The Texas Traumatic Brain Injury Advisory Board Presents
A Summary of the

Gaps in Services

in the Texas Health and Human Service Delivery System
March, 1999

Supported By:
HRSA/Maternal and Child Health Bureau,
State Traumatic Brain Injury Demonstration Grants
and
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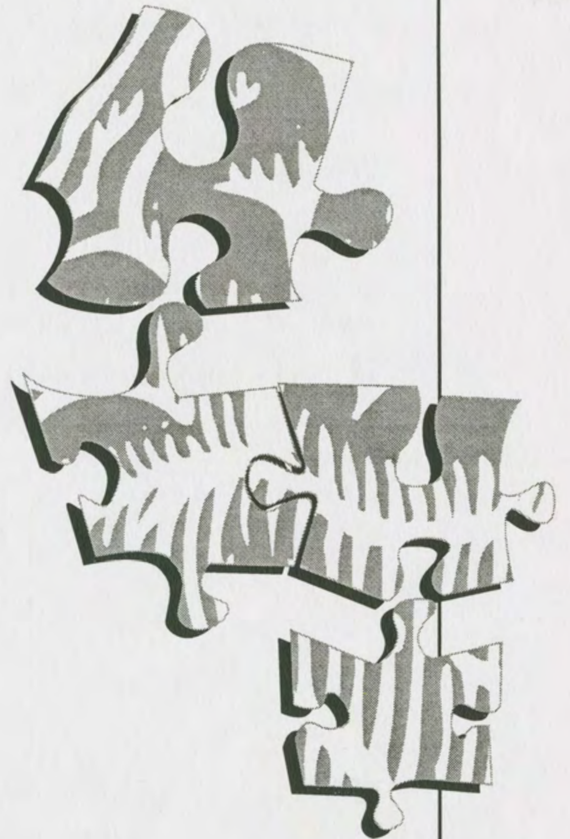

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GAPS IN SERVICES

The current health and human service delivery system in the State of Texas does not adequately meet either the short term or the long term needs of individuals with traumatic brain injury (TBI) and their families. Following are the Gaps in Services which persons with traumatic brain injury and their families face when seeking services in Texas.

GAPS IN SERVICES SUMMARY REPORT

Key Issues

Lack of Appropriate Services:

- Deficits resulting from the brain injury may not be visible.
- Cognitive and behavioral deficits may cause more long term and adjustment problems.
- Delays in accessing services may contribute to loss of functioning.
- Flexibility and timeliness are needed to maximize progress from rehabilitative and long term support services.

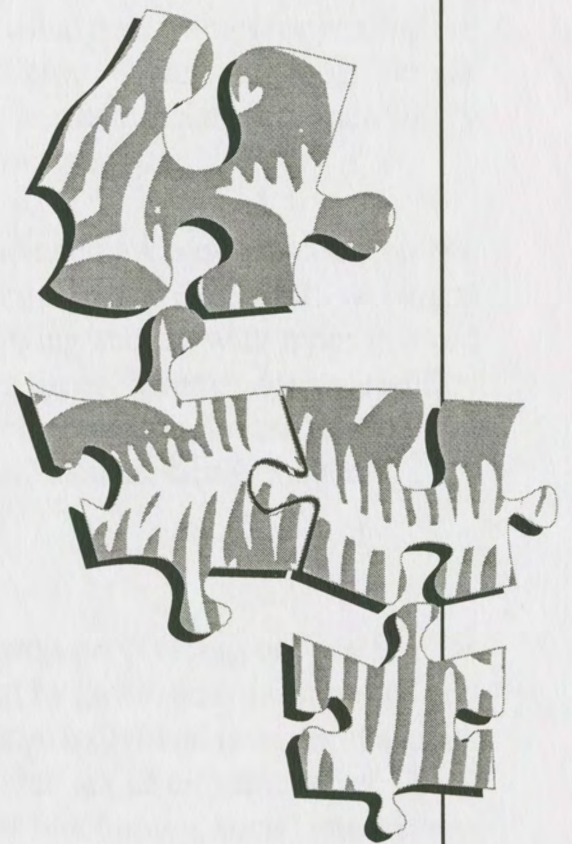
Access to Services:

- Need for a central entry and referral system regardless of geographic locale.
- Need for long term services and supports.
- Need for long term services and supports for persons over 22 years of age with cognitive or behavioral issues.
- Eligibility for services frequently requires a specific diagnostic label.
- Care coordination is a necessary element for assisting persons with traumatic brain injury and their families.

