The Texas Traumatic Brain Injury Advisory Board Presents

A Policy Analysis

of 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
The Texas Planning Council for Developmental Disabilities

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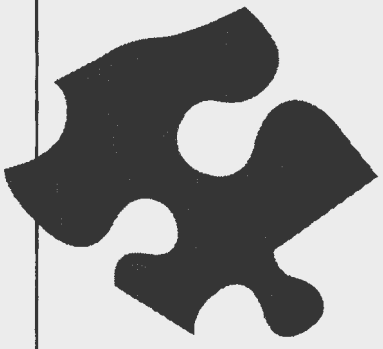

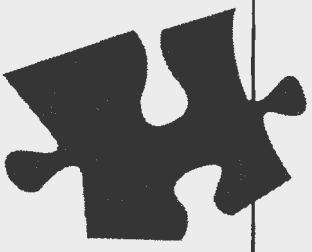

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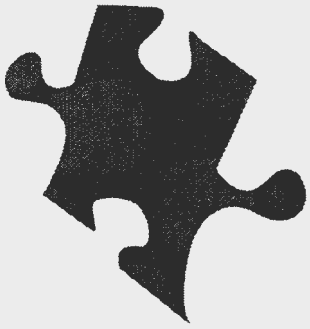
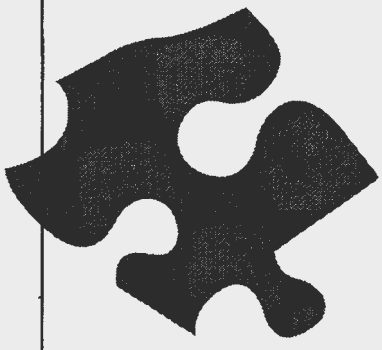
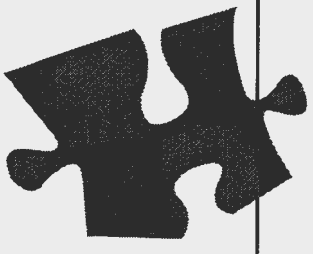


Introduction





POLICY ANALYSIS

HEALTH & HUMAN SERVICE DELIVERY SYSTEMS

In the

STATE OF TEXAS
March 1999

Statistics

Among all types of injury, Traumatic Brain Injury (TBI) is most likely to cause death or permanent disability. **Traumatic brain injury is the leading cause of death and disability in children and young adults.** The incidence and prevalence, severity, and cost reveal that traumatic brain injuries are important health problems. Nationally, it is estimated that traumatic brain injuries may result in 260,000 hospitalizations and 52,000 deaths, annually (Centers for Disease Control and Prevention). It is estimated that 70,000 to 90,000 people sustain a traumatic brain injury resulting in permanent disability each year. The costs for traumatic brain injury are unknown but certainly enormous; one estimate is $37 billion annually in direct (acute care, rehabilitation, long term care) and indirect costs (Centers for Disease Control and Prevention).

Traumatic brain injuries are largely preventable. Motor vehicle crashes, falls, and violence are the leading causes. Improved emergency medical care over the last 20 to 25 years has resulted in greatly increased survival rates that contribute to a growing population of people living with traumatic brain injury.

Each year, approximately **20,000 Texans** sustain a traumatic brain injury serious enough to require hospitalization; more than **3,000** of these injuries will result in DEATH. Preliminary 1997 data from the Texas Department of Health's Trauma Registry indicates that approximately **8,000** individuals sustained brain injuries severe enough to require in-patient hospital admission. The incidence may be higher in subsequent years as reporting compliance by hospitals improves. It should be noted that this number does not include individuals treated in emergency departments and released, hospitalized for observation for less than 24 hours, or those who visited physicians or urgent care clinics without hospitalization.

Definition

Traumatic brain injury means an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning.[1]

It is an occurrence of injury to the head (arising from blunt or penetrating trauma or from acceleration-deceleration forces) that is associated with any of these symptoms or signs attributed to the injury: decreased level of consciousness, amnesia, other neurologic or neuropsychologic lesions, or death.[2]

Legislation

In 1997, the Texas Legislature passed a law that mandated the reporting of traumatic brain injuries to the Texas Department of Health. The first step toward assessing the magnitude of traumatic brain injuries has been completed with the final adoption of the rules by the Board of Health in July 1998. The rules mandate the reporting of all occurrences of traumatic brain injuries resulting in admission to hospitals and all those resulting in treatment and admission to acute and post-acute rehabilitation facilities.

The Texas Traumatic Brain Injury Advisory Board's Mission is to:

- **Inform state leadership of the needs of persons with brain injuries and their families,**
- **Recommend policies and practices to meet those needs and**
- **Promote prevention efforts in Texas.**

In February 1998, Governor George W. Bush established the **Texas Traumatic Brain Injury Advisory Board.**[3] The Board membership is representative of the geographical areas of Texas and comprised of individuals with traumatic brain injury (TBI), family members, providers of services, and state agencies. Governor Bush, in proclaiming October 1998, Brain Injury Awareness Month stated: "I encourage all Texans to learn more about brain injuries and how to prevent them".

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[1] Definition from PL 104-166, July, 1996

[2] CDC, 1995

[3] The work of the Texas Traumatic Brain Injury Advisory Board is made possible by a grant from the HRSA/Maternal and Child Health Bureau, Traumatic Brain Injury-Demonstration Grants, funded for FY's 1998 - 1999, an appropriation from the State of Texas, gifts from public, private and not-for-profit organizations.

The Board:

- Distributed statewide, 1000+ Needs Assessment surveys to persons with traumatic brain injury, family members, service providers, and publicly funded agencies.
- Held 9 public meetings throughout Texas during the Spring of 1998.
- Completed a policy analysis of existing state supports and services.
- Published findings from the needs assessment surveys and public meetings.
- Developed a comprehensive Statewide Action Plan of supports and services for persons with traumatic brain injury and their families.

Ongoing Activities of the Board:

- Inform state leaders of traumatic brain injury issues and policies for meeting the needs of persons with brain injuries and their families.
- Recommend to state leaders policies and programs which more effectively serve persons with brain injury and their families.
- Explore and promote innovative approaches to providing services and supports to persons with brain injury and their families.
- Promote education, training, and information about brain injury issues.
- Advocate for persons with traumatic brain injuries and their families.
- Support activities aimed at reducing preventable brain injuries.
- Conduct outreach to obtain public input.

If we as a society are willing to save lives, then as society we need to be concerned with the quality of that life.

Person with Traumatic Brain Injury, Austin

Foreword

Sunset Review Process -

Texas is at the crossroads of change as a variety of factors will be affecting health and human service delivery systems. Twelve Health and Human Service agencies are currently undergoing review with possible restructuring or abolishment. Medicaid is mandated to pilot a managed care model of acute and long term care services. The state is developing more comprehensive health care for children and working on welfare reform. There are on-going efforts related to integrating access to the delivery of services statewide.

As the Sunset Review Process evaluates the health and human service agencies, it is making recommendations which will affect:

- How services are delivered,
- Which agency coordinates services to different groups,
- Which agency's programs would be more effective if consolidated with another agency,
- What services can be coordinated with other services for more efficient service delivery,
- Easier access to services and
- How to maintain cost efficiency and effectiveness of public health and human services needed by Texans.

How the health and human service delivery systems will finally be arranged and services delivered is a work in progress. Much work remains.

Medicaid Managed Care -

A new approach to providing acute and long term care services in Texas is an extended managed care system. It has been implemented as a pilot program in the Houston area and is called Star+Plus. The program is for persons who are receiving SSI and are Medicaid recipients. This program is an attempt to combine medical and preventative health care with support for the long term care needs of this population. Within the next few years more Medicaid managed care programs will be implemented throughout the state. Star+ Plus is currently getting mixed reviews and there is caution by some as it may be reducing services rather than streamlining and improving service delivery.

TIES (The Texas Integrated Eligibility System) Project -

The Texas Integrated Eligibility System (TIES) is designed to allow multiple access points to existing services and to provide enrollment and eligibility screening, all supported by technology where possible. A service access plan will be developed with the client for accessing public services and outside resources. This project is being coordinated by Texas Health and Human Services Commission through the workings of the Texas Department of Human Services, the Texas Workforce Commission and the Texas Department of Health. It is anticipated, when the TIES project is up and running, there will be access to 50 state programs.

Medicaid Home and Community-Based Waiver Services -

Medicaid Waiver programs are available in Texas. While waivers do provide a wide array of supports and services for the persons who are able to access them, relatively few individuals with traumatic brain injuries receive services and supports from the waiver programs because:

- many people do not meet the eligibility requirements,
- waiting lists are long,
- programs are limited to specific areas of the state, and
- the application process is often lengthy and not coordinated agency to agency.

In the US General Accounting Office Report to Congressional Requesters[4], *Traumatic Brain Injury, Programs Supporting Long-Term Services in Selected States,* the investigators found that waivers for persons with traumatic brain injury tend to be exclusionary instead of inclusionary. The eligibility criteria:

- "...are often strict and based on certain physical limitations, such as bathing, dressing, or eating.

- ...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 preadmission screening process may be oriented to physical rather than cognitive disabilities.

- ...with the exception of nursing facility care, most services

[4]February, 1998

provided under the standard Medicaid waiver 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 traumatic brain injury."

These trends hold true in Texas with the existing broad based waivers for home and community services.

State of Traumatic Brain Injury Services in Texas -

The State of Texas has no current delivery system which adequately meets either short term or long term needs of all persons with traumatic brain injury and their families. Existing services for persons with traumatic brain injury are:

- inaccessible,
- inappropriate, and
- significantly under-represented in Texas' health and human service delivery system.

Presently, one agency, the Texas Rehabilitation Commission, has had the responsibility for rehabilitation services post-traumatic brain injury and spinal cord injury. The program is the Comprehensive Rehabilitation Services (CRS). These services came into existence as a result of a trust fund with monies generated from fines assessed individuals with misdemeanor and felony convictions. It was legislatively established in 1991 and began serving people in the last quarter of 1991.

CRS provides acute in-patient comprehensive rehabilitation, out-patient rehabilitation, and post-acute traumatic brain injury services. CRS is available to individuals who are newly injured as well as persons who have been living with brain injury for less than 2 years. Regardless of the date of injury, all individuals must meet the eligibility criteria.

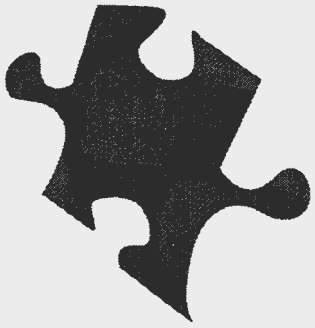
Because CRS is a payer of last resort, all other resources must be considered and used first. As beneficial as these services are, they too, are time limited and constrained by internal and regulatory funding flow issues. CRS is the only program which has designated funding streams aimed at meeting the short term needs of persons with brain injury and their families. Having only one avenue or type of programming available to this growing population of persons with traumatic brain injury is an unrealistic expectation. CRS cannot be expected to solely carry the load.

Purpose of the Policy Analysis

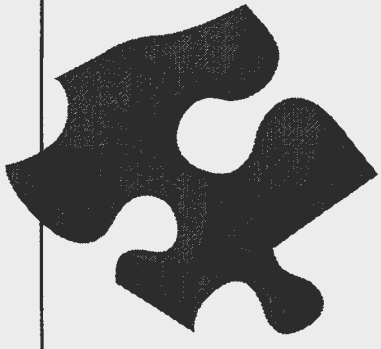
It is the intention of the Policy Analysis to present the picture of Texas' health and human service delivery systems by focusing on the gaps in services. These are contrasted with the types of services which are necessary for an individual's full participation in the community after sustaining a traumatic brain injury.

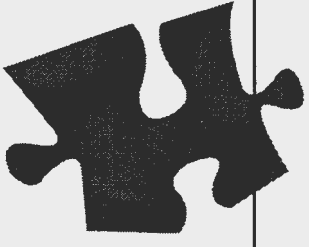
Texas has a large system of health and human services which may seem ample and accessible. **This is not true for persons with traumatic brain injury.** The number of persons with traumatic brain injury continues to grow at an alarming rate every year. This annual growing population of persons with traumatic brain injury has a cumulative effect as it is joined with the existing population of persons living with a brain injury. Unfortunately, most of the individuals who sustained a brain injury over the past 15-20 years have not received services and supports to help them participate fully in the community.

At the time of this report, there are many initiatives on both the federal and state level which are attempting to regulate and/or bring under control the spending of the public health dollar; these change on a daily basis. Therefore, this report reflects a picture of the current situation in the midst of speculation and potential changes.



List of Health and Human Services Reviewed for the Policy Analysis





Policy Analysis of Health & Human Services
Medicaid/State Funded Agencies

In very broad terms, **with no qualifiers**, the following State Programs[5] have services which may be accessed by individuals with traumatic brain injury. Those with a check mark have programming potential for persons with traumatic brain injury:

Texas Department of Health (TDH) ..... 6 programs
4 probable for TBI

In-Home total Parenteral Hyeralimenation	(Not a primary service[6])
√ Chronically Ill and Disabled Program	
Certified Respiratory Care Practioner	(Not a primary service)
√ Texas Health Steps (EPSDT)	
√Home Health Services	
√Medically Dependent Children's Program	Waiver

Texas Department of Human Services (DHS) ..... 14 programs
8 probable for TBI

√ Residential Care	
√ Respite Care	
Special Services to Persons w/Disabilities	(Not a primary service)
Special Services to Persons w/Disabilities, 24hr. Care	(Not a primary service)
√ Adult Foster Care	
Congregate & Home Delivered Meals	(Not a primary service)
Emergency Response System	(Not a primary service)
1929B of Social Security Act	(Frail Elderly)
√ Primary Home Care/Family Care	Medicaid mandated
Day Activity & Health Services	(Not a primary service/ Elderly)
√ Community Living Assistance & Support Services	Waiver
√ In-home & Family Support Services	
√ Client Managed Attendant Services	
√ Community Based Alternatives	(Disabled & Elderly Waiver)

Texas Dept. Mental Health/Mental Retardation (TDMHMR) ..... 4 programs
3 probable for TBI

Home & Community-based Services - HCS-O	Waiver (Restricted/Closed)
√ In-home & Family Support	
√ Home & Community Based Services	Waiver

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[5] Resources and documents reviewed: Agency annual reports, Web sites, agency developed charts/tables, Sunset Review Commission reports, agency self evaluation reports, agency publicity, personal interviews with agency personnel, cross referencing with the public funding needs assessment results, agency forms, agency field offices, and HCFA/Medicaid publications.

