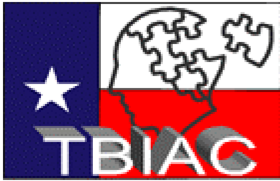


Texas Traumatic Brain Injury Advisory Council
1100 West 49th Street, Austin, TX 78756-3199 ◦ 512-458-7268

A joint endeavor of the Texas Health and Human Services Commission and the Texas Department of State Health Services

Acquired Brain Injury and Long Term Care in Texas

October 2006

EXECUTIVE SUMMARY

Acquired brain injuries (ABIs) are injuries to the brain that occur after birth and that may be caused by trauma, stroke, lack of oxygen to the brain (e.g., near drowning), infectious disease, toxic exposure, etc. The population of Texans living with a disability from ABI is enormous: approximately 440,000 Texans (2% of the population) live with a disability from traumatic brain injury (TBI) alone. The needs of individuals with brain injury may be similar regardless of the cause. Moreover, the effects of brain injury vary greatly and may not be readily apparent.

In Texas there are gaps in public services for individuals with brain injury. There is no appropriate placement for those who require 24-hour supervision since facilities are designed for individuals with mental retardation or those requiring nursing care. There are no Medicaid Waiver services for individuals who were injured as adults, do not have a medical condition requiring skilled nursing and who are able to live in the community with supports. Many are inappropriately institutionalized in nursing homes, reflecting noncompliance with the *L.C. and E.W. v. Olmstead Supreme Court Decision*. Programs are not equipped to recognize or deal with individuals who have subtle but incapacitating executive and/or behavioral dysfunctions. There is no care coordination to ensure services are accessed and that delivery of interventions is effective and efficient. Finally, there is a ten-year waiting period for services that are available.

Other States' Waiver Programs. Twenty-five states reported having Brain Injury Medicaid Waivers in place in 2004. Some have implemented a functionally based waiver rather than diagnosis based (New Mexico). Services by state tend to be highly variable.

Individuals with brain injuries are also served under other Medicaid HCBS Waiver programs. By using other Medicaid waivers to serve individuals with brain injury, states are limited in their ability to serve the full population and provide a complete array of services.

Section 6086 of the Deficit Reduction Act of 2005 [codified Section 1915(i) of the Social Security Act] could be useful in serving people with acquired brain injury. CMS is currently writing rules to implement and interpret the requirements.

Numbers Served. While 2% of the population lives with a disability from TBI, the number of individuals who are served by brain injury waivers is considerably lower: the number of beneficiaries in any one state rarely exceeds 1,000. Reasons may include problems with accessibility or lack of needed services (limited service array). Additionally, there may be a lack of insight into one's limitations or impairments. For example, unless a substitute decision maker has been appointed by the courts, the individual with brain injury may insist that there is "nothing wrong" with them and struggle with demands of daily living rather than seek or accept services. For these reasons, it is difficult to estimate the numbers who might utilize services in

Texas if eligibility requirements are expanded.

Service Needs. The service needs of individuals with brain injury vary depending on the specific consequences of the injury. The most frequently used services are respite, personal assistance services, non-medical transportation, service coordination/ case management, home modifications, behavior programs / psychology/ counseling support, therapies (Speech, PT, and OT), supported employment, specialized medical equipment, day program.

Service/Support Environment. The service/support environment and duration of services will vary greatly depending upon the functional level, specific programming needs and preferences of the individual with brain injury. Furthermore, the individual's need for a less restrictive environment will change over time as they make progress and acquire skills. Some will graduate out of the program and become self-supporting. A continuum of care is recommended with service coordination/ case management support throughout the course of care to ensure that the individual is most appropriately placed from the outset, is receiving needed supports, and transitions to a less restrictive environment as soon as possible (including graduating out of services). The precepts of Person Centered Planning and Self-Determination must be incorporated (including dignity of risk and discovery). Additionally, flexibility is required to graduate and to later move back into services as needs arise. Direct care staff must have training in brain injury, behavioral management strategies, and crisis prevention intervention.

Texas Veterans with TBI. Current trends indicate that more than half of all soldiers wounded in Operation Iraqi Freedom will have sustained a TBI. There are four VA hospitals that have specialized TBI programs, but none in Texas. There are no specialized inpatient facilities providing acute TBI evaluation and treatment in the Texas VA system. Limited post-acute care is available, but the rehabilitation service does not have a specialized TBI unit.

Recommendations. The TBIAC recommends that the Department of Aging and Disability Services (DADS) amend the eligibility requirements and service array of Medicaid waiver programs to include, regardless of age of onset, individuals who have incapacitating cognitive/emotional-behavioral/psychosocial dysfunction with or without accompanying physical disabilities. If federal waiver rules preclude amending current waivers to meet the needs of individuals with brain injury, a Brain Injury Waiver should be considered. The TBIAC recommends that sufficient funds be allocated to accommodate waiting lists for services.

The TBIAC recommends that DADS conduct a two-year pilot study, designating 10-15 small group homes (3-4 beds) for this population (with the option of entry into community based long-term care programs). Care coordination/case management services should be provided for all participants. The group homes should be based on the concept of least restrictive environment and maximizing the independence of the residents, and of meeting the social needs of the residents. The effectiveness of the program should be evaluated after one and two years.

In Conclusion. Failure to address neurobehavioral issues increases the risk of job loss, underemployment or unemployment, social isolation, substance use and abuse, inappropriate institutionalization, incarceration, and in some cases further injury or death. These situations often result in a high cost to society. However, with appropriate and timely treatment, effective interventions and supports, these problems often are manageable or can be minimized.