Funding:

- Funding at all levels is piecemeal and insufficient.
- School districts, the primary delivery source for children, need assistance in identifying and providing appropriate education for students with traumatic brain injury.

Lack of Appropriate Services



Lack of Appropriate Services

Why have we not heard of traumatic brain injury before -

Thirty years ago there was not such an urgent and critical need for services for persons with traumatic brain injury because people were not surviving their injuries. The survival rate has dramatically increased as a result of advances in life saving techniques, improvements in emergency medicine, revolutionary diagnostic tools, and sophisticated surgical procedures.

Surviving the traumatic brain injury is only the beginning because most individuals with brain injury require some level of medical, therapeutic or rehabilitation services. As a result of this growing population's needs, the relatively new field of physical medicine and rehabilitation has developed in an attempt to meet the need for treating people who survive their injuries and are living with traumatic brain injury.

Limitations -

Treatment protocols, expected medical outcome and usual time frames for healing are utilized by the medical profession to guide length of care. Such protocols do not readily apply to persons with traumatic brain injury because traumatic brain injury rehabilitation is a slow process and improvement is idiosyncratic.

In October 1998, the National Institutes of Health convened a Consensus Conference on the Rehabilitation of Persons with Traumatic Brain Injury. The draft statement concluded, "Cognitive recovery proceeds in overlapping stages, with more marked improvements in particular skills occurring at different times. Tremendous variability in behavioral performance is a fundamental feature of behavior after traumatic brain injury. Treatment protocols likely will be complex and systematically staged . . . "

Rehabilitative Progress -

Individuals with traumatic brain injury may seem to stop progressing or "plateau" as recovery is a very slow process and is greatly affected by environmental stimulus and conditions. The rehabilitative or therapeutic measures an individual receives at a given point in time are useful for that point in time and for that set of circumstances. They may not be sufficient as the person experiences greater functioning, social interactions or responsibilities.

It is critical and necessary for an individual to receive additional rehabilitative measures after having had a period of learning and then utilizing these skills. However, when the term "plateauing" is applied to a person with a traumatic brain injury, treatment often ceases under the assumption that maximum recovery has occurred. This is a fallacy. Unfortunately, re-entering the rehabilitative system for additional or new services and supports is very difficult within the traditional existing system of service delivery and funding streams.

Unique Aspects of Traumatic Brain Injury -

After a traumatic brain injury cognitive[1] and behavioral needs tend to escalate. Services generally available in Texas are designed to address medical, nursing, and therapeutic needs rather than cognitive and behavioral issues.

In the programs which provide a wider array of community-based services, the programming, albeit individually planned, is primarily for people with chronic mental illness, profound mental retardation, developmental delay or disabilities and people who are aging.

The disabilities or limitations resulting from a traumatic brain injury frequently leave the individual in need of assistance in order to accomplish the basic tasks of daily living. The availability of services such as health care and rehabilitation, home and community-based support services, job training and placement, income support and education can make the difference between a wasted life and a fulfilled life in the community.

A prescribed set of services does not work -

People with brain injuries do not require a prescribed set of services. Rather, they need the availability of a range of services that are designed to meet individual needs, are diverse and change over time. Ideally, services and supports should be flexible, allowing people with brain injuries and their families access to services when they need them and not just when the system offers them.

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[1] "Cognition is a complex collection of mental skills that includes attention, perception, comprehension, learning, remembering, problem solving, reasoning...These mental attributes allow us to understand our world and to function within it. After a brain injury, a person typically loses one or more of these skills. Cognitive rehabilitation is the art and science of restoring these mental processes after injury to the brain." Parenté, R. & Herrmann, D. (1996). Retraining Cognition: Techniques and Applications. Aspen Publishers, Inc. (pp 1)

Persons with a brain injury should have control over the services received. To be cost-efficient, the system should allow for individuals to progress to a less restrictive environment, until they reach their maximum level of independence. **If options exist in the community, these individuals can avoid stays in more expensive institutions.**

The services needed by persons with traumatic brain injury do share basic commonalities with other disability groups. However, for the person with a brain injury, the ability to access services, to meet the level of care criteria, and to have services provided by persons knowledgeable about brain injury is a segregating factor in the service delivery system in Texas.