[6] Not a Primary service for persons with traumatic brain injury

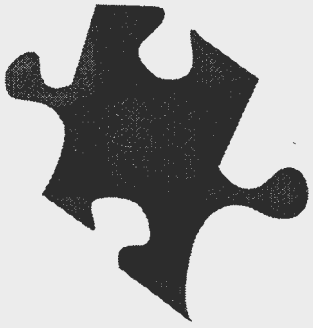
√ ICFMR	Must meet DD criteria independent of TBI

Texas Rehabilitation Commission (TRC) ..... 6 programs
5 probable for TBI

√ Comprehensive Rehabilitation Services	**Trust Fund (Primary Service)**
√ Vocational Rehabilitation	Vocational Goal
√ Extended Rehabilitation Services	Vocational Goal
√ Independent Living Services	Independent Living Goal
√ Personal Attendant Services	Vocational Goal
Deaf-Blind W/Multiple Disabilities	Waiver (Not a primary service)

ECI/TEA (ECI) ..... 1 service

Child Find - Early Childhood Intervention	(Not primary service)



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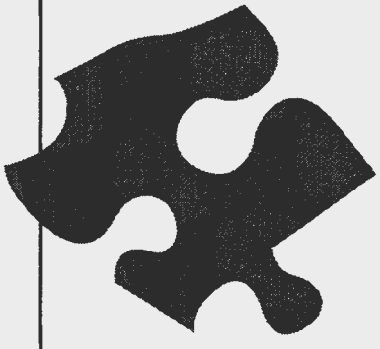

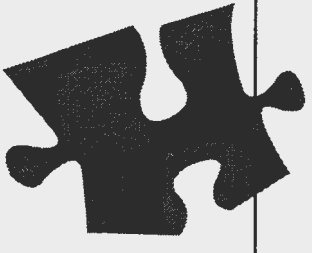

LIMITED ACCESS

Service Coordination

A Surface Reading -

A surface reading of the state's services and programs appears to hold some promise for persons with traumatic brain injury who have long-term support needs. If "need" were the only criteria for service delivery it would appear that Texas has programming to meet long-term needs. However, for persons with traumatic brain injury, this is **not** the case.

Many persons with TBI and their families give up as they do not know how to navigate the systems. "Cognitively impaired people frequently lack executive skills . . . have difficulty functioning independently. This difficulty will most likely last throughout their lives . . . 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." [7]

Service Coordination -

Texas uses the function of service or case coordination for several of its community-based programs. In the publicly funded arena, case coordination is the check and balance to the provision of the home and community-based waiver services. For the purposes of this analysis, service coordination is understood to mean:

1. Identification and outreach
2. Intake
3. Assessment
4. Service Planning
5. Community access, linking and advocacy
6. Coordination and monitoring
7. Evaluation

This system works well for those individuals who are eligible for it, however, **there is no service or case coordination in the state of Texas which identifies and assists individuals with the initial access to the state's health and human services, community links and other resources.**

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[7] GAO Report, previously cited

The Public's Response -

The results of the Needs Assessment surveys from the spring of 1998 indicated a large percentage of the respondents did not use the following publically funded services. The survey did not request information about the need for these services; but attendees at the Spring of 1998, public meetings frequently stated; once they or their family members were discharged from the hospital they were on their own and had no idea of where to turn or how to get help. **The common thread of need expressed at all the public meetings was for a service coordinator or personal advocate to help with identifying, accessing and coordinating services.**

Results from the Needs Assessment Surveys, Spring 1998

Publically Funded Services	Persons w/TBI who used services - 124 respondents	Family member who used services - 84 respondents	Total % of respondents who used services - 208 respondents	Total % who did not use services - 208 respondents
SSA (SSDI)[8]	16%	27%	21%	79%
Medicare	22%	38%	29%	71%
SSI	37%	50%	43%	57%
Medicaid	35%	42%	38%	62%
TRC	42%	42%	42%	58%
CRS	19%	31%	24%	76%
CLASS	4%	7%	5%	95%
VNS	4%	18%	10%	90%
Home Care	5%	7%	5%	95%
ILS	3%	7%	5%	95%
CBA	4%	12%	7%	93%
Food Stamps	21%	13%	18%	82%
Other Public Funding	10%	14%	12%	88%

[8] SSA and Medicare figures are strictly reporting the respondents answers. In reality, the Medicaid, Medicare, SSDI and SSI names are frequently misunderstood or misstated by the recipient. There are extenuating circumstances which may lead to receiving Medicare without SSDI eligibility, e.g. child <18 of a disabled parent

Entry Point for State Services

The programs cited in the previous chart, have entry points for receipt of the initial application for services. For many of these services, the Texas Department of Human Services local and regional offices are the entry points. However, entry is particularly difficult as there is a lack of commonly held general or public knowledge about state and publicly funded systems. If an individual or the family has not had to use the traditional services of TDHS they do not know this is the primary entry point for most of Texas' supports and services.

Treating physicians and discharge planners are not referring individuals or their families to these systems early enough after the person has sustained the brain injury. Much of the early medical care is focusing on saving the person's life and providing the next step of medical care. There is no focus on long term care needs or on maximizing the person's ability to return to the community in the most functional way. There is no system to keep every part of the rehabilitation process coordinated and progressive.

Where to go for resources -

Families and individuals who participated in the needs assessment surveys reported there was a general lack of information about traumatic brain injury as well as where to go to find services. Thirty-eight percent (38%) of all the survey respondents stated they did receive information about resources and services for persons with brain injury when they needed it. Of these, 40% were persons with brain injury and 36% were the families. **Almost 2/3 of the survey respondents did not get the information about resources and services which could have included information about an entry point to the state's systems.**

A very small medical trail -

For those individuals who are seen in hospital emergency departments and discharged, the scenario is even worse. Frequently, there is a lack of connection by the individual or the family to:

- the occurrence of the brain injury,
- a current and progressive loss of functioning,
- increased difficult behaviors,
- a changed or altered personality and
- any number of other significant changes which appeared after the brain injury.

Families and persons with the injury as well as medical personnel often fail to recognize this connection. For these people there may have been no medical tests which clearly pointed to the evidence of an injury. Therefore, identifying services to meet the escalating needs is muddy and often results in referral to the wrong type of services. This is particularly true for persons with mild or moderate brain injury symptoms.

The needs assessment survey results showed 33% of all the respondents indicated they had one day or less of acute medical care. These individuals may have been seen in the emergency departments and discharged, held overnight for observation, did not need acute medical care, or were not seen at all.

Fortunately, 8% of all the respondents who had one day or less acute medical care indicated they had received Comprehensive Rehabilitation Services (CRS), but only 4% of them reported receiving information about other resources and services.

Categorizing Traumatic Brain Injury

Traumatic brain injury does not neatly fit into a category or a box. Traumatic brain injury is not a well-defined disability with a standard set of services and medical protocols such as cancer, heart disease, Alzheimer's, chronic mental illness, or various developmental disabilities. When persons call or try to find appropriate services they are often rejected or misdirected as there are so few defined or designated services for persons with traumatic brain injury.

The NIH Draft Consensus Statement states, "Rarely are the consequences limited to one set of symptoms, clearly delineated impairments, or a disability that affects only a part of the person's life. Rather, the consequences of traumatic brain injury often influence human functions along a continuum from altered physiological functions of cells through neurological and psychological impairments, to medical problems and disabilities . . . "

Only 47% of the 208 respondents reported they had received information about brain injury when they needed it. Thirty-three percent (33%) of the persons with brain injury responding and 66% of the families reported "Yes" to the question. This means over half the respondents did not receive information when they needed it. This raises the question:. **How are these individuals able to search out services when they are not informed about the basics of brain injury and what to expect?**

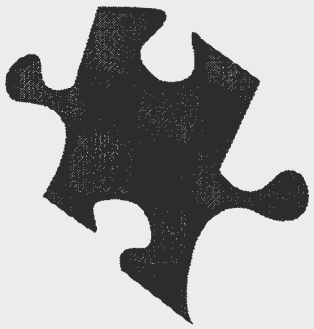
Geography and Waiting Lists

The vastness of Texas' geography is a constant which may be less imposing through the use of the INTERNET. For those individuals and families who have this capability, the INTERNET offers a way to begin navigating the state system. For those who do not have this technology, travel to the local TDHS offices remains the primary way to enroll for services.

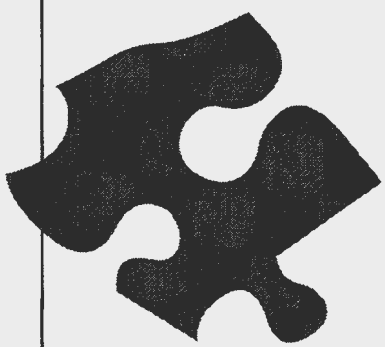
With the advent of the TIES program, initial contacts may be made by telephone. It is anticipated that required trips to the TDHS office will be reduced and thereby help in cutting down the redundancy, frustration, and lengthy enrollment/eligibility process.

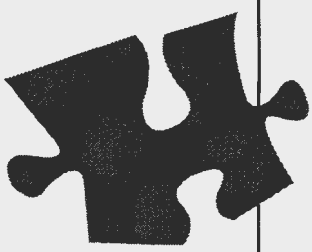
When families or persons with brain injury attempt to make application for services which have a waiting list, they become discouraged, and frequently do not apply. In spite of the lengthy waiting lists, persons with brain injury and their families need to continue with the application process and work to get the individual's name on the list.

Those families and persons with brain injury who are on a waiting list face a unique situation. When their turn comes up on the waiting list, there is trepidation regarding the kind of services they or their family member will receive. They want the long awaited services to be appropriate for their needs but, they do not want to jeopardize losing the long awaited spot by requesting specific accommodations. However, as the current situation with the waiting lists remains lengthy, not being able to assess these systems is a bigger concern than the appropriateness of service delivery for persons with a brain injury.



Eligibility





Eligibility

Age Criteria

Onset prior to the 22nd birthday -

The issue of age is one of the most significant factors limiting access into most of the health and human services available in Texas. The age limitations imposed upon state agencies are determined by a combination of factors which have been established by law, policy, and costs. In most cases the age determination has been established by federal law or policy.

Twenty-five percent (26%) of the programs reviewed for pertinence to brain injury issues, accessibility and availability require as the basic eligibility criteria, the onset of injury or disability must have occurred prior to the 22nd birthday. These programs with age limitations offer comprehensive services for the persons who are eligible and enroll, yet 54% of the persons surveyed who might have benefitted from the comprehensiveness of these programs exceeded the age limitations.

The Other Side of the "Age of Eligibility" Issue -

An interesting feature exists in several state programs of the Texas Department of Health. Eligibility for services ends as the individual receiving TDH services "Ages Out" at 21. This is because the service delivery system is designed for children and adolescents. At 21 years of age, the individual should be transitioned into services designed for the adult population.

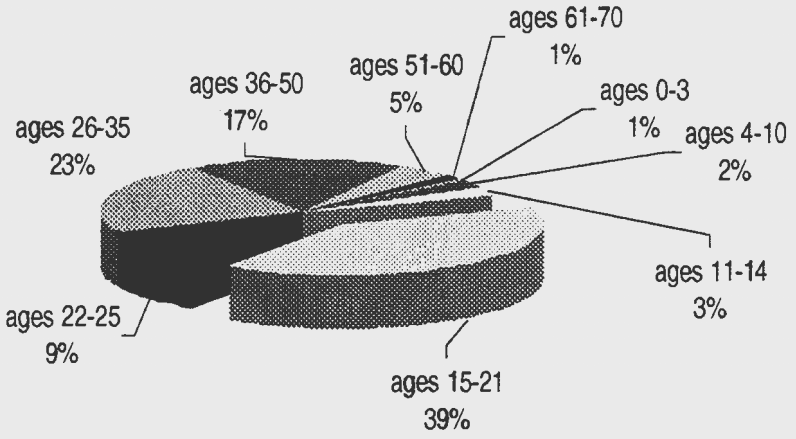
Therefore:

> CLASS and the other home and community-based waivers along with Texas Health Steps, Medically Dependent Children's Programming and the Deaf-Blind waiver require the **Onset of the disability or injury** prior to the 22nd birthday as basic eligibility criteria. Should the injury or disabling condition occur after the 22nd birthday, the services of these programs are not available to an individual. However, the individual who has the services prior to age 22 continues on with the services after the 22nd birthday and as long as there is a need for services.

Individuals who sustained injuries prior to the 22nd birthday but did not file an application for state services or need them at the time of injury may still have opportunity to apply. As time progresses after the injury, the individual may develop a need for services. If the need is directly linked to the injury an application may be submitted. Medical documentation or other key records will be needed to verify the occurrence of the injury and the individual will be assessed to determine the level of functioning.

Needs Assessment Survey and Public Meeting Results -

Ages and Percentage of each range at time of injury



Ages	0-3	4-10	11-14	**15-21**	22-25	26-35	36-50	51-60	61-70	70+
%	1	2	3	**39**	9	23	17	5	1	0
#'s	2	4	6	**83**	18	**48**	34	9	2	0

Fifty-three percent (53%) of the persons surveyed received the traumatic brain injury after their 22nd birthday thereby, eliminating them from the potential of the wider array of supports and services which are available for children and adolescents who meet the admission criteria for the majority of state agency supports and services.

Forty-seven percent (47%) of the 208 non-duplicated surveys reported the traumatic brain injury occurred under the age of 22 and only 5% of the total respondents had used CLASS waiver services. The information received through the needs assessment surveys follows the national reporting trends for statistics reporting the age of onset. These figures tend to indicate there are a significant number of persons sustaining a traumatic brain injury who are under the age of 22 and who may be in need of services which the waivers could provide.

Home and community-based waivers through MHMR were not offered as a question

on the survey. Twelve percent (12%) of all the surveys had this question checked, with 10% from individuals with brain injury stating "Yes" to other resources and 14% from families. If the respondents or their family members had MHMR services, their responses could have been cited in the "Other" category, however, no respondents volunteered or specified information in this category.

Of greater significance, a large percentage of individuals surveyed, were automatically disqualified as they or their family members were older than 22 at the age of onset. Persons who attended the public meetings, repeatedly expressed their frustration about not being to able to access services and were generally confused or disappointed about the under 22 age limitations.

Questions needing to be answered:

1. What is the number of adult individuals with a traumatic brain injury on the waiting lists whose onset date was before their 22nd birthday?

