ADDRESSING MICHIGAN'S PUBLIC SERVICE GAPS FOR PERSONS WITH TRAUMATIC BRAIN INJURY

SEPTEMBER 2004

Report of the MDCH TBI Project

Michigan Department
of Community Health

MDCH

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STATE OF MICHIGAN
Family
Independence
Agency

Brain Injury
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[1] Members of the Advisory Council comprised six workgroups. Appendix G is a list of all workgroups' members.

EXECUTIVE SUMMARY

A brain injury is any injury that results in brain cell death and loss of function. A *traumatic* brain injury (TBI) is an injury to the head caused by blunt or penetrating trauma or from acceleration-deceleration forces, such as from a fall, car crash, or being shaken (Thurman et al., 1994). TBI may or may not be combined with loss of consciousness, an open wound, or skull fracture. TBI is complex and unpredictable in its outcomes. Both mild and severe TBI can result in lifelong impairments – requiring long term care services.

Within the public sector, the State of Michigan has almost no specialized services for individuals with TBI. Rather, individuals with TBI may be served through local agencies and state and federal programs that focus on physical health, behavioral health, and other social services – each with their own referral processes, scope of services, eligibility rules, and payment sources. This can be confusing for survivors, caregivers, family members, and even agency workers to navigate or otherwise assist individuals to obtain needed services.

In order to better understand these diverse and complex systems, improve access by sharing what was learned, and improve public services for individuals with TBI, the Michigan Department of Community Health (MDCH) applied for and received a TBI Planning Grant in 1998 and a TBI Implementation Grant in 2000 from the federal Health Resources and Services Administration – Maternal and Child Health Bureau. For the past five years, the grants have funded a study of the state's TBI needs and how services could be improved. The state projects also developed and tested training materials, analyzed data, provided outreach, and set up ways to get people needed services.

With use of these funds, **Michigan** has become **the recognized leader** in data linkage and analysis regarding incidence and cost of TBI (Connors, 2004). The **non-partisan, multiple-agency, consumer-involved, data-driven efforts** of this project have culminated in the compilation of this report.

This report, *Addressing Michigan's Public Service Gaps for Persons with Traumatic Brain Injury*, contains data on:

- Incidence and risk factors of TBI;
- Medicaid Fee for Service, Medicaid Health Plan, Home Help, and Community Mental Health service use;
- Provider feedback on access to public services by individuals with TBI;
- Case studies of individuals with TBI; and
- Evaluation of piloted efforts to improve service delivery.

Most importantly, policy recommendations are made to address service gaps for this population.

FINDINGS

A. *Every year about 10,600 serious traumatic brain injuries occur to Michigan residents.*

Of this number, TBI contributes to almost 1,600 deaths and more than 9,000 TBI-related hospitalizations that do not result in death. Reliable data are not available to count the number of traumatic brain injuries that are not treated in hospitals. Not everyone who experiences a TBI will suffer long-term harm, but many will. The Centers for Disease Control and Prevention estimate that 2% of Americans are living with a disability due to TBI – approximately 200,000 Michigan residents.

B. *Annually, Michigan Medicaid covers nearly 1,500 TBI-related hospitalizations.*

Overall, 67,000 people received treatment services for TBI (including an annual average of 1,500 hospitalizations, other clinical care, and nursing home care among others) through the Michigan Medicaid Fee for Service or a Medicaid Health Plan during the four year period October 1, 1998 – September 30, 2002. Of these people, about 3,500 individuals also received Home Help personal care services, and over 12,000 received services from the Community Mental Health Services Programs during the same timeframe.

C. *Michigan Medicaid Fee for Service component pays at least $11 million dollars a year for TBI-related services.*

The study identified this amount based on services provided during the fiscal years 1999-2002. Actual costs to the State from TBI are much greater because those clients whose care was covered by the Michigan Medicaid Fee for Service program account for only one third of all identified cases of TBI – the rest are enrolled in a (managed care) Medicaid Health Plan. This $11 million in costs only covers services that are specifically identified as resulting from the diagnosis of TBI. Actual direct treatment services related to TBI are believed to be even greater and, if counted, would add significantly to the costs identified. In addition to Medicaid Fee for Service, $9 million was paid for Home Help personal care services for individuals with TBI during FY2002.

D. *There are gaps in public services for individuals with TBI.*

Over the course of the project, key features of a comprehensive service system for individuals with TBI have been identified as:

- ✓ Service providers trained and <u>knowledgeable about brain injury</u>
- ✓ A <u>screening method</u> to identify people suffering from TBI-related injury so they do not remain misdiagnosed or undiagnosed
- ✓ A <u>rehabilitation</u> program that helps people with TBI recover lost abilities to the greatest extent possible, and that helps them develop a way of dealing with lost abilities

- ✓ Coordination and planning of services to help people with TBI identify their service needs, develop a person-centered care plan, and access and coordinate needed public services
- ✓ Appropriate residential placement so those with severe disabilities are not forced into nursing homes
- ✓ Community living supports so that those with less severe disabilities can live and work independently
- ✓ Assistive technology to support function and independence – especially cognitive aids such as timers, tape recorders, and planners
- ✓ Personal care to provide supervision, reminding, or hands-on assistance in meeting basic needs (cooking, eating, and personal hygiene among others)
- ✓ Vocational rehabilitation to assist with finding and maintaining employment over the long term
- ✓ Counseling and behavioral management to treat occasional symptoms that may reoccur

Coordination of services, appropriate residential placement, community living supports, counseling, and behavioral modification services are all **available to some populations with disabilities** in Michigan. These populations may include people who qualify for services from Community Mental Health Services Programs and individuals able to access Michigan's Medicaid Home and Community Based Waiver for Elderly and Disabled. **Many individuals with TBI do not have access to these programs** because they do not meet the legal requirements of having a developmental disability or serious mental illness (populations served by Community Mental Health Services Programs). In addition, there are only 800-1000 yearly openings statewide in Michigan's Medicaid Home and Community Based Waiver for Elderly and Disabled. The limited number of openings does not make room to include many people with TBI.

Interviews with **individuals with TBI, their family members, and public service providers** revealed that, from **their perspective**:

- Case Management – which would provide appropriate referrals, help individuals bridge all the public service programs, and assist them to follow through with the required paperwork – would "vastly improve" their lives.
- There is a great need for education about TBI among both public agency staff and consumers.
- Accessing public services that do exist is difficult for people with TBI because of restrictive eligibility criteria for Medicaid and Community Mental Health Services Programs.

E. People who have survived TBI tend to be too young to be placed in a nursing home for the rest of their lives.

Analysis of the demographic characteristics of TBI survivors in Michigan finds more than 60% of people who have been hospitalized for TBI are male. More than 50% of Michigan residents hospitalized for TBI are under age 45. People treated and released for TBI from emergency departments are even younger, with over 40% being children under age 15. An unknown percentage of individuals with TBI apparently so "mild" that they were not hospitalized, will nevertheless suffer long-term impairments.

RECOMMENDATIONS

In light of the findings contained in this report, a panel of experts on Michigan's public programs and TBI issues was assembled during the Spring of 2004 to propose recommendations to state policy makers and legislators that could alleviate these problems and fill service gaps for individuals with TBI. Overall, the recommendations address long-term, medium-term and short-term policy goals to support the structure of an integrated rehabilitative system of care.

Recommendation # 1: Michigan's long term care system should have enough flexibility to provide appropriate services to those who need them (including people with cognitive deficits), and have a single point of entry into the system.

Recommendation # 2: In order to address the needs of individuals with moderate to severe TBI-related impairments, *in the medium term*, Michigan should consider creating a TBI specific Home and Community Based Medicaid Waiver as 25 other states have done.

Recommendation # 3: The Governor or the MDCH needs to appoint a TBI Services and Prevention Council to monitor and advise regarding the implementation of services for persons with TBI and the promotion of prevention efforts, which would lessen the incidence and cost of TBI in Michigan.

Recommendation # 4: The MDCH should designate one full-time equivalent position to oversee the implementation of the report and staff the activities of the TBI Services and Prevention Council.

Recommendation #5: The MDCH should provide continued support for ongoing collection, analysis, and reporting of injury and service use data; and for the development and measurement of service outcomes for individuals with TBI.

Recommendation # 6: It is essential that the State of Michigan and local communities continue to support and promote prevention efforts. Areas and ways to address TBI prevention include:

a. Maintenance of Michigan's motorcycle helmet law;
b. Education of students, parents, coaches, physical education teachers, and playground monitors in public schools, local recreation programs, and health clubs about concussion and other sports-related TBI; and
c. Support for injury prevention efforts, especially as related to transportation, violence, and falls.

Recommendation # 7: Departments, organizations, and agencies must adopt effective screening procedures to identify clients who may have TBI-related impairments. These include, among others: FIA, CMHSPs, Substance Abuse AARs, public schools, MRS, MI Choice Program, and the Michigan justice system.

Recommendation # 8: Michigan public human service providers, as well as staff in other public systems (such as the justice system), must be educated about TBI and the issues surrounding TBI. Materials for this training were developed and evaluated by the TBI Project.

Recommendation # 9: Local interagency teams of public service providers should be created and authorized to take referrals of individuals with TBI and identify and advocate for appropriate local services.

Recommendation #10: Medicaid reimbursement rates for neuropsychological examinations should be increased.

Recommendation # 11: The State of Michigan should establish a licensing category for AFC providers that have obtained accreditation and/or certification to care for people with TBI.

Recommendation # 12: The MDCH should review reimbursement policies related to AFC facilities licensed to provide TBI services to support services needed, and/or allow additional reimbursed services to be offered in such facilities.

Recommendation # 13: Home Help Services accessed through FIA should be provided to those who need supervision to accomplish activities of daily living, in addition to those who need "hands-on" assistance.

Recommendation # 14: Medicaid should consider funding cognitive aids as durable medical equipment when warranted in terms of cost effectiveness and medical necessity; *in addition,* the definition of "Medical Necessity" should be expanded to include consideration of abilities and independence so that individuals can remain in the community and have full access and independence.

Recommendation # 15: The Physical Disability Services (PDS) Fund needs to include the provision of assistive technology for cognitive disabilities as well as physical disabilities.

Recommendation # 16: Transportation issues are of great importance in many areas of Michigan and must be addressed.

a. Michigan's Medicaid Program should consider increasing Medicaid reimbursement for transportation to medical appointments; and
b. Access to transportation by individuals unable to drive due to TBI requires further study.

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INTRODUCTION

While traumatic brain injury (TBI)[1] is not a new concern, the chances of surviving TBI have improved dramatically over the past twenty years. This improvement in the survival rate frequently results in lifelong physical and cognitive impairments and the need for many services to support life after injury.

What is Traumatic Brain Injury?

A brain injury is any injury that results in brain cell death and loss of abilities. A *traumatic* brain injury is an injury to the head caused by blunt or penetrating trauma or from acceleration-deceleration forces, such as from a fall, car crash, or being shaken (Thurman et al., 1994). TBI may or may not be combined with loss of consciousness, an open wound, or skull fracture.

The Centers for Disease Control and Prevention (CDC) estimate that nationwide over 50,000 individuals die from TBI each year, and 5.3 million people or two percent of the population, live with a disability resulting from TBI (CDC, 1999).

Effects of TBI

The brain is a very complex organ, so every injury is different. Recovery after injury can range from complete recovery to total loss of function. Depending on the severity of the injury, long-term effects of TBI in both children and adults *may* include:

1. <u>Cognitive and Sensory Problems</u>: such as problems in memory, judgment, concentration, learning new information, communication, and organization;
2. <u>Behavioral and Emotional Problems</u>: such as irritability, impatience, impulse control, difficulty with anger management, increased stress and anxiety, inability to read social cues, excessive mood swings or personality changes, and depression; and
3. <u>Physical Problems</u>: such as headaches or severe head pain, lack of coordination/balance, problems with sleep/fatigue, slurred speech, trouble swallowing, and seizures.

These problems *<u>may</u>* affect an individual's ability to live independently, drive a car, go to school, maintain employment, maintain social relationships, and accomplish activities of daily living (ADLs). Findings from the Colorado TBI Registry and Follow-up System (Whiteneck et al., 2004) indicate that one year post injury, 37% of those hospitalized with TBI report an activity limitation requiring the need for assistance from another person and 71% reported experiencing one or more symptoms more frequently than before their injury (including headaches, sensory changes, seizures, fatigue, irritability, and

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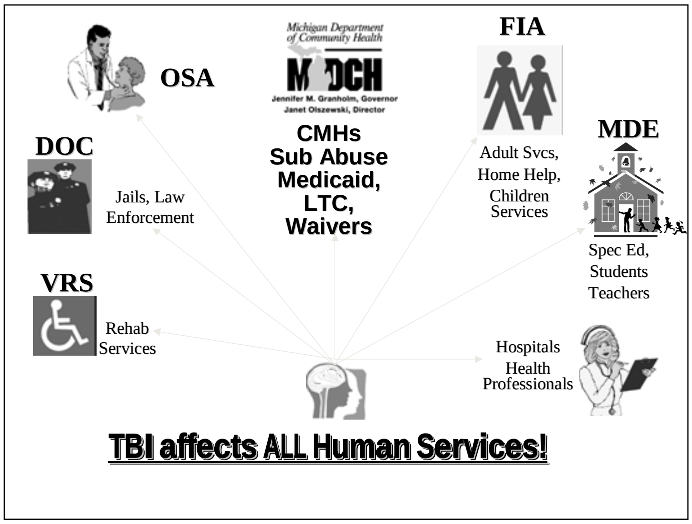
[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

dizziness). Because of the range of possible outcomes, an individual with TBI may need an assorted set of services from many agencies, for a short time or for the rest of his/her life. Moreover, individuals with TBI often do not have physical signs of disability.

Michigan's Efforts to Improve Service Delivery for Individuals with TBI

Current Programs

Michigan has a population of more than ten million persons. In December 2002, 1.27 million persons were enrolled in the Medicaid program, while more than 1 million persons had no health insurance at all (Citizens Research Council of Michigan, 2003). It is these individuals and many more with inadequate private health insurance who are or may be dependent upon the services and supports provided by public agencies. Within the public sector, the State of Michigan has almost no specialized services for individuals with TBI. Rather, individuals with TBI may be served at the local level through health care, mental health, and social service agencies depending on their needs. This creates a confusing mix of agencies and eligibility processes for survivors, family members, and even agency workers trying to refer individuals for services.



In contrast to the public system, Michigan is unique in that complete, comprehensive, life-long resource support is available through the no-fault automobile insurance system, which covers individuals who sustain injury in an automobile crash. Through the no-fault system, auto insurance companies provide payment up to $350,000 for services needed as a result of an auto crash. Insurance companies are reimbursed by the Michigan Catastrophic Claims Association (MCCA) for each case in which lifelong costs are expected to exceed $350,000. The MCCA was created in 1978 to spread the cost of this benefit across all Michigan motorists. All auto insurance policy premiums in Michigan contribute to the MCCA fund. While the MCCA is a valuable source of funding for services for many individuals with TBI, an estimated 60%-70% of Michigan residents with TBI are *not* injured in an auto crash (see Section 2 of this report). For many of these individuals, Medicaid often becomes the payment source for services needed over the long term.

The main state and local public agencies and programs that provide services appropriate for individuals with TBI include Medicaid, Community Mental Health Services Programs (CMHSP), Family Independence Agency (FIA), the MI Choice Program, Early

Intervention and Special Education Services, and Michigan Rehabilitation Services (MRS).

Medicaid. The state administered federal health care program will pay for services for people of low income who have a need. Beneficiaries must meet the income eligibility requirement to receive Medicaid benefits. Eligibility is determined through the FIA – Eligibility Services. A person without adequate personal health insurance or personal funding who needs continuing nursing home level of care services may be eligible to receive Medicaid funding for residential care.

FIA. If a nursing home is not an appropriate placement for a client, and if there are openings in other facilities, FIA may assist in placing Medicaid eligible persons in an Adult Foster Care Home or in a Home for the Aged. Home Help services are offered through FIA to individuals in need of help with ADLs to remain in an independent living situation. FIA also determines eligibility for other financial assistance programs such as the Family Independence Program, the Food Assistance Program, and the Adult Medical Program.

CMHSP. CMHSP is a Medicaid program that provides behavioral health services and community supports to eligible individuals. Individuals with TBI may be eligible for CMHSP services through the Developmental Disabilities program if their brain injury occurred before the age of 22, they have a qualifying developmental disability (DD) and they meet income and asset eligibility requirements. Persons who sustain a brain injury after the age of 21 can receive services from CMHSP only if they are diagnosed with a qualifying mental illness (MI). Whether classified as developmentally disabled or mentally ill, individuals must also meet severity criteria to qualify for services. Some CMHSP services relevant to individuals with TBI include: mental health counseling, applied behavioral therapy, physical therapy, occupational therapy, speech therapy, supported independent living, and case management.

MI Choice Program. Michigan's Medicaid Home and Community Based Waiver (HCBW) for Elderly and Disabled (MI Choice Program) offers long term care services to allow individuals to remain in their home. A qualifying consumer must require nursing facility level of care services, meet income and asset criteria, and require one or more waiver service. Some services provided by the MI Choice Program include: homemaker and chore services, adult day care, modifications to the home, counseling, and respite care.

Early Intervention and Special Education Services. Federal and State laws and regulations require that a broad range of services are available to any child through age 25, as long as the child has not graduated from high school. Needs are assessed and a treatment plan is decided upon by an interdisciplinary team. Services provided may include: speech and language services, occupational and/or physical therapy, orientation and mobility training, assistive technology (AT), hearing, vision, sensory and behavioral assistance, vocational skills, and transition planning.

Brain Injury Rehabilitation Program. The Michigan Department of Community Health (MDCH) offers a Brain Injury Rehabilitation Program for Medicaid eligible persons who have experienced a brain injury within the previous 15 months and meet medical eligibility criteria. Additional income and asset criteria may be required for eligibility. The program offers comprehensive rehabilitation services for individuals with a brain injury for three to six months. This program does not offer a cognitive rehabilitation (retraining) program for persons who do not also need physical therapy. Moreover, at any given time, there are few individuals in Michigan who meet the eligibility criteria.

MRS. Vocational services are available to persons with a permanent disability with the need for services and the capacity to benefit from services. MRS services assist persons in the achievement of vocational goals and may include: vocational guidance and counseling, training, job-related AT, job placement assistance, tools and equipment, and other support services such as interpreters or transportation.

Improvement Activities

In order to better understand these varied and complex systems, improve access by sharing what was learned, and improve public services for individuals with TBI, the Michigan Department of Community Health applied for and received a TBI Planning Grant in 1998, and a TBI Implementation Grant in 2000 from the Health Resources and Services Administration (HRSA) – Maternal and Child Health Bureau (MCHB). As part of the planning grant, the TBI Project conducted a State Needs Assessment, collecting information from consumers, providers, and state agencies. Consumers and their family members reported that care received while in the acute care setting was excellent; however, little guidance was available upon moving to community-based programs, and that identifying and accessing ongoing treatment was difficult. Providers from all arenas identified the following problem areas for community-based TBI care:

1) Funding restraints;
2) Staffing shortages;
3) Lack of specialized training;
4) Little awareness of service provision and eligibility requirements; and
5) Family issues (i.e., lack of support and knowledge regarding TBI).

From this needs assessment, challenge areas and goals were developed that led to the current TBI Project activities. Challenges included:

- To develop and provide educational materials about TBI and available services in Michigan to both consumers and providers;
- To recommend improved service delivery models and consideration of assistive technologies to improve quality of life and independence of individuals with TBI;
- To collect, analyze, and report data relative to individuals with TBI, service utilization, cost, and outcomes.

This report is the product of the latter two challenge areas, and policy recommendations are made in light of three years of data collection and analysis on the incidence of TBI, cost and service use, and interaction with public agencies in three pilot sites in Michigan.

Organization of this Report

Section 2 of this report presents data on the incidence and risk factors for TBI in Michigan. Additional detail on the methodology and results of these analyses are presented in Appendix B. Section 3 presents an analysis of claims and encounter data from the public system (Medicaid Fee for Service (FFS), Medicaid Health Plans (MHP), Home Help, and CMHSPs). Highlights of service provision and costs are presented, with additional detail in Appendix C. Section 4 presents specific data on how public services in Michigan are serving individuals with TBI. Two perspectives are presented: service providers and consumers.

Section 5 presents the results of project pilot sites in making improvements to the local service delivery system. These pilot sites included the Upper Peninsula (UP), Southwest Michigan (SW), and Southeast Michigan (SE), with associated CMHSPs, FIA Offices, MI Choice Program agents, and other participants in each region. In certain cases, participants also included representatives from local school districts and Intermediate School Districts (ISDs), MRS, Substance Abuse Access, Assessment and Referral Agencies (AARs), hospitals, the Veterans Administration, and other local groups.

Section 6 contains information on the use of AT by individuals with TBI, including a literature review and a case study illustrating how AT can have dramatic effects on the productivity and independence of someone with fairly severe impairments.

Finally, resulting Policy Recommendations are listed and explained in Section 7.

The Appendices contain additional materials for reference and materials that present greater detail on subjects presented in the body. Appendix A provides a list of all acronyms used in the report. Appendices B and C provide additional data on incidence of TBI and service use. Appendix D provides a more detailed review of evaluation results from the provider training sessions piloted in participating regions. A copy of the TBI HELPS screening tool tested by the project is provided in Appendix E. Referenced sources are listed in Appendix F. Members of the project workgroups are listed in Appendix G.

2

PROFILE OF TBI IN MICHIGAN

The CDC[1] estimates that approximately 1.5 million Americans are involved in motor vehicle crashes, falls, sports and recreation-related activities, and intentional violence incidents that result in a TBI each year. Nationwide, more than 50,000 people die annually due to TBI, representing more than one-third of all injury-related deaths. Annually, 230,000 people are hospitalized and survive, 1 million people are treated and released from hospital emergency departments, and ultimately 5.3 million US citizens, or 2% of the total population, live with a disability resulting from TBI at any given time (CDC, 1999).

A data-based knowledge and understanding of the incidence, nature, causes, severity, and the financial and service provision demands of TBI in Michigan is very important in order to understand the impact of TBI on the health care system. Injury prevention programs can be better focused to reduce these injuries. This section presents information about the following:

1) Numbers and rates for TBI-related deaths, hospitalizations, and emergency department (ED) visits in Michigan;
2) Differences in risk for TBI-related death, hospitalization, and ED visit by age, sex, and race; and
3) The leading external causes of TBI-related deaths, hospitalizations and ED visits.

A detailed description of the methodology and more detailed tables can be found in Appendix B.

Methods

The three data sources on which this section of the report is based contain information about Michigan deaths, hospitalizations, and ED visits. These sources provide information on TBI roughly corresponding to the severity of injury, with death obviously being most severe, and ED visits being least severe. Hospitalization data cover a range of severity levels in between death and an ED visit only. It should be noted that this report still provides an incomplete picture of individuals who survive a TBI as it does not include information regarding nonfatal, TBI-related cases treated outside hospitals, or those not treated at all. Please see Appendix B for a discussion of other limitations of the data and analyses.

All calculations and definitions for data presented in this section are discussed in Appendix B. Two different types of numbers are presented: rates of injury by demographic group (such as age and sex) and percentage distribution of TBI by demographic group. Rates are calculated based on Michigan's population. Percentages in this report provide a characterization of people who have experienced a TBI. Both statistics are important for different reasons. Rates are more important from a prevention point of view because rates indicate relative risk of injury. The demographic distributions of TBI are important since they are an indication of the composition of the population of TBI survivors and therefore represent who will need to be served.

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[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

Please note that the data are subject to limitations, especially the correctness with which TBI-related diagnoses are coded. The Michigan Emergency Department Community Injury Information Network (MEDCIIN) data are subject to additional limitations since they are unweighted data - derived from a stratified random sample of EDs throughout the state rather than all EDs in Michigan.

These and other limitations are discussed in more detail in Appendix B. Despite the limitations, the data provide very useful information about TBI.

Fatal TBI Cases

Mortality data from January 1, 1999 to December 31, 2002 from the MDCH Division of Vital Records and Health Statistics were analyzed for the project. These mortality data were gathered based on information obtained from death certificates, including the cause(s) of death recorded on the death certificate by the attending physician or medical examiner. Cases were included in analyses when a diagnosis indicating TBI was included in the conditions contributing to death.

Hospitalized TBI Cases

TBI-related hospital discharges from January 1, 1999 through December 31, 2002 from the Michigan Inpatient Database (MIDB) were analyzed for this report. The MIDB is a collection of hospital discharge data voluntarily provided to the Michigan Health and Hospital Association (MHA) by all but one small acute care hospital in Michigan. Hospitals in neighboring states (Indiana, Ohio, and Wisconsin) submit data on hospitalized Michigan residents to MHA as well.

This set of analyses focused on individuals who were hospitalized and survived a TBI. Cases were identified using the presence of ICD-9-CM codes indicating the possibility of a TBI in any diagnostic field (primary or secondary). Cases in which the disposition was death were excluded from analysis. It is possible that in some cases of TBI-related hospitalization, the TBI itself may not be the actual reason for hospitalization (for instance if the individual sustained a mild TBI but very serious internal injuries in the same accident, s/he could have been hospitalized primarily for treatment of the non-TBI injuries). For this reason the term “TBI-related hospitalization” will be used throughout. Because of the methods used to select cases, numbers presented here will not match statistics on Michigan injuries in other published sources. The methodology used here was chosen to best meet the aims of the project and to be consistent with guidance from the CDC.

While it is tempting to think of cases of TBI-related hospitalization as people, they are actually visits. Some people could have a TBI-related hospitalization more than once in a year, either because issues related to the TBI were not resolved with one hospitalization, or because an individual sustained multiple injuries.

Nonfatal and Non-hospitalized TBI-ED Cases

An injury surveillance system, MEDCIIN, was established in 1999 using data collected from 23 EDs in the state. Participating hospitals were chosen using a random sample stratified by geographic location and hospital size in each of the eight MHA regions and the City of Detroit. Urban, rural, and suburban hospitals are represented. The number of all injury visits in an individual hospital per year range from 1,300 to over 40,000. Data in this report are presented from 2001, which is the first year for which all hospitals in the sample contributed data.

Cases in the MEDCIIN database were identified using the presence of TBI ICD-9-CM codes in either primary or secondary diagnosis fields. ED patients with a TBI diagnosis who were admitted to the hospital, transferred to another hospital, or died in the ED (as identified by the discharge disposition) were excluded from the analysis.

Results

Between 1999–2002, an average of 1,566 TBI deaths and 9,065 nonfatal, TBI-related hospitalizations occurred annually in Michigan. These numbers as well as rates/100,000 are presented in Table 2.1. Every year, nearly 16 of every 100,000 people in Michigan experience a TBI resulting in death, and 91 of every 100,000 people experience a TBI resulting in nonfatal hospitalization. Table B1 in Appendix B presents TBI death rates by sex and year. Table B2 in Appendix B presents TBI-related hospitalization rates by sex and year. In the sample of 23 participating hospitals during 2001 there were 8,116 ED visits related to TBI.

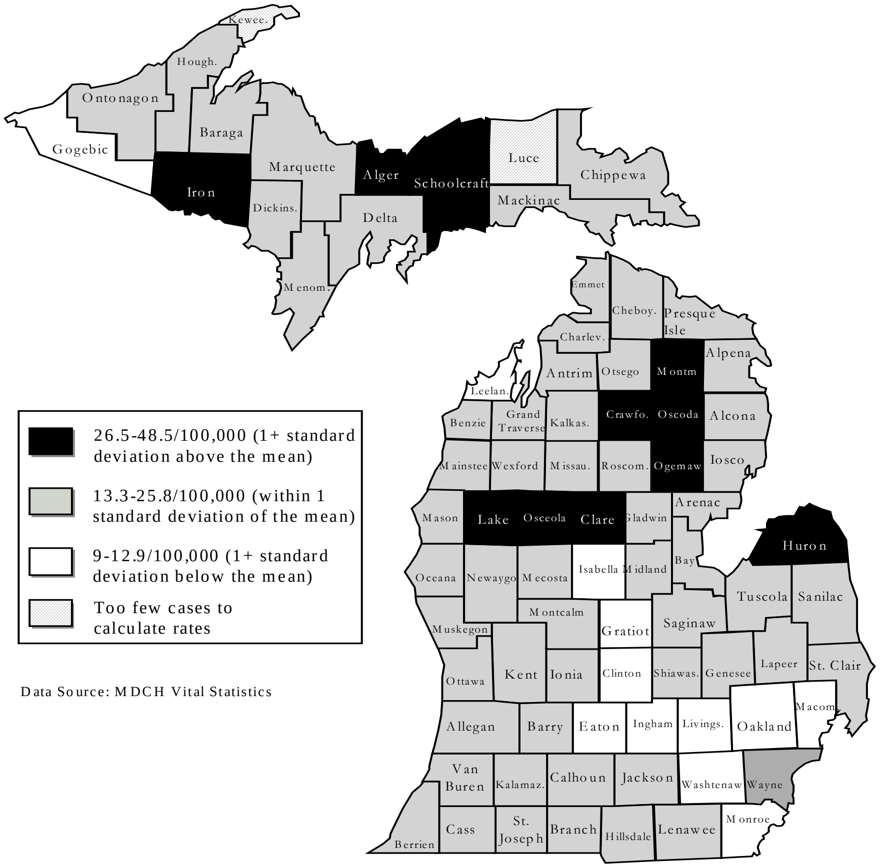
Table 2.1. Incidence of TBI in Michigan, 1999-2002

TBI-related fatalities		TBI-related nonfatal hospitalizations	
Annual avg. no.	**Rate/100,000**	**Annual avg. no.**	**Rate/100,000**
1,566	15.71	9,065	90.94

Source: Michigan Vital Statistics and Michigan Inpatient Database, Calendar Years 1999-2002; Rates were calculated using population estimates from the US Census.

Figure 2.1 shows average annual TBI death rates during 1999-2002 by county of residence. Note that the county of residence may be different from the county where the injury occurred and where the individual died.