Bound by tradition -

In most situations, the *Standards of Care*[2] for providing medical services and the traditional philosophies of service delivery do not adequately address the needs of individuals with brain injuries. The effects of traumatic brain injury are very personal as brain injury impacts the personality of each individual along with the physical, medical, and cognitive. Therefore, long term effects and needs vary greatly.

Families are grasping at straws when trying to get help for their family members because the family member with the brain injury often fails to qualify for eligibility to existing services and supports. As a result, families and individuals will accept an inappropriate label such as a psychiatric diagnosis, in order to access existing services.

Short term mental health or behavioral management services may be helpful but problems often occur when the individual or the family member with a brain injury receives services only to discover the services are inappropriate for the person's needs.

Potential for decline -

For many individuals, this results in additional emotional trauma added to the life altering changes resulting from the brain injury. This situation may have further severe consequences as many of the drug therapies for persons with chronic mental illness have deleterious effects on the persons with a brain injury. It may even worsen the effects of the brain injury and reduce the person's ability to function.

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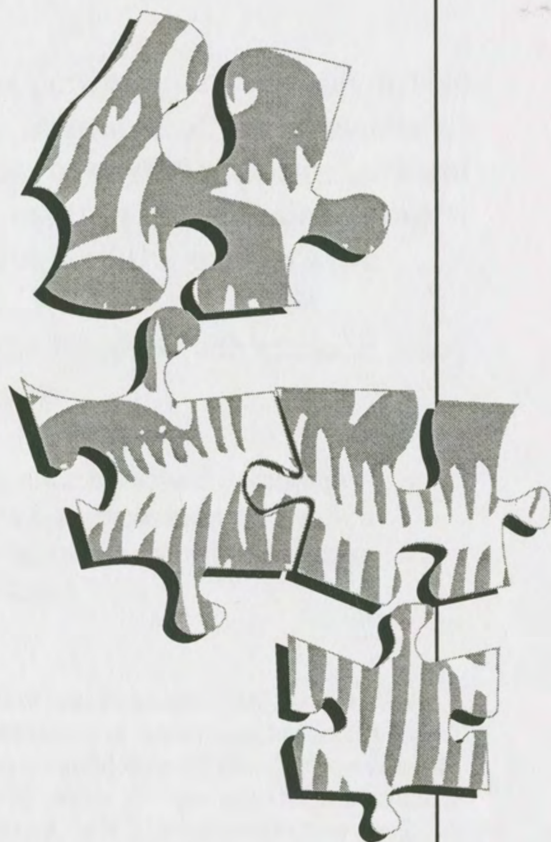
[2] *Standard of Care,* "A statement of actions consistent with minimum safe professional conduct under specific conditions, as determined by professional peer organizations." Tabers' Cyclopedic Medical Dictionary, Eighteenth Edition, 1997, E.A. Davis Company, pg. 1822. Also used in measuring outcomes and critical pathways for disease progression and treatment.

In February 1998, the US General Accounting Office, Report to Congressional Requesters, *Traumatic Brain Injury, Programs Supporting Long-Term Services in Selected States*, reported:

> "The services needed by adults with traumatic brain injury - 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 . . . Adults with traumatic brain injury often do not recognize their own limitations and lack executive skills to coordinate services . . . often have normal intelligence but are unable to transfer learning from one environment to another . . . **Without treatment, individuals with problematic or unmanageable behaviors are the most likely to become homeless, institutionalized in a mental facility, or imprisoned."**

Application for State Services



Application for State Services

Access to Services

Pre-admission Level of Care Requirements -

Most individuals with traumatic brain injury are not eligible for a majority of existing home and community-based state services as they do not meet the Level of Care (LOC) comparable to the admission criteria for Skilled Nursing Facilities (SNF) or Intermediate Care Facilities for the Mentally Retarded (ICF-MR).