Acquired Brain Injury and Long Term Care in Texas

October 2006

Every year 144,000 Texans sustain a traumatic brain injury (TBI), one every 4 minutes. Of this number, TBI contributes to almost 4,200 deaths[1] and more than 14,229 TBI-related hospitalizations[2] that do not result in death. Reliable data are not available to count the number TBIs that are not treated in hospitals. Not everyone who experiences a TBI will suffer long-term consequences, but many will. The Centers for Disease Control and Prevention (CDC) estimate that 2% of Americans are living with a disability due to TBI - approximately 440,000 Texas residents.[3]

The CDC calls TBI a "silent epidemic" because the statistics are not widely reported and individuals with TBI are often able to walk, talk, and look "normal" despite other debilitating consequences. It is recognized as the single leading cause of death and disability in young people in America—young adults, particularly young males are at the highest risk.[4]

Thirty-five years ago 50% of all people with TBI died. Since modern medicine has developed extraordinary life-saving techniques over the past 30 years, that number has been reduced to 22%. These changes have resulted in a large and growing population of individuals with TBI, many of whom are facing lifelong needs for support.[5]

While TBI is the most common, there are many other causes of acquired brain injury, or ABI (an injury to the brain that occurs after birth), such as stroke, anoxia (e.g. near drowning, carbon monoxide poisoning), toxic exposure, brain tumor, seizures, and metabolic disorders (e.g., diabetic coma). The needs of individuals with brain injury may be similar regardless of the cause.

The effects of brain injury vary greatly from person to person and may include a wide range of functional changes affecting thinking, sensation, language, emotions, behavior, as well as

[1] Centers for Disease Control & Prevention, National Center for Injury Prevention and Control (n.d.). *Centers for Disease Control and Prevention: Preliminary estimated annual rates and numbers of TBI by state.* Retrieved November 15, 2005, from the National Association of State Head Injury Administrators Web site at http://www.nashia.org/fs/CDC%20Stats.doc

[2] Kegler, S. R., Coronado, V. G., Annest, J. L., & Thurman, D. J. (2003). Estimating nonfatal traumatic brain injury hospitalizations using an urban/rural index. *Journal of Head Trauma Rehabilitation, 18*(6), 469-478.

[3] Thurman, D. J., Alverson, C., Browne, D., et al. (1999/2005). *Traumatic brain injury in the United States: A report to Congress.* Centers for Disease Control and Prevention. Information obtained from J. M. Silver, T. W. McAllister, & S. C. Yudofsky (Eds.), *Textbook of traumatic brain injury* (p. 7). Washington, D.C.: American Psychiatric Publishing, Inc.

[4] Centers for Disease Control and Prevention, National Center for Injury Prevention and Control (2005, August). *Facts about traumatic brain injury.* Retrieved January, 2006, from Brain Injury Association of America Website at http://www.biausa.org/word.files.to.pdf/factsaboutBI.8.29.05.pdf

[5] Texas Traumatic Brain Injury Advisory Council (2006, April). Traumatic brain injury in Texas. Austin: Department of State Health Services.

physical changes. It can also cause epilepsy and increase the risk for conditions such as Alzheimer's disease, Parkinson's disease, and other brain disorders that become more prevalent with age.[6]

Common types of long-term consequences are:[7]

> Difficulty with "executive control" or "keeping things straight": People with brain injury can have trouble with short-term memory, money management, time management, judgment, concentration, and planning. They may frequently get confused and frustrated.
>
> Difficulty with emotional and/or social functioning: Many people with brain injury have difficulty with self-monitoring, reading social cues, impulse control, sudden mood swings, anxiety, and depression. They may experience problems with anger control, sudden agitation, or low self-esteem. This suite of problems can result in eventual (but preventable) institutionalization or imprisonment.
>
> Difficulty with physical abilities: People with brain injury may experience difficulty with motor coordination headaches, fatigue, seizure disorders, muscle spasticity, and/or hearing, visual or speech impairments.

Brain injury affects families and communities in a variety of ways. It leads to changes in family function by affecting family members' roles, responsibilities, and lifestyle. Family members can be placed in a position of caregiving that may strain them financially, emotionally, and physically. The ability of caregivers to sustain the effort decreases as they age.

Brain injury often strains relationships with people outside of the family including friends, coworkers, and daily community contacts. Individuals who have sustained a brain injury may need periodic and, in some cases, lifelong services and supports following their injury. Without specialized services and supports, the person experiencing the injury, his or her family, and society will be negatively impacted. For example, due to fatigue, a common problem for individuals with brain injury, a nap or two may be needed during the day. Work hours may need to be adjusted to allow for these. If employers and co-workers are unaware of this physical need, the individual with brain injury may be incorrectly labeled as lazy or having special "perks" that are unfair to others.

The Problem

Individuals with brain injury who require support often live at home with their families (80%), in long-term care facilities designed for individuals with mental retardation or geriatric care rather than brain injury care, or in some cases are homeless or in prison. This can be an enormous financial and resource burden to families and society as a whole, as some individuals may need such supports throughout their lifetime. Because there are gaps in public services for individuals with brain injury, persons with brain injury are often medically under-served or inappropriately served. This is exacerbated by the fact that health insurance, if any, is quickly exhausted due to the nature and extent of the injuries.

[6] See CDC 2005 Facts about traumatic brain injury above.
[7] National Association of State Head Injury Administrators (n.d.). Traumatic brain injury facts: Medicaid.

In the state of Texas, there is no placement appropriate for individuals with brain injury who require 24-hour supervision. As mentioned, facilities that provide this level of supervision are designed for individuals with mental retardation or geriatric care. Quite often the individual with a brain injury scores well above the level of mental retardation on IQ tests even though significant problems with executive functioning interfere with the person's ability to function independently. Social needs of individuals with brain injury preclude placement in a facility for the mentally retarded or geriatric population.