Figure 2.1. Average annual TBI death rates by county of residence, 1999-2002

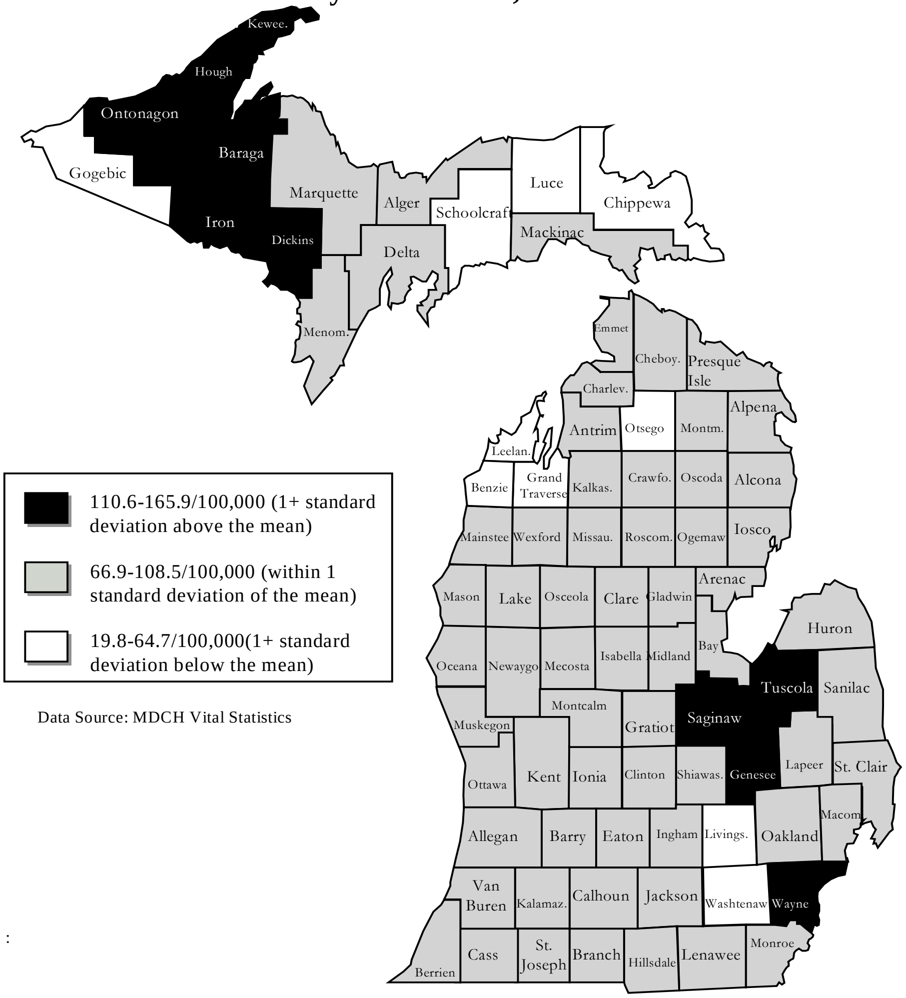


Data Source: MDCH Vital Statistics

Counties shaded in black have death rates one or more standard deviations above the average TBI death rate across counties. Lake, Schoolcraft, and Oscoda Counties, in particular have very high TBI death rates: (48.5, 39.5, and 37.1, respectively). Counties with the lowest death rates are clustered in Southeast (excluding Wayne County) and Mid Michigan. Luce and Keweenaw Counties had fewer than 5 deaths during the four years analyzed, therefore rates are not calculated. Table B3 in Appendix B lists the rates and average annual number of TBI-related deaths and nonfatal hospitalizations for each county in Michigan.

Figure 2.2 shows average annual TBI-related hospitalization rates during 1999-2002 by county of residence. County of residence may be different from the county where the injury occurred and/or where the individual was hospitalized. Counties shaded in black have hospitalization rates one or more standard deviations above the average resident hospitalization rates across counties.

Figure 2.2. Average annual nonfatal TBI hospitalization rates by county of residence, 1999-2002



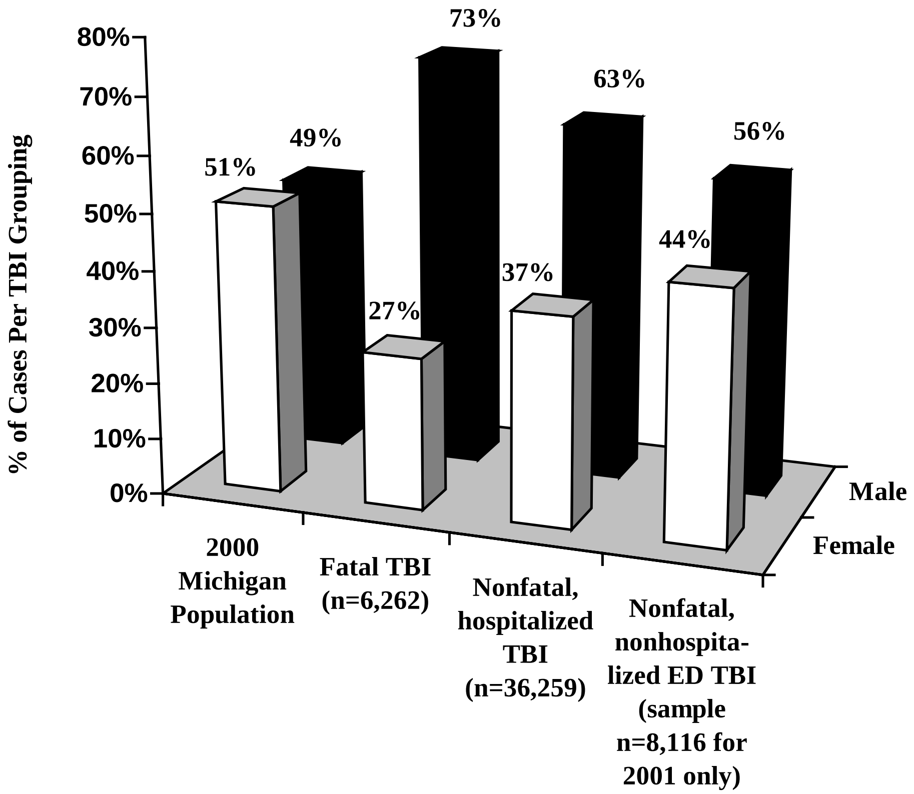
Data Source: MDCH Vital Statistics

Keewenaw, Iron, and Ontonogan Counties in particular have very high TBI-related hospitalization rates: (165.9, 157.9, and 151.2 respectively). Counties with the highest hospitalization rates are clustered in the western Upper Peninsula and below the “thumb” in Lower Michgian.

Incidence of TBI by Sex

Figure 2.3 presents the percentage of TBI cases by sex in each data source. The proportion of males increases with increasing TBI severity. Males have the most traumatic brain injuries overall and compose an especially larger proportion of deaths and TBI-related hospitalizations when compared to females. The first two bars in Figure 2.3 represent the year 2000 Michigan population. (For further analysis of TBI-related deaths and hospitalizations by sex and year, see Tables B1 and B2 in Appendix B.)

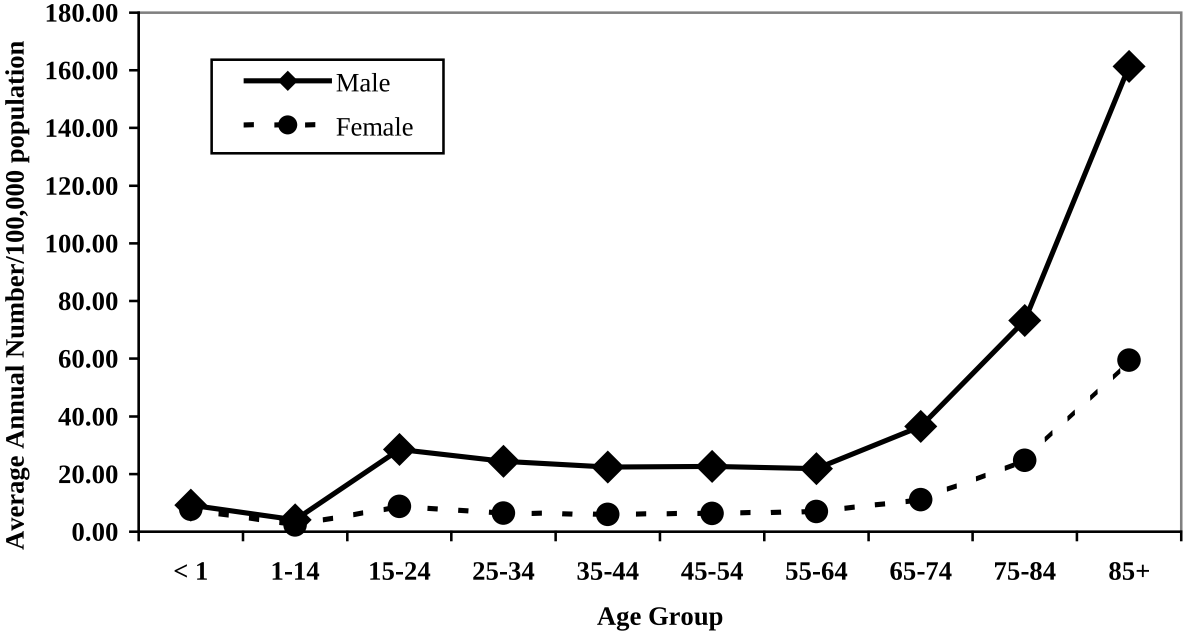
Figure 2.3. TBI cases by sex and severity, 1999-2002



Incidence of TBI by Age and Sex

Figures 2.4 and 2.5 present rates for TBI by sex and age. Rates for TBI can be considered an indication of the relative risk for TBI faced by each demographic group. Infants are presented separately from other children because of higher rates. This information is available in somewhat more detail in tabular form in Appendix B (Tables B4 and B5).

Figure 2.4. Michigan average annual TBI-related death rates by age and sex, 1999-2002

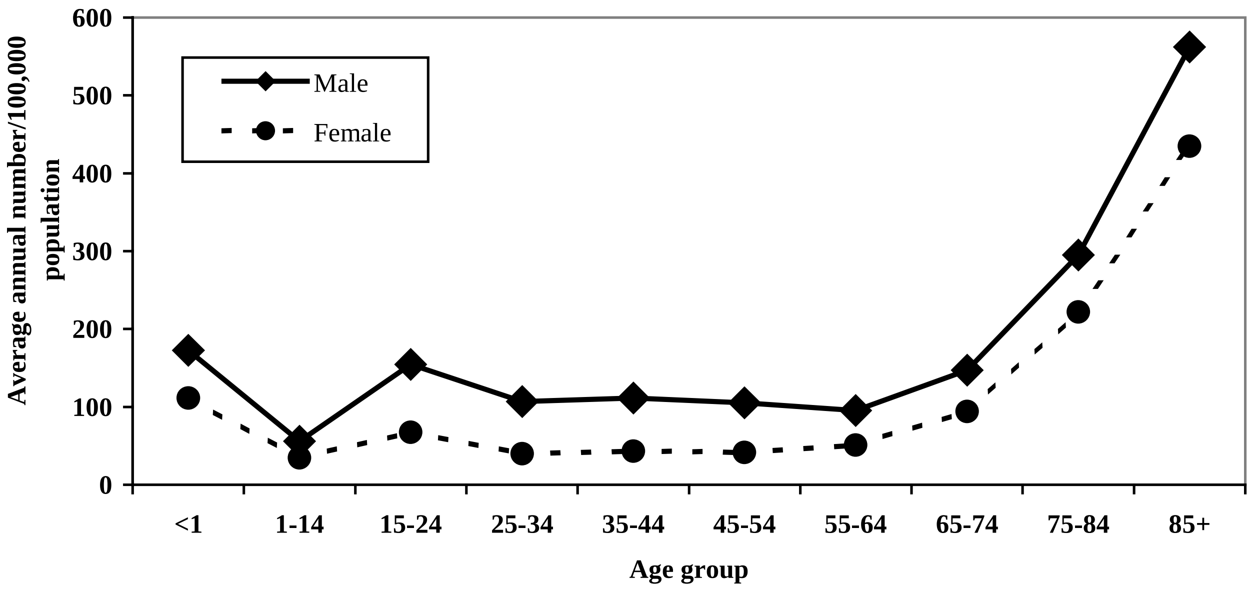


In terms of TBI deaths, one notices that starting with the age group 15-24 years, when the male death rate jumps to over 28/100,000, males are at much greater risk for TBI death than females. The TBI death rate for males declines moderately to about 22/100,000 for the age group 55-64 and then increases sharply to more than 36/100,000 for the age group 65-74, 73/100,000 for the age group 75-84, and 161/100,000 for the age group of 85 and above. In contrast, the female TBI death rate remains under 10/100,000 for all age groups until 65-74 and is lower than males for all ages.

The data show that elderly people are at much greater risk for TBI-related death than younger people. Still much more frequent causes of death for people age 65 and over nationwide are heart disease (1,651.2 deaths / 100,000 people 65+) and cancer (1,105.7 deaths / 100,000 people 65+) (Anderson & Smith, 2003).

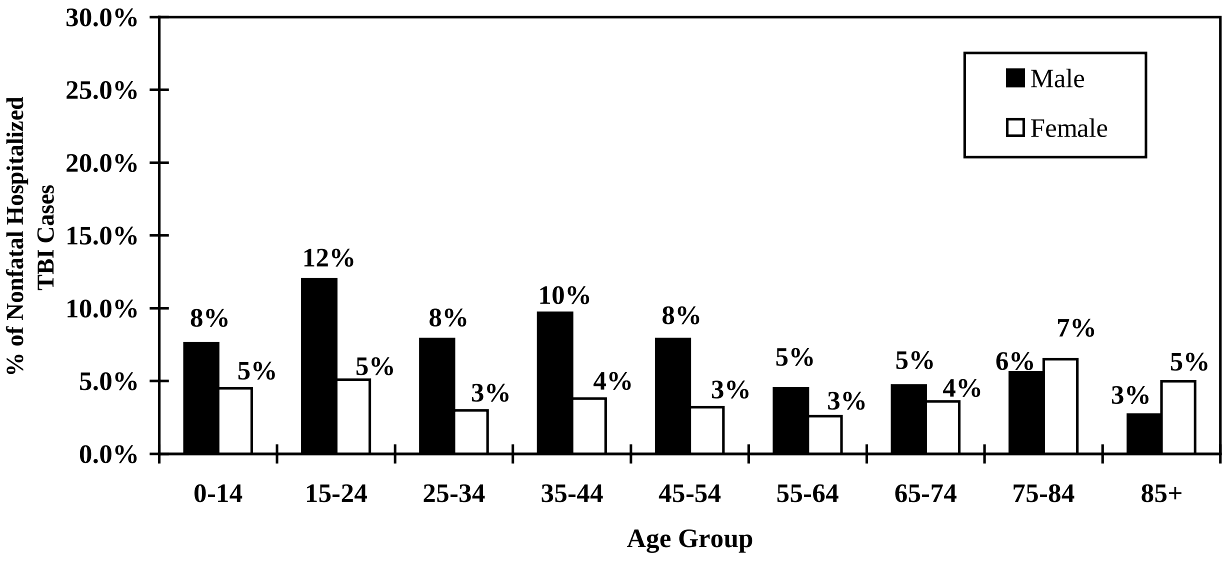
Figure 2.5 shows TBI-related hospitalization rates in Michigan. These are the number of nonfatal hospitalizations with a TBI-related diagnosis for every 100,000 people in each age/sex group. One can see from this figure that age groups at greatest risk of experiencing a TBI that results in hospitalization are infants, people aged 15-24, and people aged 65 and older. In every age category the male rate for TBI is higher than the female rate.

Figure 2.5. Average annual TBI-related nonfatal hospitalization rates by age and sex, 1999-2002



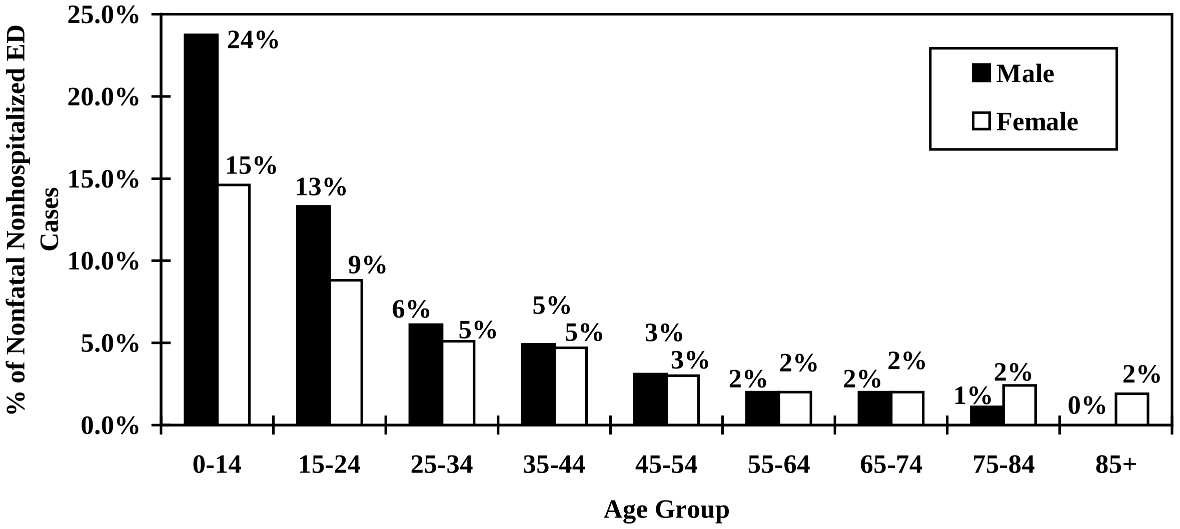
The demographic composition, such as the age and sex, of the population of TBI survivors in Michigan is presented in Figures 2.6-2.8. These are the people who *may* need long-term services following injury. Figure 2.6 presents the demographic composition of survivors of a TBI-related hospitalization. One of the first things to notice is that although a large proportion of the elderly (75 and older) suffer TBI-related hospitalization, they are not the largest age group represented among TBI survivors (because there are not as many of them in the population as a whole). Among survivors of TBI-related hospitalization, the largest single age group is 15-24 (comprising 17% of individuals hospitalized with TBI). Summing age and sex categories through age 34, we find that *40% of individuals with a TBI-related hospitalization are under the age of 35*. Young people with long-term impairments from TBI may need services for a long time.

Figure 2.6. Percentage of total nonfatal hospitalized TBI cases by age and sex, 1999-2002



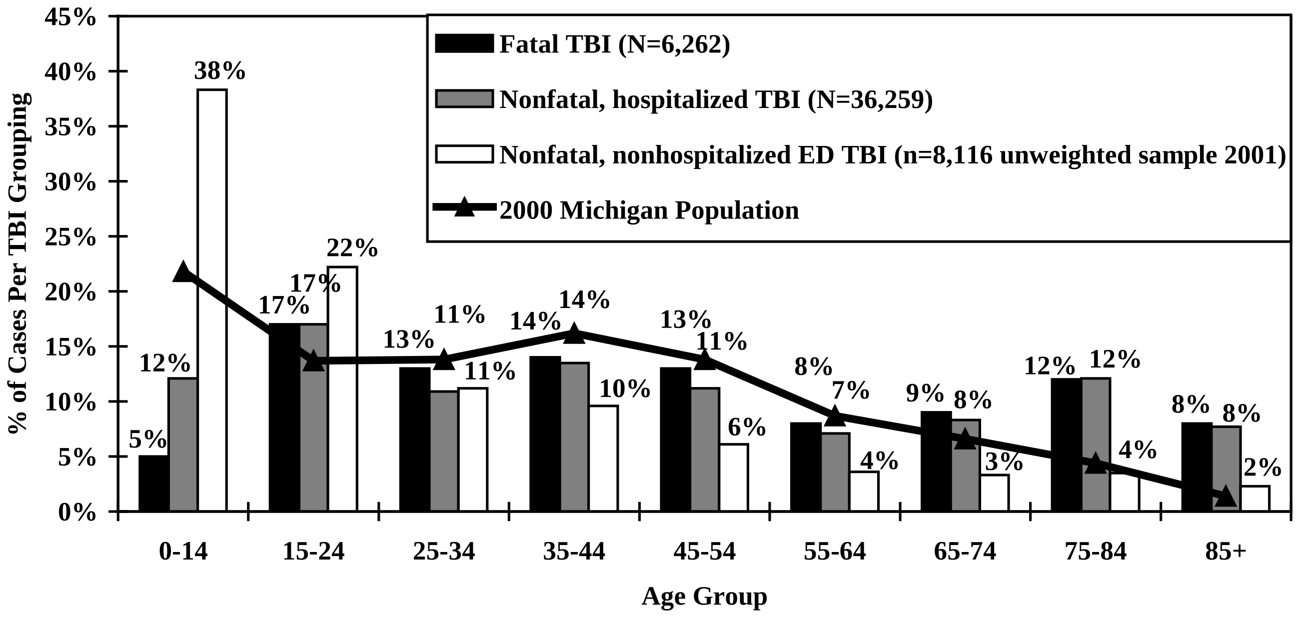
Survivors of a TBI treated in an emergency department are young (Figure 2.7). Males and females under age 15 make up 41% of all cases. An unknown percentage of survivors of mild TBI will have lifelong problems as a result of their injuries. In the case of children, some problems might be to executive functions that are not fully developed at the time of injury, in which case the impairments may not be noticed until years later when the child would be expected to be using those functions. Another noticeable difference between ED and inpatient visits is that beginning with the 25-34 year old age group, women are seen in emergency departments for TBI nearly as frequently as men. This could mean that while women are much less likely than men to sustain a moderate to severe TBI, they sustain more ‘mild’ injuries at rates similar to men.

Figure 2.7. Percentage of total TBI-related nonfatal nonhospitalized ED cases by age and sex, 2001



Fatal, hospitalized, and ED TBI cases are shown together by age in Figure 2.8. The solid line indicates the percentage of each age group in the Michigan population. As has been discussed, young people are over-represented in ED TBI cases, while the elderly are over-represented in TBI-related hospitalizations and deaths.

Figure 2.8. TBI cases by age and severity, 1999-2002



Incidence of TBI by Race

Race data are only available for mortalities and should be considered with caution. In the mortality data, race/ethnicity data might be incorrect in some cases, as this information is determined by whoever completes the death certificate. US Census figures for Michigan are used as the denominator when calculating TBI rates. As shown in Table 2.2, TBI-related death rates were higher among black males than white males during the years 1999-2002. TBI death rates for black and white women were similar throughout the time period.

Census classification methods for race underwent a major change between 1999 and 2000 and could account for some apparent trends in Table 2.2. Specifically, beginning in 2000, census respondents had the option to specify multiple races, whereas before they had to choose one. In 2000, 130,291 Michigan residents listed multiple races. These people are included in the 'other' category below, and constitute 35% of the "other" race category. This should not affect the "Black" category as drastically since only 56,334 of the 1,482,674 (under 4%) people who listed race as "Black/African American" checked more than one race.

Table 2.2. TBI-related deaths, by year, sex, and race

Year	Sex	White		Black		Other	
		No.	Rate	No.	Rate	No.	Rate
1999	All	1,255	15.26	302	21.34	27	-*
	F	353	8.41	65	8.63	11	-*
	M	902	22.40	237	35.78	16	-*
2000	All	1,298	15.95	262	18.37	27	7.21
	F	373	9.04	70	9.32	10	5.30
	M	925	23.06	192	28.43	17	9.15
2001	All	1,314	16.07	231	16.09	17	4.29
	F	353	8.52	52	6.88	7	3.50
	M	961	23.82	179	26.34	10	5.10
2002	All	1,268	15.47	226	15.67	28	6.81
	F	338	8.15	52	6.85	9	4.33
	M	930	22.98	174	25.46	19	9.35

Source: Michigan Vital Statistics, calendar years 1999-2002. Rates were calculated using population estimates from the US Census.
*Rates are not presented for the 'other' category of 1999 because the category is not comparable with later years. In 2000-2002, people who checked multiple races are included as 'other'.

Causes of TBI

Figure 2.9. TBI-related deaths by cause, 1999-2002

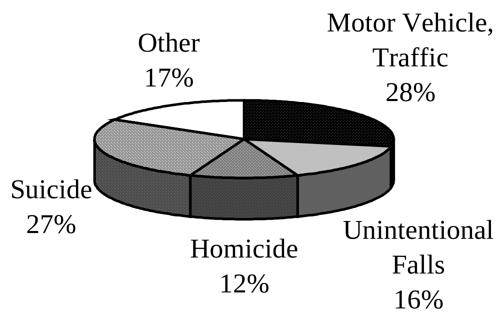


Figure 2.10. Nonfatal hospitalized TBI cases by primary external cause, 1999-2002

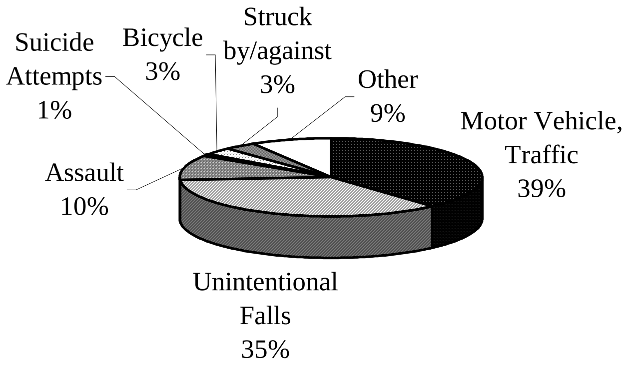
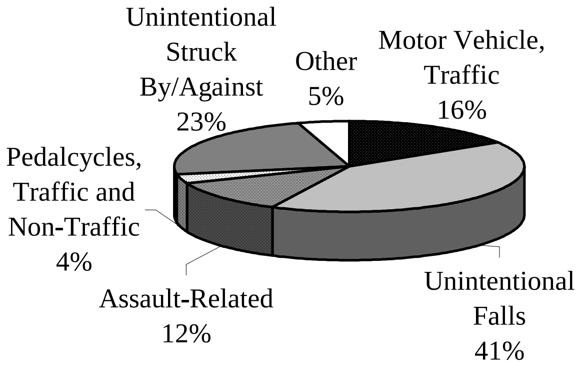


Figure 2.11. Nonfatal and nonhospitalized TBI cases by primary external cause, 2001 sample EDs (n=5,299)



Cause of injury information is presented in Figures 2.9-2.11 for TBI-related deaths, hospitalizations, and ED visits. Please refer to Appendix B for discussion of the cause information in these data sources as well as for definitions of various cause categories.

As presented in Figure 2.9, the top four causes of TBI deaths in Michigan are: motor vehicle traffic (28%), suicide (27%), unintentional falls (16%), and homicide (12%).

The top three causes of hospitalization related to TBI are (Figure 2.10): motor vehicle traffic (39%), unintentional falls (35%), and assault (10%).[2]

The top four causes of TBI treated and released in EDs are (Figure 2.11): unintentional falls (41%), unintentional struck by/against (23%), motor vehicle traffic (16%), and assault (12%).

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[2] Cause of injury coding is not complete for inpatient and ED data. Percentages in Figures 2.10 and 2.11 are calculated based on the 86% of inpatient TBI cases and 65% of ED TBI cases that had a cause recorded.

Table 2.3. Causes of fatal TBI by age – males (rates/100,000 in parentheses)

Rank	Age <1	1-14	15-24	25-44	45-64	65+
1	Homicide (4.43)	**Motor vehicle, traffic (2.36)**	**Motor vehicle, traffic (12.69)**	***Suicide (9.19)***	***Suicide (9.57)***	**Unintentional falls (19.25)**
2	**Motor vehicle, traffic (2.22)**	Homicide (0.68)	***Suicide (8.07)***	**Motor vehicle, traffic (6.71)**	**Motor vehicle, traffic (4.45)**	***Suicide (16.28)***
3		***Suicide (0.37)***	Homicide (5.23)	Homicide (3.98)	**Unintentional falls (3.17)**	**Motor vehicle, traffic (6.73)**

Source: Michigan Vital Statistics calendar years 1999-2002; rates are per 100,000 people in each age group, averaged over the four years.

The leading causes of TBI deaths are presented by age category for males in Table 2.3 and for females in Table 2.4. The fonts and shading have been adopted to help the reader identify the various causes and their rankings at a glance. Motor vehicle traffic crashes were a leading cause of TBI-related death for nearly all age and sex groups. Homicide is the leading cause of fatal TBI among infants of both sexes. The frequency of homicide as a cause of TBI then declines as age increases, disappearing from the top three causes of TBI beginning with the age group 45-64. Suicide is a prominent cause of fatal TBI, particularly for males over the age of 15. Elderly males and females are at risk for fatal TBI due to falls and other accidents.

Table 2.4. Causes of fatal TBI by age – females (rates/100,000 in parentheses)

Rank	Age <1	1-14	15-24	25-44	45-64	65+
1	Homicide (4.65)	**Motor vehicle, traffic (1.66)**	**Motor vehicle, traffic (5.61)**	**Motor vehicle, traffic (2.53)**	**Motor vehicle, traffic (2.33)**	**Unintentional falls (11.04)**
2	**Motor vehicle, traffic (1.94)**	Homicide (0.33)	Homicide (1.61)	Homicide (1.52)	***Suicide (1.36)***	**Motor vehicle, traffic (3.02)**
3		**Struck by/against (0.10)**	***Suicide (0.92)***	***Suicide (1.15)***	**Unintentional falls (0.95)**	***Suicide (0.94)***

Source: Michigan Vital Statistics calendar years 1999-2002; rates are per 100,000 people in each age group, averaged over the four years.

Causes of TBI-related hospitalizations are presented in Tables 2.5 and 2.6. Motor vehicle crashes and falls are the leading causes of TBI-related hospitalizations for both males and females. Infants and the elderly are particularly at risk of falling and sustaining a TBI that leads to hospitalization. Males aged 15-44, and infants of both sexes, are more at risk of assault-related TBI hospitalization. Bicycle crashes are the third leading cause of TBI-related hospitalization for children aged 1-14.

Table 2.5. Causes of nonfatal TBI-related hospitalization by age – males (rates/100,000 in parentheses)

Rank	Age <1	1-14	15-24	25-44	45-64	65+
1	**Unintentional falls (78.31)**	**Motor vehicle, traffic (15.51)**	**Motor vehicle, traffic (77.38)**	**Motor vehicle, traffic (41.25)**	**Unintentional falls (29.57)**	**Unintentional falls (125.13)**
2	Assault (39.90)	**Unintentional falls (14.19)**	Assault (20.34)	Assault (20.28)	**Motor vehicle, traffic (29.39)**	**Motor vehicle, traffic (34.09)**
3	**Motor vehicle, traffic (10.34)**	Bicycle (8.25)	**Unintentional falls (12.73)**	**Unintentional falls (17.15)**	Assault (12.72)	Assault (4.30)

Source: Michigan Vital Statistics calendar years 1999-2002; rates are per 100,000 people in each age group, averaged over the four years.

Table 2.6. Causes of nonfatal TBI-related hospitalization by age – females (rates/100,000 in parentheses)

Rank	<1	1-14	15-24	25-44	45-64	65+
1	**Unintentional falls (50.01)**	**Motor vehicle, traffic (12.37)**	**Motor vehicle, traffic (45.17)**	**Motor vehicle, traffic (22.56)**	**Motor vehicle, traffic (17.51)**	**Unintentional falls (117.25)**
2	Assault (27.52)	**Unintentional falls (9.10)**	**Unintentional falls (4.04)**	**Unintentional falls (5.22)**	**Unintentional falls (12.60)**	**Motor vehicle, traffic (21.87)**
3	**Motor vehicle, traffic (8.53)**	Bicycle (3.02)	Assault (2.61)	Assault (4.20)	Assault (2.00)	**Unintentional Struck by/against (1.98)**

Source: Michigan Vital Statistics calendar years 1999-2002; rates are per 100,000 people in each age group, averaged over the four years.