2. What is the potential number of children and adolescents with brain injuries who are not receiving services but would be eligible for CLASS waiver services if identified and screened?

Ages 18 and Above

The eligibility criteria for age 18 and older must be considered: it is significant for this analysis. The national traumatic brain injury statistics have shown the highest incidence of injuries occur in the male population ages 15 to 25. Yet, of the programs which require the individual be 18 or older, 42% require the individual's need be at a level of care equivalent for admission to a skilled nursing facility or an intermediate care facility for mental retardation (ICF-MR). Two of them are short term services and three require a vocational goal for eligibility into the service delivery system

There are two programs out of the eight cited that offer long-term community-based supports. One program, the Community-based Alternatives (CBA) waiver requires the individual be over 21 and meet the medical and physical needs for SNF[9] level of care. The other is the Client Managed Attendant Services. Client Managed Attendant

[9] Skilled Nursing Facility

Services generally do not work with people who have brain injuries as the client must be able to direct care. This program requires the client plan, organize, supervise and direct the attendant. To manage attendant services requires the individual's executive or cognitive skills be functioning well.

These skills are generally affected and lacking after sustaining a traumatic brain injury. The GAO report cited, ". . . TBI experts expressed concern about the ILS[10] models of consumer-directed needs assessment. Adults with TBI often do not recognize their own limitations and lack executive skills to coordinate services."

In studying the results of the needs assessment surveys, 28% of the respondents were between the ages of 18 and 25 when they sustained the traumatic brain injury and 66% of all the respondents were over 18 when the brain injury occurred. However, at the time of the survey 94% of the respondents were over 18 and reported a current need for long term supports and services. The current eligibility requirements excluded those who are over 22 years of age.

These individuals do not have the same potential for an array of services which are available for children and adolescents. A study of age eligibility relative to the numbers of people needing services is important as it is a key in determining a system of services that are accessible and age appropriate.

The services identified in the following chart, generally are services which the home and community-based waivers provide and are stated needs by persons with brain injury and their families. Outside the waiver services very few ways exist to obtain funding to pay for these needed services.

Needs Assessment Survey Results - At time of survey over 18 years of age

Services Needed by Persons 18 and older	119 Persons w/TBI	78 Family with family member	Responses to the stated need out of 197 surveys
Case Management	24%	46%	29%
Personal Advocate	15%	32%	23%
Personal Care Assistant	10%	40%	25%
Nursing Services	5%	22%	11%

[10]Independent Living Services

Services Needed by Persons 18 and older	119 Persons w/TBI	78 Family with family member	Responses to the stated need out of 197 surveys
Occupational Therapy	21%	48%	34%
Speech Therapy	20%	46%	32%
Cognitive Therapy	30%	60%	44%
Mental Health Services	35%	50%	43%

Programs reviewed for Traumatic Brain Injury pertinence, accessibility and availability 20

5 programs (25%) have 18 years of age as the minimum for services
2 programs (10%) have 21 years of age as the minimum for services
5 programs (25%) have 16 years of age as the minimum for services

TDH . . . . . **1 program**
Home Health Services . . . . . over 21
TDHS . . . . . **6 programs**
Primary Home Care . . . . . over 18
Residential Care . . . . . over 18
Respite Care . . . . . over 18
Adult Foster Care . . . . . over 18
Client Managed Attendant Services . . . . . over 18
Community Based Alternatives . . . . . over 21
TRC . . . . . **5 programs**
Comprehensive Rehabilitation Services[11] (CRS) . . . . . over 16
Extended Rehabilitation Services[12] (ERS) . . . . . over 16
Vocational Rehabilitation (VR) . . . . . over 16
Personal Attendant Services (PAS) . . . . . over 16
Independent Living Services (ILS) . . . . . over 16

[11] CRS age requirements: the youngest individuals who can be served must be at least 16 when services are completed.

[12] ERS earliest age for eligibility is 16

Funding

Medicaid Program

Out of 20 state programs reviewed for Traumatic Brain Injury pertinence, accessibility and availability, 8 programs (40%) require Medicaid eligibility.

TDH ..... **3[13] programs**
- Medically Dependent Children's Program ..... Medicaid waiver program
- Texas Health Steps ..... straight Medicaid
- Certified Respiratory Care Practioner ..... straight Medicaid

TDHS ..... **4 programs**
- CLASS ..... Medicaid waiver
- Community Based Alternatives (CBA) ..... Medicaid waiver
- Residential Care ..... straight Medicaid
- Primary Home Care/Family Care ..... straight Medicaid

TDMHMR ..... **1 program**
- Home & Community Based Services ..... Medicaid Waiver

The primary ways to qualify for Medicaid are -

1. Eligibility as a result of receiving public assistance in the way of food stamps, financial help, or determined to be MAO (Medical Assistance Only) due to the individual/family's resources meeting the income criteria for public assistance.

2. When the individual's condition is determined by the Social Security Administration to be disabling and the individual is screened for SSI (Supplemental Security Income) benefits the individual may be eligible because the individual has never paid into the system,[14] has not paid within the preceding five years or meets the income levels for Medicaid entitlement (less than $2,000 in personal resources).

3. When a person is determined eligible to receive Medicaid waiver

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[13] Certified respiratory practioners were not considered in the count of 20 programs and/or services, but may be needed by a very small percentage of the brain injury population..

[14] There has been no payroll withholding of Medicare or Social Security taxes or the person has been employed but has no contributions on record for the preceding 5 years.

services, Medicaid eligibility is conferred upon the individual based on the individual's personal financial resources. The family's resources are not calculated in the income criteria.

Medicaid is a state administered program with federal regulations and restrictions developed by the Health Care Financing Administration (HCFA). To draw down federal Medicaid dollars at the state level, the state is responsible for a proportionate share - Texas' share is 38% to the federal 62%. Currently, the state is not expanding Medicaid spending over FY98 levels and is moving to build a Medicaid managed care system.

Medicaid for Acute Rehabilitation for Persons with Traumatic Brain Injury -

In reviewing Medicaid coverage, Texas does **not** opt for acute rehabilitation through the Medicaid program. Medicaid reimbursed rehabilitation is available for children under 21, persons with chronic mental health and/or substance abuse issues, and individuals who are visually impaired through the Commission for the Blind. Therefore, **adult Texans who are Medicaid eligible and need acute rehabilitation post traumatic brain injury have few, if any, services available to assist them in their return to full participation in the community.**

"What resources have you used?"
Medicaid Usage as reported from the Needs Assessment Survey Question -

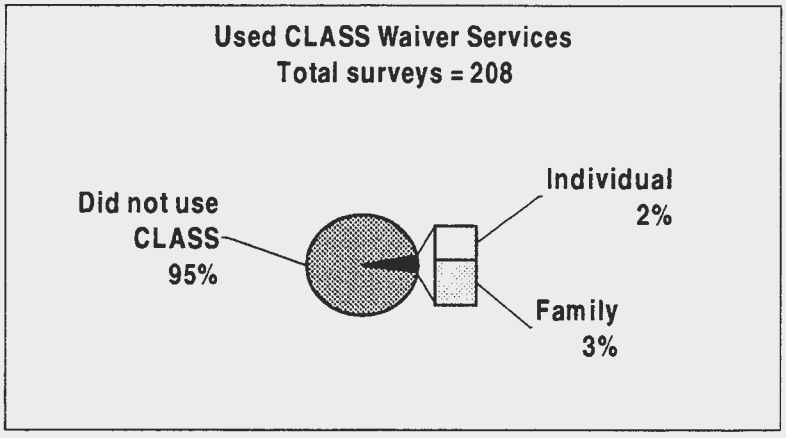
Two hundred and eight (208) non-duplicated needs assessment surveys, from the Spring of 1998, indicated that 35% of the 124 reporting individuals with traumatic brain injury have used Medicaid and 42% of the 84 reporting families have had Medicaid for their family member with a brain injury. Sixty-two percent (62%) of all the respondents have not used Medicaid.

Two of the primary Medicaid services include nursing and therapies (PT., OT, SLP) and these were addressed in the surveys. These were home health care and primary home care. The survey did not identify whether these two services were covered by the person's own insurance or publicly funded.

Ten percent (10%) of all the respondents indicated they had used visiting nurse services with the breakdown, 4% individuals and 18% families. Five percent (5%) of all the respondents used primary home care with 5% of the individuals reporting home care and 6% from family members.

Two Medicaid Home and Community-based waivers were specifically listed in the surveys, CLASS and CBA. Four percent (4%) of persons with brain injury and 12% of families reported the use of the CBA waiver for a total of 7% of all responses using CBA services.

Five percent (5%) of the responses stated they had used CLASS waiver services with 2% of the persons with brain injury reporting CLASS services and 3% of the families.



Further studies are needed to identify how many of the individuals who did not use the services which require Medicaid eligibility were disallowed because the individual did not meet Medicaid eligibility or were services not needed therefore, none were requested?

Medicare Program

Medicare is discussed as there tends to be confusion between Medicare and Medicaid eligibility, access and covered services. Individuals, who are considered the "Working Poor," tend to fall into a situation that requires a long wait time during which the disability determination process takes place.

Should a person, who has paid[15] into the SSA/Medicare System, sustain a brain injury, the individual may be eligible for Social Security Administration benefits known as Social Security Disability Insurance (SSDI). However, during the time the individual is waiting for the disability determination, there are very few, if any rehabilitative services or supports available. If the person's status is never determined eligible for disability, the potential for any type of medical or rehabilitative care is almost non-existent.

Generally, when a person receives SSDI, the individual will receive Medicare benefits. However, Medicare benefits are not immediately available when SSDI is determined.

[15] Payroll withholding

The individual generally must wait for Medicare as there is a waiting period of over 2 years from either the date of the SSA application or the date which was first claimed as the onset of disability.

Medicare benefits will provide insurance coverage for acute needs, limited therapies, and other related health costs, but will not cover rehabilitation or long-term care needs. Each person's case is individually evaluated by TRC's Disability Determination Unit and then forwarded to the Social Security Administration. If a favorable disability determination is made, a review of the person's current financial status is made before excluding Medicaid eligibility. In most cases, the person who is eligible for SSDI/Medicare will not be eligible for Medicaid.

Survey Results

Medicare Usage -

From the 208 needs assessment surveys, 23% of the 124 individuals with traumatic brain injury report they have used Medicare and 38% of the 84 reporting families have had Medicare for their family member with a brain injury. Out of all the 208 responses, 71% have not used Medicare.

Never used Medicaid or Medicare --

Fifty-two percent (52%) of the reporting individuals with traumatic brain injury have never used Medicare or Medicaid and 40% of the families have not used Medicare or Medicaid for their family member with a brain injury. Out of all the 208 responses, 47% have not used Medicare and/or Medicaid.

What the Medicaid Program means for persons with traumatic brain injury who are Medicaid eligible -

Medicaid eligible persons with traumatic brain injury who are in need of primary care medical services, physical therapy and other covered medical expenses have the ability to get these services through the Medicaid provider of their choice. The Medicaid program is available for these individuals.

Access to Medicaid services is extremely difficult for individuals who have non-medically related needs such as cognitive impairments resulting in a loss of function and/or behaviors that put the individual at risk for safety and health. Services designed

to meet these needs are available through the home and community-based waivers or community mental health centers.

However, many individuals with brain injury do not meet the medical and physical need qualifications for a level of care equivalent to the admission criteria for a skilled nursing facility or an ICF-MR as the deficits are more cognitive and behavioral. These are issues which persons with brain injury face across the country with the Medicaid waiver programs. As cited in the US General Accounting Office Report to Congressional Requesters: *Traumatic Brain Injury, Programs Supporting Long-Term Services in Selected States*, February 1998:

> "Adults with TBI might be able to 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 . . . 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."

Expressed needs of Persons with Traumatic Brain Injury and Families -

The following chart shows services that are still needed by the respondents either for themselves or for their family member with a brain injury. Should an individual be eligible and access waiver services, many of the following could be provided as part of the waiver services. The need for cognitive therapy and mental health services has been expressed as the greatest areas of need, yet these services are routinely denied by private insurance and are not covered by Medicaid. Nursing services which are covered by Medicaid option dollars were reported to have the smallest need by the respondents.

Expressed Service Needs from the Surveys Filled Out by Persons with Brain Injury or Family Members

Services Needed	Persons w/TBI	Family Member	Total of 208 surveys
Case Management	24%	38%	30%
Personal Advocate	16%	36%	24%

Services Needed	Persons w/TBI	Family Member	Total of 208 surveys
Personal Care Assistant	12%	43%	17%
Nursing Services	6%	20%	12%
Occupational Therapy	23%	52%	35%
Speech Therapy	21%	52%	34%
Cognitive Therapy	33%	63%	45%
Mental Health Services	36%	55%	44%

Statewide Public Meetings

Tabulation of the comments and needs expressed at the statewide public meetings identified availability and limitations to facilities and services as the number one need and therefore, a common thread at all the public meetings. Medicaid appears to be a significant resource for persons with traumatic brain injury and their families as 38% of the respondents indicated they had used Medicaid coverage.

Likewise, 38% of all the respondents reported having their own health insurance with 36% of individuals and 40% of the families reporting their own insurance. Twelve percent (12%) of all the respondents reported having both their own insurance and Medicaid with the breakdown: 8%, individuals and 16%, families.

Survey questions which still need to be answered:

1. What services were covered by private insurance?
2. How long has it been since the injury?
3. Is the insurance still covering the related costs?
4. How long did the personal insurance last?
5. Were comparable services being covered by Medicaid after the insurance ran out?
6. Are there opportunities for cost sharing from several payer sources?
7. Can Medicaid cover what the person with a traumatic brain injury needs in order to return to function?

Other Eligibility Requirements for Texas' Health and Human Services

Level of Care

The current structure of accessing existing supports and services for **Texans with traumatic brain injuries** is severely limited or unavailable as the nature of their impairments **do not meet the basic eligibility requirements for entry into these systems**. Many of Texas' programs offering long-term community supports require a Level of Care[16] equivalent to admission criteria for a skilled nursing facility, an Intermediate Care Facility for MR or be medically necessary with a physician's prescription for services.

US General Accounting Office Report to Congressional Requesters: *Traumatic Brain Injury, Programs Supporting Long-Term Services in Selected States*, February 1998, "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." The individual with few medical or physical needs does not meet the basic LOC criteria for entry into these programs.

Functional and Behavioral Needs Escalate -

Physical needs tend to diminish after a TBI. Functional and behavioral needs tend to escalate. However, the services available in Texas are not generally available unless the individual has specific physical needs. Secondly, when the person is able to access the services, the reality of receiving services appropriate[17] for meeting the functional and behavioral needs is unlikely.