Making the statement: "individuals with traumatic brain injury are not eligible for a majority of existing state services" raises a big question, "Why not?" Part of the answer lies in the severity ratings for traumatic brain injury. Traumatic brain injuries are classified as severe, moderate or mild. [3] Therefore, persons who have a "severe" brain injury frequently have medical needs, obvious physical impairments and other visible deficits as a result of their injuries and being unconscious for more than 24 hours.

Those who sustain a "mild" and some who sustain a "moderate" brain injury often have few visible physical signs or functional limitations to their appearance or mobility. **The problems are: a mild brain injury frequently causes cognitive and behavioral impairments or deficits that are not obvious, but result in life altering changes. These impairments may be short term or last throughout the person's life.**

The February 1998, GAO Report briefly identifies the issues which exclude many persons with brain injury from access to existing systems.

> "Adults with traumatic brain injury 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 pre-admission screening process may be oriented to physical rather than cognitive disabilities."

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[3] Severity of traumatic brain injury (TBI) - Mild: without Loss of Consciousness (LOC) and/or Post Traumatic Amnesia(PTA), with no skull fracture, cerebral contusion, laceration, or intracranial hematoma and a Glasgow Coma Scale(GCS) of 13-15, Moderate: where LOC and/or PTA occurred for > 30 mins but less than 24 hrs and a GCS, 9-12 and/or a skull fracture occurred, Severe: where LOC and/or PTA occurred for > 24 hrs or a cerebral contusion, laceration, or intracranial hematoma was present and GSC of 3-8. Paraphrased from Head Injury and Postconcussive Syndrome, Edited by Matthew Risso,MD and Daniel Tranel, PhD, Churchill Livingstone, 1996, page 23.

The *GAO Report* did not include Texas in its survey because Texas does not have a Traumatic Brain Injury Home and Community-Based Medicaid waiver. However, the report's findings about the needs and outcomes of persons with traumatic brain injury are applicable to Texas. It succinctly states the obstacles persons with brain injury and their families face when attempting to access services.

> "Adults with traumatic brain injury who can 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 . . . have difficulty functioning independently. This difficulty will most likely last throughout their lifetime . . . The lack of executive skills also complicates the ability of adults with traumatic brain injury to negotiate the various service delivery systems. People without someone to act as their personal advocate have difficulty obtaining services from multiple programs."

The National Institutes of Health Consensus Conference on the Rehabilitation of Persons with Traumatic Brain Injury draft statement addressed the complexity of brain injury and the pervasiveness of the injury's impact.

> Rarely are the consequences limited to one set of symptoms, clearly delineated impairments, or a disability that affects only a part of a person's life . . . Furthermore, when other, more urgent medical problems are apparent at onset, mild traumatic brain injury may be masked, even though the traumatic brain injury results in subtle impairments. Finally, in many cases, the consequences of traumatic brain injury endure in original or altered forms across the life span, with new problems likely to occur as a result of new challenges and the aging process.

Finding the Entry Point -

Finding the entry point to make the initial application to the State's services and supports is challenging and complicated for persons with a traumatic brain injury and their family support systems. Currently, there is no commonly held public information or publicity of where the individual needs to go to submit an application for state services. For many persons with traumatic brain injury and their families this becomes a roadblock that is exhausting and thus, they give up.

INTERNET information on "How to Apply" for Texas Department of Health, Texas Department of Human Services, Texas Rehabilitation Commission, and Texas Department of Mental Health and Mental Retardation services is a recent and welcomed improvement. Yet, the INTERNET is not a resource available to everyone seeking services. Many of the working poor and those at poverty level do not have

access to the INTERNET. Furthermore, persons with brain injury have difficulty using a computer due to the inability to process language, may have diminished eye-hand coordination, decreased retention of visual information or other cognitive processing deficits.

Access to the state systems varies from agency to agency. Currently, no central referral system is able to make appropriate referrals for persons with a traumatic brain injury. In many cases the services and supports needed for persons with traumatic brain injury are either unavailable, unidentified, or nonexistent. This lack of identifiable resources poses a challenging situation for the two referral and/or enrollment systems[4] being developed in Texas. At this time, neither system is functional statewide, nor has yet to tie all of the many sites and services together for a coordinated and comprehensive enrollment process and referral network.