The leading causes of TBI ED visits are displayed by age for males in Table 2.7 and for females in Table 2.8. Note that percentages are presented rather than rates as rates cannot be calculated from unweighted data. These more mild injuries have different causes than fatal TBI cases as described above. Injury cause patterns for TBI cases treated and released from EDs were fairly similar for males and females.

Unintentional struck by/against is the third most common cause of TBI ED visits, although it only accounted for 3% of individuals hospitalized with TBI. Many of these injuries are likely sports and recreation-related. Falls are the most common cause of TBI for younger and older individuals, eclipsed by motor vehicle crashes and unintentional struck by/against for ages 15-44. Bicycle crashes are a main cause of ED cases of TBI for children age 14 and under, but only appear in the top three causes for males aged 1-14.

Table 2.7. Causes of ED cases of TBI by age category - males

Rank	**Age <1** (n=116)	**1-14** (n=1,085)	**15-24** (n=804)	**25-44** (n=601)	**45-64** (n=236)	**65+** (n=131)
1	**Unintentional falls (81.9%)**	**Unintentional falls (48.5%)**	**Unintentional struck by/against (31.2%)**	**Motor vehicle, traffic (23.1%)**	**Unintentional falls (39.0%)**	**Unintentional falls (78.6%)**
2	**Unintentional struck by/against (12.1%)**	**Unintentional struck by/against (31.1%)**	**Motor vehicle, traffic (21.4%)**	**Unintentional struck by/against (22.8%)**	**Motor vehicle, traffic (21.2%)**	**Motor vehicle, traffic (8.4%)**
3	**Motor vehicle, traffic (1.7%)**	Pedalcycles, traffic & non-traffic (8.4%)	Assault-related (21.3%)	**Unintentional falls (22.5%)**	**Unintentional struck by/against (16.5%)**	**Unintentional struck by/against (5.3%)**

Source: MEDCIIN 2001 unweighted data from 23 hospitals.

Table 2.8. Causes of ED cases of TBI by age category - females

Rank	**Age <1** (n=84)	**1-14** (n=650)	**15-24** (n=531)	**25-44** (n=533)	**45-64** (n=247)	**65+** (n=281)
1	**Unintentional falls (84.5%)**	**Unintentional falls (56.0%)**	**Motor vehicle, traffic (29.6%)**	**Unintentional falls (27.6%)**	**Unintentional falls (59.1%)**	**Unintentional falls (86.1%)**
2	**Unintentional struck by/against (11.9%)**	**Unintentional struck by/against (21.5%)**	**Unintentional falls (23.0%)**	**Motor vehicle, traffic (25.7%)**	**Motor vehicle, traffic (15.8%)**	**Motor vehicle, traffic (6.8%)**
3	**Motor vehicle, traffic (2.4%)**	**Motor vehicle, traffic (9.2%)**	**Unintentional struck by/against (22.0%)**	**Unintentional struck by/against (21.2%)**	**Unintentional struck by/against (13.0%)**	**Unintentional struck by/against (5.3%)**

Source: MEDCIIN 2001 unweighted data from 23 hospitals.

To conclude, as identified through analysis of Michigan data, some risk factors for TBI include: being male, being an adolescent or young person, and being elderly. These different groups are at risk for TBI for different reasons. Elderly people and young children are both at risk because of the potential for falling; however, falling appears to have more devastating consequences for the former. Falls rank below the top three most common causes of TBI death for children, but they are *the* most common cause of TBI death for the elderly.

The data presented here show that males tend to experience TBI more often for violent behaviors and suicide-related events. Motor vehicle crashes are a leading cause of TBI-related ED visits, hospitalizations, and deaths for all sexes and age groups. However, serious car crashes are more likely to involve males – especially between 15 and 24 where the TBI death rate due to motor vehicle crashes is 12.7/100,000, and the hospitalization rate is 77.4/100,000. The female death rate for the same age category is less than half the male rate at 5.61/100,000, while the hospitalization rate is 45.17. Similarly, while falls are a common cause of TBI-related hospitalizations and ED visits for everyone, males in all age categories are at greater risk for falls resulting in hospitalization with TBI.

Both female and male infants are at risk of homicide and assault. Assault is the leading cause of TBI-related death and the second leading cause of TBI-related hospitalization for children under one year.

Discussion

To understand traumatic brain injury, it must be put in context with other major causes of injury and death. Table 2.9 compares TBI to common disease-related deaths in Michigan for calendar year 2002. The number of deaths related to TBI is less than that for heart disease and cancer, but higher than the number of deaths in Michigan for liver disease and AIDS. Table 2.10 presents the number of injury deaths by cause, the number of TBI deaths in those categories, and the percent of TBI to the total for each cause category. Data indicate that a large percentage of injury-related deaths in Michigan involve TBI.

Table 2.9. TBI compared to top disease-related deaths, Michigan, 2002

Cause of death	Number of deaths in 2002
All Deaths	87,534
Heart Disease	26,447
Cancer (all)	19,831
Stroke	5,740
Chronic Lower Respiratory Diseases	4,389
Diabetes	2,753
Pneumonia	2,007
TBI	**1,523**
Chronic Liver Disease and Cirrhosis	975
Atherosclerosis	564
AIDS	237

Source: TBI deaths are those as pulled from Vital Statistics for the current project, deaths due to diseases are available at: http://www.mdch.state.mi.us/pha/osr/index.asp?Id=4

Table 2.10. Percentage of injury deaths in which TBI is a contributing cause, Michigan, 2002

	All injury deaths	TBI-related deaths	TBI as % of all
Motor Vehicle	1,323	404	31%
All Other Accidents	1,919	425	22%
Suicide	1,095	443	40%
Homicide	689	163	24%

Source: Injury deaths for 2002 are available: http://www.mdch.state.mi.us/pha/osr/index.asp?Id=4. TBI-related deaths in each category were those pulled from Vital Statistics for the current analysis.

While TBI was a contributing cause for only 2% of all Michigan deaths in 2002, TBI turns out to be a much more prominent cause of death for certain age groups (MDCH, 2004):

- Age group 1-14: 13% of all Michigan deaths in 2002 were TBI-related;
- Age group 15-24: 22% of all Michigan deaths in 2002 were TBI-related;
- Age group 25-34: 13% of all Michigan deaths in 2002 were TBI-related;
- Age group 35-44: 7% of all Michigan deaths in 2002 were TBI-related.

Data analysis done by MDCH finds that injury accounted for 4.4% of all hospitalizations in 1999 and 2001. TBI accounted for approximately 10% of all injury hospitalizations in Michigan during these years (Largo and Scarpetta 2003; Largo et al 2002). Analysis of 1999 data by age, finds that TBI was the most frequent type of injury among hospitalized infants, and the second or third leading type of injury for people in age groups 1- 44 and 65 and over (Largo et al 2002).

A second question arising from the incidence data presented in this report is: How is Michigan doing compared to the rest of the country in terms of the number of TBI cases? The CDC (2004) compared TBI-related hospitalization rates using 1999 data from 22 states, and TBI-related death rates using 1999 data from 21 states. Michigan reported 1,585 TBI-related deaths in that year, for an age-adjusted rate per 100,000 of 16.8. The average reported rate across the 21 reporting states was 19.8 – Michigan's TBI-related death rate was more than 0.5 standard deviation below average.

- Only four reporting states had a lower TBI death rate than Michigan: Massachusetts-9.0, North Dakota-11.0, Hawaii-11.1, and California-13.4.
- Minnesota reported approximately the same death rate for TBI-17.1.
- Fifteen other states reported a TBI death rate higher than Michigan's: Texas-18.0, Florida-18.3, Vermont-19.5, Wisconsin-19.6, Kentucky-19.7, Washington-20.8, Kansas-21.3, Georgia-21.8, Utah-22.2, North Carolina-22.5, Nebraska-23.7, Colorado-24.5, Oklahoma-26.1, South Carolina-27.5, and Louisiana-31.2

In terms of TBI-related hospitalization rates, the average reported rate during 1999 from 22 states was 67.5 (CDC, 2004). Michigan appears to have a somewhat higher rate than the average from this group of states – 87.3/100,000 during 1999.

One might want to conclude that states with more nonfatal hospitalizations on average have fewer deaths due to TBI (reasoning that they may have better emergency services and survival rates may be higher). However, this appears unwarranted. TBI-related hospitalization and death rates as reported by the CDC (2004) for 22 states are not correlated (Pearson correlation coefficient=-.12, not statistically significant).[3]

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[3] Correlation coefficients have a possible range from –1 to 1. A correlation coefficient of –1 indicates a perfect negative correlation (the higher one value, the lower the other); a correlation of +1 indicates a perfect positive correlation (the higher one value, the higher the other); a coefficient near zero indicates no correlation.

3

USE AND COST OF HEALTH CARE BY PEOPLE WITH TBI IN MICHIGAN

To better understand what public services and supports are currently provided to persons with TBI[1] this project studied TBI-related care as paid through Medicaid Fee for Service (FFS), Medicaid Health Plans (MHP), Home Help, and CMHSPs during fiscal years 1999-2002 (October 1, 1998 to September 30, 2002). The first step was to search the FFS and MHP electronic records for diagnostic codes that identify treatment for TBI during the timeframe. General information (such as age and sex) about the people receiving these services is summarized in this report. Also summarized is some general information about the services received. Medicaid FFS costs are presented for services with TBI diagnostic codes. In addition, a subgroup of cases was studied - those with a hospitalization for TBI followed by two full years of Medicaid enrollment. Following the Medicaid FFS analysis, this section provides information on the number of people who received TBI-related treatment services through Medicaid FFS or MHP *and* who also received Home Help and CMHSP services. Information on type and amount of services received is presented for those people with a TBI-related hospitalization.

Methods

Most information presented in this section is based on a study of services received during October 1, 1998 and September 30, 2002. However, Home Help information is summarized only for a three year period: October 1,1999 – September 30, 2002. This is because some earlier data had already been deleted from the Data Warehouse. (Old records are deleted to free up space to store more recent information.) In contrast to the Section 2, findings are presented for fiscal (rather than calendar) years (FY) 1999-2002.

Medicaid Fee for Service and Medicaid Health Plans

There are two service plans for people enrolled in Medicaid: the managed care MHPs and the regular FFS plan. Most people are required to enroll in a MHP in which the Plan is paid a monthly capitated rate to provide specific services. There are a few groups of people who may choose between MHP and FFS. People who are eligible for both Medicare and Medicaid, people with long-term service needs at the nursing facility level, and certain other groups *must* enroll in Medicaid FFS.

Data files from Medicaid FFS in the form of claims records were analyzed. The relevant cases were identified by selecting those claims with a diagnosis code indicating a TBI. These are the same ICD-9-CM codes used to identify hospitalizations in the MIDB and are listed in Appendix B. Similarly, cases are identified in the MHP encounter data by ICD-9-CM codes.

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[1] Please refer to “Appendix A: Glossary” for definitions of terms and a list of acronyms used in this report.

The cases analyzed include all severity levels. Some individuals have been identified on the basis of a single emergency department or outpatient medical visit. Others have extended hospitalizations and/or nursing home services related to TBI. It should not be assumed that the numbers of individuals with Medicaid services all have long-term impairments. *Indeed, the majority of cases receiving only outpatient care may have no long-term effects from their injury whatsoever.*

Several limitations to the results presented here are important. First, other than for a limited sub-sample of cases, the only data analyzed were claims with a TBI diagnosis. There are some classes of services, such as long term care and professional visits, in which diagnostic codes are not important for billing. People familiar with analysis of medical claims data therefore tend to regard diagnostic coding for services not provided by a hospital to be incomplete or inaccurate. *It is very likely that the data presented here underestimate such types of services.*

Home Help

Home Help data were pulled from the MDCH Data Warehouse using Medicaid ID numbers of individuals who received Medicaid FFS or MHP services for TBI during the four-year time frame, FY1999-2002. Payments for Home Help services for each such individual were summed for each fiscal year FY1999-2002.

Community Mental Health Services Programs (CMHSPs)

TBI is not a DSM-IV[2] diagnostic category and therefore is not captured in the CMHSP data. Rather, the methodology used to identify people with TBI in the CMHSP system involved matching CMHSP service records to individuals identified with a TBI-related diagnosis in the Medicaid FFS or MHP system. Services received from the CMHSPs may or may not be directly related to the TBI.

The CMHSP data used in this report were gathered from administrative data provided by a CMHSP for each individual during a fiscal year. Generally, an individual should have only one record per fiscal year. Only individuals who received services through more than one CMHSP would have had more than one record. Each record included information about individual demographics, diagnoses, and a summary of all services received within that fiscal year. There are no dates for individual services.

Results

Medicaid FFS and MHP Beneficiaries Treated for TBI

About 1.4 million individuals were enrolled in either Medicaid FFS or MHP for each year during the time period studied. This number increased from 1.32 million enrollees in FY1999 to 1.58 million enrollees in FY2002. Using both the FFS claims and the MHP administrative data, 67,489 unique individuals were identified as receiving medical services for TBI at some point

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[2] Diagnostic and Statistical Manual of Mental Disorder: Fourth Edition

during the 4 year time period (that is, they received Medicaid services in which TBI was recorded as a diagnosis). As shown in Table 3.1, the annual rates of individuals receiving TBI services ranged from about 11/1,000 to 14/1,000 cases, or an overall annual average of about 18,000 people a year. Nearly 65% of these cases were enrolled in a MHP, 33% in Medicaid FFS, and just over 2% were enrolled in both plans during the four years analyzed (meaning that they changed from FFS to MHP or vise versa during the time period). A summary of this information is presented in Figure 3.1.

Figure 3.1. Medicaid enrollees receiving services for TBI, FY1999-2002

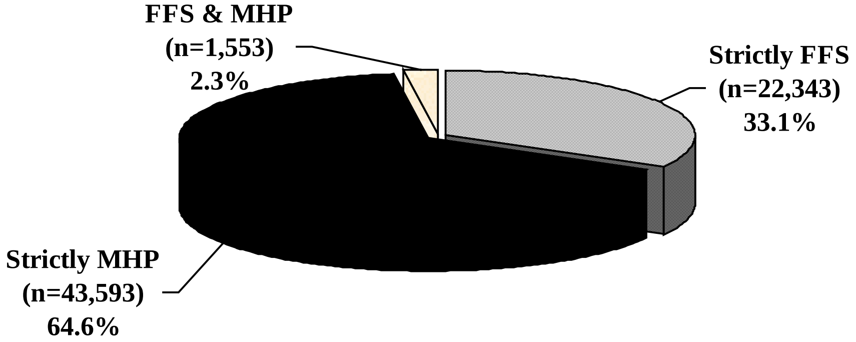


Table 3.1 shows the number of people receiving services through Medicaid FFS and/or MHP with a TBI diagnosis. In FY1999, 15,704 people received (at least one) Medicaid reimbursed service with an identified TBI diagnosis (about one third of these individuals received services through FFS and two thirds through MHP). The number of people receiving TBI services grew throughout the time period and in FY2002, 22,427 people received services with an identified TBI diagnosis. *The number of individuals receiving TBI services should be considered an underestimate as it is very likely that many people received services for TBI that were not identified by a TBI diagnosis.* TBI-related services are especially likely to be missed if the TBI occurred far in the past or if the beneficiary has comorbid conditions that may have been listed instead of the TBI.

The growth in the number of people receiving TBI-related services was faster than the growth in the Medicaid caseload. For every one thousand Medicaid enrollees in FY1999, nearly 12 people received a directly identifiable TBI treatment service. By FY2002, this rate had grown to 14 per thousand. *Further study is required to determine whether this apparent growth in rates of TBI cases within Medicaid is a long-term trend or merely a random rise which will fall again in future years.*

Of all the Medicaid FFS and MHP covered individuals receiving services for TBI, only about 8% also experienced an identified TBI-related hospitalization during the four years analyzed (Table 3.1). The non-hospitalized population received other types of services, mostly in an outpatient or clinic setting. Based on these findings, it appears that the vast majority of Medicaid cases analyzed experienced a milder TBI injury. Some individuals with mild TBI may have long-term problems as a result of their injury; but many will have no long-term effects.

Table 3.1. Michigan Medicaid TBI cases: people receiving care for TBI diagnosis only, FY1999-2002

	FY1999	**FY2000**	**FY2001**	**FY2002**	**FY1999 to FY2002**	**Average number of cases per fiscal year**
All Medicaid (all fiscal year data is on unique individuals – those enrolled in both FFS & MHP during the timeframe were only counted once)						
Number of beneficiaries	1,315,958	1,409,998	1,484,637	1,578,494		1,447,272
Number receiving services for TBI	15,704	15,758	18,807	22,431	67,489	18,175
Rate of TBI cases per 1,000 Medicaid enrollees	11.93	11.18	12.67	14.21		12.56
Number hospitalized with TBI (percent of TBI Medicaid cases in parentheses)	1,272 (8.1%)	1,385 (8.8%)	1,512 (8.0%)	1,733 (7.7%)	5,738 (8.5%)	
Medicaid Fee for Service (FFS) beneficiaries						
Number of beneficiaries	745,208	729,046	878,312	943,873		824,110
Number receiving services for TBI	5,324	4,866	6,989	8,285	23,896	6,366
Rate of TBI cases per 1,000 Medicaid FFS enrollees	7.14	6.67	7.96	8.78		7.72
Number hospitalized with TBI (percent of FFS TBI cases in parentheses)	489 (9.2%)	514 (10.6%)	690 (9.9%)	653 (7.9%)	2,305 (9.6%)	
Medicaid Health Plan (MHP) beneficiaries						
Number of beneficiaries	1,001,477	1,036,365	1,020,412	1,110,062		1,042,079
Number receiving services for TBI	10,540	11,055	12,044	14,381	45,146	12,005
Rate of TBI cases per 1,000 Medicaid MHP beneficiaries	10.52	10.67	11.80	12.96		11.52
Number hospitalized with TBI (percent of MHP TBI cases in parentheses)	810 (7.7%)	913 (8.3%)	865 (7.2%)	1,089 (7.6%)	3,571 (7.9%)	

Source: Medicaid MHP Data and FFS Claims, for dates of service October 1, 1998 - September 2002, as extracted from the MDCH Data Warehouse

It should be noted that the individuals receiving MHP services tended to be younger than those receiving FFS services. The median age for the MHP beneficiaries was 12 in contrast to 23 for the FFS beneficiaries. This may be a due to the requirement that people who are eligible for both Medicare and Medicaid are required to enroll in FFS. More than half of the MHP enrollees were children less than 15 years of age, compared to one-third of the FFS beneficiaries. Both MHP and FFS beneficiaries had similar proportions of male (52%) and female (48%) beneficiaries.

In terms of demographic groups and severity of TBI, patterns in the Medicaid data are similar to those in the data presented in Section 2 on all TBI cases in Michigan. Figure 3.2 displays more and less severe cases of TBI by sex. Cases that resulted in hospitalization or skilled nursing facility claims with a diagnosis of TBI are considered to be more severe cases. Less severe cases are defined as those that have only outpatient claims during the time period. As with the incidence data presented in Section 2, males and females are more equally represented among the less severe injuries, whereas there are more males among the more severe injuries. Similarly, as presented in Figure 3.3, children under the age of 15 are more numerous among the less severe cases.

Figure 3.2. Medicaid-FFS & MHP TBI cases by sex, FY1999-2002 (n=67,489)

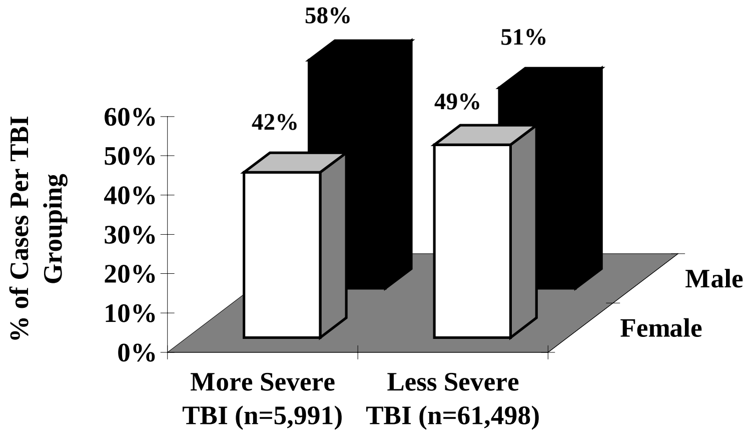
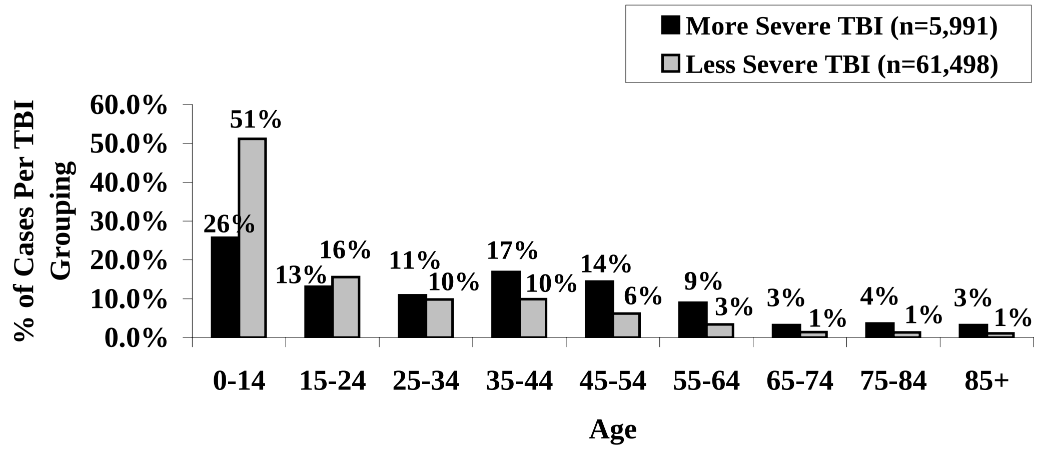


Figure 3.3. Medicaid-FFS & MHP TBI cases by age, FY1999-2002 (n=67,489)



Medicaid Cost & Service Use Analysis: Fee for Service Only

Cost information can only be presented for individuals enrolled in Fee for Service Medicaid since MHP files contain administrative data only. *For this and other reasons, cost estimates presented in this section should be considered an underestimate of the TBI-related costs to Michigan's public service system*. Other reasons include the fact that only those cases with a TBI diagnosis are included, leaving out many costs in which the TBI was not recorded as a diagnosis on the claim. And of course, only direct Medicaid charges are summarized, leaving out the cost of service provision by CMHSPs, public schools, and MRS among others.

Figure 3.4. TBI cost information by provider category Medicaid FFS, FY1999-2002

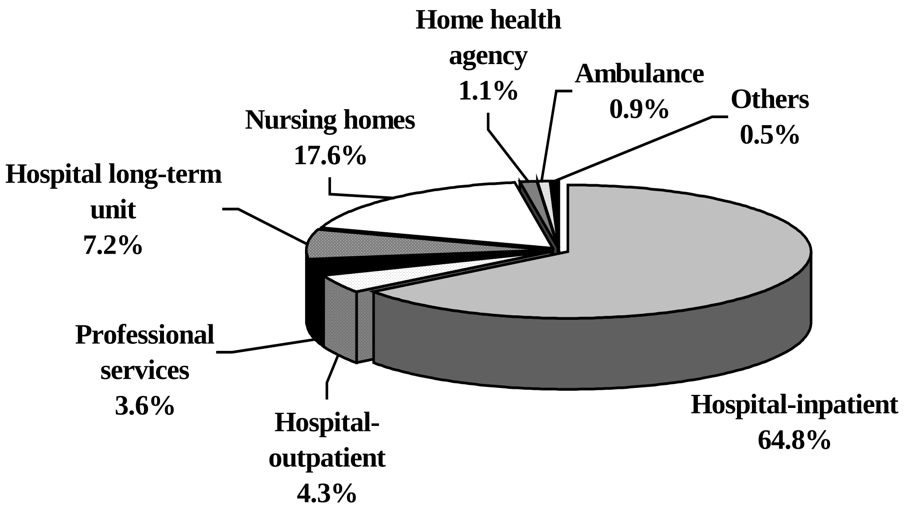


Table 3.2. TBI cost information by provider category – Medicaid FFS, FY1999-2002

	FY1999	FY2000	FY2001	FY2002	FY1999-2002	% of Total Cost
Hospital – inpatient	$ 6,845,172	$ 6,918,046	$ 7,927,015	$ 6,698,726	$ 28,388,959	64.8%
Hospital – outpatient	$ 370,463	$ 321,524	$ 561,416	$ 645,488	$ 1,898,891	4.3%
Professional services	$ 352,015	$ 332,369	$ 417,396	$ 473,922	$ 1,575,702	3.6%
Hospital long term care units	$ 884,259	$ 777,510	$ 755,531	$ 719,554	$ 3,136,854	7.2%
Nursing homes	$ 1,450,189	$ 1,996,294	$ 2,080,270	$ 2,191,532	$ 7,718,285	17.6%
Home health agency	$ 107,435	$ 120,313	$ 39,990	$ 210,431	$ 478,169	1.1%
Ambulance service	$ 11,079	$ 74,589	$ 167,828	$ 160,140	$ 413,637	0.9%
Other claim categories	$ 1,048	$ 3,573	$ 11,521	$ 208,613	$ 224,755	0.5%
Annual total cost	$ 10,021,659	$ 10,544,219	$ 11,960,968	$ 11,308,406	$ 43,835,253	

Figure 3.4 and Table 3.2 display the provider categories to which Medicaid FFS payments for a TBI diagnosis were made between FY1999 and 2002. According to these data, 65% of the total payments (more than $7 million per year on average) were made for hospital inpatient stays, despite the fact that only 8% of cases analyzed experienced an inpatient stay during the time frame. The second largest dollar amount was accounted for by nursing home expenditures (18%). On average, Michigan Medicaid FFS paid out about $11 million annually for claims in which TBI was a primary or secondary diagnosis.

Longitudinal Study of Hospitalized Medicaid FFS Cases

In order to better understand what services people with TBI receive through Medicaid, claims were analyzed for a subgroup of FFS beneficiaries. The group chosen for analysis included cases identified with a TBI-related hospitalization sometime during fiscal years 1999-2001 with two full years of Medicaid eligibility following the hospitalization for TBI, and who were enrolled in FFS during at least part of that period. One hundred sixty-six such individuals were identified. This selection methodology means that those cases selected were the most likely to be severely injured and possibly disabled. (Please see Appendix C for more discussion of the methodology and limitations.) All claims were analyzed – those with and without a TBI diagnosis.

Table 3.3. FFS Medicaid services received by subset of individuals with TBI, during the first and second year following injury (n=166*)

Provider Category	Year 1		Year 2		Year 1 or 2	
	No.	Percent	No.	Percent	No.	Percent
Hospital – inpatient[†]	152	92%	17	10%	152	92%
Hospital – outpatient	122	73%	60	36%	126	76%
Professional services	160	96%	84	51%	161	97%
Hospital long term care units	1	1%	1	1%	2	1%
Nursing homes	18	11%	15	9%	20	12%
Home health agency	22	13%	4	2%	23	14%
Ambulance service	52	31%	19	11%	60	36%
Independent laboratory	42	25%	21	13%	45	27%
Medical clinic	33	20%	28	17%	38	23%
MI Choice program	2	1%	2	1%	2	1%
Community Mental Health board	17	10%	15	9%	18	11%
Other claim categories	48	29%	49	30%	62	37%

Source: Medicaid FFS data are analyzed for a subset of individuals with a TBI-related hospitalization during FY 1999-2000, and were subsequently eligible for Medicaid for 2 continuous years, and who received services through Medicaid FFS at some point during those two years, and for whom Medicaid was primary (no other insurance).

*Note that some of the individuals in this table might have been enrolled in a MHP sometime during the 2 years. Therefore it is possible that some services are not summarized here because they were received during MHP enrollment.

[†] All individuals summarized in this table were hospitalized once at the beginning of the two year period. Only 152 of the 166 individuals had cost information on this hospitalization in the Medicaid FFS database. This means that 14 people had their initial hospitalization paid for by their MHP.

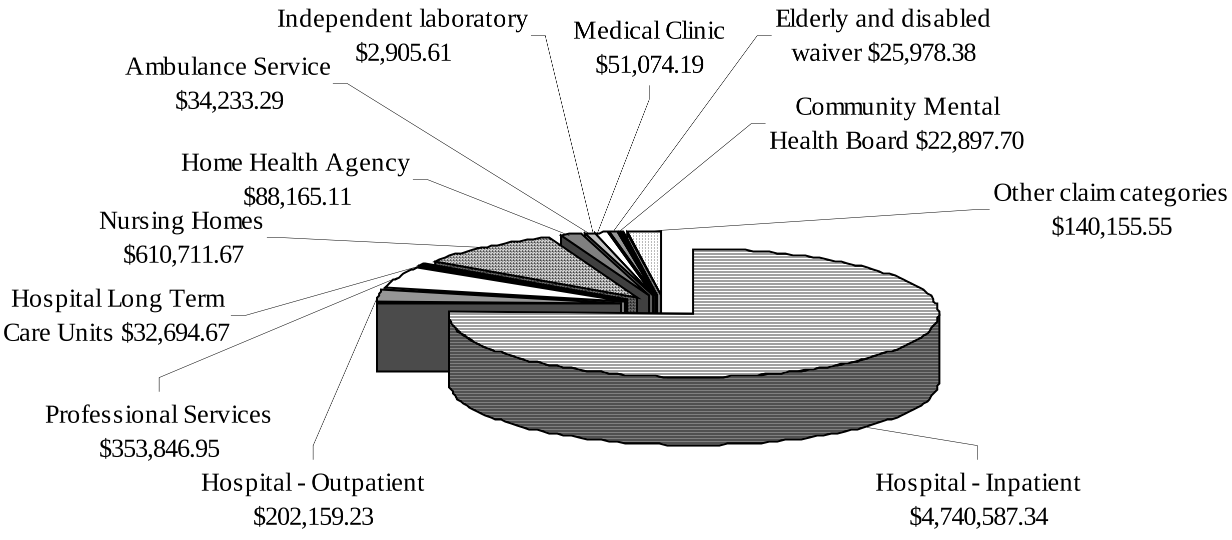
Table 3.3 presents the number and percentage of the 166 people who received Medicaid FFS services following a TBI-related hospitalization by provider category of service received. However, it is possible that not all of these services are directly linked to a TBI diagnosis. Service categories are presented for one and two years post injury. The second year of services is more likely to reflect the long-term service needs of the individual with TBI. During the second year post injury:

- 60 people (36%) required hospital outpatient services;
- 17 people (10%) experienced another hospital stay;
- 15 (9%) received nursing facility care;
- 15 (9%) received services through a CMH; and
- 2 (1%) were enrolled in the MI Choice Program.