The GAO Report states:

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[16] Process that establishes a Level of Care (LOC) determines the medical neccessity and therefore, is Medicaid reimbursable.

[17] "The GAO Report states, 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...Adults with traumatic brain injury 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."**

"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 traumatic brain injury . . . 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 preadmission screening process may be oriented to physical rather than cognitive disabilities.***"

State Programs/Services Which Require Levels of Care as Basic Criteria for Eligibility

State Agency	Service/Program Name	SNF	ICF-MR	Med Necessity
DHS	Primary Home Care			X
DHS	Client Managed Attendant Services			X
DHS	CLASS		X	X
DHS	In-home & Family Support Services	X		X
DHS	CBA	X		X
MHMR	In-home & Family Support		X	
MHMR	Home & Comm-based Services		X	X
TDH	CIDC			X
TDH	Home Health Services			X
TDH	Tx Health Steps			X
TDH	MDCP	X		X
TRC	CRS			X
TOTALS	**12**	**3**	**3**	**11**

This means, 63% of Texas' health and human service programs which could potentially benefit persons with traumatic brain injuries are not accessible at the most basic level of entry.

Vocational Goal

For the majority of the Texas Rehabilitation Commission's (TRC) services, a vocational goal is a requirement to receive their services. To identify the vocational goal, an Individualized Written Rehabilitation Plan (IWRP) is developed by the client and the TRC counselor.

Developing this type of plan may be very difficult for persons with brain injury as returning to their previous employment may not be an option. Identifying and choosing a new path to follow can be overwhelming and often a very slow process. Commonly held information in the rehabilitation community acknowledges: it takes an average of 6-7 job placements before an individual is able to sustain employment which will last for a prolonged period of time and it usually requires some type of support system.

Unless an individual is ready to develop and work toward a vocational goal, the primary TRC services are not available. Independent Living Services may be available for persons with a traumatic brain injury as these services do not require a vocational goal. However, they are short term and available only regionally in Texas.

Functional Assessment

In addition to meeting the basic eligibility criteria for Medicaid, age and medical necessity, many programs use a Functional Assessment tool for evaluation of the person's daily functioning. The functional assessment generally measures:

1. Self care
2. Self-direction
3. Learning
4. Language
5. Mobility
6. Capacity for independent living

At this time of this report there is no standardized functional assessment tool being used throughout the health and human service delivery system. This issue has been identified as an area for inter-agency review to determine if one assessment tool could be developed and used by all service delivery programs in the state.

Related Conditions

A person may be determined to have a "Related Condition" and be eligible for certain services if the following are met:

a) the condition is present prior to age 22,
b) has significant limitations in 3 of the 6 areas listed above and
c) qualifies for Medicaid Level of Care 8

Traumatic Brain Injury is listed as a Related Condition, but -

Traumatic brain injury is cited as one of the conditions covered by this category and. many persons with a brain injury are able to meet at least three of the six areas of significant limitations. But the age factor, frequently excludes them from admission. If the age limitation is not the disqualifying factor, the Medicaid level of care is, as many individuals with brain injury cannot meet that level of care regardless of their manifested difficulty with language, self care, self-direction, mobility, learning and a capacity for independent living.

Intelligence Quotient (IQ) Level -

Within the Texas Department of Mental Health & Mental Retardation (TDMHMR), the Intelligence Quotient, (IQ) is a standard measure of intellectual functioning. If a person's IQ registers 75 or lower the person may be eligible for MHMR services, providing the other qualifying requirements are met. For HCS waiver services, an IQ less than 75 is required. For the person with a brain injury, the IQ measure does not correctly report the individual's level of functioning.

A person's IQ may appear to have diminished after the TBI, however, this measure should not be the determining factor of the individual's cognitive abilities post-injury. In fact, using the IQ results as the primary measure of a person's intellectual ability post-injury can be misleading. While the individual's IQ may remain unchanged, the ability to attend, access information, make decisions, comprehend and remember new information may have been changed or altered. For an individual to move beyond these cognitive limitations, the individual requires appropriate services designed to deal with cognitive processing and compensatory strategies.

Mental Health Services

The issue of need for mental health services for persons with traumatic brain injury is very complex. When persons with brain injury or their families seek mental health services the delivery of services must be focused at meeting the whole person's needs. Persons with traumatic brain injury and their families report a significant need for assistance in working through the trauma, personality and role changes, multiple losses and other changes which occur as a result of the brain injury.

Serious Consequences -

Not being able to access **appropriate** mental health services may result in serious consequences. The GAO report indicates: "...it is a high probability, persons who do not get appropriate services ultimately end up homeless or in nursing homes, institutions for persons with mental illness, prisons, or other institutions."

To receive mental health services an individual must be diagnosed with one or more of the identified conditions:

d) Schizophrenia
e) Major depression
f) Bipolar disorder
g) Other severely disabling mental disorders which require crisis resolution or ongoing and long-term support and treatment.

Short term mental health services may be appropriate for an individual with a traumatic brain injury. If the manifested symptoms have developed post-injury, caution is required. Frequently, the manifested symptoms are the result of the traumatic brain injury. The traditional course of treatment for persons with chronic mental illness is generally inappropriate and may have deleterious effects for the person with a brain injury.

In some cases the manifested symptoms are so severe the individual is able to access community-based mental health services. When this is the case, great care must be exercised as the medication regimes used for persons with chronic mental illness frequently impede the cognitive functioning of a person with a traumatic brain injury, thereby making the effects of the brain injury worse. In either case, **the traditional mental health/mental retardation diagnoses and treatment protocols are generally not appropriate for persons with brain injuries.**

Survey - Need for Mental Health Services -

The following chart indicates responses from family members regarding the needs of their family member and from individuals with traumatic brain injury, all in need of mental health services at the time of the survey. The ages of the individuals are reflective of the individual's current age, not the age at injury.

		Totals in Each Age Category			**Requesting MH Services[18]**		
		Individuals	Family	Totals	Individuals	Family	Total %
Children	0-12	0	0	0	0	0	0
Adolescents	13-19	6	15	21	2	9	
		29%	71%		33%	60%	52%
Adults	20+	117	68	185	43	36	
		63%	37%	100%	37%	53%	43%

In reviewing the numbers of persons served through the MHMR system, it was reported that 145 individuals (25-30% of the total hospital population) diagnosed with traumatic brain injury who are patients at Vernon State Hospital, a maximum security institution for forensic (criminal) patients.

This large percentage of the hospital population with a diagnosed traumatic brain injury poses serious questions about the health and human service delivery systems for persons with brain injury in Texas. Perhaps further study is required to identify the type, amount and timeliness of services which these individuals may have received after sustaining the brain injury and are they receiving appropriate services in their current environment.

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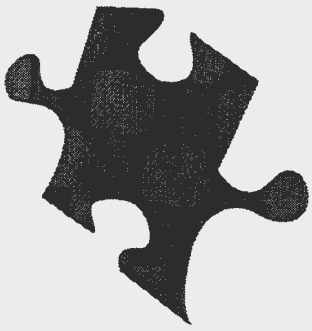
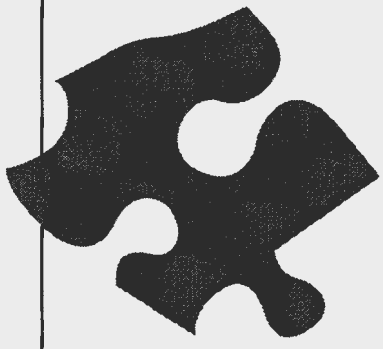
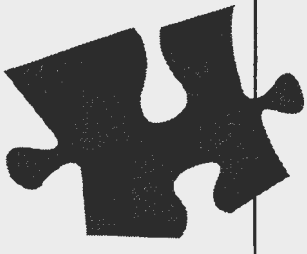
[18] Not every survey had these categories marked.



Appropriateness of Services





Appropriateness of Services

This report has repeated stated that deleterious effects may occur when the individual with a brain injury does not receive appropriate services. Often the existing state services have a negative impact on the person with a brain injury as many of them tend to be discipline specific. They are further limited in their ability to:

- to build flexibility of service delivery by the funding streams,
- deliver appropriate services as their staffs have not been trained to work with a person who has a traumatic brain injury.

Brain and Spinal Cord Focus -

Of the all the state's human service providers, CRS programming is designed to focus on brain and spinal cord injuries. The delivery of services utilized by CRS is appropriate for the needs of a person with a brain or spinal cord injury. Yet, when families and persons with brain injury finally accessed other state health and human supports and services, they had major concerns.

The participants at the public meetings very clearly stated these concerns regarding the services which were or are being received by their family member with a brain injury or on their own behalf. They were equally concerned about the lack of knowledge or information apparent in many professionals and service providers. Repeatedly, they stated it is absolutely critical to have trained staff and appropriate services in order to ensure their own or their family member's progress, safety and capability of building a satisfactory quality of life.

Service Provider's Echoes -

The service providers' surveys echoed this, as 48% indicated there is a gap in the health care professional's knowledge about traumatic brain injury. In fact, only 31% of the service providers stated they had 50% or more of their staff designated to work with people who have brain injuries.

The NIH Consensus Conference Draft Statement reports:

> A major limitation within the field of traumatic brain injury rehabilitation is the narrow

focus of current medical restoration approaches; the focus tends to be on enhancing capabilities of persons with traumatic brain injury to help them adapt to life circumstances. However, new models of rehabilitation emphasize the parallel importance of environmental modification in order to create enabling conditions for the individual...An additional shortcoming of current approaches to traumatic brain injury rehabilitation involves limited opportunities for decision-making in persons with traumatic brain injury and their families. Traditional medical rehabilitation environments often do not foster partnerships with persons with traumatic brain injury or their significant others. Therefore, the current approaches frequently result in a sense of disenfranchisement due to a lack of shared participation in goal development and program design. In addition, information provided by clinicians to persons with traumatic brain injury and their families is often insufficient..."

Programs reviewed for traumatic brain injury pertinence, accessibility and availability .20
12 programs (60%) require a functional assessment

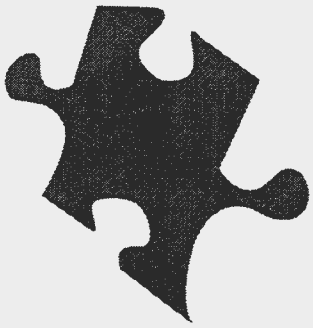
TDH ..... 1 program
- Medically Dependent Children's Program

TDHS ..... 5 programs
- Residential Care
- Adult Foster Care
- Primary Home Care
- Community Living Assistance & Support Services
- Client Managed Attendant Services

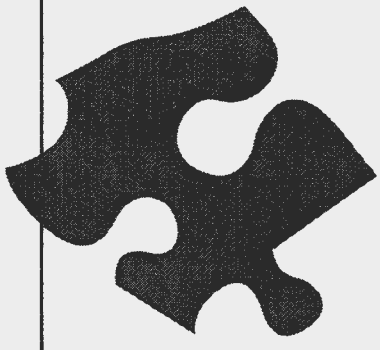
TDMHMR ..... 2 programs
- In-home & Family Support
- Home & Community Based Services

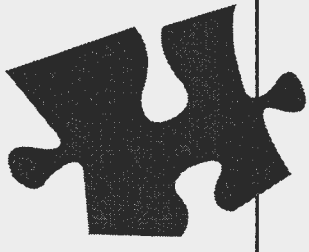
TRC ..... 4 programs
- Comprehensive Rehabilitation Services — Rancho IV[19]
- Vocational Rehabilitation
- Independent Living Services
- Extended Rehabilitation Services

[19] Eligibility for CRS is a Rancho IV level of functioning on a scale of I - VIII



Conclusions





Conclusions

In analyzing the state Health and Human Service programs[20] relative to serving persons with traumatic brain injury, the following are summary statements regarding access, eligibility and appropriateness of the state's health and human service delivery.

- No one program exists which can offer the needed supports and services to persons with TBI nor is there coordination of efforts, information, and funding between state agency programs. Persons with traumatic brain injury would have a greater chance to receive needed services if a method for cost sharing without duplicating services or billing could be implemented. This could offer the person with a brain injury a wider array and possibly, a more appropriate set of supports and services without burdening any one system.

- Should an individual who has sustained a traumatic brain injury need home health nursing services, therapies, or standard medical services, these are available to persons who are Medicaid eligible. However, if the person is not able to qualify for Medicaid, has no insurance or other financial resources, very little is available. This is particularly true if the individual is an adult because fewer services are available for adults than for children.

- Service coordination is absolutely necessary to assist people with traumatic brain injury and their families in their search and obtaining of the needed supports and services.

  As shown in the GAO Report: major service access barriers were described by the selected programs reviewed in the report. They identified three groups of persons who have the greatest difficulty accessing services. They are individuals who:

  - are cognitively impaired but lack physical impairments,
  - are without personal advocates and
  - have problematic behaviors.

[20] For a listing of services available at each state agency, please refer to the Appendix.

- Persons with brain injury are able to benefit from appropriate psychological services. There are two programs[21] in the state's service delivery system which have psychological services as part of their array of supports and services. TRC offers guidance and counseling[22] through its various programs as does the CLASS waiver programs. TRC programming is available statewide while the CLASS waivers are only available regionally.

- There are pockets of service delivery throughout the state in which state contractors are utilizing creative and innovative methods and resources in an attempt to meet the needs of their clients who have sustained traumatic brain injuries. These providers and their staffs are masterful at identifying resources which may offer a piece or two of the client's total needs. The bottom line is, the provider or agency contractor has used the initiative to look at the situation creatively and has advocated for the appropriate services for the individual with the traumatic brain injury.

- Texas is one the of states which has a very active and well used trust fund from misdemeanor and felony convictions. These fines support the Comprehensive Rehabilitation Services Program of TRC. An individual[23] as young as 15 can receive medical and short term rehabilitative services through this program, however, all services are time limited and there is a waiting list.

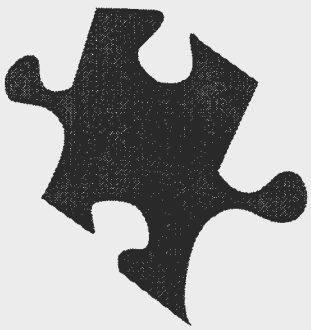
  As needed and beneficial as this program is, it doesn't solve the long-term care needs for supports and services for persons with TBI and their families. Even so, at this time, the CRS program is the only practical service delivery system for persons with TBI.