Services Limited to a Specific Geographic Region or Catchment Area

The vast Texas geography adds to the difficulty of providing service delivery statewide. Some of the long-term, community-based service delivery systems are in either limited service areas (CLASS, HCS) or available only regionally. This becomes a problem as much of the state is rural with few resources and services in these areas.

The metropolitan or urban areas of Texas have clusters of private and publicly funded services. Identifying and accessing long-term care services becomes a very large challenge as they are not available in the more sparsely populated areas of the state. Persons in an urban area with a brain injury have a better chance of accessing services than those who live in rural communities.

Of the state-funded services available throughout the state, securing providers to deliver the services often becomes a problem. Anecdotal information suggests providers in the Northern part of the state are often reluctant to accept individuals with public funding, whereas providers in many parts further south in Texas and the Valley do not have those concerns.

[4] Texas Information and Referral Network (TIRN), Health and Human Services Commission, and the Texas Integrated Enrollment and Services (TIES), Department of Human Services

Lengthy Waiting Lists

Due to lengthy waiting lists, accessing services through the Medicaid waiver and other long term community-based programs is almost insurmountable. The need for services requires immediate access when a person sustains a traumatic brain injury. Waiting for services can be detrimental to the person's ability to progress. In fact, when a person does not receive timely services, loss in the ability to function or decompensation occurs. This can affect the total life long recovery process. Frequently, families are discouraged from making application by local offices of the state agencies because the individual's need for services is so severe that waiting is not an alternative.

Seven state programs[5] provide services designed to assist in facilitating an individual's rehabilitative progress. Of the seven programs, access to the Texas Rehabilitation Commission's Comprehensive Rehabilitative Services (CRS) is possible in a timely manner, but CRS also has a waiting list.

CRS has been a benefit to persons with a traumatic brain injury, but the services are short term and often no systematic transitioning into other services occurs when CRS support ends. Even so, CRS funding may provide the only realistically available system of services for many as most other programs have such lengthy waiting lists.

Service Coordination

Case Management -

State programs and insurance companies utilize case management. The case managers are internal to these systems and are actively measuring outcomes against set time frames and practice guidelines. Generally, this model of case management or service coordination does not work for persons who have traumatic brain injuries as the rehabilitative process is so slow.

However, this **does not mean** that persons who have brain injuries cannot benefit from case management or service coordination. **Service coordination was continuously specified as a significant and unmet need by participants at the statewide pubic meetings in the spring of 1998.**

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[5]CLASS, CBA, HCS, MDCP, Tx Health Steps, IHS, CRS (short term only)

Lack of Service Coordination -

Attendees at the public meetings held statewide in the spring of 1998, cited case management or care coordination as a high priority need. Many families and individuals with TBI reported they were floundering. It is common for the family to be overwhelmed by the needs of the person with the brain injury and traumatized in the ability to act on the behalf of their family member. In many cases, they did not know where to go or what might be available. They indicated, if an advocate or guide had been available to provide information and assistance into or through systems, greater progress could have been realized by the person with the traumatic brain injury and less stress placed on the families.

When the individual has no family support system, it is highly unlikely the person will be able to identify, apply, access, or develop a service plan. As stated in the *General Accounting Office Report*, ". . . people without an effective and knowledgeable advocate would [will] probably not receive services . . . "

"Access to initial care and subsequent rehabilitation for persons with TBI [traumatic brain injury] may depend greatly on insurance coverage, geographic location, knowledge of available resources, and the ability to navigate the medical care and rehabilitation system successfully.[6]"

[6] Draft Statement from the October, 1998, National Institutes of Health Consensus Conference on Rehabilitation of Persons with Traumatic brain injury.

Age Limitations

Onset prior to the 22nd birthday -

Texas has not requested a waiver of Medicaid regulations which restrict eligibility to age of onset of disability. Therefore, most of the community-based waivers[7] in the state have an age limitation for entry into these services. Should an individual acquire a traumatic brain injury after the 22nd birthday, few long term services are available in the State of Texas.

