health Resources and Services Administration (HRSA) to carry out demonstration projects to improve access to services for the assessment and treatment of TBI. A total of $24.5 million for fiscal years 1997 through 1999 was authorized for the act.

In response to the authorizations included in the Traumatic Brain Injury Act, CDC issued grants to 11 states in July 1997 to develop new TBI surveillance projects and planned to submit reports to the Congress on surveillance projects in spring 1998 and in 1999. A grant to develop an additional state TBI registry is scheduled to be awarded in summer 1998. NIH plans to conduct a TBI consensus development conference in October 1998. The consensus panel will address the epidemiology, consequences, treatment, and outcomes of TBI and make recommendations regarding rehabilitation practices and research needs. HRSA awarded demonstration project grants to 21 states, which became effective October 1997.

Scope and Methodology

We focused our study on post-acute services provided to individuals who sustain a TBI as adults. We defined post-acute services as those provided after hospital discharge. In most of the states we contacted, individuals injured at age 22 or older are considered differently than individuals injured prior to age 22, who receive services from programs for persons with a developmental disability.

Based on a review of the literature and interviews with individuals knowledgeable about TBI, we assembled a list of 35 states that have developed programs targeted to persons with TBI. From that list, we selected nine states: four with Medicaid TBI home and community-based waivers and five with state programs providing direct services to adults with TBI. We selected the TBI waiver states with the largest (New Hampshire) and second smallest (Colorado) estimated per capita cost for 1996.

Categories of Services Provided by States We Contacted

Figure III.1 provides an overview of the broad categories of services provided to adults with TBI by standard Medicaid programs, by broad-based and TBI Medicaid home and community-based waivers, and by VR and ILS programs. Although there is substantial overlap among the general categories of service, there are differences in the groups to whom services are targeted, the requirements to obtain them, and the length of time services are provided.

Figure III.1: Broad Categories of Services by Program Provided in One or More States We Contacted

Service Category	Program: Standard Medicaid Program	Medicaid Broad-Based Waiver	Medicaid TBI Waiver	VR	ILS
Case Management	✓	✓	✓		
Medical Services	✓			✓	
Rehabilitation Services	✓	✓	✓	✓	✓
Personal Care Services	✓	✓	✓	✓	✓
Cognitive Therapy and Behavioral Program			✓	✓	
Alternative Residence		✓	✓		
Vocational Training				✓	
Supported Employment Services			✓	✓	
Other Services (e.g., equipment, transportation)	✓	✓	✓	✓	✓

Services Covered by Four States' TBI Home and Community-Based Waivers

Figure IV.1 shows the specific services offered to adults with TBI by four of the states that we contacted—Colorado, Minnesota, New Hampshire, and New Jersey—under their TBI home and community-based Medicaid waivers.

Figure IV.1: TBI Home and Community-Based Waiver Covered Services in Four States

Service	Colorado	Minnesota	New Hampshire	New Jersey
Case Management	✓[a]	✓	✓	✓
Personal Care	✓	✓	✓	✓
Respite Care	✓	✓	✓	✓
Environmental Modifications	✓	✓	✓	✓
Day Treatment/Care	✓	✓	✓	✓
Transportation	✓	✓	✓	✓
Behavioral Program	✓	✓	✓	✓
Alternative Residential Care	✓	✓		✓
Mental Health Services/Counseling	✓	✓		✓
Cognitive Rehabilitation		✓	✓	✓
Chore Services		✓		✓
Companion		✓		✓
Extended Therapies (PT, OT, ST)[b]		✓		✓
Hearing and Language Therapies		✓		✓
Assistive Technology	✓	✓	✓	
Independent Living Training	✓	✓	✓	
Specialized Medical Equipment and Supplies	✓	✓	✓	
Homemaker		✓		
Other Services[c]	✓	✓	✓	✓

[a]Case management is a Medicaid administrative function in Colorado.

[b]PT, OT, ST are physical, occupational, and speech therapies.

[c]Other services include substance abuse counseling, home health care, family support services, crisis response, community support, supported employment, or night supervision.

Source: Medicare and Medicaid Guide, Commerce Clearing House.

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