Traumatic brain injury is at epidemic proportions and is a major public health issue. Work must be done to meet the needs of persons living with traumatic brain injuries and their families.

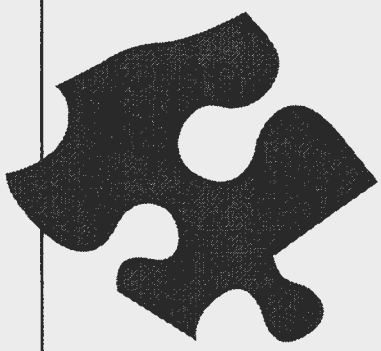
[21] HCS and CLASS

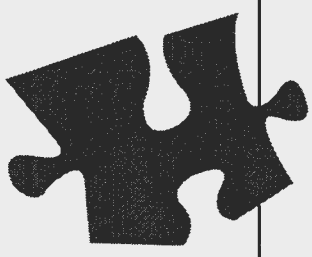
[22] CRS and VR offer guidance and counseling services

[23] Must be 16 years of age when services are completed.



Recommendations

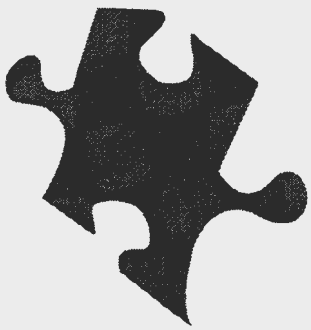




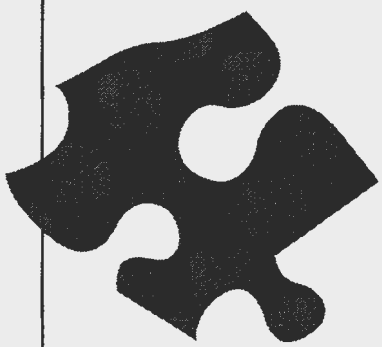
Recommendations

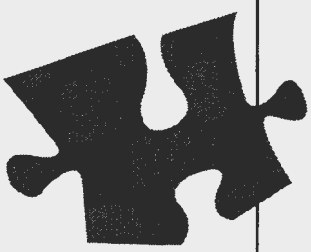
It is anticipated the State of Texas will need to look at the following relative to the issues of Traumatic Brain Injury:

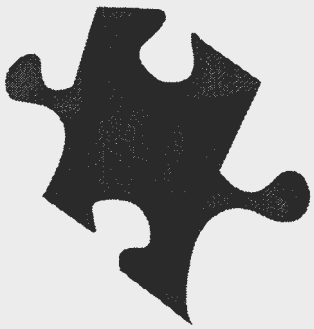
- Implement effective interagency service coordination.
- Expand eligibility for existing services and supports.
- Increase access to appropriate services for children and adults with traumatic brain injury and their families.
- Provide funding for coordinated, flexible service delivery through a partnership of public and private resources to offset cost of acute, rehabilitative and institutional care.
- Empower consumers by providing choice and flexibility in health care resources, supports and services.
- Educate and train providers and the public about traumatic brain injury.
- Promote efforts to reduce preventable brain injuries.
- Establish a Brain Injury Advisory Council to advise state leadership of the needs of people with traumatic brain injury and their families.



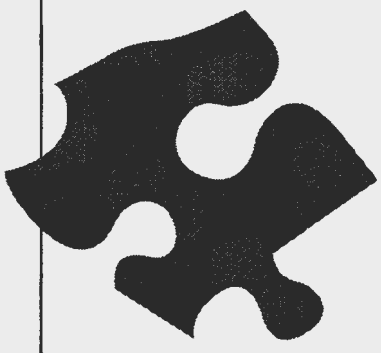
Appendix

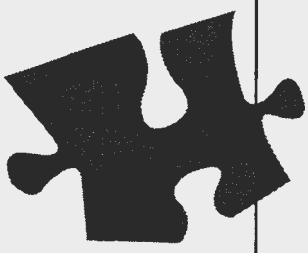






Board Roster





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Cathy Rossberg

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Support provided by: Texas Planning Council for Developmental Disabilities
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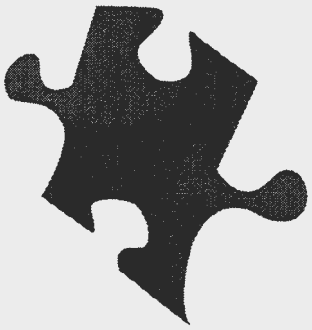
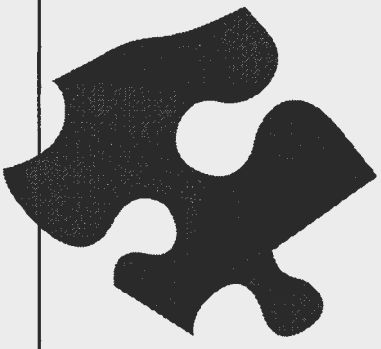
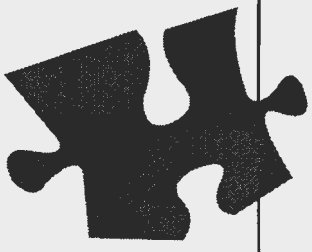


Results of the Statewide Needs Assessment Surveys





Results of the Statewide Traumatic Brain Injury Needs Assessment Surveys From the Spring, 1998

METHOD OF DISTRIBUTION -

In the Spring of 1998, The Texas Traumatic Brain Injury Advisory Board distributed more than a 1000 Needs Assessment Surveys throughout Texas. They were by the following methods:

- Brain Injury Association of Texas (BIA of Texas) Chapter and support group meetings,
- Board member distribution,
- 9 statewide public meetings and
- individual requests for surveys.

In an effort to gain information from multiple perspectives, four types of surveys were utilized with two of them translated into Spanish. Surveys were designed for:

- Individuals with traumatic brain injury (English and Spanish[1]),
- Families of persons with traumatic brain injury (English and Spanish),
- Providers of services to persons with traumatic brain injury and
- Publicly funded agencies and programs.

SURVEY COLLECTION and DATA ANALYSIS -

Survey Collection -

Two hundred and fifty-three (253) surveys from individuals and families were returned, 100 from providers of services and 14 from publicly funded agencies. Forty-five (45) of the individual and family surveys were disallowed as they were either duplicates[2] or the mechanism of injury was not a traumatically acquired brain injury[3] as defined by

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[1] The Spanish language surveys were available at the public meetings, however, none were submitted for inclusion in the data gathering.

[2] Three were of the duplicates were traumatically acquired brain injury but the the majority of duplicates were from individuals or family members with non-traumatically acquired brain injury.

[3] Stroke- 8, Illness - 20, Other -17

the federal definition, PL 104-166[4]. Of these, 64% were mailed in and 36% were completed at the statewide public meetings[5].

Data Analysis -

The data was reviewed and analyzed by members of the Board, the Board Coordinator and the Texas Department of Health, Bureau of Epidemiology.

[4] Traumatic Brain Injury means an acquired injury to the brain. Such term does not include brain dysfunction caused by congenital or degenerative disorders, nor birth trauma, but may include brain injuries caused by anoxia due to near drowning.

[5] There was no identification on the surveys to indicate whether the respondent had attended a public meeting and then mailed in the survey.

BASIC DESCRIPTIONS OF THE RESPONDENTS -

Fifty-two percent (52%) of the surveys specified gender as male. Thirty-three percent (33%) were from females and 15% had no gender[6] specified. Of the 208 surveys used for this report, 124 or 60% were from individuals who are living with brain injury and 84 or 40% were from family members. Of the family responses, 55% percent were from parents, 24% from spouses, 18% from the child of a person with a brain injury, and 3% from siblings.

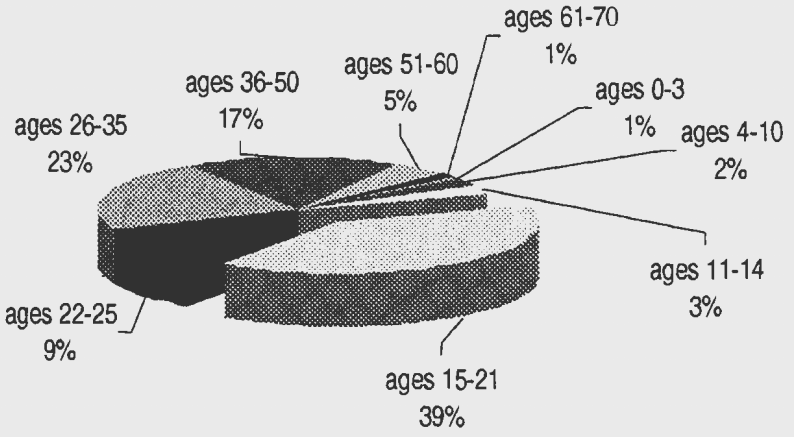
The surveys represent 96 cities, towns, or villages and 24% of Texas' 254 counties.

AGE OF RESPONDENTS -

In reviewing the results of the 208 needs assessment surveys from individuals and families, the following table illustrates the numbers of individuals in each specific age category at time of injury and percentages of the total.

Ages	0-3	4-10	11-14	**15-21**	22-25	26-35	36-50	51-60	61-70	70+
%	1	2	3	**39**	9	23	17	5	1	0
#'s	2	4	6	**83**	18	48	34	9	2	0

Ages and Percentage of each range at time of injury



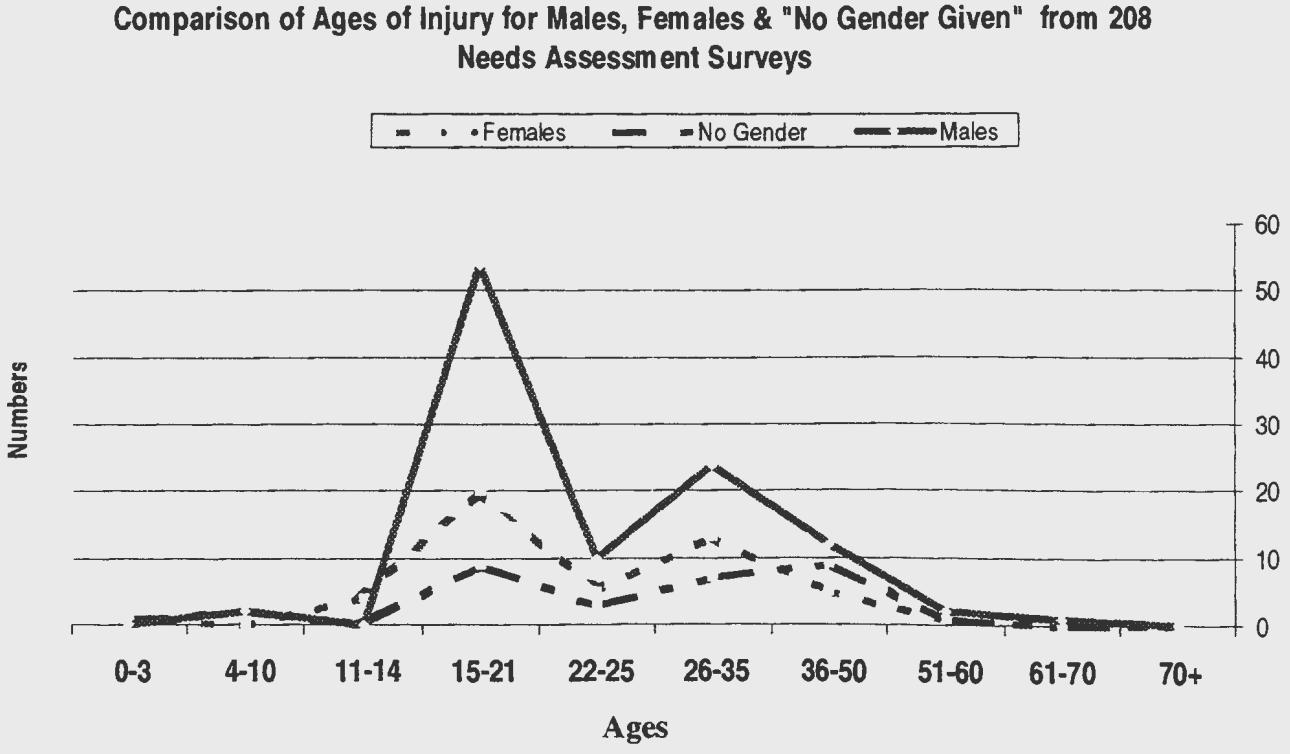
[6] The first distribution of surveys had no category to specify gender; it was used as the first piloting of the survey and is included as it is representative of the geographical area of the state in which a public meeting was not held.

The following three tables represent the breakdown of ages and gender for each age category. The results of the Texas Traumatic Brain Injury Advisory Board Needs Assessment Surveys follow the trend from the national findings of those at greatest risk for sustaining a traumatic brain injury. **The group which indicated the injury occurred between 15-25 years of age represents almost half of all the surveys. Thirty-eight percent (38%) of persons injured were between 15-20 yrs of age, prime school age years.**

Information from the Centers for Disease Control and Prevention, the US Government Accounting Office Report, Report to Congressional Requesters, on Traumatic Brain Injury, February 1998, the National Institutes of Health Consensus Conference, November 1998 and the Brain Injury Association, Inc., all agree, **the 15-25 year-old male is at greatest risk for sustaining a traumatic brain injury.**

Correlations of Ages at Time of Injury, Ages at Time of Surveys and Years Post Injury

The following charts developed from the surveys are gender specific. Males between ages 15-21 were injured up to 1 ½ times more than females in the same age category. The total of the age categories 21-50, including those responses with no gender specified is 107 or 51% of all the surveys. This number is greater than the total of the 15-20 age groups. The median age for this group is 23 and the mean is 27.