If an individual has a diagnosed injury or suspected traumatic brain injury[8] prior to age 22 but did not need services immediately after the injury, an application for services may still be submitted if the individual has:

- the inability to provide self-care,
- impaired or progressive inability to be mobile,
- diminishing cognitive functioning or
- escalating problematic behaviors which can be directly linked to the initial injury or incident.

"Ages Out" -

Several programs in the Department of Health are solely for children under age 21. In these programs an individual "ages out" at 21. Consequently, the individual, family/guardian or service coordinator must plan ahead. Applications for similar services delivered through other health and human service systems must be submitted long before the individual turns 21. If this is not done, the individual is at risk for losing services. For children and young teens, transitioning generally works because

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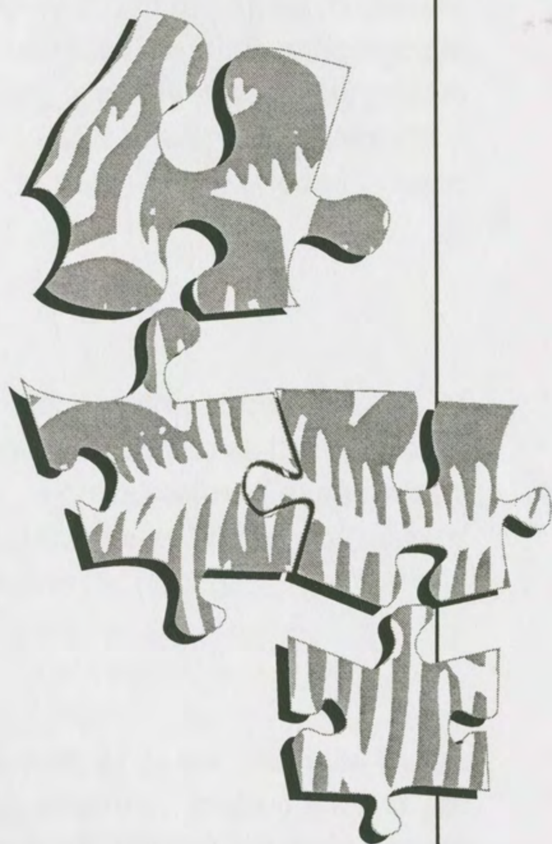
[7] Under waivers, states with HCFA approval, can waive standards, comparability of services, and equal provision of services as long as the cost of providing these services will not exceed the cost of institutional care. A state may select the services, the service definition, the target population, service delivery area, 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 non-medical transportation services. Paraphrased, US Government Accounting Office, Report to Congressional Requesters, Traumatic brain injury, Programs Supporting Long-Term Services in Selected States, February, 1998

[8] If the incident or injury does not have a specific medical record or diagnosis, determining eligibility is more difficult.

there may be time to out wait the waiting lists. For the individuals who are over 15 or 16 years of age when they first access services, transition into other services at 21 may be impossible due to the lengthy waiting lists and the minimal attrition rate. Therefore, the individual is at great risk to lose services necessary for health, safety, and the ability to function in the least restrictive environment.

Funding for Traumatic Brain Injury Services and Supports



Funding for Traumatic Brain Injury Services and Supports

Comprehensive Rehabilitation Services -

As cited earlier in this document, Comprehensive Rehabilitation Services (CRS) is the program of the Texas Rehabilitation Commission that serves persons with spinal cord or traumatic brain injury. The reimbursed services cover a wide array of rehabilitative measures; however, they are time limited, subject to waiting lists, and constrained by funding allocations. All other insurance or medical coverages must be exhausted before CRS is able to pay.

Managed Care and Insurance Coverage -

For persons who have private insurance coverage, it is very quickly exhausted as the acute medical hospitalizations and services are very costly. HMO's and traditional insurance coverage generally have no provisions for rehabilitation or long term services and supports. Many individuals with traumatic brain injury do not need long term acute medical care, but do require cognitive, behavioral and functional training or therapeutic modalities. Cognitive rehabilitation or cognitive therapy is rarely covered by private medical insurance and Medicaid. In fact, cognitive and IADL (Independent Activities of Daily Living) training and psychological services are specifically excluded in some health plans.