Figures 3.5 and 3.6 summarize total Medicaid FFS costs by provider category for the first and second years after a TBI for the entire subgroup of 166 people with a Medicaid-paid, TBI-related hospitalization and two continuous years of Medicaid eligibility. As expected the first year is very expensive since it includes the acute care in the hospital.

- Total costs during the first year post injury for the 166 individuals studied were $6,254,335.50.
- Hospitalization accounted for three quarters of these costs at over $4.7 million.

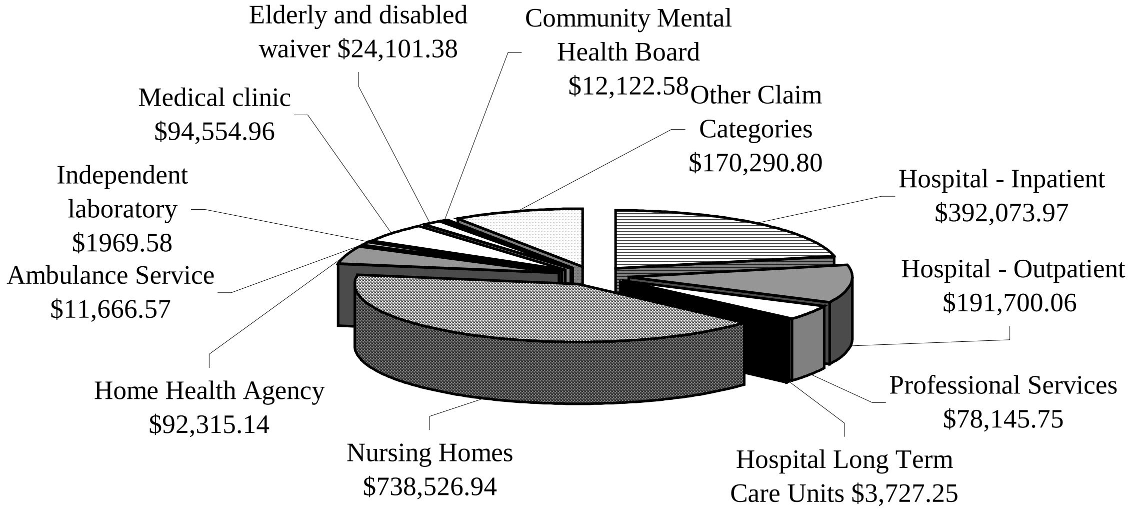
Figure 3.5. Medicaid FSS cost information by provider category for Year 1 following TBI hospitalization (n=166)



Of the 166 people studied, only 103 of them had Medicaid FFS costs during the second year after their injury (all were eligible for Medicaid).

- Total costs during the second year post injury were much lower: $1,716,640.02.
- The largest cost category during the second year following injury was for nursing homes, accounting for $738,526.94, or 43% of the total.

Figure 3.6. Medicaid FFS cost information by provider category for Year 2 following TBI hospitalization (n=103)



Individual costs were summarized for years 1 and 2 post injury for these 166 individuals by calculating means and medians. The mean is the average cost (the total cost divided by the number served). The mean is not necessarily typical, since a small number of high cost cases can drive up the mean. Therefore, the median cost was calculated. The median can be regarded as a more "typical" of the group.

- The *median* amount paid through Michigan Medicaid FFS for these 166 people during the first year post injury (which includes their initial hospitalization) was $13,594.50.
- The *average* amount paid for these individuals during their first year was $37,676.
- The *median* year two amount paid through Michigan Medicaid FFS for the 103 people who had second year costs post injury was $1,200.04.
- The *average* amount paid for year two was $16,666.41.

Home Help Service Use by Individuals with Identified TBI

Home Help Services are unskilled, non-specialized services performed in the beneficiary's home or other community setting *to assist* individuals in accomplishing activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs include: eating, bathing, toileting, grooming, dressing, transferring, and moving about. IADLs include: taking medication, preparing meals, laundry, housework, shopping and errands. As of February 2004, 45,896 individuals were receiving Home Help services in Michigan.

Medicaid ID numbers of Home Help beneficiaries during FY2000-2002 were matched with Medicaid ID numbers of people with an identified TBI treatment service through Medicaid FFS or MHP during fiscal years 1999-2002.

- Of the 67,489 Medicaid beneficiaries with an identified TBI, 3,577 (5%) received Home Help services between October 1, 2000 – September 30, 2002.

The age of Home Help beneficiaries with TBI ranged from 3 years to 104 years, with a mean age of 50 years. Yearly cost data for these 3,577 Home Help beneficiaries with a TBI are summarized in Table 3.4. Home Help costs and number of people served are broken down by fiscal year. Costs for all three years are summarized in the final column. During the most recent year analyzed (FY2002), 2,869 individuals with an identified TBI in the Medicaid FFS and MHP databases received Home Help services, for a total cost of over $9 million. The median annual amount paid for Home Help services for an individual with an identified TBI during FY2002 was $2,706.

Table 3.4. Home Help Services cost information for individuals with TBI, FY2000-2002

Cost	FY2000	FY2001	FY2002	FY2000-FY2002
Total cost	$5,191,736	$8,321,264	$9,253,256	$22,776,256
Median cost/ beneficiary	$1,995	$2,731	$2,706	$2,415
Maximum cost/ beneficiary	$27,404	$45,414	$47,831	$47,831
Minimum cost/ beneficiary	$18	$6	$16	$6
Number of cases with charges*	2,324	2,621	2,869	3,577 (unique individuals)

*Cases with charges of $0.00 were not included in the analysis. These individuals were approved for Home Help – but did not receive services.

Home Help Service Use by Individuals with Identified TBI Hospitalization

Analysis of Home Help service use was also conducted separately on the 5,738 Medicaid beneficiaries who had a TBI-related hospitalization during FY1999-2002.

- Of these 5,738 individuals with a TBI-related hospitalization, 640 (12%) received Home Help services during the three-year period October 1, 1999 – September 30, 2002.

Analysis was also conducted comparing date of TBI hospitalization to first date of Home Help service use. Only the years that services were provided to individuals with TBI were available in the Home Help data provided for analysis. Years of initial service provision were compared to the year of hospital admission for those with TBI hospitalizations in the Medicaid data. For most cases with a TBI hospitalization, it can be reasonably assumed that this hospitalization marks the approximate date of their injury. However, it could not be determined for sure from the data whether Home Help services were received as a result of a TBI. Therefore, the purpose of this analysis was to determine whether people with a TBI hospitalization were injured first and then needed Home Help, or whether individuals already receiving Home Help experienced a TBI.

There were 570 individuals with TBI that received Home Help services between October 1, 1999 and September 30, 2002 with dates of hospitalization between FY1999 and FY2002. Of these 570 individuals:

- 194 individuals (34%) received Home Help services during the fiscal year prior to TBI hospitalization in 2001 or 2002 (Home Help data for 1999 were not available to compare with 2000 hospitalization data, and 2003 hospitalization data were not available to compare with 2002 Home Help data.)
- 233 individuals (41%) received their first Home Help service during the same fiscal year as their TBI – it is unclear whether the TBI came first or second
- 143 individuals (25%) had their first Home Help service during the fiscal year after their TBI hospitalization.

The numbers show that about one-third of individuals with TBI were receiving Home Help Services during the year prior to their TBI-related hospitalization. The remaining two-thirds of the individuals received Home Help services during the year of their TBI-related hospitalization or during the year following their TBI-related hospitalization, although it is not possible to determine if these individuals received services as a result of their TBI.

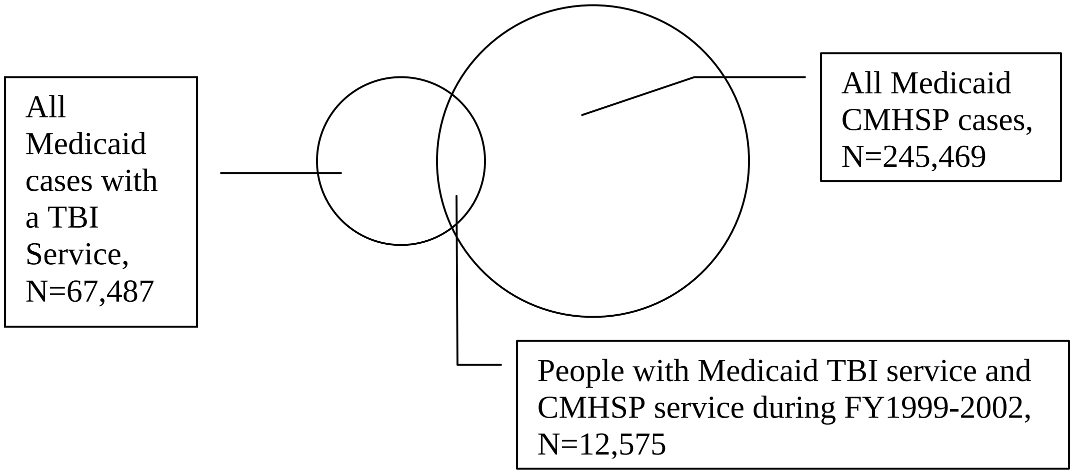
Costs of Home Help services were analyzed for the subgroup of people with a TBI hospitalization. Median costs were slightly higher for this subgroup than for those with TBI but no identified hospitalization; however, the differences were not considered substantial enough to present separately.

Community Mental Health Services Programs

This section presents the information about CMHSP services utilized by those individuals identified as being treated for TBI in the Medicaid data.

The methodology involved matching those cases identified in the Medicaid data who received TBI-related services with those in the CMHSP database. This process is illustrated below in Figure 3.7. (Searching the CMHSP database for a diagnosis of TBI would not yield information for multiple reasons, including the use of DSM-IV diagnostic categories and the fact that TBI is not a priority diagnosis in the CMHSP system.)

Figure 3.7. Matching people treated for TBI through Medicaid with Medicaid CMHSP clients, FY1999-2002



As depicted in Figure 3.7, out of 67,487 people identified as having been treated for TBI in the Medicaid database and 245,469 Medicaid clients receiving CMHSP services, 12,575 individuals were in both databases during FY1999-2002. These individuals accounted for 18.6% of the people identified as being treated for TBI through Medicaid in the timeframe. Individuals with an identified TBI in Medicaid during FY1999-2002 accounted for 5% of all CMHSP clients during the same years.

Table 3.5 provides demographic information on CMHSP consumers with an identified TBI. For comparison, demographic information on the rest of the Medicaid CMSHP population is also presented. The CMHSP clients with a Medicaid-identified TBI are more likely to be younger (aged 0-44), and receiving services as a person with a mental illness as compared to the CMHSP clients with no identified TBI. Individuals with a Medicaid-identified TBI receiving CMH services were about half males and half females.

Table 3.5. Demographic overview of CMH cases by Medicaid-TBI status, FY1999-2002

	CMH & Medicaid-Identified TBI		**CMH, No Medicaid-Identified TBI**	
	Number	**Percent**	**Number**	**Percent**
Age Categories				
0-14	3,148	24.9 %	53,791	23.1 %
15-24	2,203	17.4 %	37,535	16.1 %
25-34	2,033	16.2 %	34,553	14.8 %
35-44	2,496	20.0 %	42,859	18.4 %
45-54	1,481	11.8 %	29,382	12.6 %
55-64	688	5.6 %	13,242	5.7 %
65-74	262	2.0 %	7,182	3.1 %
75-84	181	1.4 %	5,572	2.4 %
85+	83	0.6 %	3,518	1.5 %
Unknown	0	-	5,260	2.3 %
Total	12,575	100.0 %	232,894	100.0 %
Gender				
Male	6,297	50.1 %	107,033	46.0 %
Female	6,278	49.9 %	120,102	51.6 %
Unknown	0	-	5,759	2.5 %
Total	12,575	100.0 %	232,894	100.0 %
Race				
White	7,658	60.9 %	133,923	57.5 %
Black	3,012	24.0 %	53,255	22.9 %
Other	762	6.1 %	13,573	5.8 %
Unknown	1,143	9.1 %	32,143	13.8 %
Total	12,575	100.0 %	232,894	100.0 %
CMH Category				
MI Only	9,971	79.3 %	159,772	68.6 %
DD Only	1,093	8.7 %	28,392	12.2 %
DD & MI	822	6.5 %	33,785	14.5 %
Neither DD or MI	689	5.5 %	10,945	4.7 %
Total	12,575	100.0 %	232,894	100.0 %

Race is also available in the CMHSP dataset. The racial composition of the individuals receiving both Medicaid TBI and CMHSP services is about 61% white, 24% black, and 6% other.

Seventy-nine percent (9,971) of the people with a TBI identified through Medicaid data who also received CMH services qualified for CMH services as a consumer with a mental illness (MI). Consumers classified as "developmentally disabled" (DD) include those classified as DD only, as well as those classified as both DD and MI. About 15% (n=1,915) of the individuals with a TBI identified through the Medicaid data receiving CMH services qualified for services by being classified DD.

CMHSP Service Use by Medicaid Beneficiaries with a TBI-related Hospitalization

The remainder of this section presents CMHSP service use for those individuals who experienced a TBI severe enough to require hospitalization. (Please note that these are cases with a medical hospitalization for TBI as identified in the Medicaid database – these do not necessarily include cases with a psychiatric hospitalization as identified in the CMHSP data.) These cases may be a more uniform group: because they were hospitalized with a TBI, they are more likely to have sustained long-term TBI-related impairments. As presented in Table 3.1, there were 5,738 people in the Medicaid database with a TBI-related hospitalization during FY1999 to FY2002. Of these, 1,262, or 22%, were also receiving services through a CMHSP during the same timeframe. Of the 1,262 individuals with a TBI-related hospitalization also receiving CMHSP services during the timeframe analyzed, 167 (13%) were classified as DD and 1,011 (80%) were classified as MI. (Seven percent had no information on whether they were classified as DD or MI – only those classified as one of these will be summarized in Tables 3.6 and 3.7 below.)

It could not be determined from the data whether a TBI occurred first and necessitated services from a CMHSP or whether existing CMHSP clients experienced a TBI. Without service dates in the CMHSP data or dates of injury in the Medicaid data, this question is difficult to answer with certainty. However, we were able to compare the first year in which CMHSP services were obtained to hospital admission dates for those with TBI hospitalizations in the Medicaid data. It was assumed that most TBI-related hospitalizations occur close to the date of injury.

Only 686 individuals were identified with dates of hospitalization in the Medicaid datasets who also received CMH services during the four years. Of these:

- 295 (43%) received CMHSP services during the fiscal year prior to their TBI hospitalization
- 202 (29%) received their first CMHSP service during the same fiscal year as their TBI – it is unclear whether the TBI came first or second
- 189 individuals (28%) had their first CMHSP service during the fiscal year after their TBI hospitalization

These numbers indicate that a very large number of those who are hospitalized for TBI and received CMH services may not necessarily be in the CMHSP system because of a TBI. Further research would be required to determine the number of people with TBI who are served by a CMHSP specifically because of impairments or symptoms resulting from the TBI. Nevertheless, the following tables present service use information on individuals with a TBI-related hospitalization.

Table 3.6 presents a comparison of the types of services used for Medicaid CMHSP clients with a TBI hospitalization and those with no evidence of TBI. Results are also presented for those classified in the CMHSP system as DD, MI-children, and MI-adults. Twenty-nine classes of services are present in the CMHSP database during the years 1999-2002. Of these, the only services presented in Table 3.6 are those accessed by at least 10% of any service category of Medicaid CMHSP clients with a TBI-related hospitalization.[3]

The following key findings are presented in Table 3.6:

- People with a TBI-related hospitalization appeared more likely to receive community inpatient services, and supports and services coordination.
- People with a TBI-related hospitalization in the service category MI-Adults appeared more likely to receive the following services: Emergency services/Crisis stabilization (64%), Crisis residential (11%), and Specialized residential (10%).
- People with a TBI-related hospitalization and classified as DD appeared less likely to receive Enhanced health care-staff.
- People with TBI in all service categories commonly received mental health clinic services, but people with a TBI-related hospitalization seemed less likely to do so than CMHSP clients with no identified TBI (particularly in the DD category).

In addition to summarizing the number of people who received services, the quantity of services received can also be summarized for 2001 and 2002. These results are presented in Appendix C, Table C2.

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[3] Other services not likely to be accessed and thus not presented are: state inpatient, supported independent housing, outpatient partial hospitalization services, clubhouse programs, intensive crisis stabilization services, family support/skills-DD, family skills development-MI, community living equipment-DD, community living environmental modification-DD, enhanced health care-pharmacy-DD, extensive observation beds-MI, wraparound, and prevention services.

Table 3.6. Most frequently used CMHSP services by Medicaid beneficiaries with TBI hospitalization, FY1999-2002

Services	**Medicaid CMHSP cases with TBI hospitalization**						**Medicaid CMHSP cases - no identified TBI**					
	DD (n = 167)		**MI Adults (n = 850)**		**MI Children (n = 161)**		**DD (n = 62,177)**		**MI Adults (n = 104,841)**		**MI Children (n = 51,360)**	
	No.	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**	**No.**	**%**
Mental health clinic	70	41.9	657	77.3	132	82.0	37,530	60.4	88,018	84.0	42,872	83.5
Emergency services/Crisis stabilization	51	30.5	541	63.6	52	32.3	23,270	37.4	42,922	40.9	14,063	27.4
Community inpatient	26	15.6	393	46.2	33	20.5	5,006	8.1	20,245	19.3	4,587	8.9
Supports & services coordination	122	73.1	377	44.4	44	27.3	40,663	65.4	37,973	36.2	10,776	21.0
ACTC	6	3.6	106	12.5	4	-*	1,919	3.1	9,016	8.6	490	1.0
Crisis residential	4	-*	97	11.4	1	-*	896	1.4	5,647	5.4	337	0.7
Specialized residential	53	31.7	82	9.6	2	-*	12,545	20.2	5,651	5.4	765	1.5
Day programs	38	22.8	82	9.6	2	-*	15,809	25.4	5,313	5.1	464	0.9
Community living - staff	37	22.2	48	5.6	4	-*	13,091	21.1	5,865	5.6	1,261	2.5
Skill building assistance-Supported integrated employment	33	19.8	29	3.4			9,818	15.8	5,040	4.8	281	0.5
Housing assistance	16	9.6	29	3.4			4,936	7.9	3,181	3.0	173	0.3
Enhanced health care - Staff – DD	98	58.7	20	2.4	3	-*	47,293	76.1	8,383	8.0	3,760	7.3
Skill building assistance - All other	37	22.2	19	2.2	1	-*	13,827	22.2	2,542	2.4	296	0.6
Home-based services	11	6.6	17	2.0	31	19.3	2,301	3.7	2,693	2.6	8,171	15.9
Respite care	33	19.8	5	0.6	8	5.0	8,074	13.0	461	0.4	4,387	8.5
Assistance for challenging behaviors - DD	26	15.6	3	-*			8,739	14.1	291	0.3	145	0.3

* Percentages are not calculated when number < 5.

Considering all 29 possible services, analysis was conducted to determine whether people with a TBI-related hospitalization who were also receiving CMH services tended to receive a wider variety of CMH services than people with no identified TBI. The number of different CMH services each individual had throughout the four-year period was counted. Individuals classified as DD tended to receive the greatest number of services and children with mental illnesses the least number of services. As shown in Table 3.7, adults with a TBI hospitalization classified as MI received close to four different CMH services on average, whereas their counterparts with no identified TBI received closer to three different CMH services on average. In the service categories, DD and MI-children, average differences in the number of services received by those with and without a TBI hospitalization were slight.

Table 3.7. Average number of different CMHSP services received during FY1999-2002

	DD			MI-Adults			MI-Children		
	n	**Ave.**	**S.D.**	**n**	**Ave.**	**S.D.**	**n**	**Ave.**	**S.D.**
TBI Hospitalization	167	5.2	3.2	850	3.8	2.4	161	2.8	1.6
No identified TBI	62,177	5.1	2.6	104,841	3.1	2.0	51,360	2.5	1.5

Discussion

The data presented here provide a first look into public service use by people with TBI in Michigan. Approximately 18,000 individuals receive direct TBI-related services per year through Medicaid FFS and/or MHP. Also, we now have a bottom estimate for the cost to Medicaid FFS (*only*) of over $11 million per year spent on services for TBI. (In other words, these are only the identified costs – the limitations of the data analyzed prohibit identifying complete TBI-related costs.) Based on provider categories presented here, it appears that much of that amount is spent on acute care rather than post acute or community based care. However, it is very likely that many of the long-term costs of caring for people with TBI are not captured in this analysis because claims for those services may not contain complete diagnostic coding. *Note also that the $11 million figure does not include costs for the 65% of Medicaid clients with a TBI who are enrolled in a MHP.*

In order to better understand long-term costs for those individuals with serious TBI, all claims were analyzed for a subset of cases: those with a TBI hospitalization, two continuous years of Medicaid eligibility, and costs paid for by FFS. Once these selection criteria were imposed on the data, 166 cases were identified – who no doubt had the most serious, debilitating injuries. First year Medicaid FFS costs for these 166 people were in excess of $6 million. Second year costs were $1.7 million. Forty-three percent of all second year costs were spent on the 10% of the group that required nursing home services.

Analysis also shows that about 4% of all Medicaid beneficiaries with an identified TBI used Home Help services sometime during October 1, 2000 – September 30, 2002. In FY2002, Home Help costs for the 2,869 individuals with a TBI totaled over $9 million.

In terms of CMH service use, nearly 19% of Medicaid beneficiaries with an identified TBI accessed CMH services during the four years analyzed. This amounts to about 5% of the total CMH population served during this four-year period.

In order to have a better understanding of Home Help and CMHSP service use by a more uniform group of TBI survivors, those with an identified TBI hospitalization were analyzed separately.

- About 12% of individuals with a TBI hospitalization accessed Home Help during the years analyzed
- About 22% of individuals with a TBI hospitalization accessed a CMH during the years analyzed.

4

A LOOK AT PUBLIC SERVICES FOR INDIVIDUALS WITH TBI IN MICHIGAN

This section contains a description of Michigan's public service system for individuals with TBI[1] from two viewpoints. First, five consumer case studies are presented to show the features of Michigan's public system, as well as the problems and service needs of this population. Secondly, provider views are presented from two different surveys.

Five Consumer Case Studies

Methods

Four face-to-face interviews and one telephone interview were completed with individuals with TBI and family members in Michigan. The following section shows how people were selected for the interviews and how the interviews were done.

<u>Identification and Selection of Interview Subjects</u>
People to be interviewed were identified by members of the TBI Project Team as having experienced some common issues faced by individuals with TBI. In addition, BIAMI asked support group and chapter leaders to help identify possible volunteers.

Consumers to be interviewed were supposed to have the following features:

- TBI occurred three to six years ago (to ensure that information is available/fresh in individuals' minds, but long enough ago that outcomes were not affected by pilot site activities);
- Individual, family, and caseworker(s) should still be reachable by phone;
- The individual came in contact with FIA, CMH, or MI Choice Program;
- Eligibility and impairment conditions of the individual show that s/he could have been served by CMH, FIA, or MI Choice Program; and,
- People may have been *either* difficult or easy to find services for.

Cases with the following characteristics were to be *excluded* from consideration:

- People receiving adequate services through the no-fault system;
- People institutionalized before the brain injury; and
- People referred to Worker's Compensation.

Because it was hard to find enough people with the above features, the first requirement was changed to include anybody injured within the last six months to six years, as long as the person tried to get services for at least six months.

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[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

Conducting Interviews

Each interview lasted about one hour and was done in the person's home. People unable to speak independently were assisted by family members. One person and family member lived too far away to meet for a face-to-face interview, so a telephone interview was done.

An introductory/consent statement was read aloud to each participant (and his or her guardian when appropriate) before the interview. Participants (and their guardians, if any) were required to sign and date the form. Each participant received a copy of this form. All interviews were tape recorded and the tapes were typed out so they could be reviewed.

In some cases, additional information was collected from other parties, such as advocates or care providers. Nevertheless, what is presented here is primarily information from the respondents' (people and their guardians) .

Results

This section presents a summary of each case, including background information, description of injury, contact with public agencies, and unfulfilled needs. A fictitious name is assigned to each case to tell it apart from other cases and to protect the person's identity. In some cases, minor details of a respondent's story were changed to better protect that person's identity. Note that *only a small number of interviews were done* and that, *consumers with the greatest need may have been those most likely to volunteer to be interviewed*. The results listed here are only a sample of the larger population, but do showl that service gaps exist in Michigan's public service system and how they affect individuals with TBI.

Case #1: "John"

Background

Several years ago, John lived on his own, had completed some college, and worked as a salesman. In 1996 (two years prior to his injury), he began experiencing epileptic seizures and subsequent medical problems. Due to those problems and the medication he was taking in response, he moved in with his parents and took a part-time job at a restaurant.

Description of Injury

In 1998, while at a hospital receiving inpatient care for seizure-related problems, John fell after getting out of bed on his own to use the restroom. He was heavily sedated at the time. While the details of the injury event are unclear (though his family suspects that he hit his head on a bathroom fixture while falling to the ground), one specialist said that the severe damage to John's brain looked like he had fallen out of a three-story window. He was comatose and rigid immediately afterward and remained unconscious for approximately three hours. According to CT results, he had a large blood clot in his temporal lobe (which was later excised) and four smaller clots in his frontal lobe. He was left totally paralyzed and required a tracheostomy tube, feeding tube, and pressure drain. He underwent surgery within two days of the injury and was kept in an induced coma afterward.

John's parents sued the hospital for negligence and reached a structured settlement. The settlement set up a trust fund that was to be used to pay for services not available through public agencies. Unfortunately, having this trust fund did not guarantee that he would receive all of the services he needed or that he would have enough funding to pay in full for all of these services for as long as he needed them.

Although John has made significant improvements, getting to this point had been a challenge. After his injury, he required aggressive rehabilitation (including physical therapy, occupational therapy, and speech therapy), neuropsychiatry services, 24-hour care, home help, and multiple medications (including a Baclofen pump that requires special monitoring). He needs assistance in most daily functions, requires a shower chair, uses paralanguage computer software to improve his reading skills, and requires transportation assistance.

Contact with Public Agencies

1. In 1998, John was transferred from the hospital to a private care facility owned by the hospital. He spent four years there until a settlement was reached with the hospital. At that time (2002), the settlement stopped paying for his care, and his parents were informed that John must get his care from Medicare or Medicaid. Up to that time, neither he nor his family had any contact with Medicaid or any other public agencies. The hospital-owned care facility where he was living did not accept Medicaid or Medicare, and his parents were forced to begin looking for another facility. They were adamantly opposed to placing John in a nursing home.

2. John’s parents first submitted an application for Social Security Disability Insurance (SSDI) but were turned down because of a documentation error. Later, however, they reapplied and were approved. John began receiving SSDI, and along with it came Medicare.

3. When John’s parents heard that he must transfer to a new facility, his father contacted FIA for assistance. FIA staff said they could not help and that FIA does not support individuals in group homes. John’s father then spoke to someone in Medicaid who recommended contacting CMH.

4. John’s parents first contacted the CMH in the county where John was living at the time. However, because he was not a resident of that county at the time of his injury, they referred him to a different CMH. Eventually, John’s father made contact with someone at the CMH who assured him this was not a problem and advised him to complete the necessary paperwork. Unfortunately, the application was delayed by the CMH. After waiting for quite some time with no response, John’s parents contacted legislators to intervene with the CMH, and were introduced to an MDCH official. His parents also wrote letters to the CMH asking if John was eligible for services. In September of 2002, the CMH issued a denial of eligibility and said his parents had a right to appeal and have a different CMH psychiatrist review the case. John’s parents appealed twice. Both appeal hearings were unsuccessful, and the appeals were dropped. His parents paid for an independent psychological evaluation that, according to his parents, indicated that he should have been eligible for CMH services. However, the administrative law judge did not feel that treatment of TBI is a covered service that CMHSPs are required to offer.

5. Eventually, because of the intervention of an MDCH official, John obtained admission to the MDCH TBI Rehabilitation Program for six months, beginning in February 2003. While undergoing inpatient rehabilitation, John was able to get a Baclofen pump installed and made improvements from physical, occupational, and speech therapy.

6. Upon completion of the TBI Rehabilitation Program, Medicaid staff advised John’s parents that John should go to a nursing home and that he had made no improvement. Staff began looking for a nursing home and advised his parents to apply for the MI Choice Program. However, John’s parents were told that all MI Choice slots available through the AAA had been used up and that they could not evaluate John because he was living in a licensed facility/group home. Again, MDCH officials intervened to address impediments to the MI Choice Program and an evaluation was performed to determine eligibility. Although they determined that John did qualify for assistance, there were no slots available. Further intervention from MDCH allowed a slot for John in the MI Choice Program.

7. John’s parents also applied for Home Help through FIA but never received a decision from FIA about this service. They eventually went to an administrative law hearing to appeal, but since they had never received an official denial, they were advised that the only thing they could do was to reapply. Unfortunately, the supplemental special needs trust that was set up after John’s injury will only fund services for which no state or federal program will pay, so John must receive an official denial before trust funds will be issued. His parents have made several requests for a new application, but FIA has refused to send the application.

8. John currently has a case manager through the MI Choice Program Agency. His parents feel that she really tries to help and visits every couple of months. However, they believe that this case management is ineffective because, for example, he still has not received a shower seat or new wheelchair – both of which he should have received a long time ago. MI Choice currently pays for 11 hours per day of personal care services. John is unable to receive personal care at night because MI Choice limits the number of hours of help for which they will pay. SSDI and Medicare currently pay for his medical treatment.

John’s parents believe that he may live a long time and are quite worried about how he will pay for long term care. They are “fighting to hang on to as much of that trust as [they] possibly can for when he gets older, because the system may get worse instead of better.”

Unfulfilled Needs
According to his parents, John needs the following services and equipment:

- Neuropsychiatric treatment for behavioral problems. John was denied public assistance to cover this service because, as his father said, the CMH concluded that "he is not seriously mentally ill."

- A replacement electric wheelchair that has a special support feature to keep him from leaning too far over.

- A safer shower chair than the one he's currently using. He has been waiting to receive a new chair for some time but cannot seem to "get any answers" about when he can expect the new chair.

- Transportation. John's transportation was previously paid for by MI Choice, but then it was denied. Now his parents are paying for it out of their pockets. According to his father, Medicaid is supposed to provide transportation to and from medical appointments and therapy; however, they will only pay $0.32 per mile, and no transportation providers will accept that rate.

- Assistance with finding a job. John has not worked since his injury. His parents took him to a private service organization to inquire about working; however, he was not interested in the type of work they had to offer (he felt it was "busy work"). He would like to look for a different type of job and is interested in seeking help from MRS. He is especially interested in working once he gains arm strength and movement.