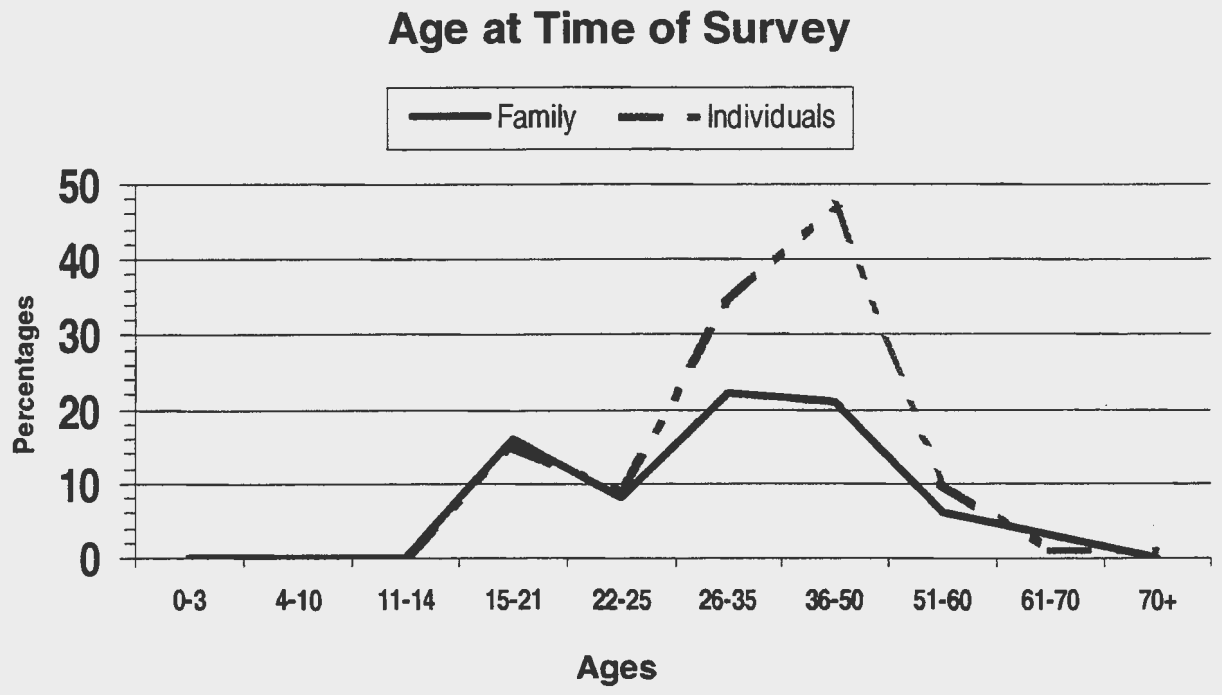


People in these age groups are generally in the process:

- **of completing formal education,**
- **establishing careers and**
- **building families.**

The results of this survey indicate over half of the respondents sustained a traumatic brain injury when they were over the age of eligibility for the majority of the state's health and human service programs.

Sixteen percent (16%) of respondents, either an individual with a brain injury or a family member of a person with a brain injury, are currently between ages 15-21, key



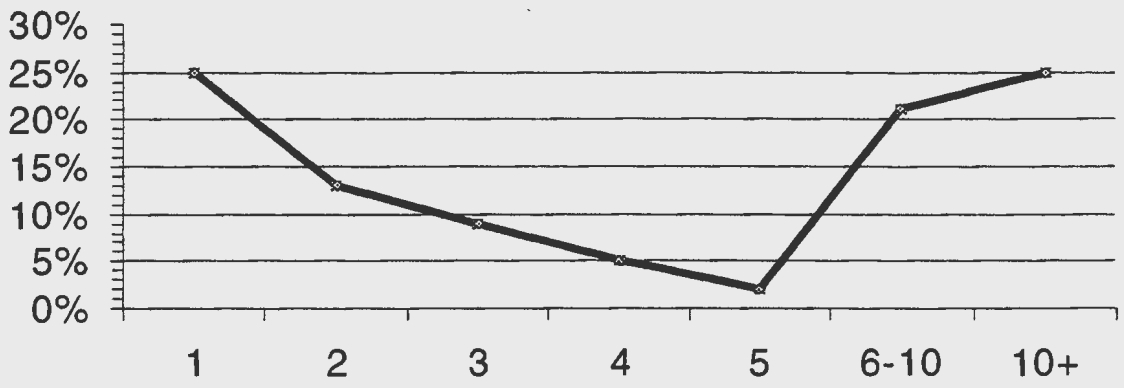
educational years. Seventy-two percent (72%) of all respondents are between ages 22-50, key years for completing education, starting and maintaining a family and peak career development years.

Total of all responses in each age category

Ages	0-14	15-21	22-25	26-35	36-50	51-60	61-70	70+
%	0	16%	9%	30%	35%	8%	.05 %	1.5%
#s	0	33	19	60	71	16	1	4

The median of "current age or age at time of survey" is 32. The mean age is 35.

Percentages of the Years Post Injury



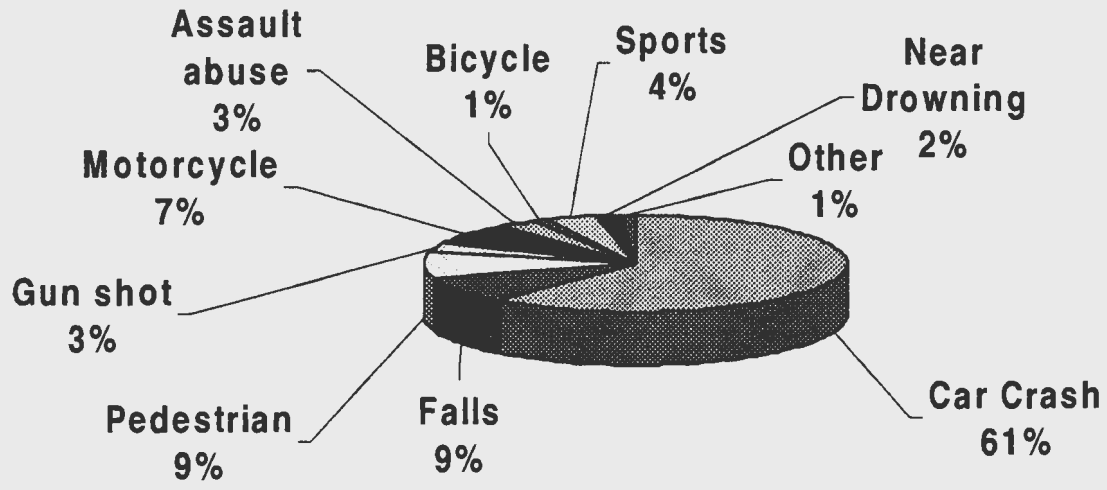
Years Post Traumatic Brain Injury

The results of "Years Post Injury" indicate the median years post-injury at the time of the survey is four (4) years, (mean 7.4 years). Twenty-five percent (25) of the respondents are 10 years or more post-injury and the median years for this group of people is 17 years.

Thirty-two percent (32%) of the respondents whose brain injury occurred 10 years or more ago reported they still need services.

Injury Specifics -

Percentages of the Mechanisms of Injury from 208 Surveys



National statistics indicate over 50% of all traumatic brain injuries occur as a result of motor vehicle accidents. The results of the survey sample indicate a higher percentage sustained a traumatic brain injury as a result of a motor vehicle accident (MVA) than the national average for MVA's. There were an equal number of reports (18) indicating either a fall or a motor vehicle/pedestrian accident. Falls are the second most frequent cause of brain injury according to the Brain Injury Association, Inc. and the Centers for Disease Control and Prevention.

From the 208 Surveys, the Dates of Injury sorted by decades:

Date of Injury from earliest reported date to most recent:	Reports.
1930's	1
1950's	1
1960's	4
1970's	20
1980's	46
1990's	136

Even though the surveys indicate a large response from persons whose injury is less than 10 years post, this does not presuppose there is a rise in the occurrence of traumatic brain injury in the 1990's. These numbers only reflect a greater number of respondents in this sample whose injury or the family member's injury occurred during the 1990's.

ACCESS TO SERVICES

Respondents were asked if they had received services for the traumatic brain injury. Ninety-three per cent (93%) of the respondents indicated they had received services. The questions for the respondents who had indicated they received services related to:

- acute hospitalization,
- in patient rehabilitation,
- out-patient rehabilitation,
- non-hospital residential and
- nursing home.

These responses cannot be measured in terms of type of medical or rehabilitative care received or how much time may have elapsed between services. It is only an affirmative response to the receipt of services and the Length of Stay (LOS).

Children - 0-12 years of age at time of injury - 9 surveys or 4% of all respondents

Children 0-12 years of age	No LOS[7]	1 day	2 days +	Median Stay of 2+ days
Acute Hospitalization[8]	11%	0%	88%	42 days
In-Patient Rehabilitation[9]	55%	11%	33%	42 days
Out-Patient Rehabilitation	88%	11%	0%	1 day
Non-hospital out-patient	88%	11%	0%	1 day
Non-hospital residential	44%	11%	44%	10 years
Nursing Home	78%	0%	22%	5 years

[7] Length of Stay

[8] The individual may have received emergency department services in an acute care setting and discharged.

[9] One day of rehabilitation is reported as it was marked on the surveys, however one day of rehabilitation will not allow the person to be evaluated nor properly admitted. At one day LOS, no services are provided.

Adolescents - 13-19 years of age at time of injury - 77 surveys or 37% of all respondents

Adolescents 13-19 years of age	No LOS	1 day	2 days +	Median Stay of 2 + days
Acute Hospitalization	20%	15%	65%	30 days
In-Patient Rehabilitation	20%	17%	63%	1 month
Out-Patient Rehabilitation	40%	15%	45%	5 months
Non-hospital out-patient	75%	3%	22%	1 year
Non-hospital residential	72%	3%	25%	1 year
Nursing Home	92%	1%	7%	4 months

Adults - 20-80 years of age at time of injury - 124 surveys or 59% of all respondents

Adults 20-80 years of age	No LOS	1 day+	2 days +	Median Stay of 2+ days
Acute Hospitalization	34%	9%	57%	30 days
In-Patient Rehabilitation	35%	13%	52%	1 month
Out-Patient Rehabilitation	48%	11%	41%	3 months
Non-hospital out-patient	82%	4%	14%	3 months
Non-hospital residential	93%	2%	5%	6 months
Nursing Home	90%	2%	8%	1 year

Information about traumatic brain injury, resources and services -

Respondents were asked if they had received information about brain injury as well as resources and services when they were needed. Sixty (60%) percent of the individuals with traumatic brain injury indicated they did not receive information about the brain injury and 55% stated they did not receive information about supports and services. Thirty-six percent (36%) percent of the families stated they did not receive information about the brain injury and 52% reported they did not receive information about resources for their family member.

Case Management and Need for Personal Advocate -

Fifty-eight percent (58%) of the respondents indicated they do not have a case manager nor a care coordinator. The surveys showed 38% each, individuals and families, expressing a current need for case management services. Thirty-six percent (36%) of the families and 16% of the individuals[10] indicated a need for a personal advocate.[11]

Sixteen percent (16%) of the respondents listed the type of case management services currently being received.

- 1% reported case management services were provided by TDMHMR,[12]
- 2% provided by TRC,[13]
- 2% provided by waiver case managers and
- **the remaining 95% were receiving case management by a family member, friend or service provider, none whose role or training is case management or care coordination.**

Insurance case management was not listed by any of the respondents.

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[10] With a traumatic brain injury

[11] It should be noted: inherent to a case manager's role and responsibilities is the function of client advocacy. However, the surveys did not distinguish differences nor similarities between a case manager or a personal advocate. Therefore, there is an assumption the need may be higher than 38%.

[12] Texas Department of Mental Health/Mental Retardation

[13] Texas Rehabilitation Commission

Responses from Service Providers[14] -

Service providers were asked to identify their referral sources in an effort to gain an idea of how persons with brain injury move from one service to another. Of the 100 surveys received from service providers the following are their responses to the question, "What are the referral sources?"

- 13% reported they received their referrals from case managers,
- 19% from insurance companies,
- 22% from individuals in need of services and
- 46% did not respond to the question on the survey.

Additionally, the providers were asked where they saw gaps in services:

- 14% percent said there was a gap in client advocacy
- 26% reported a gap in traumatic brain injury knowledge,
- 7% indicated they provided family education, training and information,
- 5% provide family education, training and information to families of children[15] and 6% to families of adolescents[16] and adults[17].

[14] The remaining data received from Service Providers follows the Individual and Family response section.

[15] Ages 0-12

[16] Ages 13-19

[17] Ages 20-80

Education and Employment

Education and employment are two critical areas where persons with brain injury have a great deal of difficulty and frequently need supports and services in order to participate and benefit from school and to obtain and maintain employment.

School -

Forty-four percent (44%) of all respondents indicated they were in school or their family member was at the time of the survey. Of these, 58% of the responses were from persons with brain injury and 42% from families.

Currently Attending School

Currently attending school	% of total number (91)	% of Individuals at each grade level	% of Family responses at each grade level	Have received special education services
Elementary	0	0	0	0
Jr. High/Middle School	0	0	0	0
High School	26%	54%	46%	75%
College	34%	77%	23%	29%
Vocational or trade school	5%	100%	0%	40%
Other	4%	100%	0%	75%
Did Not Specify School Type	30%	38%	62%	34%

Thirty-seven percent (37%) or 77 responded to highest grade level pre-injury

Pre-Injury grade level	% of total number (77)[18]	% of Individuals at each grade level	% of Family responses at each grade level	Have received special education services
Elementary	5%	50%	50%	100%
Jr. High/Middle School	12%	66%	33%	66%
High School	53%	60%	40%	40%
College	27%	86%	14%	10%

Twenty-four percent (24%) or 50 responded to highest grade level post-injury

Highest grade level post-injury	% of total number (50)[19]	% of Individuals at each grade level	% of Family responses at each grade level	Have received special education services
Elementary	0%	0%	0%	0%
Jr. High/Middle School	0%	0%	0%	0%
High School	64%	60%	40%	40%
College	30%	74%	26%	33%

Further study needs to be completed to determine at what grade levels special education services were used, how long were they needed and if the person had received special education services prior to the brain injury.

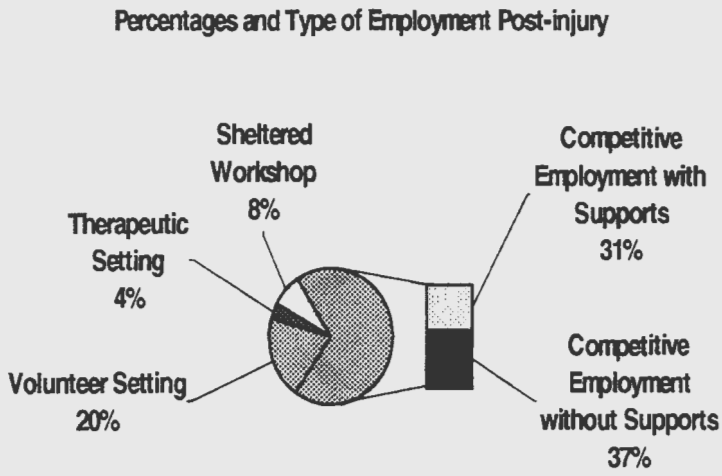
[18] 3% marked "G" which is assumed to indicate graduated

[19] 6% marked highest grade level as G and 2.