Medicaid Home and Community-based Waivers -

Medicaid waivers provide many services, but eligibility requires a certain level of medical need. Therefore, access to the waivers is frequently denied as the individual does not meet the medical or physical requirements. For those few Texans with a brain injury who are able to access the existing Medicaid home and community-based waivers, the potential for achieving and sustaining progress is hopeful.

Medicaid -

Medicaid reimbursed acute rehabilitation for an adult over 21 is **not** provided by the state of Texas. Rehabilitation is necessary after a traumatic brain injury if the individual is going to return to function and be able to work toward full participation

in the community.

Private insurers and Health Maintenance Organizations recognize the importance of early rehabilitation for persons who have had strokes, aneurysms, benign brain tumors, and other neurological disease processes. They have found rehabilitative measures facilitate return to function.

Persons with traumatic brain injury require the same urgency and medical care. The reality is, only 1 in 20 persons who sustain a traumatic brain injury receives the needed rehabilitation. Ironically, it is not a covered cost by Medicaid, HMO's or most private insurance. One explanation for this may be: most individuals who sustain traumatic brain injuries tend to be younger and may be uninsured or under insured.

Frequently, individuals who have sustained a traumatic brain injury have physical needs which diminish over time, while the cognitive and behavioral needs become greater. Those who have few physical needs are frequently denied Social Security benefits regardless of the deficits which limit their ability to manage their lives or function safely on a daily basis. Consequently, these individuals cannot access the Medicaid system from which they might have been able to receive some of the needed services.

"Working Poor" -

Persons who have been working at a minimum wage or just above it are often unable to receive the traditional state/federal medical insurance coverage. The following issues which they face are identified here as Texas has a significant number of people who are in an income bracket known as the "Working Poor". When one of these individuals sustains a brain injury, Medicaid coverage may not be available as the person's resources exceed the state income limitations for Medicaid. Individuals in this group of people may have other types of insurance coverage, but it is quickly exhausted when a brain injury occurs.

This is not the only issue for people who are working but remain close to or at the federal poverty level. Because these individuals have worked, they have paid into the Social Security and Medicare systems. Should they receive an injury or have an illness for an extended period of time, they will probably not be eligible for Medicaid simply because they have been employed and have paid into Social Security and Medicare.

However, in some instances the person may be Medicaid eligible as the Social Security Disability Insurance (SSDI) monthly income may be lower than the allowable monthly

Supplemental Security Income (SSI) cap. Therefore, the person may be eligible for Medicaid, Medicare and SSI/SSDI.

If the individual is determined eligible for a community based-waiver, and begins to receive those services, Medicaid eligibility is conferred and the person has Medicaid coverage regardless of the family's resources.

Waiting for Disability Determination -

When a person is waiting for the Social Security disability determination to be made, access to publicly funded health care coverage is not available. Some public funds cover medical emergencies, but access to publicly supported community-based health and human services is not a reality. The inability to acquire needed medical and/or rehabilitative services may further impede the individual's ability to move forward. Not being able to access rehabilitation in a timely and appropriate manner has long term adverse effects to both the individual and the community, and therefore, to the State of Texas.

Temporary Assistance for Needy Families (TANF) -

Some individuals may be eligible for TANF public assistance and therefore, Medicaid. However, it is infrequent that young, single males (the high risk group for sustaining a brain injury) receive TANF assistance unless they are single parents with dependents under the age of 18 and are financially eligible as they fall below the federal poverty level for TANF.