Case #2: "Mary"
Background
Prior to her injury, Mary was employed part-time in retail. She had also worked as a nurse for many years before that. She lived by herself and was going through a divorce.

Description of Injury
In November 2001, Mary was a passenger in an automobile crash in which a much larger vehicle crashed into the side of the car where she was sitting, which was then slammed into a stationary object. Mary hit the windshield, dash, and the steering wheel. She was unconscious for some time, although it is not clear how long she remained this way. When she regained consciousness, she felt terrible pain in her head. An ambulance arrived, but she refused to be taken to the hospital because she had no health insurance at the time. Instead, a co-worker drove her to the hospital. She was seen in the emergency department and had a CT scan.

After receiving treatment in the emergency department, Mary went home and called her auto insurance company. This is when, she claims, "the intimidation began." She then called her attorney, who told her what she was entitled to. She did not visit a physician right away because she lived far away from an office. Instead, she stayed at home and took care of herself, using a cervical pillow and other necessary treatment. It was the decision to not visit a doctor that prompted the first challenge to receiving compensation for her injury. Mary's auto insurance company claimed that, because she did not see a doctor right away and she did not choose to have follow-up care for her injuries, she was non-compliant with the terms of her policy.

Within ten days of her injury, Mary received a cervical spine MRI and was told she had a disc problem. Her auto insurance company sent a case manager to her home to check on her a couple of times and set up an appointment at an outpatient clinic. There she saw a neuropsychologist who told her that he could not operate because of the risk to the spine. He suggested massage therapy for her head. She also began having difficulty walking and performing tasks at home. Her auto insurance provided funding for assistance in the home and additional therapy, including acupressure three times a week. In April 2002, however, her insurance company "cut her off completely" for reasons she did not understand. At this time she had no choice but to find financial assistance elsewhere.

After suffering from jaw pain, Mary requested payment for dental services from her auto insurance company, but they denied her claim. Later, the auto insurance company decided to hire an independent dentist to evaluate her, but it was the same dentist she saw originally when they denied payment. That dentist refused to work for the auto insurance company due to a conflict of interest; the insurance company then approved payment for her testing and treatment. She received a series of "sophisticated" tests (totaling approximately $5,000), which revealed that she had a closed head injury. Up to this time, she was not aware that she had a TBI.

Some of the long-term effects of Mary's TBI have included, but are not limited to: difficulty concentrating or paying attention, difficulty planning and staying organized, difficulty remembering things (e.g., she's afraid that she left her stove on when she's not at home), increased anxiety, panic attacks, depression, suicidal thoughts (due to pain and worrying about money), severe headaches, and other physical effects.

Contact with Public Agencies

1. Mary was referred to a pro-bono case manager and social worker through an attorney. This case manager was Mary's first link to public agencies since her injury occurred. In 2003 (approximately two years after her injury), he accompanied Mary to FIA to apply for assistance. He also sought help from the community, made deals with medical providers, and was able to obtain money to pay for an operation that Mary could not pay for herself. Mary was unemployed and thus had no health insurance to cover the surgery.

2. Mary applied for Medicaid, but did not qualify. She believes this is due to the money she received from selling her house, the divorce settlement, and/or her savings. Unfortunately, she did not have enough money from these sources to cover living expenses and medical care. Mary's daughter helped her to obtain utility assistance through the local utility company and she received counseling through a church-supported shelter at minimal cost. She currently has no health coverage, although she will be eligible for Medicare soon due to her age. She gets blood tests and other screening at a local senior center and found a clinic for individuals without insurance where she can

receive medical care and free medication samples. In addition, she currently participates in a support group for individuals with TBI, which she found on her own through a television commercial. She loves being part of this group.

3. At the time of her injury, Mary was eligible for Social Security benefits because of her age. She currently lives on Social Security and a pension. She also receives food assistance.

Unfulfilled Needs
Some of Mary's current needs include:

- Home Help.

- Assistance with finding a job. After Mary's injury, she worked part-time in an administrative position; however, she lasted only a short time because her health problems made it too difficult for her to work. She is interested in working again out of financial necessity.

- Assistance with medical bills and paperwork. Mary has stacks of bills and paperwork to review but feels that she does not know where to start and lacks organizational skills to handle it.

- Additional medical testing. Mary feels that she needs another CT scan but cannot afford it.

Case #3: "Sue"
Background
In 2000, Sue owned and operated multiple businesses and lived with her children.

Description of Injury
On Christmas Eve of that year, Sue's life took a drastic turn, though she did not realize at first how much her life would change. While pulling into her driveway after her drive home from church, another vehicle crashed into Sue's car. She was wearing her seatbelt at the time. She remembers her head striking the window, but does not remember anything after that. When she came back into consciousness, she did not think that she had been seriously hurt, but her head hurt badly. After the police completed their report, she went inside her home and went to bed. The next morning, Sue's kids came over and she was "in a coma by then." Her children did not call for help for two days. Two days after Christmas, she drove to her sister's home (a very familiar route). On the way there, she got lost and had to rely on her children to direct her the rest of the way. By the time they arrived at the home, Sue was "acting funny" and her sister took her to a hospital. Hospital staff sent her to a different hospital, where she was diagnosed with a closed head injury based on CT scan results. Upon discharge, she was instructed to go to a "rehab" center for further diagnosis. But for some reason, Sue's sister did not understand the orders. Nothing happened afterward, she just slept a lot. She tried to go back to work but nothing was working. Then her sister took her to a drug clinic, where Sue was told she did not need to be. Later, she says, they "tried to have [her] committed."

Approximately nine months after her injury, Sue was involved in a second motor vehicle crash that she believes was a result of her TBI. While driving home from a family trip, Sue’s “head dropped” and she lost control of the car, which rolled several times. Her head smashed out a window; she suffered multiple facial abrasions, arm and back injuries; and she was extremely agitated.

After Sue’s second motor vehicle crash, she “knew something was really, really wrong.” She did not always make sense and cried a lot. Her acquaintances saw a different person in her. She thought she was having a nervous breakdown. Sue’s friend started putting the pieces together (e.g., personality changes, lifestyle changes, increased sleeping, severe migraines often accompanied by vomiting) and took her to a university where she had neurological evaluations, neuropsychogical exams, blood tests, scans, and more. She also saw a head injury specialist. She was told that she needed to begin intense rehabilitation to re-learn everything (e.g., by this time she could not read).

At this time, Sue made an informal deal with her ex-husband such that the children would live primarily with him until they figured out what was wrong with her. However, when she went to the university for evaluation, her ex-husband went to the Friend of the Court and said she abandoned her children. The judge awarded him full custody.

Sue did not file a claim with her health or automobile insurance at the time of her first injury. Following her second automobile crash, she and her parents went to see an attorney. The attorney was convinced that she had a promising case and agreed to help. After a number of problems with her attorney, the case finally went to arbitration and a settlement was reached with her automobile insurance company for $100,000; however, she will only receive $14,000. The settlement was designed to cover wage loss, home health care, and rehabilitation, with the understanding that her current health insurance company must pay all claims first and the settlement would cover anything unpaid by insurance. Unfortunately, for reasons that are unclear, the settlement has not paid anything. Instead, she has relied on a health insurance policy she picked up after the injury, which covered most of her medical expenses with the exception of approximately $10,000 that remains unpaid to a rehab facility and a few other miscellaneous bills.

Some of the long-term effects of Sue’s TBI have included, but are not limited to: difficulty concentrating or paying attention, altered perception (she often runs into walls, etc), difficulty planning and staying organized, difficulty remembering things, taking longer to think, increased anxiety, low self-esteem (especially related to scars on her face from her second injury), depression, hormonal changes (pituitary-related), and severe migraines.

Sue went without a vehicle for a long period of time and had trouble finding and paying for housing. She also moved twice to be near her children. She is currently not able to work, but would like too, and is in school trying to earn a degree. She has struggled in school and failed her second term. She had a tutor, but was still unable to study as much as other students. She only attended classes about 60% of the time, was without a car for a while, and missed exams. She’s not sure if she will be able to catch up after failing the second term. She currently has a scholarship/federal grant (her tuition and books are fully covered), but cannot take enough credits to get a larger grant. She would like to be able to get extra money for living expenses, but will probably have to take out student loans to do that.

Contact with Public Agencies

1. Although Sue has little recollection of how she first came into contact with public agencies, she was able to obtain Medicaid and Social Security benefits through FIA. She suspects that she must have gone to the FIA office after she stopped working following her injury, but does not remember the details. She feels that FIA has been very helpful. She received back-pay from Social Security from the time of her injury, but a majority of that money went to her ex-husband for child support. Sue currently receives half of her Social Security benefit; the other half pays for child support.

2. After Sue's evaluation at the university, she was referred to an outpatient rehabilitation facility. At first, she did not like it there and refused to stay. A few months later, she finally gave up and said, "I can't fight anymore…I've got to go take care of this." She was accepted into a TBI rehabilitation program on an outpatient basis (although she does not remember how this happened or with whom she worked to make this happen). During this time, Sue and her children stayed at her boyfriend's house. When it came time for her children to return to school and live with their father, she became quite upset and wanted to leave the rehab program so she could be closer to them. She knew she was not finished with rehab and should not leave the program; however, she felt it was more important to be near her children. She had no idea how to find housing, find funding, transfer public assistance, etc. or where to go for help. Around that time, she met someone from BIAMI and began receiving the BIAMI newsletter.

3. Sue learned about a pro-bono case manager/social worker through the BIAMI newsletter. She noticed that he worked in the region where she hoped to move and thought he might be a good resource. He took her to FIA and worked with the case worker there to get her enrolled in the MI Choice Program and to help her obtain food assistance. He also raised money through community groups and church members for a vehicle and housing expenses. He helped Sue to obtain support staffing (Home Help) when she was not able to obtain it through MI Choice, which she had in her previous area of residence but did not transfer when she moved. At first, she received approximately 30 hours of Home Help (e.g., cleaning, paying bills, running errands, etc.) each week; she now receives approximately 10 hours per week.

4. Sue applied for public utility assistance, but was denied because her rent is too high for her income.

5. Sue was interested in working and contacted Michigan Works!. However, she never starting working due to doctor's orders.

6. A local service organization also provided some type of assistance and was helpful, but they eventually closed Sue's case.

Unfulfilled Needs

- Housing assistance.
- Quality Home Help. Sue still needs assistance at home but claims that her previous home helpers have stolen items from her home. She is nearly ready to give up on that option.
- Advocate. Sue feels that she needs an advocate in many aspects of her life including school, family court, and accessing public agencies. She thought her school was being sensitive to her situation, but feels she could use an advocate to explain the effects of TBI and help her to get additional help with schoolwork/tutoring. A friend and former Home Help provider is now acting as an advocate and recently wrote a letter to the family court judge on her behalf. She also contacted state legislators about her case, but has only received quick-fixes rather than long-term solutions.
- Case management. Her pro-bono case manager no longer has the time to handle Sue's case. She desperately wants one person who can help.
- Financial assistance for living expenses. Sue is not sure how she will sustain herself over the long term. She has to move out of her current residence soon and is not sure if she will receive any insurance settlement funds by then. If not, she does not know what she will do.
- TBI-specific resources (e.g., support). Sue has tried contacting everyone in the TBI brochure, but cannot seem to get any help. They all send her to someone else. She believes there are no more resources left. Although the TBI website is helpful, she believes that there are not many individuals out there who are in her shoes to whom she can turn for support.
- Coordinating and paying bills. Sue has a difficult time keeping up with her bills and reviewing them for accuracy.

Case #4: "David"

Background

Less than a year ago, David worked off and on in food service but struggled to hold down a solid job. He had started college, but dropped out. He had no auto or health insurance and was struggling financially. He lived with his sister in a home owned by their mother.

Description of Injury

In July 2003, David took a road trip to visit his mother who had moved out of state. He lost control of his vehicle on a curve (possibly from falling asleep) and crashed. He was not wearing his seatbelt and was ejected from the car. David was unconscious when the ambulance arrived to transport him to a hospital in a nearby city. At the hospital, he had a CT scan immediately, which was followed by emergency surgery. Afterward, he was put into an induced coma to keep him from moving.

David suffered extensive, severe injuries. According to his doctor, he would have been much worse off had he not been so physically fit prior to the injury. His injuries included: multiple contusions, bleeding in the brain (closed head injury), five broken ribs, a punctured lung, fractured pelvis, and a lacerated liver. He lost his spleen and his bladder had to be reconstructed. As David's father said, he amazingly had no marks on his face.

At his father's request, David was flown from the state where he was injured to Michigan and was admitted to a hospital in his father's hometown. There, he received occupational, speech, physical, and recreational therapy, as well as neuropsychological evaluations. David's family worked with a case manager at the hospital to find a care facility to which he could go after discharge from the hospital. The case manager looked into a number of programs and facilities, and decided on one that was most appropriate for David's particular needs. The facility had a good reputation and she was able to contact them directly and set up his transfer. David's case manager was in contact with the rehabilitation facility on a daily basis until he was discharged from the hospital, and had little difficulty getting him into the facility. His rehabilitation was provided as part of MDCH's TBI Rehabilitation Program.

After completing the normal amount of rehabilitation funded by the MDCH TBI Rehabilitation Program, David was approved for a 30-day extension. During that extension period, a situation arose and David was placed on a 24-hour emergency discharge plan. The circumstances surrounding this discharge are in dispute between the family and the facility. Regardless, David was immediately discharged and taken to a CMH Emergency Services facility (Note: this CMH facility is different than the CMH located in David's place of residence prior to his injury). However, when David arrived at the CMH, staff claimed that they could not help him because he was not a resident of their county prior to his injury, and he needed to find a place where he would be eligible for services. So, the CMH transported him to a homeless shelter near Detroit. This all occurred on a Friday afternoon and David's father, who lived far away, was not immediately available to assist. The shelter placed him in a psychiatric hospital; at that point, his father interceded. With help from a social worker at the psychiatric hospital, his father learned about the CMH system and contacted the CMH facility located in David's county of residence prior to his injury.

Through the second CMH, David was placed in his current home, a care facility for mentally and physically challenged individuals with 24-hour staff and nurses. He is happy there, but at times acts out if provoked by staff. David has a case manager there who is very helpful. He has just recently begun acting out more than normal in hopes that the facility will "kick him out." He is currently on a waiting list for a TBI rehabilitation program through a university where he will receive extensive therapy, including more intensive behavioral therapy. David's father speaks very highly of the program and hopes that David will soon be accepted on scholarship. If he is accepted, he will stay in the program for three months. Afterward, his father plans to bring him home on a trial basis. If that does not work out, David will most likely go to a nursing home.

David currently uses a wheelchair and walker. He can walk with assistance or walker and is gaining strength in his arm. His speech has improved to only a slight slur. Despite these improvements, he has suffered from many long-term effects including: difficulty concentrating/paying attention, altered perception, difficulty staying organized, difficulty speaking, understanding, reading, writing, short-term memory problems, decreased judgment, taking longer to think, increased anxiety, low self-esteem (he calls himself a “retard”), increased mood swings when provoked, depression (treated with medication), altered speech (though this has improved over time), double vision, muscle spasms, fatigue, and other physical problems. According to his father, David also has some behavioral health problems.

Contact with Public Agencies

1. At the time of his injury, David did not have auto insurance and therefore was not covered under Michigan’s no-fault system. Instead, he had to rely on public assistance. His father’s first contact with public agencies was through the hospital case manager, who referred him to FIA to apply for Medicaid. He went to the office, completed the appropriate forms, and David’s case was approved very quickly.

2. The hospital case manager also arranged for David to begin the MDCH TBI Rehabilitation program after being discharged from the hospital.

3. David first came into contact with CMH when he was discharged on an emergency basis from his rehabilitation facility (the circumstances of which are currently in dispute). However, because of his place of residence, the local CMH to which he was first taken would not accept him and transferred him to a shelter in Detroit. Soon after, he was transferred to a psychiatric hospital. A social worker at the psychiatric hospital put David’s father in touch with a different CMH in David’s original county of residence. According to his father, staff at that CMH were extremely helpful and took care of all arrangements to place him in an appropriate facility.

4. David currently receives SSDI (approximately $450 per month), which his father manages. His father gives him some money each month to use for activities and minor purchases. The remainder goes into savings as a back-up for the future should David ever need it for long term care expenses.

5. David expects to receive SSI soon. His father recently made initial contact.

Unfulfilled Needs

- Assistance locating services and facilities that are staffed by TBI specialists.

- Support groups. David’s father is aware of TBI groups, but has only found groups that are private or covered only by insurance. He is not sure if there are any TBI support groups at David’s current facility or if there are any in the region of the state where he may be living in the future if he moves home with his father. His father feels that David would benefit from this type of support.

- Substance abuse treatment. David’s father feels that David may need this therapy now or in the near future. His father does not want to be responsible for counseling and monitoring his son, but he is currently doing so.

Case #5: "Sam"

Background

In 2000, Sam was an active high school student who worked part-time at a local restaurant and enjoyed sports. He and his twin brother hoped to one day join the military together.

Description of Injury

In July of that year, while competing in a motocross race, Sam came over a hill, flipped over his handlebars, and landed on his head. Although he was wearing full safety gear (e.g., pads and a helmet), he was immediately knocked unconscious. On-site paramedics rushed to assist him; soon after, he was airlifted to a hospital by helicopter.

Upon arrival to the hospital, Sam received CT scans and was diagnosed with a severe bleed in the brain stem and two other brain bleeds. He suffered no other injuries. Hospital staff monitored his brain pressure and performed a tracheostomy. He remained in a coma and was placed on a ventilator. He also had numerous bouts with kidney stones while in the hospital. After some time, Sam's doctors and nurses suggested taking him off of life support, but his family made a collective decision to keep him alive. Soon after a social worker became involved with his case and asked his parents what they intended to do with their son once he was discharged from the hospital. His parents were still in a state of shock and did not realize that he would be discharged so soon. They had not even begun thinking about other options at this time. The social worker gave them paperwork to complete and literature on several transfer options to consider. His mother, who is a nurse, visited several facilities in-person before making a decision. In the meantime, the hospital social worker processed all paperwork and contacted his parent's health insurance company to set-up the transfer and complete all necessary steps to obtain approval.

Sam stayed at the hospital for five weeks. He was then transferred to a subacute nursing facility followed by a rehabilitation center soon after. Due to his illness, he was unable to receive much rehabilitation at that facility. His doctors determined that he had a paralyzed vocal cord and was aspirating his own secretions; therefore, he received another tracheostomy, which remains in place today. Approximately four months after arriving at the rehab facility he returned home to live with his family.

Although Sam opened his eyes from time to time, he did not fully come out of his coma until after he returned home, approximately six months after his injury. His family made a number of modifications to their home to make it possible for Sam to live there. For instance, they converted their first-floor dining room to a bedroom and built wheelchair ramps. They also purchased a van with a lift to accommodate his wheelchair.

Sam's TBI resulted in many severe long-term effects, including right-side paralysis, inability to speak, and inability to hear. He is completely non-ambulatory and is confined to a wheelchair when he is not in bed. He cannot sit on his own but must be strapped into his wheelchair with a special vest. Because he cannot speak, he uses a special keyboard to communicate. He cannot hear; however, he was fortunate to be the second person with a TBI to receive a cochlear implant from a facility in Ann Arbor. Although his doctors expect him to take about two years to recover his hearing with the implant, Sam is able to read lips and manages to communicate using his keyboard.

Other long-term effects of Sam’s TBI include, but are not limited to: decreased judgment, problem-solving skills, and personal safety skills; taking longer to think; vision problems, including a drooping eyelid caused by “third nerve palsy;” and muscle spasms. In addition, he is unable to eat solid foods and requires tube feeding.

Despite these severe physical and cognitive difficulties, Sam’s mother believes that his spirits are generally high and he has maintained his old sense of humor. He is certainly not happy about his condition or the way he now looks, but is very motivated to improve physically. He even wanted to return to school because he missed the socialization and he has just completed the final credits necessary to finish high school.

Contact with Public Agencies

Because Sam was covered under his parents’ health insurance policy, through his father’s employer, he has been fortunate not to have to rely fully on public assistance. His parents’ insurance policy covered his stay at the hospital, subacute nursing facility, and rehabilitation facility. It also covered home health care initially, which included home nursing care as well as home physical, occupational, and speech therapy. After that, Sam received therapy from a head injury program, where he has completed physical therapy and occupational therapy and will continue to receive speech therapy.

Sam will continue to receive primary health coverage through his parents’ policy because he is disabled. However, the policy does not cover everything he needs, thus he and his family have recently been and will continue working with the following public agencies to obtain secondary support:

1. During Sam’s hospital stay, his parents learned about Children’s Special Health Care Services (CSHCS). Through CSHCS, Sam was able to receive case management and funding for his electronic communication device that cost $7,000, his wheelchair, and other home modifications. These items did not come easy. These charges were all first denied by his parents’ health insurance policy. His parents are satisfied with their experience with CSHCS.

2. Sam’s family learned about Social Security from a nurse at the rehab facility. The nurse helped them complete the necessary paperwork, and they had no problems obtaining SSI. Sam currently receives $350 each month. The nurse also put his parents in contact with a mother who lived nearby and was facing a similar situation with her injured child. The two families have developed a strong relationship and turn to each other for support and education.

3. Sam’s parents also contacted FIA after hearing about it from two different sources. First, his CSHCS case worker told his parents that they could receive transportation reimbursement through FIA. In addition, after his mother quit her nursing job to stay at home and care for her son full-time, an accountant advised that she may qualify for income through FIA. So his parents contacted FIA and a representative came to their home to determine eligibility and calculate costs. His parents were required to complete a timeline of the time his mother spent caring for him and the different tasks involved with that care. She now receives $1,700 a

month and was paid retroactively for a couple months prior to her approval. FIA arranged for a case worker to visit the home every six months. Sam's mother uses part of her FIA income to pay for a home helper that visits five days a week.

Although Sam's parents feel very fortunate to receive funding through FIA, they are unsatisfied with their experience at FIA. They are upset that FIA staff did not initially tell them about services that they may be eligible to receive. They were shuffled from one person to the next, berated for completing paperwork incorrectly, and told by staff that FIA had too many cases to handle and therefore could not devote time to their case.

4. Sam also receives Medicaid as a secondary payor for health care. So far, his family has had no problems getting Medicaid to pay their son's claims.

5. Finally, the school system has played a major role in Sam's life after his injury. While receiving inpatient rehabilitation, he had a psychological evaluation and was referred to a program run by the local intermediate school district. Through this program, he has received at-home physical therapy, which he will continue to receive through the summer, and "parapro" assistance to complete the two and-a-half credits he needed to receive his certificate of completion. This school-funded service, overseen by special education, provided him with an assistant who stayed by his side throughout the half-day he attended school and helped him with assignments and other needs.

6. Although Sam is not yet ready for a job, his mother anticipates he will be ready in about a year and will seek assistance through the intermediate school district. Until then, his mother would like him to focus on his physical therapy.

Unfulfilled Needs

- Behavioral health services. After Sam's injury, he began displaying delusional behavior. He also did not understand his physical limitations. His parents took him to a psychologist, which they paid for out-of-pocket because their insurance policy denied the claim. He now receives neurobiofeedback therapy, which was originally paid by insurance but is now paid for by his parents. His mother believes that he has benefited from this therapy and would like to contact the local CMH to find out if he is eligible for additional services. She only recently learned about CMH through the school system and does not know if her son is eligible for services. She does not feel that he would benefit from support groups due to his physical and cognitive limitations.

- Additional home modifications. Sam's parents would like to add on a room to their home so Sam will have his own bedroom rather than staying in the dining room. They do not have the money to do this and hope they can find some type of charity assistance to carry out this plan.

- TBI resources. Sam's parents would like additional resources for individuals with TBI. They are unfamiliar with the public agencies and do not know what type of respite care is available in their area. They rely heavily on family for assistance. They also feel that social workers at hospitals and rehab facilities are not fully aware of TBI specific resources. For example, his

> parents did not know anything about BIAMI until they met someone who had attended a seminar. After that, they attended the annual conference and are very happy with the information they received during the conference.

Provider Views: Feedback from the Front Line

Methods

Data in this section come from two sources: 1.) a mail survey sent out by MDCH to all CMH, FIA, and MI Choice Program offices in March 2002; and 2.) key informant interviews with providers from these same agencies covering the following participating pilot counties: Alger, Allegan, Berrien, Branch, Calhoun, Cass, Delta, Kalamazoo, Lenawee, Livingston, Luce, Marquette, Monroe, St. Joseph, Van Buren, and Washtenaw.

The MDCH survey was designed to collect agency-level information to identify the awareness and understanding of TBI among agencies and to identify problems found by agencies serving persons with TBI.

CMH, FIA, and MI Choice Program employees in the three project pilot regions were interviewed to identify service coordination issues and service gaps in the systems from the perspective of state staff and to verify staff opinions on what makes service delivery difficult for cases involving TBI. The interviews were done over the phone by MPHI and included closed and open-ended questions. The interview participants were chosen by members of the pilot committees and had to have some experience serving individuals with TBI.

Results from 20 service provider key informant interviews were reviewed. Participants included five providers in the UP, eight in the Southwest region, and seven in the Southeast region. Adult Services (n = 4) and Eligibility (n = 2) workers from the FIA, Developmental Disabilities (n = 7) and Mental Illness (n = 2) workers from CMHSP, and MI Choice Program agents (n = 5) were interviewed.

Job functions of the 20 key informants include intake, needs assessment, eligibility determination, and care planning/case management. All but one provider interviewed served in more than one of these functions.

Fourteen (74%) of the respondents were familiar with TBI efforts being pilot tested in their area. Eight of the respondents (40%) had attended a TBI Project training in their local area prior to participating in the interview. Three respondents were interviewed prior to any TBI trainings in their local region.

Results

This section provides results from the MDCH mailed survey and the key informant interviews in the following order: 1) provider description of how individuals with TBI enter and flow through the public service system in Michigan, and 2) provider evaluation of the gaps and problems, as well as good points, of the system.

Flow Through the System

To determine where persons with TBI are entering the public service system, state offices were asked whether or not they receive referrals from the organizations and agencies listed in Table 4.1 below.

Table 4.1. Percentage of agency offices that receive referrals from listed organizations

Agency office	**CMH (n=37)**		**FIA (n=73)**		**MI Choice Program (n=4)**	
Organization	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
Hospital	75%	25%	84%	16%	75%	25%
Family physicians	68%	32%	68%	32%	75%	25%
Area CMH	N/A	N/A	73%	27%	N/A	N/A
Area FIA	65%	35%	N/A	N/A	75%	25%
Psychologists	45%	55%	44%	56%	0	100%
School districts	43%	57%	49%	51%	0	100%

From the responses summarized in Table 4.1, it looks like persons with TBI often enter the public service system after being seen in the hospital or by a family physician. Responses also show many referrals between the public service agencies: CMH, MI Choice Program, and FIA offices. When asked how often FIA and CMH offices collaborate, or work together with, other organizations to find services for persons with TBI, respondents to the MDCH survey indicated that FIA offices collaborate “almost always” with home care providers (42%), followed by rehabilitation providers (17%), and residential programs (16%). Survey responses showed that CMH offices collaborate “almost always” with residential programs (18%) and home care providers (18%).

Key informants who participated in the telephone interviews were asked to identify agencies that they are typically in communication with, make referrals to, or receive referrals from, when assisting individuals with TBI. See Table 4.2 for a list of agencies and the percentage of respondents that coordinate with each one. In addition to the agencies listed in the table, informants mentioned collaboration with hospitals, rehabilitation agencies, Centers for Independent Living, and primary care physicians. Seven out of eight key informants from CMH reported that they “typically” make referrals to, or receive referrals from, substance abuse services. In contrast, none of the five FIA key informants, and only one of five MI Choice agents, reported “typically” making referrals to a substance abuse agency. Similarly, all eight CMH respondents reported making referrals to, or receiving referrals from, the jails or justice system, while none of those interviewed from FIA or the MI Choice Program reported that they “typically” coordinate with the jails or justice system when serving individuals with TBI.

Table 4.2. Percentage of respondents making and/or receiving referrals from listed organizations

Agency	Yes	No
*FIA (n = 13)	92%	8%
Social Security (n = 18)	72%	28%
*CMH (n = 11)	55%	45%
MRS (n = 18)	50%	50%
Jails/Justice System (n = 18)	44%	56%
Substance Abuse (n = 18)	44%	56%
*MI Choice Program (n = 13)	38%	62%
Special Ed/School System (n = 18)	28%	72%
MI Works! (n = 18)	17%	83%

*Only applicable responses were included for calculating percentages - respondents were not asked if they make referrals to their own agency.

Unique Needs of TBI

Based on experience, the twenty key informants were asked to judge whether individuals with TBI were more likely than other types of clients to need services from more than one agency. Twelve respondents (60%) felt that TBI clients were more likely to need services from more than one agency, while the remaining eight felt that TBI clients were less likely or about the same as other clients to need services from more than one agency.

Many reasons were given to explain why individuals with TBI are unique in needing services from more than one agency. One respondent explained that many persons with TBI must contact every agency to receive needed services because “there are so many different problems that individuals with TBI have.” Another person described as a common situation, a young adult who lost the ability to work and earn an income due to a brain injury. This consumer spent all her savings to cover living expenses while waiting for services. She needs assistance for herself and her children everyday and will likely need services indefinitely.

Based on key informant responses, the variation of problems among individual cases makes them nearly impossible to treat with a “cookbook” program; the combination of services that meet one individual’s needs will not necessarily meet the needs of other persons with TBI. The following was one respondent’s comment: “There might be some individuals who can prepare food, but not without supervision. There might be some individuals who can go to classes at a community college, but will never drive an auto. There might be someone who could work in a woodshop if supervised. There are so many gradations.”

Although the question was not asked directly, six key informants volunteered that there is a need for services that are specific to TBI. One key respondent explained that individuals with TBI currently receive the same services as individuals with other disabilities. And while those services may be help to treat the symptoms of TBI, they do not address TBI as a whole. Several respondents from the UP noted the lack of a TBI-specific rehabilitation facility in the region; one respondent commented that, “in a rural setting such as the UP, sometimes services that would be available in another area just don’t exist.” Respondents in all pilot areas expressed a need for long-term residential placements for younger adults with TBI that are more appropriate than nursing homes.

Four respondents stressed that having help from a family member, advocate, or case manager is key to getting needed services for individuals with TBI. Due to memory problems, difficulty communicating, anxiety, or other impairments, even individuals with mild TBI may not be able to find services without significant help. Individuals with TBI may not remember to show up for an appointment with a service provider due to memory problems caused by the injury and, as a result, will not complete the application or assessment process. Service providers may not realize that individuals with TBI may have difficulty communicating and may require additional time to express their needs. On top of that, service providers do not have the resources or time necessary to determine the needs of individuals with TBI.