Employment

Forty-seven percent (47%) of all respondents indicated working after the traumatic brain injury. The chart at the right identifies the types of employment and percentages of respondents who worked post-injury. Seventy percent (70%) of the respondents were individuals with a brain injury and 30% from families of persons with brain injury.

Thirteen percent (13%) of all the surveys had responses to the "Length of time on their current job," with the median length of time 1 year. Eighteen percent (18%) had the number of hours worked each week with the median at 28 hours a week.



Sixty percent (60%) of the respondents indicated the person with the brain injury has not worked since the brain injury and cited the following reasons. Fifty-four percent (54%) of the respondents were individuals with traumatic brain injury and 46% from families of persons with brain injury.

Reasons for Not Working

Reason for not working	% Total	% Individuals	% Families
Inability to find work	22%	70%	30%
Inability to get along with co-workers, boss	5%	33%	66%
Inability to perform a previous job	25%	71%	29%
Inability to perform any job	33%	61%	39%
Inappropriate behaviors or comments	6%	29%	31%
Other	8%	50%	50%

Fifty-one percent (51%) of the surveys reported: longest length of time for employment since the brain injury occurred.

Longest Period of Time for Holding a Job

Longest time a job was held	% Total	% Individuals	% Families	Median years job held
< 1 month	21%	70%	30%	2 yrs.
1-3 months	16%	71%	29%	6 yrs.
3-6 months	8%	44%	56%	3 yrs.
6-9 months	8%	88%	12%	7 yrs.
1 year	10%	55%	45%	9 yrs.
1-3 years	19%	85%	15%	10 yrs.
3-5 years	8%	75%	25%	10 yrs.
5-10 years	10%	30%	70%	14 yrs.
> 10 years	1%	0%	100%	2 yrs.

Eighty-six percent (86%)[20] of the surveys were from persons with a brain injury who were 20 years or older at the time of the survey and from families whose family member with a brain injury is 20 or older.

Living Arrangements at the Time of the Survey for Persons over 20 years of Age.

Living Arrangements	% 111 of Individuals	Individuals-Median age	% of 67 Families of Individuals	Family Member-Median age
Parents	26%	27	28%	30
Alone	35%	40	12%	37
Spouse	30%	38	22%	41
Roommate	1%	30	7%	22
Group Home	1%	50	11%	27
Nursing Home	1%	80	6%	32
Rehabilitation Facility	5%	27	11%	24
Other/Unknown	3%	35	3%	48

❖❖❖❖❖

Transportation -

Forty-eight percent (48%) of persons with a brain injury reported they drive and 24% of the families reported their family member drives. The median age for those who drive is 36 for both individuals and family responses. Twenty-eight percent (28%) of individuals and 49% of families indicated the main means of transportation for the person with the brain injury is riding with family or friends. The median age for individuals who ride with family/friends is 28 and it is 27 from the family responses.

Twelve percent (12%) of families stated a personal attendant is responsible for providing transportation and 6% of individuals reported having a personal attendant.

[20] 4% or 8 surveys did not answer - living arrangements

The median age for individuals requiring a personal attendant is 32 and 33 for family members.

Seven percent (7%) of individuals and families reported transportation is provided by the facility in which the individual is a resident. The median age for individuals is 26 and 39 for family members.

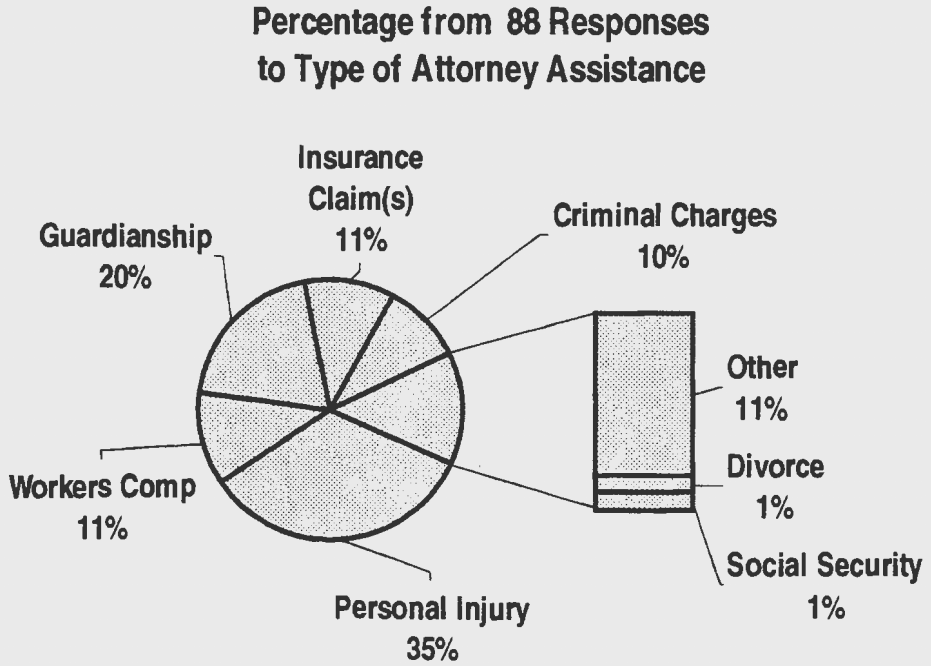
Three percent (3%) of the individuals use public transportation, 2% of family members and individuals use special transit, 1% use a taxi and 3% walk. The median age for this group of people is 28.

Socially Active -

Sixty-nine percent (69%) of individuals indicated they are socially active and 61% of families reported their family members are socially active. The median age for individuals is 32 and 30 for those reporting on their family member's behalf.

Legal Issues -

Seventeen percent (17%) of all respondents reported they have had legal trouble with 42% requiring an attorney and 10% having spent time in jail. Twenty-one percent (21%) of respondents admitted to using alcohol and 3% have been jailed because of alcohol and drug issues.



Frequently, the family of a person with the brain injury or the individual require the assistance of legal counsel after the injury. The need for legal counsel can range from:

- criminal defense,
- advocacy for benefits such as social security or workers compensation
- representation in a personal injury lawsuit.

Without proper representation, persons with brain injury risk losing benefits which may be due them, may be improperly tried and sentenced or may lose everything which allows them to be self-supporting. More study of individuals' needs for legal counsel must be done as the outcomes of inappropriate or lack of counsel can affect the expenditure of public funding in Texas.

Changes in Life Style -

A traumatic brain injury frequently results in significant changes in the individual's life as well as the family's. Employment, living situation, relationships, psychological and medical changes are the domains of life which appear to affect both the individual and the family.

The large numbers reflected in "Changes in marriage" is a critical area as 42% of all the respondents reported the initial injury occurred prior to the 20th birthday. A small percent of these respondents may have been married at the time of the injury, however, the surveys did not ask if the individual was married at the time of the injury.

Individuals with traumatic brain injury reported the injury caused changes in these areas of life:

- 73% - employment
- 60% - psychological changes
- 56% - living situation
- 54% - medical changes
- 40% - education
- 34% - parenting skills
- 29% - marriage

Family Members reported these changes in the life of their family member with a brain injury:

- 71% - psychological changes
- 68% - employment
- 61% - living situation
- 57% - medical changes
- 46% - education
- 32% - marriage
- 31% - parenting

Family members reported changes in their own lives as a result of the brain injury:

- 51% - changes in own living situations
- 50% - own psychological changes
- 49% - own employment
- 49% - parenting skills
- 33% - own marriages
- 23% - medical change
- 19% - own education

Quality of Life (QOL) -

There were no responses representing individuals or family members with brain injury under the age of 13 at the time of the survey.

Six (6) responses were received from persons with brain injury and fifteen (15) from family members in the 13-19 age category and from 115 individuals and 68 family members over 19 years of age[21].

Quality of Life Responses

Ages <19	Poor	<Average	Average	> Average	Excellent
Individual	0%	33%	33%	33%	1%
Family	20%	30%	10%	40%	0%
Family's QOL	10%	20%	30%	40%	0%
Ages >19					
Individual	5%	35%	15%	40%	5%
Family	8%	45%	17%	28%	3%
Family's QOL	3%	25%	25%	44%	3%

[21] 4 responses did not indicate age, therefore, are not included.

PROVIDERS OF SERVICES SURVEY RESPONSES

Geographical Locale of Respondents -

Central Texas:	16%	East Texas:	5%	Houston area:	24%
The Valley:	8%	West Texas:	20%	Dallas/ Ft. Worth	27%

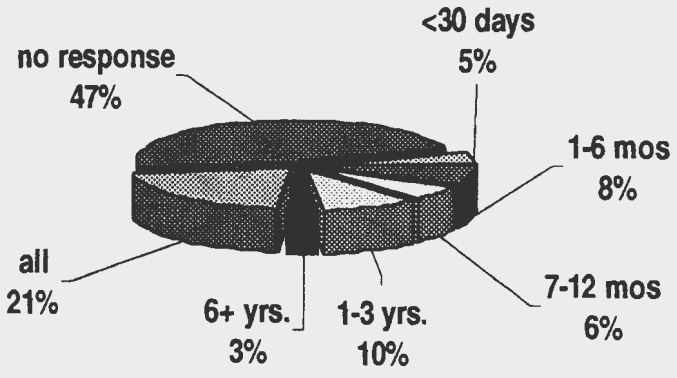
Basic Description of the Respondents -

Five percent (5%) of the respondents were individuals in private practice and 95% were service providers from the following:

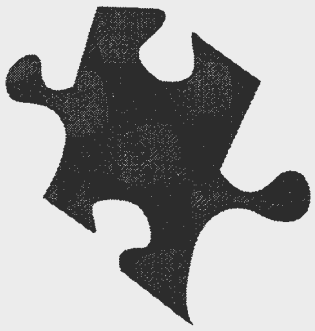
- agencies
- independent living centers
- home health agencies
- rehabilitation facilities
- primary care
- waiver programs,
- educational services
- acute care
- MHMR providers
- associations. [22]

Twelve percent (12%) of the respondents stated they provide acute medical services, 8% rehabilitation services, 33% long term community supports, 25% educational services, 21% employment services and 7% financial support for patients or clients. Of these 100 providers, 57% indicated they provide brain injury services while 31% have at least 50% of their staff designated to provide services for persons with traumatic brain injury.

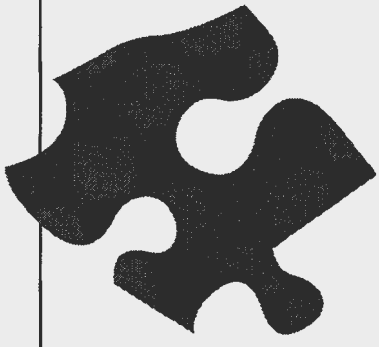
Percentages in length of time when referrals for services are received

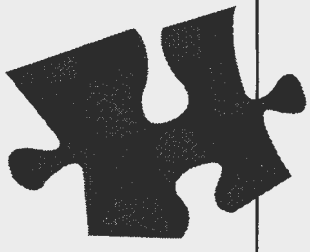


[22] The surveys did not provide a question specifying the primary nature of the provider's purpose or health care focus therefore, the specific breakdown of how many in each category is unavailable.



Results of the Statewide Public Meetings





RESULTS OF THE PUBLIC MEETINGS

Sites and Number of attendees at the Public Meetings held in March, April and May 1998 -

City	Date	Attendees
Dallas	3/26/98	47
Fort Worth	3/31/98	48
Amarillo	4/28/98	12
Lubbock	4/29/98	40
El Paso	4/30/98	27
Tyler	5/4/98	17
Houston	5/6/98	31
McAllen	5/7/98	15
Austin	5/14/98	24

The public meetings were comprised of individuals with brain injury, family, friends, professionals from all areas of medical care, state agency personnel, press, radio, TV and interested persons from the communities. At these meetings, the attendees were able to express their concerns, needs and wants as well as tell their stories. The results of the public meetings are added at this point at it underscores the public's concern about the lack of availability and access to services and supports as well as the need for advocacy measures.

All the oral comments were tabulated and 98% of the comments fell into 10 categories with 2% into a miscellaneous category and prioritized by percent of responses for each category.

Seventy-eight percent (78%) raised concerns and questions about the limitations and availability of supports and services with 40% stating a need to educate themselves and the public, which included the medical professionals.

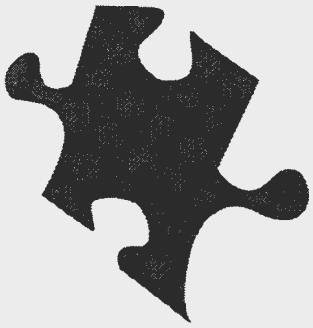
Attendees ranked education and awareness of traumatic brain injury as the second priority with 40% of the participants requesting more education to all sectors of the public and 27% requesting information about brain injury and its uniqueness.

Repeatedly, comments were made that the families and individuals were alone in searching out information and resources. They indicated a case manager or personal advocate is a service which is needed for linking them with information and supports and services.

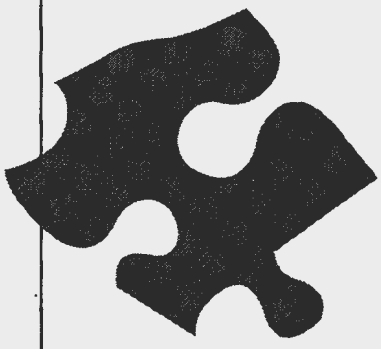
Priorities Areas of Need from the Public Meetings

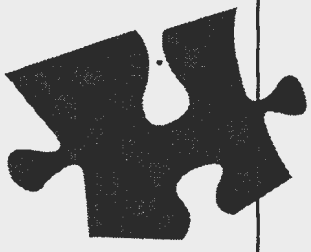
	Categories of Concerns & Need	% of responses from total of 240 attendees
1.	Availability and limitations of facilities and services	78%
2.	Education, public awareness and education and public service efforts	40%
3.	Advocacy and central clearinghouse	35%
4.	Insurance coverage and funding options	35%
5.	Diverse needs and vulnerabilities of brain injury (uniqueness of traumatic brain injury's effects)	27%
6.	Research	26%
7.	Employment and work issues	18%
8.	Education about brain injury for public schools and Vocational training options for persons with brain injury	18%
9.	Support and network building	17%
10.	Transportation	10%
11.	Miscellaneous	3%

In response to the concerns and needs from the public meetings and the needs assessment surveys, the Texas Traumatic Brain Injury Advisory Board has selected the first 5 priority items and collapsed them into 4 Outcome Statements in the Statewide Action Plan. Likewise, they have been utilized in the general recommendations needing to be addressed by the State of Texas.