In the state of Texas, there is no Brain Injury Medicaid Waiver to serve individuals who are able to live in the community with supports. The Department of Aging and Disability Services (DADS) offers Community Based programs for Medicaid, Medicaid Waiver and State funded Long Term Care services. Coordination of services, appropriate residential placement, community living supports, counseling, and behavioral modification services are all available to some populations with disabilities in Texas. **However, a large segment of the population of individuals with brain injury do not have access to these programs because they do not meet the legal requirements of having a *developmental disability* or do not have a *medical condition requiring skilled nursing care*.** For example, a waiver may require that the injury occur prior to the age of 22 or that the individual meet diagnostic criteria for mental retardation to meet eligibility requirements (few individuals with brain injury meet this diagnostic criteria). Another waiver may serve individuals who were injured after age 22, but require that they have a medical condition necessitating skilled nursing care, which is not the case for most individuals with brain injury.

Others are inappropriately institutionalized in nursing homes, reflecting noncompliance with the *L.C. and E.W. v. Olmstead Supreme Court Decision*. According to the decision, states must plan for community alternatives to inappropriate institutional care.

Additionally, stringent requirements regarding community living preclude group home living, which may be more appropriate for those with impairment that necessitates regular supervision. There is no care coordination/case management to ensure services are accessed and that delivery of interventions is effective and efficient. ***Finally, at the current time there may be up to a ten-year waiting period for services.***

The U.S. General Accounting Office report describes the limitations of waivers as a resource for patients with brain injury.

- Firstly, many state programs favor those with physical disabilities and are not equipped to recognize or deal with individuals who have subtle but incapacitating executive and/or behavioral dysfunctions.
- Advocates are often needed to negotiate social service systems, especially for those individuals with brain injury who have cognitive impairments.
- Finally, programs tend to exclude patients with problematic or aggressive behaviors; funding is typically not available to provide the structured settings and professional supports needed to properly manage individuals with brain injury who have behavioral problems.

It is noted in the report that Brain Injury Waiver programs are currently expanding, a trend that the authors hope will continue as policymakers are made more aware of the utility and cost-effectiveness of long-term community-based care for brain injury.[8]

Brain Injury Waiver programs

Twenty-five states reported having Brain Injury Medicaid Waivers in place in 2004. In Maryland the waiver became operational in fiscal year 2003-04; and in Delaware, the waiver has not yet become operational. Since the 2004 survey, New Mexico implemented a functionally based waiver rather than diagnosis based.

> In some States the number of persons served using the Brain Injury Waiver is unknown. In those States administrators reported the number of service slots in the most recently completed fiscal year for which data was available. Some States serve persons with brain injury and spinal cord injury within the same waiver making it difficult to obtain an exact count of persons with brain injury. Since it is possible for one individual to access Medicaid Waiver services during part of a year and another individual to access services the remainder of the year, the National Association of State Head Injury Administrators (NASHIA) estimates that more than 8,000 persons were served by Brain Injury Waivers in 2004.[9]

A Brain Injury Waiver focuses on culturally appropriate wrap-around, "whole-person" care with attention to physical, cognitive, emotional/behavioral and psychosocial aspects of living with brain injury. Given the *unique and varied needs* of individuals with brain injury, there is merit in having a specific Brain Injury Waiver rather than trying to adapt the rigid eligibility requirements (e.g., meeting a diagnosis of mental retardation; medical needs requiring skilled nursing care) and limited service array of other waivers. Services by state tend to be highly variable (See Appendix I).

Using Existing Waivers

"Individuals with brain injuries are also served under other Medicaid HCBS Waiver programs. For example, 31 States serve individuals with brain injury under Developmental Disabilities Waivers; 26 States serve individuals under Aging and Disabled Waivers; 10 States serve individuals with brain injuries under Elderly Waivers; and 11 States serve individuals using Physical Disabilities Waivers. In the State of Georgia, 30 slots are set-aside for persons with TBI in the State's Independent Care Waiver. Montana reports that a set of services appropriate to persons with TBI is included in its Aging and Physical Disabilities Waiver. In most States neither the financial or demographic data on persons served, service type, nor cost is known."[10] By using other Medicaid waivers to serve individuals with brain injury, states are limited in their ability to serve individuals who sustained their injury as young or middle-aged adults and who do not have physical disabilities.

---

[8] U.S. General Accounting Office (1998). Traumatic brain injury programs supporting long-term services in selected states (Publication No. GAO/HEHS-98-55).

[9] National Association of State Head Injury Administrators (n.d.). Medicaid waivers. Retrieved June 16, 2006 from the National Association of State Head Injury Administrators website at http://www.nashia.org/issues/medicaid.html

[10] See National Association of State Head Injury Administrators (n.d.) above.

Deficit Reduction Act Opportunities

The Deficit Reduction Act (DRA) of 2005 contains provisions at Section 6086 [codified in Section 1915(i) of the Social Security Act] that enable States to provide Home and Community-based services under a Medicaid State Plan Amendment to individuals who would otherwise require the level of care provided in a hospital, nursing facility or ICFMR. These services are defined as: case management, homemaker/home health aide, personal care, adult day activity, habilitation, respite care, day treatment, partial hospitalization, psychosocial rehabilitation and clinic services.

Section 6086 is not of interest to State geriatric and MR/DD programs, as the existing 1915(c) waivers allow a broader array of services and serve a greater income range, but Section 6086 could be useful in serving people with acquired brain injury. CMS is currently writing rules to implement and interpret the requirements of Section 1915(i).

Eligibility

Typical eligibility requirements for the brain injury waiver are as follows. The person must be medically stable and meet the state's definition for moderate to severe brain injury. Adults who are already categorically eligible for Medicaid are eligible. Age limits are set state by state, with the majority adopting an age range of 16 – 65. States vary regarding eligibility criteria, using diagnosis, a functional approach, or both. An assessment process generally is used to determine capacity to benefit from services.

Cost Containment and Reduction

Due to differences in waiver services offered and accounting measures state by state, it is impossible to compare the success of cost containment or reduction across waivers. In Kansas, costs per person with TBI receiving services through the home and community based waiver program were $3,151 per month for an average length of stay on the waiver of 20 months (total of approximately $63,000). In comparison, institutionalized care at a head injury rehabilitation facility may cost in excess of $21,000/month with an average length of stay of six months (total of over $126,000). Overall, the costs of waiver services are approximately half of the costs of institutionalized care in Kansas. This is just one example.