Another way in which individuals with TBI are unique is, in some cases, the presence of cognitive and/or behavioral impairments without any physical limitations. For instance, a person is eligible for Home Help services only if they meet all eligibility requirements, including a need for “hands-on” assistance in one or more ADL. Persons with TBI often have cognitive difficulties and do not require “hands-on” help, but do still require assistance with ADLs. The “hands on” rule may limit the eligibility of persons with TBI for such needed services. One key informant described a client whose only need was a simple verbal cue once a day that enabled the client to live independently, yet this person technically was not eligible for services.

Reason for Communication Between Agencies

Key informants were questioned on the reasons that they communicate with other agencies regarding cases of TBI and how often for each reason. Responses are summarized in Table 4.3 below.

Table 4.3. Reasons for communication with other public agencies	In most cases	More than half the time	About half the time	Less than half the time	Rarely or Never
To obtain more information about a client’s history (n = 17)	8	4	2	2	1
There are service gaps for individuals with TBI requiring inter-agency, individualized solutions (n = 17)	6	3	5	2	1
The client’s service needs outstrip program caps in the referring agency, necessitating cost sharing (n = 17)	3	4	1	5	4
To obtain additional complementary services that are not offered by the referring agency (n = 16)	3	2	8	1	2
The referring agency does not feel the services it provides are appropriate for the person with TBI (n = 15)	3	2	4	2	4
The individual does not meet the referring agency’s eligibility requirements (n = 17)	3	1	4	6	3
There are no open program slots in the referring agency (n = 17)	0	4	2	2	9

Coordinating to obtain information about a client's history was the most common reason for communication with other agencies. Service gaps that require interagency, individualized solutions were identified as the next most common reason for coordination with 14 out of 17 or 82% of key informants stating that they coordinate "about half the time" or more for this reason. When asked for more information on service gaps for individuals with TBI, responses included: eligibility is limited if the level of impairment is not severe; there is a lack of general care coordination; lack of independent living services; lack of transportation services; lack of understanding of needs of individuals with TBI (patience, taking extra time to listen); and individuals with TBI need a greater intensity of services.

Some comments in answer to the above questions included the following from an FIA Adult Services worker: "When clients get to me, typically they have already been through many agencies and have not gotten needed services." Another FIA worker stated that they "don't cost share with CMH because they [CMH] fear the cost of TBI cases." A CMH worker noted that they "are unable to provide services because [TBI] does not qualify under the current mental health code. [Individuals with] TBI [are] not perceived as DD (developmentally disabled) [so we] send [them] to FIA."

Several respondents commented that they find it necessary to coordinate more for cases involving TBI if the clients do not qualify for services for other reasons, such as mental illness or a physical disability. Respondents also commented that it is typically easier to provide services if clients are over 65 years of age and eligible for Medicare and other senior services.

Provider Evaluation of the Public System

In the 2002 MDCH TBI survey, providers were asked whether or not they felt TBI was a problem adequately addressed by their agency. The majority of CMH and FIA respondents do not think so. Responses by agency are broken out below in Table 4.4.

Table 4.4. Agencies adequately address TBI

Agency	Yes	No
CMH (n = 34)	13 38%	21 62%
FIA (n = 77)	25 32%	52 68%
MI Choice Program (n = 4)	3 -*	1 -*

* Percentages not calculated when n < 5.

Among the 34 respondents from CMH offices, only one stated that they have a specific person to whom all individuals with TBI are directed. Seven of the 77 FIA offices responding indicated that they have a person to whom cases involving TBI are referred. None of the four MI Choice Program offices that responded have a specific person to whom cases of TBI are referred. When asked how many individuals with TBI each office assisted in one year, responses ranged from zero to 75, with a large number of blank responses or answers of "unknown" (42%).

Service Gaps

An open ended question to key informants about the public system asked for the three most significant unmet service needs for persons with TBI. Transportation was named as the most significant unmet need for individuals with TBI. Providers cited issues with transportation as either the Medicaid payment being too low or simply a lack of available transportation services in a community, especially in the UP. Case management or advocacy was cited as the second most significant unmet need for individuals with TBI. Responses are summarized in Table 4.5.

Table 4.5. Most significant unmet service needs for TBI (n=18)

Unmet Service Needs	Number of responses
Transportation	6
Case management/advocacy	5
Employment services	4
Medicaid (not eligible due to income requirements)	4
Medical care	4
Services specific to TBI	4
Affordable housing	3
Education about TBI	3
Independent living services	3
Long-term mental health needs	2
Residential placement	2
Substance abuse services	2
Behavioral services	1
Financial assistance	1
Home delivered meals	1

Interagency Coordination

When asked to describe a situation where service coordination among multiple agencies went well, 13 out of the 20 respondents were able to provide a positive example. Reasons given for the successful coordination included (number of responses denoted in parentheses): agency staff made an extra effort to coordinate services with other agencies (7); providers were knowledgeable about TBI and the local resources available for persons with TBI (6); good communication between all involved parties (5); one agency took the lead/responsibility for coordinating services (5); a case manager took the lead in coordinating services (4); and getting to know clients better to understand their needs (1). In one case where coordination went well, the respondent noted that they “even used the *Michigan Resource Guide for Persons with Traumatic Brain Injury and Their Families*,” which was produced by the TBI Project. Another respondent, who is a member of one of the pilot interagency teams, stated that the team was helpful in finding appropriate services for one client with a severe TBI. One respondent explained that his/her agency stays knowledgeable about available community resources by holding monthly meetings with representatives from several community organizations. One key informant was not able to give an example of coordination that went well, but remembered one case that was “resolved after a lot of hassle.” Another response was that no single case stands out because coordination is “going well generally.” Four respondents were not able to come up with an example when coordination for a TBI case went well.

Twenty-six percent of FIA offices responding to the MDCH survey encountered coordination problems with area CMH offices “almost always,” and 59% of FIA offices reported problems coordinating with CMH offices at least “half the time.” When asked the same question, only 7% of CMH offices reported “almost always” having coordination problems with area FIA offices, and 31% reported having problems “about half the time” or more frequently. The next highest occurrence of coordination problems that CMH offices had was with home care providers; 28% of CMH offices reported problems “half the time,” or “more than half the time.” FIA offices also reported that collaboration problems occur at least half the time with residential programs (20%), home care providers (19%), and local intermediate school districts (19%).

Key informants were asked to rate how often the goals of coordination across public agencies, which were specified by the State TBI Project, are met. Interviewers also asked for explanations of the reasons goals were not achieved. The goals of coordination and participant responses are summarized in Table 4.6. Respondents were most likely to report achievement of the following care coordination goals: coordination of services is person-centered, care plans are flexible, services are planned to complement each other, and service delivery is cost effective. Even so, a substantial minority felt that these same goals were not achieved with regularity. The majority of respondents reported that goals of “no wrong door” and identification of TBI were not frequently achieved. Responses tended to be either achievement or non-achievement, with few responses that goals were achieved “about half the time.” When the data were examined by individual agency, these differing responses were also evident.

Table 4.6. Achievement of goals for interagency service coordination Is this achieved:	In most cases	More than half the time	About half the time	Less than half the time	Rarely or Never
Coordination of services across public agencies should be person centered (n = 17).	9	1	0	7	0
The plan of care should be flexible to meet changing needs over time (n = 17).	8	2	1	5	1
Services should be planned to complement each other (n = 17).	6	3	1	7	0
Cost effective service delivery should be obtained (n = 16).	5	4	2	3	2
Agency staff serving the client know that the person sustained TBI (as this may affect how the service provider interacts with the client as well as which services are most appropriate) (n = 16).	4	2	1	8	1
There is no wrong door: no matter what agency is approached first, the client with TBI will receive the most appropriate services for which s/he is eligible in a timely fashion (n = 16).	1	3	1	7	4

Lack of knowledge was cited as a barrier to every goal of service coordination; twelve respondents commented on a lack of knowledge among service providers and families about available resources for individuals with TBI, as well as a general misunderstanding or lack of understanding about TBI. Another common reason stated for poor service coordination was that no agency is identified as the lead agency or that there is no case manager to serve as the lead in coordination of services between agencies.

Lack of funding and a shortage of staff/time were high on the list of reasons that goals of care coordination are not met. Comments included: “care plans are reactionary, changes are made to put out fires. It is difficult to have a visionary plan given limited time and funds;” “we often don’t have time to be flexible when we’re short staffed and overtaxed.”

Access and eligibility issues were brought up by key informants as significant barriers to service coordination. Examples include unclear guidelines for eligibility, lack of recognition of TBI as a diagnosis by CMH, and “funding guidelines are not followed and are misinterpreted.” The fact that TBI has unique characteristics was recognized as inhibiting achievement of the care coordination goals. For example, lack of follow through is a common problem among individuals with TBI, yet cases are closed when a client does not follow through.

Positive comments included that care is person centered and services are planned to complement each other to the extent services and resources are available. One CMH respondent who recently began using HELPS, a brief TBI screening tool, was “shocked at how many positive [results].” An FIA worker participating in the pilot program was “amazed how many individuals throughout the agency have called me [for advice on TBI cases], CMH is also calling me.”

Barriers to Service Coordination

After the discussion as to why specific care coordination goals were not achieved, service providers were asked to rank the significance of a list of barriers already identified by the project during service provider trainings, consumer trainings, consumer focus groups, and from previous surveys. The leading barriers identified are listed in Table 4.7. Respondents were asked to rate the extent to which they personally experience each barrier as an obstacle to service coordination.

Table 4.7. Barriers to service coordination The following are barriers to service coordination:	A lot	Some	Only a little	Not at all
There is no clear policy on which agency should take a lead role for individuals with TBI (n = 19).	12	5	1	1
Agency staff lack knowledge about the signs and symptoms of TBI (n = 20).	11	7	1	1
Needed services for this population do not exist or are insufficient (n = 19).	10	8	1	0
There is insufficient public funding to pay for services for individuals with TBI (n = 17).	10	6	1	0
Agency staff lack knowledge of services available through other public agencies for individuals with TBI (n = 19).	9	7	2	1
Agency staff lack knowledge about what services would be appropriate for individuals with TBI (n = 20).	8	9	2	1
There is no clear policy on how to handle situations in which overlapping services are offered by multiple agencies (n=18).	6	7	3	2
Agencies do not follow their own eligibility guidelines (n = 19).	1	6	8	4

The majority of respondents rated almost all barriers as occurring “some” or “a lot.” The barrier rated in this manner most often (12 of 19 respondents) was that there is no clear policy for providing services to this population. The next most often occurring barriers were that there is insufficient public funding to pay for services for persons with TBI (94% of respondents) and that there is a lack of staff knowledge about the signs and symptoms of TBI (90% of respondents).

Follow-up questions were typically asked when participants indicated that a given barrier was a problem “a lot” or “some.” The barrier that was rated as occurring “a lot” most often (12 responses) was that there is no clear policy on which agency should take a lead role for individuals with TBI. Further details provided regarding the lack of a lead agency were that this is “a serious problem and why individuals get bounced around. No one knows where to send them.” Another comment was that, if multiple agencies are providing services, how should it be decided who does what without it “becoming confusing?”

Three participants named Substance Abuse and CMH as hesitating to take the lead, or not recognizing that there are problems that need to be addressed. One CMH worker expressed that "having specialized programs within CMH for individuals with brain injury that they could have eligibility requirements for would work a whole lot better."

Several respondents suggested that CMH should be the lead agency, although this question was not asked directly. Related responses included: that CMH should be the lead agency and FIA should provide supportive services as needed; CMH should be the lead agency because TBI is an injury to the brain; it does not make sense that CMH offers services to individuals with TBI under age 22 if they have a qualifying level of need, but not if they are 22 or older with the same needs. One respondent strongly discouraged identifying TBI as a priority population for CMH stating it would "create another pool of individuals and another program that we have to fund…new programs might take away from [existing] programs."

Other comments regarding who should take the lead role in providing services to persons with TBI did not identify one agency as appropriate for serving all individuals with TBI, but suggested policies that would help persons with TBI to get services. "The state should develop a clear direction that includes individuals with TBI in its policy making," one person responded. Another stated, "there should be some sort of policy…and program guidelines on how to get [individuals with TBI] resources."

Conclusions of Consumer and Provider Feedback

Interviews of key informants from FIA, CMH, and MI Choice Programs overwhelmingly confirmed that service providers are passionate about their jobs and constantly strive to meet the needs of their clients. Workers are frustrated by funding and staffing shortages, but are aware of the current economic environment. Lack of knowledge and restrictive policies may force workers to turn clients away or may lead to service provision that is not cost effective or appropriate. Results from the consumer and provider interviews demonstrate that large service gaps exist for this population. Services that do exist are often not accessible to, or effective for, individuals with TBI.

Of the five consumers that were interviewed, all of them received *some* services from public agencies. Additionally, the needs of three of the five consumers seem to have been fairly well met. Although, achievement of service provision required effort, and in one case, substantial activism on the part of family and others to address barriers.

Overlapping themes from the two sets of feedback illustrate the greatest needs as seen by both service providers and consumers, and are discussed below. Again, due to the small number of consumers and providers interviewed, results cannot be generalized to the larger population. (Limitations are described in detail at the end of this section.)

Desperate need for coordination and planning of services and supports for this population

In every interview, consumers mentioned the tremendous need for case management. Not one respondent indicated that they were able to manage their lives without any assistance (including paying bills, completing paperwork, accessing public services, and scheduling and keeping medical and other appointments). In fact, most respondents expressed feeling helpless because they were without a case manager. Guidance in coordinating and planning of services is a critical need for this population because most individuals with TBI need a diverse set of services and many also have difficulty planning or staying organized. Thus, it is unrealistic to expect them to manage themselves or to access public services and funding on their own. Some individuals are able to rely on family members who can act as surrogate case managers; consumers without family or friends nearby are not so fortunate.

"I feel left out in the cold.
I don't know what to do."

While some respondents were assigned a case manager at some point after their injury, either by an insurance company or public agency, most were only temporary. Several respondents discussed how frustrated and helpless they felt once they no longer had a case manager. According to one consumer's former case manager, "This is the <u>one</u> service that would vastly improve these individual's lives."

Likewise, providers felt that cases involving TBI were most successful when an agency or a case manager was identified to lead the coordination of services. Having one person or agency committed to finding the necessary services for an individual was mentioned several times as a reason for successful coordination of services. Additionally, providing a "no wrong door" system of service provision was cited as the goal of successful coordination that was achieved least often. This means that, without a case manager, a consumer may never even get referred to the appropriate agency.

Difficulty accessing public services

"The system was broken. It took [an MDCH official] and others at the top to crack it."

The most widely expressed concern across all consumer interviews was difficulty accessing public services. This was not surprising given that several of the questions directly asked about difficulties accessing services. In many cases, a consumer or his/her family was unable to access particular services unless an advocate, TBI Project personnel and/or pilot project members intervened on his/her behalf.

Some consumers felt that they were given the "run-around" when it came to getting services from CMH. For example, one county CMH office didn't want to accept a case based on the residency of the consumer prior to injury. Additionally, one consumer's family was led to believe that they would be eligible for services and, after waiting several months, were told that they were not eligible. Delays in processing applications and issuing approvals or denials of eligibility were a source of frustration.

Providers from FIA and CMH expressed frustration with the fact that a person with TBI is often treated by CMH if the injury occurred before the age of 22 and meets the developmental disability qualifications, but a person over 22 with a similar injury is not eligible for CMH services unless they have an accompanying severe and persistent diagnosed mental illness. Based on provider comments, persons with TBI often do not meet CMH eligibility requirements, even though they might have significant behavioral and cognitive issues.

As discussed earlier, the FIA Home Help Services program is targeted toward consumers that have a need for “hands-on” assistance in one or more activity of daily living. This limitation possibly excludes individuals with TBI who need verbal cueing, rather than physical assistance, to perform activities of daily living.

Providers cited a lack of transportation services that accept Medicaid payment rates as a significant service gap. Additionally, there are areas in Michigan where no transportation services exist whatsoever, such as rural areas.

Another issue repeatedly raised by key informants is that Medicaid income eligibility levels are too low and exclude many consumers from eligibility for services offered from FIA or CMH. The MI Choice Program allows for slightly higher income levels, but is restricted to persons with a need for nursing home level of care. The TBI Project Team realizes that the current economic environment cannot support a significant increase in the Medicaid caseload, which would be the likely result if the Medicaid income eligibility level were raised.

The general impression gathered while interviewing service providers was that they are typically doing everything they can to provide services to consumers, but that sometimes services simply cannot be provided due to eligibility restrictions. In contrast, more than one consumer described extremely negative interactions with service providers from CMH and FIA.

Training and education

Key informants identified training as the greatest overall need among service providers at the CMH, FIA, and MI Choice Program. Service providers requested additional training on the characteristics of TBI, strategies for working with persons with TBI, and resources available for persons with TBI.

Consumers, in turn, felt service providers did not adequately educate them about TBI or local resources for persons with TBI. For example, several respondents said that after they or a family member were diagnosed with a TBI, hospital staff, social workers and health providers either 1) knew little about other TBI resources in the area (public and/or private) and thus were not able to provide them with much information; or 2) simply recommended a nursing home without considering other options or referring them to a public agency for further assistance. Consumers also noted that care facility staff lack experience working with individuals with TBI. Furthermore, several respondents stated they felt helpless after learning they or their family member had a TBI. They did not know where to go for help, who to contact, which services they might obtain, or which care facility options to explore. Based on feedback from both providers and consumers, there is a great need for education about TBI among public agency workers, care facility staff, and consumers.

Needs specific to individuals with TBI

One theme apparent in the results was the need for services that are specific to individuals with TBI. Key informants stressed the need to treat TBI as a whole rather than treating each symptom individually. Several steps factor into the process of treating TBI as a whole, beginning with identification. Particularly in less severe TBI cases, invisible or delayed effects can act as barriers in a number of ways. If an individual is not diagnosed with a TBI, he or she may not immediately seek medical care. For example, one consumer was involved in a motor vehicle crash and was treated in an emergency room for multiple injuries, but was not diagnosed with a TBI. Months later, after her life had begun spinning out of control, she was medically diagnosed with a TBI.

One barrier to getting services that key informants in the UP identified as a regional issue was a lack of rehabilitation facilities that specialize in TBI. Currently, residents of the UP that experience a more severe TBI must travel long distances to receive appropriate rehabilitation services. In all regions, providers cited a lack of appropriate residential placements as a service gap for individuals with TBI. One consumer commented that most facilities are not properly equipped or do not employ staff that are trained to adequately handle TBI consumers.

Individuals fall through the cracks of the no-fault automobile insurance system

Three of the five TBI consumers interviewed were injured in motor vehicle crashes. Two of them had automobile insurance at the time of their crash. Yet neither of them were able to rely solely on Michigan’s no-fault automobile insurance system to cover medical care and other expenses related to their injuries. Instead, they have faced a number of barriers to funding for medical care and rehabilitation, transportation, housing and living expenses, home help, and other costs related to their TBI.

In conclusion, while both providers and consumers expressed frustrations with the CMH system, it appears that providers are, for the most part, following the current eligibility policies. Individuals with TBI obviously are not getting all of their needs met by the public service system, yet, given the current environment with tight budgets and lowered staffing, service providers are doing what they can to provide services to individuals with TBI. Perhaps the first steps toward improving service delivery should be to address two needs strongly expressed by both consumers and providers: case management and education of consumers and providers.

Limitations

As with all case studies, the results from the consumer interviews may not be the same in the larger population. In addition, a limited number of interviews were conducted and could represent a portion of the population having greater than average difficulty accessing services. However, case studies can provide a wealth of detail not often obtainable using other research methods.

The consumer population under study is unique (some have cognitive difficulties, memory problems, difficult speaking, etc.). Self-report data may not be entirely accurate or events may have been reported out of their true order of occurrence. Where possible, family members were asked to clarify or elaborate. Nevertheless, cases in which the true sequence of events seems jumbled or confused illustrate well the difficulty individuals with TBI may have in negotiating the system and reflect their increased need for help with coordination of services.

Selection of service provider participants may have been biased, as most pilot site members asked to provide names of workers to interview were supervisors. The supervisors may have chosen their most knowledgeable or most proficient workers to participate in the study. Additionally, service providers may have been reluctant to state their opinions freely, despite the anonymous and aggregated presentation of the results. For these reasons, and because of the small sample size, the results are not generalizable to all service providers.

5

RESULTS OF A PILOT TEST USING ENHANCED SERVICE DELIVERY PROTOCOLS

As the TBI[1] project gathered data on incidence of and service use for TBI in Michigan, a structure was set up to guide the project's educational efforts and pilot testing of service delivery improvements. Michigan's TBI pilot efforts focused on three initiatives: 1) developing and disseminating information about TBI and currently available services; 2) improving identification of people in the public service system with TBI; and 3) improving interagency coordination of care for people with TBI. This section summarizes these efforts and evaluation results.

Pilot Testing Methodology

Three regions were identified to serve as pilot sites. Leaders within CMHSPs, local FIA offices, and MI Choice Program agencies approved participation and named staff to serve on local pilot committees. The three regions were: 1) Upper Peninsula (UP), with participating agencies located primarily in Marquette and Delta Counties; 2) Southwest Michigan (SW), with participating agencies located primarily in Calhoun, Van Buren, and Allegan Counties; and 3) Southeast Michigan (SE), with participating agencies located primarily in Washtenaw, Livingston, Lenawee, and Monroe Counties. The three pilots did not begin at the same time.

The following process was used to develop and test project products. First, informational materials about brain injury and existing services were developed. Provider and consumer materials were developed together. All educational products for consumers and providers were developed with input from consumers and providers through TBI project workgroups. Feedback on key documents was also obtained through focus groups and surveys.

A one-day provider training session was developed by BIAMI to train providers in local public agencies. Trainings were presented at two pilot sites during the Fall of 2002: 1) UP (Marquette), and 2) SW (Lawrence and Battle Creek). These training sessions and later meetings were also used to include participating pilot site agencies in a discussion of improvements that could be made at a local level to the public service delivery system.

The results of the first round of provider training and subsequent community-level discussions led to the revision and refinement of educational products, as well as the development of the following enhanced service delivery protocols: a process and tool to screen clients for a history of TBI and interagency care coordination teams to take referrals of difficult-to-serve clients with TBI. A second training was then developed and offered in the two participating pilot sites in the Fall of 2003.

These provider trainings also shared information about the enhanced service delivery protocols.

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[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

It was also at this time that a third regional pilot site came on board encompassing the Southeastern counties of Washtenaw, Livingston, Lenawee, and Monroe.

Enhanced service delivery protocols were evaluated through tracking the implementation process for protocols in the pilot sites, collecting information on outcomes for consumers served using these protocols, and obtaining feedback from frontline agency staff. Efforts to contact and interview consumers met with limited success, as a result consumer outcomes presented come mostly from service provider reports. This section of the report presents summary information and evaluation results for the educational products and enhanced service delivery protocols developed and tested by the TBI project.

Educating about TBI and Available Services

The project developed several different educational materials in order to improve access to information and promote services for individuals with TBI. The materials were assembled with the guidance of the appropriate state agencies, private organizations, TBI advocates, and consumers. Materials were prepared and distributed for both consumers and public service providers.

The following products were developed for public agency service providers:

- **"Important Information about Working with Persons with Brain Injury and their Families"**

This brochure provides information about brain injuries that may help service providers assist individuals with TBI. It includes the definition of TBI, helpful tips, and the contact information of helpful resources. This document is available in English, Arabic, and Spanish.

- ***Traumatic Brain Injury Provider Training Manual (Manual)***

BIAMI (a project partner) developed the *TBI Provider Training Manual* to be distributed at all pilot site trainings. The purpose of the *Manual* is to assist agencies with meeting the needs of people with brain injury. The *Manual* consists of three sections: an Introduction to Brain Injury, Characteristics of Brain Injury, and Suggestions for Working with People with TBI.

- ***Access Guidelines to State Services for Persons with Traumatic Brain Injury (Access Guidelines)***

This document summarizes for providers what services are offered by key agencies, the eligibility criteria for those services, and how to contact the agency office. Services are summarized in tables; flow charts summarize intake and eligibility determination processes. The *Access Guidelines* describe services relevant to individuals with TBI from four main public agencies:

- ▸Michigan Department of Community Health – Mental Health and Substance Abuse Services Administration
- ▸Family Independence Agency (FIA)
- ▸Michigan Department of Community Health – Long Term Care (LTC)
- ▸Michigan Department of Education – Office of Special Education and Early Intervention Services

- **Service Provider Training**

As described above, service provider trainings were held in two rounds. Materials and presentation were revised for the second round trainings that were held in the UP (Marquette, Houghton, Sault Ste. Marie) and in the SW Pilot Site (Kalamazoo) in Fall 2003. Trainings were conducted in the newest TBI pilot site (the SE) in Spring 2004, with all-day trainings in Howell and Ann Arbor. A shorter version of the training (2-2.5 hours) was tested in Monroe and Adrian.

The full-day training consists of an overview of the project; introduction to brain injury, including definitions, significance, and severity of brain injury; consequences of TBI; and suggested interaction strategies. The afternoon portion of the training is the introduction of the enhanced service delivery protocols: the *Access Guidelines*, the HELPS Screening Tool, and local resources for referral. The basic training package allowed for changes to address local needs. For example, two counties elected to have a panel of local service providers present services available in the area.

In order to conduct the shorter training, the material presented was condensed. In other words, the same content as the full day training was presented, but in a shortened version.

The following products were developed for consumers:

- **"Resources for Persons with Brain Injury and their Families"**

This brochure provides information about brain injuries that may assist individuals with brain injury and their families to better understand brain injury and obtain services. The brochure includes the definition of TBI, characteristics of brain injury, available support services, and tips for finding supports. This document is available in English, Arabic, and Spanish.

- ***Michigan Resource Guide for Persons with Traumatic Brain Injury and Their Families***

The *Resource Guide* is not a directory, but rather provides critical contact points for statewide organizations and tips for finding local agencies and organizations. The goal of the *Resource Guide* is to help link people with state and local services. There are six sections. The first section gives an overview of TBI and supplies a list of important organizations that provide general information, advocacy, and other services. The second section provides information on the types of services commonly needed that are available in Michigan. Section three gives information on potential sources of financial aid to cover needed services. Section four provides an overview of the main agencies and resources described throughout the *Resource Guide*. The fifth section lists the contact information for all agencies and resources. The last section is a glossary.

Initially, 5,000 *Resource Guides* were printed and distributed. The TBI Project Marketing and Dissemination Workgroup developed a statewide list of various state agencies, advocacy organizations, qualified health plans, hospitals, and independent living centers to send materials. The first 5,000 copies were distributed within a year, so an additional 5,000 *Resource Guides* were printed and are being distributed upon request. The *Resource Guide* was also translated into Arabic and Spanish. All translated versions have been made available for free on the MDCH website.

Methods for Evaluating Educational Products

All products were developed with project workgroups and the Advisory Committee. Thus a diverse group of consumers, agency personal, brain injury experts, and advocacy organizations had input throughout the process. In addition, the following formal evaluation methods were employed.

Feedback from Pilot Site Participants

At the conclusion of the pilot site activities, a survey was distributed to key pilot site participants asking for feedback on all project activities. This evaluation addressed specific products and activities of the project and requested feedback to make improvements to the products, if necessary. Additionally, a questionnaire was developed and sent out to HELPS screeners for feedback on the screening tool. Finally, members of the Interagency Care Coordination Teams were interviewed to provide feedback on how these Teams worked.

Provider Training Evaluation

Training attendees were asked to complete an evaluation addressing the training format, presentation, and usefulness of the materials presented. In addition, for the first round of training, a series of knowledge questions were included on pretests and posttests to measure improvement. Three months following the first set of pilot site trainings, a survey was mailed to training attendees to judge the use of project materials since the training and retention of information.

Mailed Surveys

In November 2002, three months following the statewide distribution of the *Michigan Resource Guide for Persons with Traumatic Brain Injury and Their Families*, 400 surveys were sent to the *Resource Guide* recipients soliciting feedback on the *Resource Guide* and consumer brochure. After several follow-up letters, 64 completed surveys were returned for a response rate of 16%.

Focus Groups

Two consumer focus groups were convened prior to the printing and distribution of the *Resource Guide*. One consumer focus group was held in Detroit and the other in Petoskey, resulting in feedback from geographically and socially diverse perspectives. Feedback was incorporated into the final version of the *Resource Guide*.

Evaluation Results of Project Educational Efforts

This section summarizes the evaluation findings of all educational materials developed by the TBI project. To gain an idea of the relative value placed on project products by pilot site participants, pilot site representatives were asked to rate the value of each, “very valuable,” “valuable,” or “of limited value”. Table 5.1 presents a summary of their responses. Most people surveyed were not familiar with the data collection and analyses project activities. Educational materials prepared as part of the grant were very well received, especially the *Access Guidelines* and brochures. The TBI screening tool and the pilot site care coordination efforts received mixed reviews. When asked to comment on the HELPS screening tool, one respondent stated “I am concerned that screening obligates [an] agency to connect [a] person with a positive screen to resources that are not available.”

Table 5.1. Summary evaluation of project efforts by pilot site participants

TBI Grant Product or Activity N=13	Number Responding			
	Not Familiar with Product	Very Valuable	Valuable	Of Limited Value
Michigan Resource Guide for Persons with TBI & their Families		5	8	
Consumer brochure	2	5	6	
Provider brochure	2	6	5	
Access Guidelines	2	8	3	
TBI Provider Training Manual	2	6	5	
Provider training session	2	8	3	
HELPS screening tool	1	6	3	3
Local interagency Care Coordination Teams	3	3	3	3
Data analyses of incidence and risk factors of TBI in MI	2	3	8	
Data analyses of Medicaid costs and service use for TBI	5	1	5	1
Data analyses of CMSHP service use by people with TBI	5	1	5	1

To date, 360 service providers have attended trainings offered in three pilot regions. Each attendee was provided with additional copies of training materials and instructed to share them with colleagues. The provider training was found to lead to a statistically significant increase in knowledge of attendees. Training sessions were rated very highly by participants. Attendees were asked to rate each section of the training, including presentation and content, on a scale of one to five, with one being equal to poor and five being equal to excellent. Table 5.2 shows the summary scores by content section from the second round of trainings. Additional information on the trainings is available in Appendix D.