Children's Services -

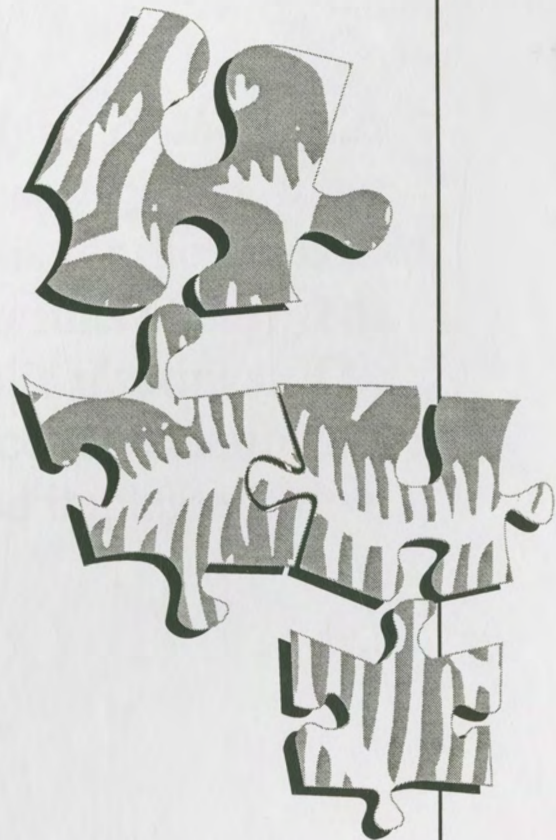
When a child under age 21 needs rehabilitative services, a larger system of supports and services is available through Medicaid and the public school systems. However, identifying these resources in no way assures accessability to the services or appropriateness of service delivery for individuals under the age of 21 who sustain a traumatic brain injury.

Public schools are required to comply with Public Law 102-119, Individuals with Disabilities Education Act (IDEA), assuring all students with disabilities a free and appropriate public education (FAPE). This may include providing necessary accommodations and therapies to assure an environment that meets the child's needs in order to learn. The public schools are the primary source of therapies and

interventions for children and adolescents.

Parents of children with traumatic brain injury, who attended the statewide public meetings in the Spring of 1998, expressed concerns over many of the state's school districts. They reported the schools with which they had experience, did not provide the learning environment most appropriate for their child with a traumatic brain injury. They reported having a lengthy waiting time for educational diagnostic evaluations and their children were inappropriately placed either by grade level or classroom environment. When behavioral problems were manifested, the student was either suspended or expelled from school. Frequently their children had teachers who were not trained to work with students who have traumatic brain injuries.

Concluding Remarks



Concluding Remarks

The services identified as "Gaps" are those that either are not available or are difficult to obtain for persons with traumatic brain injury and their families in the State of Texas. This document focused on both. This is a brief review of what is currently available in the state's services and supports as well as the funding streams contrasted with the types of services needed by persons with traumatic brain injury.

In the document, *Policy Analysis of the Texas Health and Human Service Delivery System,* more detail is provided and is the basis for the *Gaps in Services.* It is interspersed with results of the needs assessment surveys and the public meetings. The *Statewide Action Plan* offers recommendations to the State of Texas for action and implementation.

The information presented in these recommendations to the State of Texas is driven by

The startling impact that Traumatic Brain Injury:

- Frequently kills or threatens the life and well-being of the individual who sustains the brain injury.
- Respects no one - All Texans are at risk for sustaining a traumatic brain injury.*
- Is the number one cause of death and disability of children and young adults.
- Frequently occurs as a result of risk taking or reckless behaviors.
- Is often unrecognized or misunderstood.
- Is frequently undiagnosed or misdiagnosed thereby leaving the individuals without services and supports.
- Results in many individuals who look "OK" but are unable to function "OK" and may have life-long cognitive and behavioral impairments.
- Is frequently trivialized and misrepresented by the media.
- Requires appropriate services and supports ranging from acute medical care to long term community-based services and supports many of which are not readily available in Texas.
- Results in a growing number of Texans with traumatic brain injury whose only service delivery system is a homeless shelter, a prison or a state institution, thereby costing Texas more for their care than it would have had these individuals received the necessary rehabilitation and community-based services.
- Is an injury whose effects rapidly travel beyond the individual and may significantly affect or alter the family and the community as well.
- Has a high price tag in terms of lost tax revenues, productivity and the provision of medical care.
- **Is preventable.**

*Anyone engaged in movement either as an occupant or rider of a moving vehicle be it motorized or human driven; a participant in activities which involve motion by foot, by machine or by propulsion; someone either engaging in risk taking behaviors involving speed, motion or physical contact or the recipient of someone else's inattention, negligence, or violence.

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