Some states estimate cost neutrality from those receiving care in nursing homes or ICF-MR facilities, from those receiving services in out-of-state placements, and Medicaid Fee for Services.

Numbers to be Served

As mentioned, it is difficult to obtain an exact count of persons with brain injury who are served by Brain Injury Waivers, since some states serve persons with brain injury and spinal cord injury within the same waiver. In addition, persons with brain injury may go on and off the waiver as they recover. Some states, wary of costs and the number eligible, may set a limit to the number served under the waiver. These are often called "model" waivers.

While a large percentage of the population *lives with a disability* from TBI (approximately 2% of the population), the number of individuals who are served by state Medicaid waivers is considerably lower. Even in those states providing waiver services for brain injury, the number

of beneficiaries rarely exceeds 1,000[11] (see Appendix II). As mentioned, it has been estimated that, nationwide, Brain Injury Waivers served about 8,000 persons in 2004.[12]

There may be many reasons for the discrepancy between the large number of those disabled by brain injury and the number of those who have used waiver services. Many state program administrators acknowledged problems with accessibility or lack of needed services (limited service array) as reasons for low numbers of individuals seeking services relative to the size of the disabled brain injury population.

Unique characteristics of the population of individuals with brain injury may also explain the reason that few utilize waiver services. One of the consequences of brain injury (particularly damage to the right hemisphere of the brain) is a lack of "self-awareness" or insight into one's limitations or impairments. For example, unless a substitute decision maker has been appointed by the courts, the individual with brain injury may insist that there is "nothing wrong" with them and struggle with demands of daily living rather than seek or accept services. For these reasons, it is difficult to estimate the numbers who might utilize services in Texas if services are expanded to include those over age 22 with cognitive/behavioral/psychosocial disability.

Cost Per Person

"It is not possible to estimate an average per person cost of Medicaid Waiver services nationwide because the scope and duration of services varies widely depending on the eligibility criteria applied in each State. For example, in New Hampshire only individuals with acquired brain injuries that need 24-hour access to care are served under the State's waiver program. Consequently, the per-person cost is significantly higher than in States where the primary brain injury Medicaid Waiver service may be case management."[13]

Information regarding Waiver Services and Total Waiver Expenditures for Persons with Brain Injuries (nationwide) is attached for review (See Appendix II; Personal communication, Russ Spearman[14], May, 2006).

Service Needs

"In addition to the standard menu of services under a 1915(c) Waiver, many States provide other services such as transportation, day treatment, behavior modification, cognitive rehabilitation, assistive technology, independent life skills training, specialized medical equipment, and environmental modifications for individuals with brain injury. ***As the result of the L.C. and***

[11] U.S. General Accounting Office (1998). Traumatic brain injury programs supporting long-term services in selected states (Publication No. GAO/HEHS-98-55).

[12] King, A., & Vaughn, S. L. (2005, June). Federal/state funding. *Guide to state government brain injury policies, funding and services.* P. 77. Bethesda, MD: National Association of State Head Injury Administrators.

[13] King, A., & Vaughn, S. L. (2005, June). Federal/state funding. *Guide to state government brain injury policies, funding and services.* P. 77. Bethesda, MD: National Association of State Head Injury Administrators.

[14] Russell C. Spearman is the Senior Research Associate and Project Director for the Idaho Traumatic Brain Injury Implementation Grant at Idaho State University, Boise Center, Idaho. He has presented at state and national conferences and published in numerous scientific journals on Medicaid Brain Injury Waivers and community-based long-term supports for brain injury. Mr. Spearman has many legislative achievements.

E.W. v Olmstead Supreme Court Decision, States must plan for community alternatives to inappropriate institutional care. HCBS Waivers provide a vehicle for developing and paying for community-based services and supports that provide an alternative to institutional or nursing home level of care."[15]

The service needs of individuals with brain injury vary depending on the specific consequences of the injury. Following are services and supports offered by states that serve individuals with brain injury:[16]

Service Coordination/ Case management
Personal Care, In-home Assistance
Respite Care
Long Term Residential Services; Supported living
Day Treatment/Care
Assisted Transportation (non-medical)
Cognitive Rehabilitation
Vehicle modifications
Assistive Technology Devices /Medical Equipment and supplies
Employment (Pre-voc; supported; competitive)
Independent Living Training/Skills Building
Home & Community Support Services
In Home Nursing/Dietitian
Personal Emergency Response Systems
Interpreter Services
Interim Medication Monitoring & Treatment
Companion/Homemaker services
Housing Supplements/ Subsidies
Counseling
Environmental/ Home modifications
Transitional Living
Substance Abuse Treatment
Assessment/ Evaluation
Therapies (speech/language, physical, occupational, cognitive retraining, respiratory)
Behavioral Programs / Services
Money Management
Personal Care/Attendant Services
Home Delivered Meals
Family counseling & training
Assisted Living
Community & Family Education
Recreation

The most frequently used services are (Personal communication, Russ Spearman, May, 2006):

Respite
Personal Assistance Services
Non-Medical Transportation
Service Coordination/ Case management
Home Modifications
Behavior Programs / Psychology/ Counseling Support
Expanded Therapies
Supported Employment
Specialized Medical Equipment
Day Program

Two major concerns are appropriate habilitation/rehabilitation and neurobehavioral or neurocognitive treatment issues. Traditional and other long-term care settings such as ICF-MR

[15] See National Association of State Head Injury Administrators (n.d.) above.
[16] King, A., & Vaughn, S. L. (2005, June). Services and supports. *Guide to state government brain injury policies, funding and services.* pp. 115-150. Bethesda, MD: National Association of State Head Injury Administrators.

typically are not appropriate settings for brain injury survivors. Appropriate residential settings for brain injury survivors usually require both supervision and privacy. The social needs of individuals with brain injury vary and should be considered in choosing the appropriate setting (e.g., social needs are generally consistent with those of adults with average intelligence).