Table 5.2. Summary of training evaluations, offered Fall 2003 – Spring 2004

Training Site	I. Overview of TBI	II. Overview of Access Guidelines	III. HELPS Screening Tool	# of Attendees	# of completed evaluations
Houghton	4.19	3.36	3.73	15	15
Marquette	4.40	4.14	4.35	16	10
Sault Ste. Marie	4.38	4.10	4.01	31	17
*Lenawee	4.32	3.87	Not part of training	47	32
*Monroe	4.43	4.26	Not part of training	36	31
Livingston	3.66	3.69	3.58	34	23
Washtenaw (WCHO)	4.31	3.69	4.10	57	47
Kalamazoo	4.32	4.07	3.85	33	26
* Shorter version of training					

A follow-up survey to the first round of trainings asked attendees to comment on how often they had referred to the *Access Guidelines* and *Provider Training Manual* and how useful they found the documents to be. Of approximately 88 surveys sent out to training attendees (64 surveys were completed and returned), 10 respondents reported referring to the *Access Guidelines*. Of those 10 people, 6 people found them to be "very useful" overall. Seven people found the tables/overviews of services to be "very useful". Six people found the descriptions of services to be "very useful". Six people found the determination of needs and eligibility section to be "very useful". Six people responded that the flow charts and decision trees were "very useful". Eight of these ten people have referred to the *Access Guidelines* to answer a question or to try to find services offered by another agency. Eight of these ten people responded that they now have a better understanding of the services offered and determination of needs for other agencies.

The same survey asked people to comment on the *Provider Training Manual*. Of the 64 respondents, 29 (45%) stated that the Usefulness of Brain Injury Characteristics section in the *Provider Training Manual* was "very useful" or "somewhat useful". Twenty-four respondents found the Suggestions for Working with TBI section to be "very useful" or "somewhat useful".

The *Resource Guide* has been very popular with consumers and providers alike. In response to a mailed survey soliciting feedback on the *Resource Guide*, a majority of survey respondents (87.5%) stated they found it to be useful. Of the 64 respondents, 57 (89%) gave the *Resource Guide* to their staff. At the time of this survey, 19 had given the *Resource Guide* to consumers, with 14 respondents (22%) stating they had not yet had the need to give to consumers. Survey comments regarding the *Resource Guide* included: "very clear, concise," "easy to follow," and "well chosen info".

The project has also received a lot of praise for the *Resource Guide* from other people who have used it. The *Resource Guide* has been distributed at two BIAMI Annual Conferences. Multiple consumers and providers have commented on how helpful and easy the *Resource Guide* is to use. One consumer even needed a new *Resource Guide* as hers was falling apart from so much use!

Screening for TBI

Agency staff participating in the pilot sites expressed the need to better identify clients with TBI. Therefore, a literature search was conducted to identify a brief TBI screening tool. No published results were found on any short tools, so a five-question tool that had been developed by staff of the International Center for the Disabled (the HELPS tool) was modified by the project to reflect recent recommendations by the CDC on the diagnosis of TBI. A nationally recognized expert in TBI was consulted regarding the modifications to the HELPS tool (Wayne Gordon, personal communication, April 16, 2003).[2]

The screening tool is referred to as the HELPS screening tool, with each letter in the acronym HELPS serving as a question prompt (please refer to example in Appendix E). The screening tool questions if a consumer has ever been hit on the head or hit their head; ever visited an emergency room because of a head injury; experienced a period of being dazed or loss of

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[2] Dr. Gordon also communicated that he thought a much longer tool was necessary to get useful information and avoid a high level of false positives.

consciousness; experienced problems in daily life, such as headaches and dizziness; and had any significant sickness, such as brain tumor or stroke. A positive screening result requires a consumer to answer yes to an event that could have caused a brain injury, yes to a period of loss of consciousness or of being dazed, and the presence of two or more problems. Included on the instructions for the use of the HELPS Screening Tool are local resources that provide services to individuals with TBI. In addition, information is provided on how to obtain consumer educational materials produced by the Project.

Agency screeners were provided with a form to track their use of the HELPS screening tool. This information was reported to staff at MPHI each month. In a few cases, agency screeners were able to obtain consent forms for call-backs from individuals who screened positive. Individuals providing consent were contacted several months following their encounter with the public agency to determine if they have been diagnosed by a physician as having a TBI and if necessary services were ever obtained. Of the seven consent forms obtained, only one person was available to discuss her situation. Inability to follow-up with consumers meant that we were unable to determine the accuracy of the HELPS screening result.

Table 5.3 displays the number of individuals screened and the number of positive results as reported by pilot site agencies. Agencies comprising the pilot sites did not choose to use the HELPS screening tool in the same way, nor did all begin use at exactly the same time. Consequently, the month in which the screening tool was first used, the number of screeners per agency, the number of clients screened, and the proportion of positive results all varied by agency. Due to staff shortages and heavy workloads, some agencies actively participating in the pilot sites were not able to use the screening tool and other agencies elected to narrow the screening criteria, as it would not be possible to screen everyone at intake. For example, some providers chose to screen all consumers they came in contact with, while others screened only consumers who presented with a known head trauma. Some agencies decided to ask the first question and only if the consumer answered yes would they administer the rest of the screening.

Table 5.3. Use of HELPS screening tool in pilot sites

County	Pilot Site	Time Period	Number of Individuals Screened	Number of Positive Screens	Ratio of Positive Screens to Total Screens
Screened all individuals at intake					
Allegan CMH	Southwest	11/1/2003 to 3/31/2004	567	28	1/20
Marquette Waiver	UP	7/21/2003 to 4/30/2004	320	0	0
Escanaba Waiver	UP	8/1/2003 to 4/30/2004	160	3	1/53
WCHO Access	Southeast	2/1/2004 to 6/1/2004	758	70	1/10.9
Washtenaw Homeless Shelter	Southeast	3/8/2004 to 6/7/2004	123	36	1/3.5
Washtenaw AAA-1B	Southeast	3/26/2004 to 5/31/2004	22	3	1/7.3
Screened individuals who answered yes to: “have you experienced trauma that might have resulted in brain injury?”					
Summit Pointe (Calhoun CMH)	Southwest	12/1/2003 to 4/30/2004	116	74	1/1.5
Screened individuals with known head trauma or no other explanation for difficulties					
Marquette CMH	UP	8/1/2003 to 4/30/2004	32	7	1/4.5
Screened individuals applying for specific programs or services, or a specific population					
Branch FIA	Southwest	12/1/2003 to 4/30/2004	2	2	1/1
Van Buren FIA	Southwest	9/1/2003 to 4/30/2004	16	8	1/2
Washtenaw MRS	Southeast	2/1/2004 to 5/30/2004	14	11	1/1.3

Evaluation of HELPS Screening Tool

Agency screeners in the three pilot sites were given the opportunity to provide feedback on the screening process and the tool. A brief survey was conducted to determine the use of the screening tool and how easy it was to score and administer, the result of positive screens, how well the pilot site grant goals were achieved, and the value of the HELPS.

As agencies implemented the tool at their own discretion, screeners were asked who was screened. Only 13 (57%) respondents reported administering the tool to everyone who comes to the agency for services. The other 10 respondents indicated that the tool is used in situations such as when a person has unexplained problems or a known head trauma.

Of the 23 respondents, 20 (87%) stated that the tool was easy to administer and 17 (74%) found the tool easy to score. Two survey respondents had yet to use the tool. Even though most respondents found the tool easy to use and score, 8 respondents (35%) felt that the use of the tool did not completely rule out the possibility of a TBI. In other words, just because a client screened negative on the screening tool does not mean that the person does not have a TBI and vice versa. Five respondents stated that because clients cannot always recall their history or are unwilling to share it, as in the case of the elderly or substance abuse clients, a TBI cannot be ruled out.

Eight respondents (35%) answered that they did not perceive any benefits for clients as a result of the screening. However, three of these respondents commented that they had no contact with the consumer beyond the screening and half of the eight responses are attributed to one pilot site. Five respondents elected not to answer this question. Seven respondents (30%) stated that clients did in fact benefit from the screening; perceived benefits included: increased awareness of TBI, acquisition of additional information and history from consumers, increased referrals to direct service providers and, if all resources were exhausted, the results of the tool could aid in getting services. One respondent commented that: “I feel this tool has helped us to start telling about the needs of these consumers.” The lone consumer with whom MPHI was able to follow-up with after a positive screen said that after being screened by an FIA worker, she was referred to her family doctor. The doctor diagnosed her as having a TBI and she was able to secure financial assistance.

Screening results have been used in varying degrees across pilot sites. A SW Pilot Site CMH conducted a chart utilization review of individuals screened to determine if a TBI was ever diagnosed or if services were ever acquired. It was determined that a note was made in the client’s file, but it did not appear to be taken into consideration in the actual treatment or in doing further assessments. In the SE Pilot Site, a local group is planning to follow-up with positive screens to see if TBI was diagnosed. The group is also discussing what protocols and practices should be in place for follow-up on positive HELPS screenings to determine implications for treatment for a given individual. The survey of HELPS screeners found that only three respondents were aware if cases were actually diagnosed with a TBI. Two respondents routinely provided the results of the HELPS screening to the care planner and two respondents made a note of the screening in the client’s file.

Four respondents indicated that the addition of another form to fill out (the HELPS Tool) and the additional time required was a drawback. Additional drawbacks to the screening tool included: “it was embarrassing asking the elderly such generalized and simplistic questions” (one respondent); the tool was too “intrusive” to clients (one respondent), and many clients do not want to answer the questions (one respondent). Two other respondents commented that, while it was helpful to know that a client might have a TBI, there was nothing different that could be done to provide services.

Overall, 16 respondents (70%) stated that it would be worthwhile to permanently incorporate the HELPS tool into existing eligibility or needs assessment protocols. Two respondents indicated that it is not worthwhile to implement the HELPS at intake with their particular population, but that it might be more appropriate to have a care planner administer the screening later in the evaluation process.

Interagency Care Coordination Committees

The third initiative of the TBI pilot sites was to improve interagency coordination of care for people with TBI. The TBI Project team met and concluded that the most feasible way to improve communication between agencies was to create local care coordination teams (Teams) to handle referrals of complicated cases involving TBI. Local Teams consisted of representatives from the agencies involved in the project (FIA, CMH and Waiver Agencies) as well as representatives from local organizations that provide services to individuals with TBI.

Teams were created first in the UP pilot area, followed by the SW, and later the SE pilot site. Each Team differed in composition and organization. At the end of the data-gathering period, Team members were interviewed to gather feedback on the success of each Team. A summary of each pilot site Team follows.

UP Care Coordination Team

UP Composition & Organization

Members for the UP Team were selected by the existing pilot site committee, which consisted of 10 representatives from FIA, CMH Waiver Agencies, Marquette General Hospital, and Keweenaw Bay Indian Community. The selected Team members were 1) a CMH care planner, 2) a director of Waiver Agencies, 3) an FIA Adult Services supervisor, and 4) a case manager from Marquette General Hospital. The CMH member of the Team was chosen to be the chairperson. The Team members created a plan to guide their efforts. Tasks of the Team included meeting as needed to discuss cases of TBI requiring services from more than one agency and recording meeting dates, minutes, and details of case discussions. Goals the Team hoped to accomplish included: 1) promotion of interagency communication and coordination of service delivery for difficult cases; 2) identification and use of all available funding sources; 3) provision of services to consumers in a more timely manner; 4) provision of more appropriate services; and 5) spending of less time on individual cases by service providers.

The UP Team met via phone conference due to the fact that members were located in different areas of the UP. Several meetings were held to discuss and revise the Team plan. Contact information for the Team was distributed to service providers that attended the second round of TBI trainings in the Fall 2003. Service providers were instructed to contact a Team member if they encountered difficult cases involving TBI or cases that potentially required services from more than one agency. If the contacted Team member could not solve the problem easily, he/she called a meeting of the Team. The Team then discussed the case until a solution was found. The pilot testing period ended April 30, 2004.

During the nine-month pilot of the Team, members met three times to discuss cases involving TBI. Each case was resolved and resulted in provision of services. One case was discussed with state level administration and resulted in the transfer of the consumer to a rehabilitation facility in Lower Michigan. The chairperson of the Team received several calls regarding general information on TBI or referral information and was able to provide necessary assistance without calling a meeting of the Team. The UP Team plans to continue to meet on an as needed basis. The Chair of the Team recently retired and a replacement from his agency was brought onto the Team.

UP Evaluation

All four members of the UP Team found the idea of an interagency team to be very valuable and recommended that Teams be organized in other regions of the state. When asked what characteristics are necessary for the functioning of a local Team, members responded that commitment on the part of the members, as well as support from their organizations to participate on the Team, were vital. Having a leader within the committee to facilitate regular meetings was also cited as a necessary aspect of the Team.

One reason given for the low number of referrals was that distribution of information about the committee to service providers was limited. Members suggested scheduling regular meetings in the absence of referrals to keep all members up to date on any policy or eligibility changes within the agencies or happenings related to TBI around the state.

When asked to evaluate whether the goals of the committee (as listed above) were achieved, responses were very positive. Goal number five, service providers will spend less time on individual cases, was the only goal that was not seen to be achieved “some” or “a lot” by all Team members. Two members responded that goal number five was achieved “only a little,” because one case that was discussed by the team required significant efforts to accomplish service provision. One member commented that, without the collaboration fostered by the Team, appropriate service provision for this case involving TBI might not have been achieved.

SW Care Coordination Team

SW Composition & Organization

The TBI Team in the Southwest Pilot area consisted of seven members: three from FIA, one from CMH, one from an ISD, one MI Choice Program agent, and one from a Center for Independent Living. Members for the SW Team were mostly from Calhoun and Van Buren Counties. The CMH member of the Team was chosen to serve as chairperson. The group planned to meet on a monthly basis to discuss procedures of the Team and cases referred to the Team. Due to scheduling conflicts, a meeting of the full Team was not possible. Several partial meetings were held and Team procedures were discussed.

The chair of the Team received several calls regarding use of the HELPS screening tool (discussed earlier in this section) and several calls regarding difficult cases. The chair was able to answer all questions without convening a Team meeting. Data collection for the Team stopped at the end of April 2004.

The SW Team plans to combine their efforts with a local brain injury committee consisting of 50 service providers from approximately 30 private and public organizations in the area. Members of the Team plan to attend quarterly meetings and will bring cases referred to them to the meetings for discussion.

SW Evaluation
Four members from the SW were interviewed regarding the experience of the Team.
When asked if they would recommend that other counties or regions establish a Team, two respondents stated that collaboration is beneficial. One respondent was not able to attend any Team meetings and did not feel qualified to rate the value. One respondent elected not to answer this question. Three of the responding members of the Team would like to continue to be a member of the SW Team.

Reasons given for poor participation included lack of time to attend meetings and that agencies did not recognize the Team as a priority. Members suggested scheduling regular meetings and to establish a structure for the meetings. Getting commitment from agencies to participate was also cited as necessary for success of the Team.

SE Care Coordination Team

Members of the SE pilot site were organized slightly differently from the UP and SW pilot sites. Since this pilot site came on board during the final project year, not all counties were able to participate in all aspects of pilot site initiatives. First, interested members from each county brought the project to their local Multipurpose Collaborative Body (MPCB)[3] – both to disseminate information and to identify other local organizations who would like to participate. The MPCBs in three of the four SE pilot counties formally approved of the TBI local project initiative and pledged to participate: Lenawee, Livingston, and Washtenaw. Livingston and Washtenaw MPCBs established committees to organize TBI efforts. The Livingston Committee planned the local provider training and are currently meeting to determine how to implement screening and care coordination efforts.

The Washtenaw Committee planned the local provider training, coordinated local implementation of HELPS, and identified a mechanism to ensure better coordination of TBI cases. Specifically, another subcommittee of the Washtenaw MPCB, called the Barrier Busters, agreed to take referrals of people with TBI who are difficult to serve. The Barrier Busters are comprised of representatives from numerous public and private social service agencies and organizations in Washtenaw County, all of whom have access to the director of their organization. Each participating organization contributes a small amount of funding that can be used to obtain emergency services for individuals in crisis and without other sources of support. Five members of the Barrier Busters agreed to serve as referral points for individuals with TBI who are having difficulty accessing other services. As of early July, no referrals had been

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[3] There are currently 76 State-endorsed Multipurpose Collaborative Bodies covering the entire state of Michigan. These bodies comprise leaders of social service agencies, community organizations, and individuals. They meet on a regular basis to collaborate and move the community's agenda forward to benefit children, families, adults and seniors who live and work in their community.

received. The group plans to contact service providers to determine if the absence of referrals can be attributed to a lack of awareness.

Information about Barrier Busters was disseminated at the Washtenaw TBI training in February 2004. Because of the limited timeframe and experience in applying the service coordination protocols for individuals with TBI, interviews were not conducted with the Barrier Busters in Washtenaw County.

Discussion and Conclusion of Pilot Site Activities

Pilot site activities addressed 1) education of public service providers about TBI and services available, 2) improved identification of TBI in the public system, and 3) increased local service coordination and delivery between agencies. Agency participation was voluntary and came at a very difficult time, given the ongoing state budget difficulties and multiple waves of retirements that affected FIA in particular.

Education

The project's educational efforts were perhaps the most well received of all pilot activities. Feedback on the provider and consumer products was very positive. The provider training also seemed to meet a need among the pilot agencies. Attendance was low at some training sessions. This is believed to be due to insufficient advertising, combined with very low travel budgets at most agencies. Some agencies did not participate at the expected level for other unknown reasons. Surely, FIA was hampered by staffing shortages caused by retirements. Nevertheless, most of those who did attend the training expressed very high satisfaction. Indeed, the project received several requests to make additional presentations to agency staff. Perhaps the least well reviewed section of the training was the presentation about local agencies and services offered. This may be due to the timing of this presentation (after lunch when people were tired), but also because this session was generally presented by project participants rather than professional trainers. Although an abbreviated version of the training was developed in response to a request from one pilot site, many participants expressed that it was difficult to absorb the materials in such a short time.

HELPS Screening Tool

Pilot sites implemented the HELPS screening tool in very different ways, not allowing for a very useful comparison of the data collected. The wide divergence of positive screens can probably be entirely explained by differences in populations screened. Additionally there may be too much room for individual variation in interpretation and scoring. This could be addressed by further wording refinement. Feedback on the tool was mixed; some providers found the tool to be beneficial for consumers, while other did not. Some found the tool to be time consuming, while others found it to be too simplistic. Several providers commented that the tool was not appropriate for their clientele, especially among the elderly or during initial intake. Prior to broad implementation of the TBI screening tool, consideration should be given to whom should be screened and when in the intake and care planning process administration would be most appropriate. Incorporation of the screening tool into an agency's existing assessment may reduce paperwork and time spent on the TBI screening.

The HELPS screening caused some frustration among service providers because of the lack of resources available for handling cases that screened positive. While it is generally accepted that it is important for proper treatment to identify cases involving TBI, a positive screen or even a diagnosis of TBI, does not necessarily increase the likelihood that a consumer will meet the eligibility requirements. If a screening tool is implemented in the public service system, agency workers should be given clear instructions on how to address positive screening results.

Overall, the tool was found to be easy to administer and easy to score. Additionally, the majority of respondents felt that it would be worthwhile to implement the screening into the intake or assessment process of each agency.

Care Coordination Teams (Teams)

Despite the variation of composition and organization of the Teams, each pilot region stressed that commitment of individual members, along with agency support, is key for successful coordination. Training evaluations show that the section introducing the Team to service providers could be improved; a clearer and more detailed explanation of the Team and guidelines for contacting the Team could be incorporated into the training. Additionally, distribution of Team contact information and instructions was limited to training attendees. Further marketing of the Team may have resulted in an increased demand for its TBI expertise.

Some counties or regions of the state have existing committees that address service provision issues. The SW pilot group decided to work with an existing committee that addresses TBI-specific issues, while the SE pilot group added TBI to the agenda of a group that meets to discuss service provision issues for a variety of populations. The SE pilot site, where existing local sub-committees created by the MPCBs took responsibility for project efforts, seemed to be most successful at eliciting local commitment in the shortest period of time. All three Care Coordination Teams have found the efforts of the project to be beneficial, and each Team plans to continue meeting once the grant period ends.

6

REPORT ON ASSISTIVE TECHNOLOGY FOR INDIVIDUALS WITH TRAUMATIC BRAIN INJURY

From July 2003 through January 2004, a group of service providers and advocates experienced in the use of assistive technology (AT)[1] by people with TBI met regularly to discuss AT-related policy changes in Michigan. The workgroup discussed issues that would have a positive impact on the lives of individuals with TBI, including access, support, and training in relation to AT. Policy recommendations were proposed that address the funding and availability of services and devices, especially those that are inexpensive and low technology, and that improve the quality of life for individuals with cognitive disabilities. (The AT Recommendations have been included in the Policy Recommendations.) In support of these recommendations, a case study and review of the literature are presented.

Claudia's Story

The following depiction of an individual with TBI is presented in order to show how simple and inexpensive technology can be adopted in order to overcome common cognitive impairments experienced by persons with TBI.

Until 1988, Dr. Claudia Osborn had an inner-city Detroit hospital practice in internal medicine and was an associate clinical professor of internal medicine. On July 11, 1988, Claudia was bicycling in her suburban neighborhood when she was struck by a car and thrown from her bike. For weeks after her injury, she routinely slept 22 hours a day, could not use her right hand, and was unable to return to her medical practice. She was diagnosed with a moderately severe head injury. Eight months after her injury, Claudia's lacked ideas for discussion and her language skills were impaired.

In March 1989, Dr. Osborn began an extensive rehabilitation program in Manhattan at the Head Trauma Program founded by Dr.Yehuda Ben-Yishay at the New York University Medical Center. Upon returning to Michigan, Claudia began to write. After seven years, and with much assistance from her mother, Claudia's book *Over My Head* was published in 1999.

Claudia would not be able to meet her personal and professional obligations without the use of assistive technology devices. Claudia uses three different assistive technology devices on a daily basis: a dual timer, a digital recorder, and a simple day planner.

The dual timer, costing less than $20, is set to "beep" every 15 minutes, bringing Claudia to attention and addressing her adynamia (loss of initiation). In other words, the timer is an external cue for Claudia to ask herself "What am I doing?" and "What needs to be done?"; otherwise her safety could be compromised and tasks would remain uncompleted.

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[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

The digital recorder, costing between $50-60, is used as a memory tool. It is impossible for Claudia to multitask, so she uses the recorder to “make notes.” For example, after parking her car in a parking lot she tells her recorder the exact location of where it is. If she is cooking and the telephone rings, before answering it she tells the recorder what she was doing so that she can pick up where she left off after the telephone conversation.

The simple day planner is used to compensate for her executive functioning difficulty. By referring to the planner she is able to easily determine the plan for the day and what tasks need to be completed.

In addition to the dual timer, digital recorder, and day planner, Claudia uses a computer and a service dog. The computer enables her to organize, track, plan, and sequence activities and her overall day. Her service dog Micah augments the other technologies. In order for the timer and digital recorder to be effective, Claudia has to remember to activate them, but Micah operates on his own. He has been trained to keep Claudia alert and attentive and allows her to function with ease.

Claudia’s devices are paid for through her automobile insurance. With the exception of Micah, the devices can be purchased at local retail stores, such as Radio Shack. Due to daily use, the timer and digital recorder need to be replaced every few years. The planner, as it is usually for one calendar year, needs to be replaced annually. Unless approved as an exception based on medical justification, these items would not be covered by Michigan Medicaid.

Though a timer can be relatively easy to set, it took time for Claudia to learn to incorporate the devices into her daily activities and practice using them consistently. Family members served as coaches to remind and reinforce the use of the devices.

These devices increase Claudia’s quality of life, responsibility, functioning, and independence. The use of the assistive technology devices impacts reliability and consistency. If a person is not dependable, it is possible that they will be excluded from events and outings, decreasing the richness of one’s life. Claudia’s assistive technology devices are relatively inexpensive to purchase, but the increased independence they bring to her life is priceless. For many individuals with TBI, it is possible for devices to serve as substitutes for staff or caretakers.

As a graduate of Vassar College and Michigan State University College of Osteopathic Medicine, Dr. Osborn is currently Associate Clinical Professor of Internal Medicine at Michigan State University. In addition, she lectures all over North American on traumatic brain injury rehabilitation and related issues. Without assistive technology, these pursuits would not be possible.

Literature Review

Data from the 1990 US Census Bureau's National Health Interview Survey on Assistive Devices show that more than 13.1 million people in the US used AT devices in 1990. It is important to note that 62% of people using mobility devices, 69% of people using hearing devices, and 51% of people using vision devices are over 65 years of age (Smith, 1998).

- Assistive technologies (also known as adaptive technologies or adaptive equipment) are any item, piece of equipment or product, or service that is used to increase, maintain, or improve functional abilities of individuals with disabilities, as defined by the Individuals with Disabilities Education Act (IDEA) Amendments of 1997. There are two major purposes of assistive technology (AT): 1) to enhance an individual's strengths, so that his or her abilities can counterbalance the effects of the disability; and 2) to provide an alternative means of performing a task so that the effect of the disability will not interfere with everyday activities.

This literature review provides examples of AT with an emphasis on those addressing the cognitive limitations of individuals with TBI. It also discusses the limitations of AT for individuals with TBI and reviews outcomes, cost-effectiveness, and funding of AT. In sum, devices are available to meet the needs of individuals with TBI; however, care needs to be taken in the assignment of appropriate devices to individuals with cognitive disabilities (including TBI) and to train the user on the proper use of the device or system. Moreover, further research is needed to document outcomes of AT for individuals with TBI. It is important to note that the AT devices are not necessarily "hi-tech" or expensive – even very simple items, such as a transparent shower curtain, should be considered types of AT devices and accommodations.

AT can be easily divided into 13 product families (Rehabtool, 2003).

1. Communication Aids help individuals with writing or speech disabilities communicate. Examples include a page with letters that a individuals points to or a sophisticated speaking computer. Sub-categories include speech and augmentative communication aids, as well as writing and typing aids.

2. Computer Access Aids are hardware and software products that enable a person with disabilities to access and interact with computers at home, work, or school. Sub-categories are alternative input devices, alternative output devices, accessible software, and universal design.

3. Daily Living Aids are self-help devices that assist individuals with disabilities in daily living activities such as dressing, personal hygiene, bathing, home maintenance, cooking, eating**.** Sub-categories include clothing and dressing aids, eating and cooking aids, home maintenance aids, and toileting and bathing aids.

4. Education and Learning Aids include cognitive software focusing on categorization, matching, association, reasoning and decision making, problem solving, memory skills,

perceptual skills, talking, word processing, word prediction/completion software, cognitive retraining or rehabilitation tools, etc.

5. Environmental Aids are environmental and structural adaptations that remove or reduce physical barriers for individuals with disabilities. Sub-categories are environmental controls and switches and home adaptation devices.

6. Ergonomic Equipment reduces the likelihood of repetitive stress injuries.

7. Hearing and Listening Devices include hearing aids, text telephone, and TDD/TYY devices.

8. Mobility and Transportation Aids are products that help mobility impaired individuals move within their environment and give them independence in personal transportation. Sub-categories include ambulatory aids, scooters and power chairs, wheelchairs, and vehicle conversions.

9. Prosthetics and Orthotics replace, substitute, or augment missing or malfunctioning body parts with artificial limbs or other orthotic aids.

10. Recreation and Leisure Aids are products that help individuals with disabilities participate in sports, social, and cultural events. Sub-categories include sports aids, toys and games, and travel aids.

11. Seating and Positioning Aids are products that provide mobility-impaired individuals with greater body stability, maintenance of upright posture, trunk/head support, and reduction of pressure to the skin.

12. Visual and Reading Aids are products designed to assist the blind and visually-impaired.

13. Support Services for people with disabilities or their caregivers help them to select, acquire, or use adaptive devices. Services also include functional evaluations, training on or demonstration of devices, and purchasing or leasing devices.

Products for Individuals with Cognitive Disabilities

In November 2001, the Brain Injury Association of America was awarded a grant from the National Institute on Disability and Rehabilitation Research to administer a five-year, multi-phase project on AT for individuals with cognitive disabilities. The project has produced a catalog of existing portable devices for memory organization (DMO) with a list of features. The first version was issued in February 2003. Future plans include a white paper describing findings, tip cards for families to assist in purchasing devices, and recommendations for DMO modifications and features for manufacturers. The project will also develop a web-based assessment tool for individuals with cognitive disabilities.

Table 6.1 provides information on the following categories of technologies: personal digital assistants (PDAs) and handheld computers, voice organizers and recorders, general purpose reminders, medication reminders, watches, and smartphones. Information on manufacturer; price range/size/battery; input/accessories; functions; and product review source link is provided for most products (the cost of training and upgrades is not reflected in the price).

6.1. Examples of available assistive technologies

Category	Approx. Number of Products Available	Cost Range ($)	Examples
PDA/handheld computer	50	50-500	Wizard OZ-730PC, Clie NR70
Voice organizer/recorder	30	50-299	Perfect Data 52, Parrot Voicemate
General purpose reminder	7	50-500	Multi-alarm Timer gem 107, The Jogger
Medication Reminder	15	50-299	Automated Med Dispenser gem 125, Medicaid Reminder (12 alarm) Watch
Watches	11	50-99	Beeperwear Pro Pager Watch 80011, DataBank Watch DBC30-1
Smartphone	7	100-500	NeoPoint 1000, Communicator 9290

Of course, prices listed do not include the entire cost. The cost of AT also needs to include evaluation, training, follow-up, and maintenance. Often the effort of identifying an appropriate intervention can be more involved and costly than the device or service itself (Warren, 1993). The consultation and evaluation phase, conducted by experienced clinicians, is often the most important phase of a successful intervention.

AT for Individuals with TBI: need for careful consideration and extra support

The wide range of cognitive and/or perceptual problems for individuals with TBI can have a direct impact on performance with an AT device or system. Specifically, attention, orientation, memory, verbal reasoning and problem solving, perceptual and analytical abilities, social reasoning, and executive abilities can be impaired. But, these are the same skills that might be necessary to operate some devices (Levine et al., 1992).

Because individuals with TBI often have overlapping disabilities (possibly two or more disabilities), matching a person with the proper device has unique challenges (Noakes, 2001). Levine et al. (1992) reviewed the use of scanning communication systems and power wheelchair controls by individuals with TBI. The researchers concluded that with devices used to address mobility disabilities or increase capability, the cognitive and perceptual requirements may actually hinder the performance of the user. Consequently, clinicians and users need to have a heightened awareness of the cognitive difficulties that assistive technologies can introduce.

New learning on the part of an individual with TBI is also a barrier to using AT devices (Noakes, 2001). As individuals might have decreased short-term memory and trouble processing information, additional training may be necessary.

Benefits of AT devices

The National Council on Disability (1993) studied 136 individuals with disabilities (not necessarily TBI-related) to evaluate the costs and benefits associated with the use of different kinds of devices. Four age groups were evaluated: infants and toddlers; schools-age children; working-age individuals; and senior citizens. The study showed that the majority of infants with disabilities benefited from the use of AT by having fewer health problems. Almost three-quarters of school-age children were able to remain in a regular classroom. Among the elderly, 80% were able to reduce dependence on others. Devices for home and van modifications were reported to be technologies that made the biggest difference in the study participants' lives. Additional benefits of AT included time savings in activities of daily living and household chores.

The literature on assistive technology for cognitive disabilities has limitations. There are no comprehensive, large-scale studies of a variety of devices, rather much of the literature includes case studies of a few people; and many studies evaluate AT in a therapy-setting, as opposed to a daily living community setting.