Programs Reviewed for the Policy Analysis





PROGRAMS REVIEWED FOR THE POLICY ANALYSIS

State Dept.	Program	Services	Restrictions	Eligibility - Other
TDH	**Texas Health Steps (formerly EPSDT)**	Medically necessary private duty skilled nursing, Comprehensive Care Program, Straight hourly medicaid therapies, OT, PT, ST, durable and disposible supplies, medical and dental check-ups for medicaid eligible children.	No Day care nor respite for parents/care givers, no acute services.	
TDH	**Home Health Services**	Home Health Visits (LVN, ST, PT, OT, AIDS, some DME, consumable medical supplies, home IV, antibiotic therapy for children w/CF), skilled nursing visits, parent training, acute services.	Pre-approved, 50 visits a year (excepted with prior authorization), homebound restriction removed recently.	Straight medicaid benefits
TDH	**Medically Dependent Children's Program**	In-house/out-of-home licensed nursing, respite care, regular Medicaid State Plan Benefits (including EPSDT-CCP). Home modifications, adaptive aids, adjunct support services, skilled RN while care giver is at work. Similar to CLASS, automatically become Medicaid eligible if receiving services.	Projected annual cost of service cannot exceed the cost of Medicaid nursing facility ($25,000 per year). Funding based on TILE (functional assessment) score with $10,000/annually to $25,000/annually. All providers of services must enroll to be accepted as a provider including individuals, family, house parents.	Dollar amount per/client based on TILE score, medical necessity waived based on functional score.

State Dept.	Program	Services	Restrictions	Eligibility - Other
TDH	**In-Home total parenteral hyperalimenation supplies**	TPN - supplies, patient education, nurse visit, enternal supplies & equipment.	If over 21 years limited to 4 diagnoses.	Limit 4 Diagnosis over 21.
TDH	**Chronically Ill and Disabled Children Program**	Medical services including Home Health Care Pilot services, CIDC providers required arranging and reimbursing for medical transportation.	State funding limits the number of participants, payor of last resort, few providers and limited reimbursement for services.	Meets income criteria & covered diagnosis.
TDH	**Certified Respiratory Care Practioner**	Respiratory therapies & services disposable supplies.	Client is respirator dependent at least 6 hr/day.	Vent dep at least 6hr/day.
ECI/TEA	**Child Find - Early Childhood Intervention**	19 services tailored to individual/family including PT, OT, SLP, service coordination.	State/federal funding.	Meet DD req., diagnosis with physical or mental condition w/high probability of DD or exhibits atypical development.
DHS	**Primary Home Care**	Nontechnical, medically related personal care services prescribed by MD and performed by aide. Aide supervised by RN.	Functional assessment score of 24+, maximum of 50 hr/wk. A non-technical medical service prescribed by MD and supervised by a RN.	Referral by MD., 50 hr/wk eligible Medicaid clients whose chronic health problems impair daily living.
DHS	**Day Activity & Health Services**	Daily supervision at facility, M-F, 8-5 - nursing and personal care, physical rehabilitation, meals, transportation, social, educational, and recreational activities.	Medical diagnosis & MD's orders. Functional Disability (Adult 18), Title XX funds Primarily senior centers and services by licensed day care facilities, statewide as in every region, SSI eligible for Title XIX funds and for Title XX funds based on income levels.	Meets Social Services block grant income eligibility, guidelines and resource limits.

State Dept.	Program	Services	Restrictions	Eligibility - Other
DHS	**Comm. Living Assistant & Support Services**	CM, habilitation, respite care, RN, psych., PT, OT, SLP, adaptive aids/supplies, minor home modifications, two service providers - one for case management and one for service delivery - Individual. Service Care Plan approved by DHS approved as CLASS providers needed for service delivery.	Individual client cost ceiling based on waiver formula calculations ($51,603/yr), MR and RC only, have a demonstrated need for services which is based on functional assessment, FY'97 expand to 75 counties.	ICF-MR/RC level of care, reside in catchment area, cost-effective alternative to institutional placement.
DHS	**In-home & Family Support Srvs.**	Direct grant to client which enables to live in community. Client empowered to choose and purchase services to assist them for staying in own home. Attendant care, home health services, aides, chores that provide assistance with training, ADL's, ambulation, and food preparation. Counseling and training programs to help provide proper care for an individual w/disability. Medical, surgical, therapeutic, diagnostic and other health services related to person's disability.	Lifetime limit of $3,600 for purchase of minor housing mods., or for adaptive aids or spec. equip. $3,600/annually for purchased services and supplies. First year eligible for $7,200 - lifetime for modifications and $3,600 for purchased services. Statewide in every county. State funding limits # of participants (waiting list - approx. 8,000).	Four+ yrs, co-pay when income is more than 105% of state median income for household size, phys. disability which substantially limits person's ability to function independently, sliding scale based on household income.
DHS	**Residential Care**	Supervised living - 24 hr setting - client, if able, is expected to contribute to total cost of care. Client keeps mo. allowance for personal and med. expenses. Emergency care provides a time limited 24 hours living arrangement while caseworkers seek a permanent care setting. No co-payment is required. Services, personal care, home management, escort, 24 hour supervision, social & rec. activities, transp, food, and room. Doesn't require a RN.	Number of facilities contracted affect the availability of preferred slots. statewide, but not in every county, providers are enrolled. Board & Care - Client is expected to contribute, if able, to total cost of care. Monthly allowance for personal & medical expenses. Title XX funding is for emergency care while case workers seek permanent care arrangements. Emergency care clients do not contribute to their cost of care.	Functional assess score of 18>, client needs must be with in facility's capability under its licensed capacity, two programs: supervised living and emergency care.

State Dept.	Program	Services	Restrictions	Eligibility - Other
DHS	**Respite Care**	Respite for the care giver not to exceed 14 days/yr. Provided in variety of settings: hospital or SNF or personal care home, adult day health care facility, or in the individual. home by a sitter or home care attendant, where ever the client is or needs to be given care.	Max services - 14 days/yr Short term services as care giver is either unable to temporarily provide care or under severe stress and needs relief from care giving duties. Applying for services is through local Aged & Disabled Programs.	Elderly or disabled adult - needs supervision or care. Care giver relief, Medicaid recipient or meet income guidelines.
DHS	**Special Services to Persons with Disabilities**	Interpreter services (Austin), adult day care, counseling, personal care, life skills development with Client/variety of settings.	Available in Dallas, Texarkana, Beaumont, & Austin.	Medicaid recipient or meet income guidelines.
DHS	**Special. Services to Persons w/disabilities - 24 hr. Attendant. Care**	24 hr attendant, services are provided on a scheduled basis, unscheduled requests for attendant care are met based on availability of staff. Client live independent in cluster living arrangement and use service to achieve habilitative or rehabilitation goals.	Services limited to one apartment complex in Houston. State funding limits number of residents served.	Living in same apt complex where services available, functionally limited in ADL's.
DHS	**Adult Foster Care**	24 hr living arrangement with supervision for persons who are unable to function independently in own home. Services include minimum help with ADL, provision of or arranging for transportation. Clients pays for room and board. Version of Board and Cares.	Applicants must be willing to live in someone else's home and need min supervision and assistance. Providers must be willing to share common living area with clients and live in home. DHS must license any home with over 3 adult residents.	Functional assessment score of <18 Medicaid recipient or meet income guidelines Title XX funding, limited dollars.
DHS	**Congregate & Home Delivered Meals**	Nutritious meal served in either a central dining area or taken to client's home.	TDHS contracts for home delivered meals TX Department on Aging contract with area agencies on aging for large congregate meals program and an expanding home delivered meals program.	Local resources, functionally limited in preparing meals. TDH on Aging primary eligibility is 55>.

State Dept.	Program	Services	Restrictions	Eligibility - Other
DHS	**Client Managed Attendant Services**	Personal care, housekeeping, meal preparation, escort.	23 counties or 8 regions, must be able to self-direct care and have a disability expected to last at least 6 months from date eligibility is determined.	Medicaid eligibility and/or meet income criteria, Mentally and emotionally capable of directing the care of someone else or have someone else supervise the attendant if client is unable to do so. Must have physical disability and must need at least 5/hrs of attendant care weekly and at least one personal care task.
DHS	**Emergency Response System**	Electronic monitoring system used by functionally impaired adults who live alone or who are socially isolated in the community in an emergency, the client presses a call button to summon help.	Provider enrollment and must meet licensure requirements of TX Board of Private Investigators and Private Security Agencies. Client signs release allowing for forced entry if provider is asked to respond and there is no other entry.	Be alone for 8/hrs+/day, have mental capacity to operate the equipment, have telephone with private line, Medicaid recipient or meet income guidelines.
DHS	**Community Based Alternatives**	Adaptive aids, med. supplies, adult foster care, assisted living/residential care, emergency response, RN, home modifications, OT, PT, ST, personal assistance services and respite care.	Individual cost ceiling based on SNF payment rate, waiting list at end of 96, expanding FY'98, aged and disabled adults, PASSAR review and deemed appropriate Medicaid eligible in community under SSI, MAO protected status or income guidelines for Medicaid SNF.	Meet medical necessity criteria for SNF, cost effective ISP.

State Dept.	Program	Services	Restrictions	Eligibility - Other
MHMR	**Home & Community Based Services**	Adaptive aids, CM, dietary, habitilitation, minor home mods., Rn, OT, PT., SLP, Psych services, respite, social services.	Client's IPOC for HCS-O cannot exceed 125% of estimated annual cost of ICF-MR services. CM if placed out, PASARR review, MR needs <75 IQ, If RC, then <18yrs/RC and no IQ Score, but not over 22. MHMR is charged with placing individuals in appropriate community settings.	Be directly from SNF, SSI eiligible or meet SSI eligibility, meet financial criteria for M/D or be member of family with full M/D benefits as a result of AFDC and choose the HCS-O over ICF-MR program.
MHMR	**In-Home & Family support**	Grant to child's family which enables children to live in the community w/family	Grants for purchase of services and supports, shall not exceed $3,600/yr., additional grant available to make minor home modifications or purchase adaptive aids or special equipment.	Children 4yrs.+ with diagnosis of MR or emotional disturbance (Physical disabilities handled by DHS)
MHMR	**Home & Community-Based Services**	Respite, homemaker, Rn, habilitation, counseling, social services, and OT, PT, SLP, audiology, psychology services, dietary, LSW, CM, adaptive aids, minor home mods. Provided in own home or in home not exceeding 3 other client beds.	Client's individual POC for HCA servs cannot exceed 125% of estimated annual cost for ICF-MR services. <75 IQ for MR, 18-22age for RC (based on ICD-9 codes) with no IQ score, Some expansion, but cap is being considered.	SSI eligible & meet financial criteria for Medicaid <19 in level I or II foster care with DPRS, or a member of family receiving full med. benefits resulting from TANS & choose the HCS pragm or ICF-MR pgrm, eligible for ICF-MR level of care I, V, or VI.
TRC	**Deaf - Blind with Multiple Disabilities Waiver**	Standard waiver services with an Intervener to serve as a bridge to the community, behavior communications specialist, and orientation/mobility services. Family training and summer camping for D-B waiver recipients.	Feasibility of services tend to cluster in larger metro areas. Contact for access is Steve Schoen, TRC, 1-512-424-4185 or 1-800-628-5115. Projected there are 250 individuals statewide who meet waiver criteria.	Deaf-Blind and eligible for waiver services if has the legal definition for deafness-blindness and has one other disability ie., MR, autism which results in impairment to independent functioning and requires 24 hr. support.

State Dept.	Program	Services	Restrictions	Eligibility - Other
TRC	**Comprehensive Rehabilitation Services**	Inpatient comp. medical rehabilitation outpatient services, post-acute TBI services.	Time limited to a max. of 6 mos., limitation of time post injury for service eligibility*. Waiting list, first come, first serve. Must have a traumatically induced brain injury, not be a client of another TRC counselor as same time. *Acute Rehabilitation for a maximum of 90 days 1 year or less, post injury. Out-patient rehabilitation for up to 120 hours and 2 years or less post injury.	Have received a TBI or SCI, payor of last resort - vocational goal not necessary. for services, citizen or immigrated within 6 mos. of services., or family member in state in last 6 mos., willing to accept treatment, sufficiently medically stable to participate actively in program of services. must be TBI and require CRS purchased services.
TRC	**Vocational Rehabilitation Program**	Evaluation, guidance and counseling, training, adaptive equipment, medical/therapeutic treatment, rehabilitation technology, job placement, follow-up services, IWRP for each client. Two TRC brain injury speciality c counselors in TX.	Documented disability which limits ability to get or keep employment. Large caseloads.	Vocational goal, major disability which results in substantial problems in getting work, VR services. are required to get or keep a job, and person is able to get or keep job after receiving services.
TRC	**Extended Rehabilitation Services**	Mobility assistance, job coaching, transportation to and from job, activities to improve ADLs, assistance in developing self-help and adaptive skills, assistive tech necessary for employment. Not limited to the job site.	Not time limited	Capable of achieving employment outcome, legal resident of TX, capable of earning 15% of minimum wage
TRC	**Independent Living Services**	Guidance and counseling services, training and tutorial services, Adult basic education, tech aids for hearing impaired, vehicle modification, assistive devices to stabilize or improve function, other services. needed to achieve independent. living objects e.g. transportation, interpreter and maintenance.	Blind served by the Texas Commission for the Blind...Priority services to persons who are receiving services through ILC's. Available in 10 cities (El Paso, Lubbock, Amarillo, Ft. Worth, Austin, Crockett, Houston, San Antonio, McAllen, Dallas).	Persons with major disabilities except blind, vocational goal not required. Reasonable expectations the TRC/IL Services will improve person's ability to live independently. IL counselor certifies eligibility for IL Services.

State Dept.	Program	Services	Restrictions	Eligibility - Other
TRC	**Personal Attendant Services**	Attendant care services	Limited to Houston, Orange, San Antonio, Austin, and Dallas with their surrounding counties	Have a disability, need assistance with at least one personal assistance task, need 7 hr/wk and no more than 35 hr/wk of personal attendant services a week, working a minimum of 20 hr/wk for at least minimum wage or self employed with net income of at least $300/month.