Failure to address neurobehavioral issues increases the risk of job loss, underemployment or unemployment, social isolation, substance use and abuse, inappropriate institutionalization, incarceration, and in some cases further injury or death. These situations often result in a high cost to society, or result in the survivor being unable to make a living or a contribution to society. However, with appropriate and timely treatment, effective interventions and supports, these problems often are manageable or can be minimized.

Best practices include the provision of an environment that is supportive and teaches new skills and strategies, that assists with overcoming lost skills and promotes independence, while not underestimating the person's current knowledge base or skill set and takes into account a person's individual clinical needs. The Money-Follows-the-Person (MFP) program, while benefitting individuals with brain injury who are inappropriately institutionalized in nursing homes, will not benefit those who need services but are living at home or on the streets with inadequate supports and services.

Start up problems identified include (Personal Communication, Russ Spearman, May, 2006):

- Difficulty starting new waiver services where they did not previously exist
- Lack of good providers
- Budget problems
- Lack of professionals with expertise and knowledge about brain injury
- Limited # of waiver slots (based on state FMAP or matching rate)
- Lack of affordable/accessible housing stock
- Lack of consumer owned homes

Service/Support Environment

The following represents a description of the continuum of care for brain injury. Depending upon the characteristics of the injury and needs of the individual being served, one setting or several settings over the course of time may be most appropriate. It is recognized that options may be limited by inflexible Medicaid rules at the Federal level.

The service/support environment and duration of services will vary greatly depending upon the functional level, specific programming needs of the individual with brain injury, and the survivors' and family members' preferences. Furthermore, the individual's need for a less structured environment will change over time as they make progress and acquire skills. Some will graduate out of the program and become self-supporting (over the course of months for some and years for others). A continuum of care is recommended with **service coordination/ case management** support throughout the course of care to ensure that the individual is most appropriately placed from the outset, is receiving needed or desired supports, and transitions to a less structured environment as soon as possible (including graduating out of services). **The precepts of Person Centered Planning and Self-Determination must be incorporated (including dignity of risk and discovery).** Additionally, flexibility is required to graduate and

to later move back into services as needs arise. Direct care staff must have training in brain injury, behavioral management strategies, and crisis prevention intervention.

Additional services such as those listed above under "Service Needs" may be required in any setting. It should be noted that the need for face-to-face therapy (OT, PT, Speech, Cognitive Retraining) may be reduced by the use of a "home program" developed by the therapist to address functional skills, carried out by direct care staff as scheduled by the therapist, and overseen on a consultation basis. Staff training in the therapeutic regimen will be required. Medication management and assistance with medication should be available in all settings.

Group home facilities. Adequate staffing to ensure safety of participants and staff members, structured daily schedule, options for leisure activities, and support for individual needs (e.g., escort to appointments, vocational/volunteer site, etc.). Staffing options may include itinerant staff member support (e.g., floating staff member on call to more than one program for crisis intervention/general support). Larger group homes with more than one staff member may be preferred to 3-4 person homes with 1 staff member to ensure safety, social support, transportation, and leisure activity options for participants. Awake staff support may be needed during overnight shifts for physical assistance or supervision with toileting, transferring and mobility, behavioral problems, supervision of participants with sleep-cycle problems, prompting and reminding of medication, etc. Medical and nursing support should be available on an intermittent basis and as needed (e.g., weekly rounds).

> *Behavioral Program* – Minimum staffing ratio 3 to 1 with more than one staff scheduled at all times. At least one awake staff member at night (may have a "sleeper" in facility). Support for clients who become physically aggressive toward others or self, persistent illegal behavior, or who pose an elopement risk (if courts have appointed a substitute decision maker for medical care and/or placement), or wander risk.
>
> *Supported Living* – Minimum staffing ratio 4 to 1. Composition of the staffing arrangement may vary depending upon the specific needs of the participants. A minimum of two staff members should be scheduled at all times for individuals with a tendency toward agitation, sexual inappropriateness, verbal aggression, drug seeking behavior, etc. The arrangement may involve one staff member on schedule with itinerant staff member support for individuals who are stable emotionally and behaviorally, but who require support for assistance with daily living tasks (ADLs), structured activities, and basic skills training/support.
>
> *Community Re-entry* – Minimum staffing ratio 6 to 1. Support for clients who are able to follow a block schedule independently, who are able to be unaccompanied in the community up to two hours without incident, and who do not display significant behavioral problems that would pose a threat in the community (e.g., agitation, stalking, stealing, substance abuse, etc.). Support services may include independent living skills training, training in use of public transportation, pre-vocational training, strategies for using leisure time, etc.

Assisted Living – This living arrangement has certain benefits in regard to client privacy and ensuring that basic needs are met. Clients who require some support with ADLs and environmental upkeep, and who do not pose a threat to self or others would benefit from this

arrangement. Since the environment is contained, assistance can be provided for those who tend to wander, have problems with judgment or who require assistance in the community. Some structured leisure and vocational activities can be provided in this setting. Supervision in this setting would not be adequate for those individuals with problems with aggression and/or psychosocial problems/judgment that affect safety. Some facilities have operated a workable program by devoting a floor or wing of the facility to brain injury and serving the geriatric population in another area. Consideration should be given to the social needs of individuals with brain injury who are younger.

Supported Apartment – Minimum staffing ratio 8 to 1. On-site support is needed for clients who are able to cook independently (conventional oven or microwave), able to be safe while unaccompanied in an apartment, independent in ADLs, able to use leisure time to personal satisfaction. Do not pose a significant or threat to self or others in community or those who provide care. Staffing is onsite. Specific services that may be needed: financial management; assistance with medication, transportation; oversight for health/safety; assistance in planning leisure activities; liaison with employer/ supervisor at volunteer site.

Community Living Supports – This setting is suited for those with less severe disabilities who can live and work independently with intermittent supports and services. Some individuals with brain injury would benefit from this type of service, particularly those with minimal behavioral problems.

The reader is encouraged to reference Appendix III for Case Studies at each level of care described above.

Texas Veterans with Traumatic Brain Injury

Sixty-four percent of Wounded in Action (WIA) injuries in Operation Iraqi Freedom have occurred as a result of blast injuries from bombs, grenades, land mines, and missiles. Blast injuries frequently result in TBI when the brain moves violently inside the skull. Current trends indicate that more than half of all wounded soldiers will have sustained a TBI. In addition, soldiers have received TBI as a result of falls, motor vehicle accidents and gunshot wounds to the head and neck. Nearly two-thirds of injured U.S. soldiers sent from Iraq to Walter Reed Army Medical Center have been diagnosed with traumatic brain injuries. If current trends continue, over half of all injured soldiers will have a brain related injury. [17]

The Department of Veteran Affairs is planning for the large influx of veterans with TBI from the current conflicts that will need continuing care during the coming years. According to Dr. Deborah L. Warden, a neurologist and psychiatrist at Walter Reed Army Medical Center, "*These are people who are going back into our communities all across the country, who are potentially going to be struggling. Keep in mind, these patients, because of the nature of their brain injuries, can be the ones at highest risk of falling through the cracks*."[18]

[17] U.S. Department of Health and Human Services (2005, October). *America's soldiers paying the cost of survival: A look at the new faces of traumatic brain injury.* Draft publication of the Health Resources and Services Administration, Maternal and Child Health Bureau. Forwarded November, 15, 2005, by National Association of State Head Injury Administrators.

[18] Okie, S. (2005, May 19). Traumatic brain injury in the war zone. *The New England Journal of Medicine, 352*(20), 2043-2047.

Given the large number of Texans who are in the military (1 in 4 enlistees are from Texas), these findings pose a significant concern regarding accessibility to state and VA health services. Dr. Kimberly Arlinghaus, Mental Health Care Line Deputy Executive and Senior Consultant for Psychiatry at the Michael E. DeBakey VA Medical Center in Houston, reported "*the VAs in Texas are not organized in their delivery of care to veterans with TBI. There are four VA hospitals that have specialized TBI programs: Tampa, Richmond, Minneapolis, and Palo Alto, but none in Texas. There are no specialized inpatient facilities providing acute TBI evaluation and treatment in the Texas VA system. Limited post-acute care is available, for example in Houston; however the rehabilitation service does not have a specialized TBI unit which is a serious limitation*" (personal communication, September 1, 2005).

The current Texas healthcare service delivery system is not capable of addressing the myriad chronic disability issues related to TBI for the current civilian population. The additional influx of returning veterans will only add to the demands on an already overburdened system.

Recommendations

The TBIAC recommends that the Department of Aging and Disability Services (DADS) amend the eligibility requirements and service array of Medicaid waiver programs to include, regardless of age of onset, individuals who have incapacitating cognitive/emotional-behavioral/psychosocial dysfunction with or without accompanying physical disabilities. If federal waiver rules preclude amending current waivers to meet the needs of individuals with brain injury, a Brain Injury Waiver should be considered.

Persons with brain injury have a wide range of housing needs depending on their level of cognitive and physical disability. The TBIAC endorses that persons with brain injury always be given the option to choose to live in the least restrictive environment that ensures their safety and the safety of others. Options for care should include provision of functionally based support, behavioral management, community integration services, medication management, family training, as well as intensive support if needed (e.g., structured setting; professional supports to properly manage cognitive and behavioral problems including aggressive behavior). The TBIAC recognizes that not all persons with brain injury will be able to live independently.

The TBIAC recommends that sufficient funding be made available to ensure capacity in community-based programs for individuals with disabilities; that funds are allocated to accommodate waiting lists for services.

The TBIAC recommends that DADS conduct a two-year pilot study, designating 10-15 group homes for this population (with the option of community re-entry into community based programs). Care coordination/case management services should be provided for all participants. The group homes should be based on the concept of least restrictive environment and maximizing the independence of the residents, and of meeting the social needs of the residents. The effectiveness of the program should be evaluated after one and two years.

Issues to Consider

Texas must comply with the *Olmstead Supreme Court Decision* by developing the home and community based services waiver expansion to meet the service needs of adult individuals with brain injury.

Service providers need training about brain injury.

Screening methods are needed to identify people with brain injuries so they do not remain undiagnosed or misdiagnosed.

Rehabilitation programs are needed to help people with brain injury recover lost abilities to the greatest extent possible.

Service coordination and planning (case management) is needed to help people with brain injury identify their needs. Generally, there are two types that are needed: administrative (cost-centered) and targeted (working directly with the individual and his/her support system).

Appropriate residential placement is needed so those with severe disabilities are not forced into nursing homes.

Community living supports are needed so those with less severe disabilities may live and work independently.

Counseling, behavioral management and neuro-cognitive therapy are needed to help survivors and family members adjust to living with brain injury and to treat occasional symptoms that may reoccur or as new skills are learned to progress to a higher level of functioning.

Assistive technology is needed, especially cognitive aids such as timers, tape recorders and planners to support function and independence.

Personal care is needed to provide supervision, reminding or hands-on assistance in meeting basic needs (cooking, eating, personal hygiene among others).

Vocational rehabilitation is needed to assist with finding and maintaining employment over the long term.

How does a TBI waiver differ from Money Follows the Person (MFP)?

MFP focuses on persons institutionalized in nursing homes and determining if there are alternatives.

Brain Injury Waivers focus on appropriate services for persons with brain injury in any setting.

Both are similar in that the person with brain injury is the focus for determining the most appropriate services and the most appropriate residential setting.

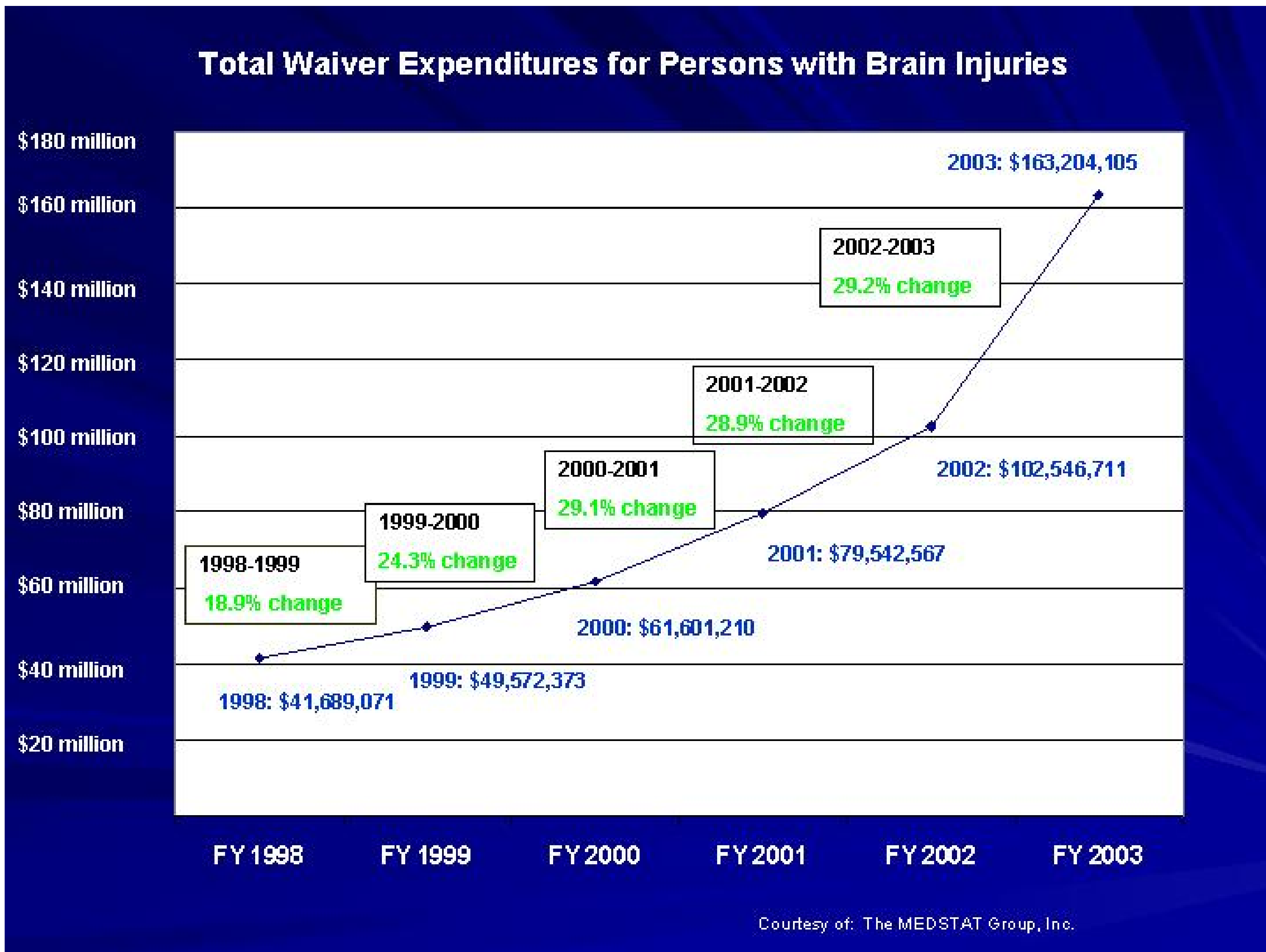
Appendix I

1915 C TBI WAIVERS AS OF 1/01/2005

Services	CO	CT	ID	IL	IN	IA	KS	KY	MA	MN	MD	NE	NH	NJ	NY	ND	PA	UT	VT	WI	WY
Residential Habilitation (Includes Supported Living)																					
Adult Family Foster Care																					
Transitional Living																					
Independent Living Skills Training & Development																					
Day Programs (adult day health, day habilitation)																					
Home & Community Support Services (Homemaker/Chore, Companion)																					
Substance Abuse/MH Counseling																					
Psychology & Counseling Support (behavioral/Substance Abuse)																					
Employment (Pre-Voc/Supported/Competitive)																					
Intensive Behavioral Support/Crisis Support																					
Home Modifications																					
Specialized Medical Equipment & Supplies/Assistive Technology																					
Assisted Transportation (non-medical)																					
Respite Care																					
Personal Care/Attendant Services (PAS)																					
Skilled Nursing/ Dietician																					
Home Delivered Meals																					
Personal Emergency Response Systems(PERS)																					
Expanded State Plan Therapies --																					
Physical,																					
Occupational,																					
Speech,																					
Cognitive Rehabilitation Therapy (relearning)																					
Respiratory																					
Service Coordination (Case Mgmt) Administrative																					
Targeted (optional and/or waivered service)																					
Family Counseling and Training																					
Neuropsychological Evaluation																					
Interpreter Services (limited based on age)																					
Interim Medication Monitoring and Treatment (children only)																					

KEY: Children = IA = 20 & under
MA/MN/IL= Children & Adults NE=Assisted Living/Case Mgmt.

Spearman, R., presented at Medicaid Brain Injury Waivers: A National Perspective; January 7, 2004, Santa Fe, New Mexico


Total Waiver Expenditures for Persons with Brain Injuries
$180 million
$160 million
$140 million
$120 million
$100 million
$80 million
$60 million
$40 million
$20 million
2003: $163,204,105
2002-2003
29.2% change
2001-2002
28.9% change
2002: $102,546,711
2000-2001
29.1% change
1999-2000
24.3% change
2001: $79,542,567
1998-1999
18.9% change
2000: $61,601,210
1999: $49,572,373
1998: $41,689,071
FY 1998
FY 1999
FY 2000
FY 2001
FY 2002
FY 2003
Courtesy of: The MEDSTAT Group, Inc.

Appendix II

Brain Injury HCB Waivers: # Served by State and Fiscal Year[19]

	2003-2004
CO	360
CT	190
DE	Approved; Not Impl.
FLA	253
ID	21
ILL	2,300
IN	176
IA	572
KS	123
KY	110
MD	10
MA	100
MN	1,016
MS	441
NE	35
NH	130
NJ	250
NY	1,400
ND	31
PA	79
SC	160
UT	75
VT	55
WI	310
WY	85

Please Note: The state of Georgia has 30 slots in its Independent Care Waiver reserved for persons with brain injury.

[19] National Association of State Head Injury Administrators (n.d.). Brain injury HCB waivers: # served by state and fiscal year. Retrieved December, 2004 from National Association of State Head Injury Administrators Web site at www.nashia.org. Information no longer available for download.

Appendix III

Case Studies at Each Level in the Continuum of Care for Brain Injury

Group Home

Behavioral

Client #1 requires constant supervision during waking hours or will wander. Within seconds of being unsupervised, Client #1 will quickly disappear and become lost.
Is confused and perseverative. Enjoys playing one card game repetitively. Overnight supervision involves bed checks every 30 minutes, but usually sleeps through the night. Mood is usually upbeat; appropriate with females. May provoke others and engage in physical altercations with other clients whom he does not like.

Client #2 may appear to be in a good mood, however, without warning may strike out to others or property, curse, and spit on others. These events occur approximately 3 times per month. Incidents have occurred while in the vehicle to attend leisure activities in the community. Has a history of altercations with the police and striking healthcare workers (e.g., his psychologist, a rehabilitation educator, a nurse). Client #2 is approximately 6’5” and of average weight. Behavioral management plans are effective in the very short term only, and with written reminders of the plan due to significant problems with memory.

Supported Living

Client #3 has long history of obtaining and using marijuana when unsupervised. Also, when unsupervised will not maintain hygiene routine. Client #3 may agree to shower upon request, however, may not use soap and or wear clothes that have not been cleaned. Responds to feedback regarding need for thorough shower with clean clothes provided discreetly, and to contingency plan (e.g., will shower properly when provided desired leisure activities in the community). Client #3 has tended to refrain from using drugs when home visits (provided every month) are contingent upon his staying sober. Does not initiate activities. Is generally amiable and happy and appropriate with females. Has a tendency to provoke other clients by giving them information that is not true.

Community Re-Entry

Client #4 has a history of aggression toward family members, paranoia and poor social judgment/disinhibition (e.g., calling the mayor of his town to complain about his situation at 10:00 p.m., unable to conclude conversations at the appropriate junctures, misinterpreting information and feedback and responding with threats). Client #4 has been able to work in construction within the supported employment environment due to need for supervision for behavior. Emotion/behavior stabilized with medication change and Client #4 exhibited skills and social judgment to function in the supported apartment setting. Within a relatively short period of time, was able to obtain his driver’s license, maintain competitive employment and prepare to move home with his family.

Supported Apartments

Client #5 is able to prepare meals independently and volunteer in the community (at school for disabled and nursing home). Needs support for transportation and medication (gets confused). Mood is generally positive; has a good sense of humor and is well liked. Exhibits hoarding behavior and fills large areas of the apartment (e.g., her bedroom) with cardboard, plastic, wood, organic materials. Within a three-month period of time the room is filled (up to 7 feet high) making it impossible to open the door of the room and creating a fire hazard. Periodically removing the materials causes great offense, and results in Client #10 refusing to talk to staff or cooperate for several weeks (e.g., refusing to take medication). More effective (and acceptable to client) intervention involves provision of transportation from work/volunteer sights to home contingent upon submission to inspection for hoarded materials and agreement to leave them behind. Periodically it is necessary to remove materials from the apartment, as Client #10 is able to accrue them while on foot in the neighborhood or community.

Community Living Supports

Client #6 has organic brain dysfunction that was present at birth. While a congenital disorder, his clinical presentation is not unlike that of an individual with acquired brain injury. Client #6 has been able to hold down a job for several years at a fast-food restaurant, to live in an apartment, and to get around safely in the community on his bike or using the public transportation system. Problems are related to impulsivity, higher executive functioning (problem solving, judgment) and infrequent, unpredictable conflicts resulting from poor social skills/judgment. He may not respond to social cues: he may talk too much or impose on others. For example, he may walk past the firehouse and walk in the door. Since he is a nice person others are kind to him, which encourages repeat visits. Eventually, it is necessary to ask him to leave or stop visiting. He has befriended others on chat rooms on the Internet; met them in person, and later has been charged with stalking. He has been taken advantage of and considered selling his possessions and giving the money to strangers he met on the Internet. Since he is responsive to guidance and direction from community support staff, they have been able to identify potential problems and intervene. With his permission, community support staff has been able to liaison with employers and recommend a specific approach to address problems. Staff has also been able to liaison with contacts in the community as well as the local police who have provided natural, but appropriate consequences once the nature of his disability is understood. Community support staff have a financial meeting with Client #6 for one hour per week in which he balances his checkbook and pays bills. A second meeting is scheduled every week for community support to ensure that home/domestic responsibilities are completed, monitor for problems at work, and provide guidance regarding social decisions/social skills training. He continues to have problems financially and socially in the community. However, without community supports, Client #6 would be unable to maintain employment and would be on Welfare. He would be involved in the criminal justice system.