Findings from the literature indicate that:

- In a rehabilitation setting, exercises and drills intended to restore memory and cognitive disabilities are not effective when compared to compensatory techniques, such as notebooks and planners (Wilson, 2000);
- With appropriate training and reinforcement, a simple assistive device like a notebook can enable an individual with brain injury to live independently and maintain a job (Evans et al., 2003);
- Portable voice organizers have the ability to aid individuals with TBI to recall goals and plans discussed with their clinical case manager (Hart, Hawkey & Whyte, 2002);
- The use of PLAMs (a device that provides verbal cues) in rehabilitation can assist brain injury patients with maintaining a daily inpatient therapeutic schedule (Burke et al., 2001) without the assistance of staff;
- The use of cognitive orthotics, such as a specialized computer, has the ability to improve the execution of tasks, enhance self-esteem, and provide satisfaction for a person with TBI (Bergman, 2002); family and friends benefit by experiencing relief and reduced stress from the newfound independence of the user;
- Subjects who have severe memory impairment can use a memory notebook effectively in performing daily activities (Cicerone et al., 2000);
- A portable pager system can be effective as a memory aid for individuals with memory disorders (Cicerone et al., 2000);
- An apartment outfitted with electronic aids can positively impact the rehabilitation of persons with acquired brain injury (Erikson et al., 2004).

Gamble and Satcher (2002) examined the vocational rehabilitation outcomes for individuals with TBI using assistive technology. The sample consisted of 1,145 consumers with TBI; thirty (2.6%) of the consumers were provided assistive technology as part of rehabilitation and 1,115 (97.4%) consumers were not. Of the consumers that were provided with assistive technology, 22 (73.3%) were newly employed at the time of their case was closed, whereas 545 (48.9%) who were not provided AT were working. The authors propose that because of study findings, AT might influence a person’s ability to obtain a job. AT referred to any device or service designed to remove barriers faced by individuals with disabilities.

Public Funding for Assistive Technology

The National Council on Disability published a report (2000) that describes the barriers in federal assistive technology policy to increasing the availability of and access to assistive technology devices and services. The report recommends refining, refocusing, and expanding public programs; creating incentives for the development of alternative ways to fund AT; refining and refocusing the health care system; creating tax incentives for improved technology access; refining and expanding the core of civil rights and technology access; mandating the concepts of universal design; and making use of the important developments in telecommunications and changing public policy.

The remainder of this section reviews what funding is available for AT in Michigan and eligibility issues and limitations to it.

Michigan Medicaid

FIA determines eligibility for the Michigan Medicaid program. Once the scope of coverage has been determined, beneficiaries may be eligible to receive such services as prenatal care, physical therapy, occupational and speech therapy, and medical supplies. In addition, Medicaid may cover AT devices, such as wheelchairs, prosthetics and orthotics, and augmentative communication devices as prescribed by a physician. All items must be medically necessary and cost-effective.

A Medicaid-approved durable medical equipment (DME) provider must submit the necessary paperwork and prescription to MDCH for authorization. A decision as to the medical necessity of an item must be made by MDCH within 15 working days from the arrival of proper documentation. Denials may be appealed through an Administrative Law Judge. Delays may occur in equipment delivery due to stocking issues, complexity of devices, and/or paperwork processing.

A person who is eligible for both Medicare and Medicaid, also known as “dually eligible”, has to meet additional program guidelines. If Medicare decides that a device is "not deemed a medical necessity" Medicaid cannot approve coverage. Medicaid can consider coverage if an item is not covered under Medicare policy.

Physical Disability Services

The focus of Physical Disability Services is to assist adults with physical disabilities to function as independently as possible. Eligible persons are medically stable and mentally capable of participating in services planning. Customers with mental retardation or mental illness as a primary diagnosis are not eligible.

An FIA adult service worker will authorize services only after completing the assessment and service plan. Authorized services must address the individual's functional limitations as identified in the assessment and services plan.

The local FIA office completes Prior Authorization requests. Requests that exceed $1,000 must be approved by MDCH. PDS funds up to $5,000 that may be used for home modifications, vehicle modifications, assistive equipment not paid for by Medicare or Medicaid, such as lift chairs, bath benches, and ceiling lifts.

The annual allocation each FIA District Office receives is determined by FIA.

Children's Waiver

The Children's Waiver Program (CWP) is a federal entitlement program that provides Medicaid-funded home and community-based services to children (under age 18) who are eligible for, and at risk of, placement into an Intermediate Care Facility for the Mentally Retarded (ICF/MR). Children with developmental disabilities who also have challenging behaviors and/or complex medical needs are served through this program. The CWP enables children to remain in their parent's home or return to their parent's home from out-of-home placements, while receiving regular Medicaid State Plan services (e.g., case management, private duty nursing) and waiver services, regardless of their parent's income. The waiver services include: family training, specialty services (e.g., music, recreation, art and massage therapy), community living supports, transportation, respite care, environmental accessibility adaptations, and specialized medical equipment. The program has a capacity to serve 417 children statewide. Although the program is at capacity, a waiting list is maintained, using a priority rating system to add new children to the program when openings occur. Application to the program is made through the local CMHSP.

Public School System

The Individuals with Disabilities Act (IDEA) was passed by Congress in 1975 (with significant amendments in 1997) and provides federal funds to schools to help meet the costs of educating students with disabilities. Key components of the statute include: children with disabilities have the right to free, appropriate education through age 21, students will receive their educational services in the least restrictive environment, and a written individualized education program (IEP) will be developed for a child with disabilities. These key components are used by the family to advocate to school districts for the provision of AT devices. For example, the amendments passed as part of IDEA 1997 stipulate that the IEP Team consider each child's AT needs (Hager & Smith, 2003).

Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) are civil rights acts for persons with disabilities, so their application is mandatory and has a major impact on schools. Section 504 applies to entities that receive federal funds and the ADA applies to virtually every agency, organization, or business, expect churches and private clubs. Section 504 and the ADA use a different definition of disability and a different approach to eligibility than does the IDEA law, resulting in many children who are not eligible under IDEA being protected by Section 504 and the ADA.

Two primary requirements of Section 504 and the ADA for school-aged children are nondiscrimination and the provision of a free, appropriate public education (FAPE). This includes the provision of AT devices to children with disabilities. There may by discussion during the development of a child's Section 504 Plan and/or the IEP about who is responsible for repair and maintenance of the device and whether the student is required to return devices to the school district upon graduation and/or age 22. But once the plans are in place, it is essential that the device is provided according to the child's plan(s).

Michigan Rehabilitation Services

Michigan Rehabilitation Services (MRS) is a part of the Michigan Department of Labor and Economic Growth. MRS works with a wide range of individuals whose disability, including brain injury, interferes with preparing for, finding, or keeping a job. A rehabilitation counselor helps a client decide on an employment goal, develop a plan, follow the plan, and reach the goal. The following services are offered: eligibility assessment, vocational evaluations, counseling, training, job placement services, and follow-up services. MRS services are provided on the basis of the individual plan for employment and are time limited. MRS assists with assistive technology evaluations and equipment when it is needed for the individual to succeed in achieving their employment goal.

Children with Special Needs Fund

A child must be a Michigan resident to receive benefits from the Children with Special Needs Fund. Families with a child enrolled, or medically eligible to enroll, in the Children's Special Health Care Services (CSHCS) Program may apply to the Children With Special Needs Fund. The CSHCS Program enrolls children under age 21 that have been diagnosed with a severe disability or illness, such as muscular dystrophy and cancer. Partial or full funding may be made available for the following: wheelchair ramps into homes, van lifts and tie downs, therapeutic tricycles, air conditioners, adaptive recreational equipment, and electrical service upgrades necessitated by the eligible child's equipment. Additional requests may be considered. In addition, a special application is available for a summer camp scholarship. Application is made through the local health department.

MI Choice Program

The MI Choice Program is the Home and Community-Based Waiver (HCBW) for the elderly and the disabled, aged 18 and older. An individual must apply for Medicaid benefits and an assessment will be conducted by a nurse to determine if the individual meets the Nursing Facility Level of Care. An individual must also have a need for a MI Choice service, be willing to accept a MI Choice service, and need that service for at least 30 days. Services offered to participants that relate to AT include: 1) specialized medical equipment and supplies such as devices, controls, or appliances which enable beneficiaries to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live; 2) and home modifications (also called environmental accessibility adaptations) such as physical adaptations to the home, required by the individual's plan of care, which are necessary to ensure the health, welfare, and safety of the individual, or which enable the individual to function with greater independence in the home and without which the individual would require institutionalization. Examples include the installation of ramps and grab-bars, widening of doorways, and modification of bathroom facilities. There are currently 8,000 individuals in Michigan enrolled in MI Choice. People must be meet the need for nursing home level of care to be eligible. In addition, MI Choice cannot cover state plan DME.

Habilitation Supports Waiver

The Habilitation Supports Waiver (HSW) is a home and community-based waiver for individuals with developmental disabilities who are Medicaid eligible and who are at risk of placement into an ICF/MR. There is no age requirement for enrollment in the HSW. Individuals enrolled in the HSW are entitled to receive mental health services through the Pre-Paid Inpatient Health Plans (PIHP) that can be accessed through the local CMHSP. Services available through the HSW include: chore services, community living supports, enhanced dental, enhanced medical equipment and supplies, enhanced pharmacy, environmental modifications, family training, out-of-home non-vocational habilitation, personal emergency response systems, prevocational services, private duty nursing, respite, supports coordination, and supported employment. The HSW serves over 8,000 individuals with developmental disabilities. Application is made through the PIHP and sent to the Michigan Department of Community Health for enrollment.

Managed Specialty Supports & Services Waiver 1915 (b)

CMHSP’s provide durable medical equipment that is not available through other Medicaid coverage or through other insurances. Coverage includes adaptations to vehicles, items necessary for independent living, special personal care items that accommodate the person’s disability, and communication devices. A person may not meet CMHSP’s eligibility requirements if they acquired a traumatic brain injury after the age of 22 (prior to age 22 impairments from TBI may meet the definition for developmental disability), or do not have a diagnosed mental illness, or if their impairments do not meet the specified severity criteria.

MATCH

The Assistive Technology Act of 1996 (P.L. 105-394) authorized funding for 56 state and territory programs. The RESNA Technical Assistance Project was funded to provide assistance to the AT Act Grantees to assist them in reducing barriers and increasing access to assistive technology devices and services for consumers with disabilities of all ages. This project will also provide technical assistance in such areas as universal design and funding of AT. As a result of the grant, Michigan has implemented the Michigan Assistive Technology Project and the Michigan Assistive Technology Clearinghouse (MATCH).

MATCH is a centralized, integrated, statewide assistive technology information system for use by participants in the Michigan Assistive Technology Project, including Community Assistive Technology Councils, information and referral services, assistive technology providers, consumers, families, and employers.

Michigan Assistive Technology Loan Fund

The Michigan Disability Rights Coalition (MDRC) has established the Assistive Technology Loan Fund to help people with disabilities purchase assistive technology devices and services. The fund is supported by the National Institute in Disability and Rehabilitation Research and the

Dow Foundation. UCP Michigan, the Financial Health Credit Union, and Centers for Independent Living have joined together to offer this program to individuals with disabilities and their family members.

The Loan Fund provides low-cost financing to individuals with disabilities to purchase assistive technology devices that allow for greater access, increased mobility, enhanced communication, and job opportunities. Loans will be considered for the purchase of assistive technology devices and services, including modification of vehicles and homes. Loans may also cover cost of training, warranties, and service agreements.

The MDRC is the recipient of a Federal Assistive Technology grant for FY2005. MDRC will develop a website that will provide a variety of tools for an online market to be used for AT devices. The website will serve: as an auction and barter system for equipment, as a forum for AT-related problems and discussion, as a loan closet, as an avenue for the development of a community of practice among used equipment holders and providers, and as a source of information on best practices in assessment, warranties, maintenance, and repair, or equipment.

New Freedom Initiative

The *New Freedom Initiative* (2002*)*, introduced by President George W. Bush in February 2001, has several key components. The first component is to increase access to assistive and universally designed technologies. The second component is to expand educational opportunities for Americans with disabilities. Funds will be provided to states for low-interest loans for individuals with disabilities to purchase computers and other equipment necessary to work from home. Technical assistance will be provided to small businesses to hire more people with disabilities. Lastly, to promote full access to community life, supports will be put in place to improve access to polling places and ballot secrecy for people with disabilities.

In May 2002, the Bush Administration issued a progress report for the *New Freedom Initiative*. To date, the Administration has produced technical guidance and training materials that will be helpful to private businesses, state and local government, manufacturers and vendors, and individuals with disabilities in complying with Section 508 of the Rehabilitation Act. Section 508 requires that all federal government electronic and information technologies be accessible to individuals with disabilities. The President secured $65 million for FY 2002 for the Department of Education to support the National Institute on Disability and Rehabilitation Research in its work to coordinate disability research programs and to award matching grants to states to help individuals with disabilities purchase AT devices.

In February 2003, President Bush established an Interagency Working Group on Assistive Technology Mobility Devices (Press Release). The Working Group identified existing federal government programs and resources that are designed to help individuals with disabilities obtain AT mobility devices they need for education and employment. A report on available resources was presented to the President in August 2003. Federal resources include: Centers for Medicare and Medicaid Services, HRSA block grants, Social Security Administration, Department of Education, Department of Veterans Affairs, and the Department of Labor (White House Domestic Policy Council, 2003). An additional report has been requested that will summarize eligibility criteria, description of benefits, and payment policies for all state, local, and tribal programs.

In sum, the Progress Report released in early 2004 shows that *New Freedom Initiative* has established a web portal <DisabilityInfo.gov> that provides information on disability-related resources, created a workgroup to develop strategies, and proposed funds that could be used to promote community-based services for people with disabilities and similar objectives.

Conclusion

Currently there are several sources of funding available for assistive technology services and devices. Historically these devices have been intended to address *physical* disabilities and not cognitive disabilities most often experienced by individuals with TBI. In addition, due to the characteristics of a TBI injury, individuals can require additional follow-up and retraining that is not typically offered by state programs. State funding already available for AT needs to be made available for devices for cognitive disabilities, as well as ongoing support and training. The perception of AT devices is that they are expensive and address a specific (and usually visible) disability: for example, a wheelchair is used by an individual for mobility. There are many different, and in some cases inexpensive, devices that can be used to compensate for deficits in such areas as memory, organization, and reasoning. Medicaid will not fund these devices and/or services if they are not deemed medically necessary.

7

TBI POLICY RECOMMENDATIONS

Available data indicate that Traumatic Brain Injury (TBI)[1] affects a large number of individuals in Michigan and nationwide, yet is largely unrecognized. The consequences of TBI can be severe and lifelong. Even mild or moderate cognitive impairments can have serious implications for the capacity to organize one's life and maintain employment and relationships. Analyses of Michigan's Medicaid data show that *at a minimum* an average of $11 million dollars are spent annually by Medicaid through Fee for Service (FFS) payment mechanisms for TBI-related costs. Since only one-third of individuals receiving Medicaid TBI treatment services are enrolled in FFS – two thirds-are enrolled in a (managed care) Medicaid Health Plan (MHP) – and since many services might not have a correct diagnosis listed, *this cost is an underestimate of the total cost of TBI for Medicaid*.

Dealing with the impairments related to TBI is a relatively new public problem, because only recently has advancing medical technology allowed those with severe TBI to survive their injuries. However, public services have not kept up with advancing medical technology. Those surviving TBI who have long term care needs may experience large service gaps, and services that do exist are often not accessible or effective. This situation can and *must* be remedied. This final section of the report first outlines what a system of care for individuals with TBI should look like, and then suggests specific policy changes in order to achieve such a system. Policy recommendations presented here are the result of five years of study and planning by multiple project partners: Michigan Department of Community Health (MDCH), Family Independence Agency (FIA), Michigan Department of Education (MDE), the Brain Injury Association of Michigan (BIAMI), and the Michigan Public Health Institute (MPHI). In addition, many participants from other public agencies and private organizations have participated throughout the process. These include: Michigan Rehabilitation Services (MRS) of the Department of Labor and Economic Growth, local school districts, local Community Mental Health Services Programs (CMHSPs), Michigan's Medicaid Home and Community Based Waiver for Elderly and Disabled (MI Choice Program) agents, TBI rehabilitation providers, advocacy organizations, consumers and family members, and many others.

An Appropriate System of Care

Figure 7.1 depicts an appropriate system of care for individuals with TBI in Michigan. Boxes shaded in dark gray are areas of substantial current service gaps for individuals with TBI. Boxes shaded in light gray represent services that exist and that individuals with TBI may be able to access which nevertheless, require some modification in order to better serve individuals with TBI. Clear boxes show where people are currently able to get services. Even so, staff at the agencies involved may require much more training to properly serve people with TBI. Bars across the bottom indicate some *possible* types of service needs that individuals with TBI may have. The chart provides only some examples. People would use the TBI system of care at various times through their recovery and their conditions change.

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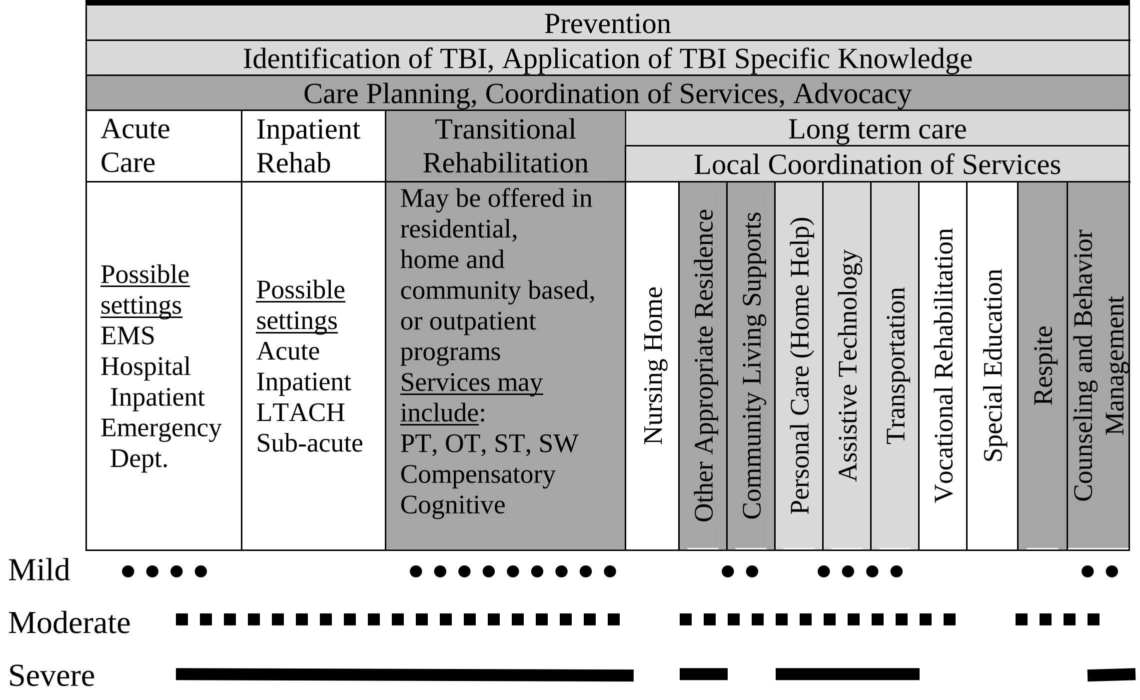
[1] Please refer to "Appendix A: Glossary" for definitions of terms and a list of acronyms used in this report.

Figure 7.1. Rehabilitation model of TBI services



Terms used in Figure 7.1 include the following (listed in roughly sequential order as illustrated in Figure 7.1):

<u>Care Planning, Coordination of Services, and Advocacy</u>: Individuals with TBI need someone who will assist them to develop a care plan. They also need assistance in coordinating services across agencies and advocacy on their behalf. Finally, they need help to follow-up with services to ensure the requested services were delivered. Such services are available to individuals who receive CMH services, under the title "Targeted Case Management."

Section 13 of the Medicaid Provider Manual (modified 4/1/04) defines the role of "Targeted Case Management" in relation to mental health and substance abuse services as follows: "assists beneficiaries to design and implement strategies for obtaining services and supports that are goal oriented and individualized … [and] include assessment, planning, linkage, advocacy, coordination, and monitoring…." Moreover case management services "must be available for all children with serious emotional disturbance, adults with serious mental illness (MI), persons with a developmental disability (DD), and those with co-occurring substance use disorders who have multiple service needs, have a high level of vulnerability, require access to a continuum of mental health services…, and /or are unable to independently access and sustain involvement with needed services."

Some of this language is a very apt description of individuals with TBI who because of cognitive impairments lack judgment, organizational skills, short-term memory, and have difficulty learning new skills and dealing with change. Moreover, the importance of case management was illustrated by the consumer case studies, as well as provider feedback on the system – both presented in Section 4. Service providers cited a lack of case management as the second most common reason for failure to achieve service coordination. Unfortunately, it is difficult for individuals with TBI to access CMHSPs and the MI Choice Program, which are major sources of case management services in the public system. Case management is not reimbursed as part of Medicaid FFS, and may or may not be offered by Medicaid managed care providers.

Brain Injury Rehabilitation: Persons sustaining TBI have a recovery phase (several months to several years, depending on the degree of injury) where the brain will heal. Rehabilitation provided during this period will minimize life-long complications and is the prime time to teach patients and families how to live successfully with a disability and overcome participation handicaps. Initial rehabilitation is called acute rehabilitation or sub-acute rehabilitation. This is followed by transitional rehabilitation. Further rehabilitation services may be needed, even after this early phase, as reasonable goals are identified, though the emphasis should be on “quality of life” and community inclusion.

Individuals with TBI frequently need an acute or sub-acute rehabilitation program specializing in TBI following acute care for the medical stabilization of TBI, in order to get them back into the community. Acute rehabilitation programs provide a minimum of three hours of licensed therapy daily, provide skilled nursing, and complete the medical stabilization of the injured patient. Average length of stay nationally for TBI patients in acute rehabilitation is 16 days (Uniform Data Systems, 2004). Subacute rehabilitation programs, often based in skilled nursing facilities, provide the same type of service but serve the more severely injured and have longer lengths of stay (Uniform Data Systems, 2004). Long Term Acute Care Hospitals (LTACHs) are also playing a role in early medical stabilization of TBI patients, when acute care needs are prolonged with an average length of stay of 30 days.

Transitional rehabilitation programs provide a similar set of therapy services after the patient has progressed to a point in their recovery where they do not need daily skilled nursing and physician care, though custodial care needs may be constant. Goals are functional independence, patient/family education, and reintegration into their home community.

Impairments of cognitive functioning are a significant cause of disability after TBI and stroke, and interventions to reduce cognitive disability are a common component of brain injury rehabilitation. The American Congress of Rehabilitation Medicine, in 2000, developed clinical recommendations for the practice of cognitive rehabilitation, based upon an evidence-based methodology (Cicerone, 2000). Compensatory cognitive rehabilitation does not try to restore lost abilities but rather focuses on providing techniques to reduce disability or handicap, and should always be directed toward improvements in everyday functioning. These may include the use of visual cues, written instructions, memory notebooks, watches, beepers, computers or other devices to trigger self-monitoring behavior. Therapists assist by simplifying complex tasks, capturing the patient’s attention, reducing distractions, and teaching self-monitoring procedures. Compensatory cognitive rehabilitation may also include training of family members, caregivers and other people close to the person with TBI (Chesnut et al., 1999), since the key to change is practice over an extended period of time. Compensatory cognitive rehabilitation may be offered within more traditional rehabilitation services such as occupational therapy, physical therapy, and speech therapy, depending on the needs of the individual.

There are many TBI rehabilitation providers throughout Michigan who serve only individuals with private insurance, typically Michigan automobile no-fault insurance or Worker's Compensation. Such rehabilitation programs may be offered in residential, community-based, or outpatient settings. These providers report typical costs of $700 per day and typical lengths of stay of 90-120 days for 24-hour residential rehabilitation. The costs of these programs are beyond the means of Medicaid beneficiaries.

MDCH has a small program in which TBI rehabilitation providers offer services to a limited number of individuals for Medicaid rates. At any given time about 20 individuals meet the eligibility criteria and are enrolled. Patients are often only accepted if they have a "discharge plan" back to the community and if the patient can tolerate or participate in a minimum of three hours of therapy. When beneficiaries do qualify for the TBI Rehabilitation Program, once they complete the program, there are few residential placement opportunities where the beneficiary can continue with less intensive rehabilitation.

Specialized TBI Home and Community-based rehabilitation programs and outpatient rehabilitation/day treatment programs are more cost-effective but are not currently covered by Medicaid.

Long Term Care: Long term care is the medical, social, personal care, and supportive services needed by individuals who have lost capacity for self-care due to a chronic illness or condition. It is different from acute health care because medical management and assistance is required for an indefinite period of time. In the past and presently, long term care efforts and dollars are focused on nursing homes and other institutional settings for frail elders and persons with disabilities. Nationwide, current efforts focus on increasing opportunities for beneficiaries to remain in their homes and communities by providing less costly and more effective services to individuals in community settings (as Michigan's Community Mental Health [CMH] system does now).

Appropriate Residential Settings: For individuals with long term care needs who require extensive supervision or monitoring, an appropriate residential setting must be found. Licensed facilities in Michigan include: nursing homes, adult foster care homes, and homes for the aged. Many consider nursing homes to be an inappropriate long-term setting for a young person with TBI. Assisted Living is a general term for a range of housing facilities in which residents maintain varying degrees of independence. Facility staff members are available to provide assistance to residents with things such as: medication reminders, organizing activities, and periodically checking on them. Such facilities may or may not be licensed. Adult Foster Care means the provision of supervision, personal care, and protection in addition to room and board for 24 hours a day, five or more days a week. MDCH licenses Adult Foster Care Centers, and FIA–Adult Services will assist Medicaid eligible consumers with placement. Unfortunately, finding an appropriate residential setting for someone with TBI can be very difficult, as will be discussed further below.

Community Living Supports: Community Living Supports can be provided for those individuals enrolled in the Habilitation /Supports Waiver for Persons with Developmental Disabilities. (TBI only qualifies as a DD if the injury occurred before age 22 and the resulting impairments meet severity criteria.) Community Living Supports can be provided in a residence or community setting and include: reminding, observing, guiding or training the beneficiary with meal preparation, routine household care and maintenance, activities of daily living (ADLs) (bathing, eating, dressing, personal hygiene), shopping, etc; and assistance, support, or training in areas of money management, medications, non-medical care, socialization and relationship building, and attendance at medical appointments. For individuals with TBI who have less than full-time care/supervision needs, this model would be ideal and could incorporate the use of cognitive aids to assist in performance of these activities.

For individuals with TBI who are able to work, these services should also include ongoing vocational services and supports. While MRS offers vocational rehabilitation to persons with disabilities, the focus is typically short-term assistance. Individuals with TBI may need a longer period of support in order to maintain employment.

Personal Care (Home Help): Home Help Services are unskilled, non-specialized services performed in the beneficiary's home or other community setting *to assist* individuals in accomplishing ADLs and instrumental activities of daily living (IADLs). ADLs include: eating, bathing, toileting, grooming, dressing, transferring, and moving about. IADLs include: taking medication, preparing meals, laundry, housework, shopping, and errands.

Assistive Technology: As presented in Section 6, there are simple devices that may enhance independence and improve quality of life while preventing the need for more costly long-term care services. There are policy barriers to accessing these devices that can be overcome. However, while the promise of assistive technology (AT) is great, successful adoption and use requires professional assistance in choosing the right device, training on use of the device, and assistance and support in appropriate daily use of the device and maintaining the device. Access to these supports for AT is very limited.

Respite Care: Respite services may be provided in an individual's or family's home or outside the home to temporarily relieve the unpaid primary caregiver. The goal is to provide short-term relief from the stress of care-giving. Currently in Michigan respite services may be provided to participants in all of the HCBS Waivers (Children's Waiver, Habilitation Waiver, and MI Choice Program). Unfortunately, individuals with TBI are often not able to access these programs.

Counseling and Behavior Management (including substance abuse treatment): Behavioral services are designed to reduce maladaptive behaviors, maximize behavioral self control and/or restore normalized psychological functioning, reality orientation, and emotional adjustment. This enables individuals to function appropriately in interpersonal and social relationships and in community or employment settings. For individuals with brain injury, the methods for achieving these results may be similar or different from those used for individuals with MI. Specifically, counseling or holistic neuropsychological rehabilitation may be emphasized over, or in conjunction with, medications for behavior management for individuals with TBI.

Three consumers profiled in Section 4 indicate the use or need for these types of services by individuals with TBI. Individuals with TBI are frequently unable to access the CMH system (where these services are provided) unless the brain injury occurred before they were 22 (in which case, if their impairments are severe enough, they may be able to get into the CMHSP system by being classified as developmentally disabled).

To conclude, these and other services are seen as necessary for individuals with TBI, who may be young or old, male or female, able to live and work independently or not. *Unfortunately, the following areas – although of critical importance – are largely <u>inaccessible to individuals with TBI who are on Medicaid</u>:*

- Case management
- Rehabilitation (including cognitive)
- Community living supports
- Respite
- Counseling
- Behavioral management

Individuals with TBI face barriers to accessing other services, though they may be theoretically available.

The recommendations presented on the following pages are structured to achieve the ideal system presented in Figure 7.1. Long-term and medium-term policy recommendations that provide the structure of the model are presented first. This is followed by recommendations to support monitoring of TBI initiatives, prevention, education, screening, and removal of barriers to existing services. The order of listing of the recommendations roughly follows the diagram in Figure 7.1.

Policy Recommendations

It is the strong recommendation of the TBI Project that the service delivery system presented in Figure 7.1 should be achieved through redesign of Michigan’s long term care system to benefit both its elderly and individuals with TBI and other disabilities. The TBI project presents the following recommendations:

<u>Recommendation # 1</u>: Michigan’s long term care system should have enough flexibility to provide appropriate services to those who need them (including individuals with cognitive deficits), and have a single point of entry into the system.

The term <u>single point of entry</u> refers to a service system in which one agency or organization serves as a front door for all public services. From this single point of entry into the public service system, an individual is able to access necessary services from multiple agencies and funding streams. The agency that has been designated as the single point of entry does not necessarily provide direct care services.

Within this flexible system, individuals with TBI will need to have a designated agency worker (such as a case manager or supports coordinator) to assist them to develop a care plan, access services across agency boundaries, and follow up to ensure services were received. This staff person should have training or experience in working with brain injury cases, and become involved as early as possible in the recovery process.

Data from the project (see especially Section 4) indicate that crossing public agency boundaries to obtain services from multiple agencies is difficult. Providers report that the service goal of "no wrong door" (i.e., a consumer with TBI will obtain appropriate and timely services regardless of which agency he or she approaches first) is rarely achieved for individuals with TBI. Survivors and family members report confusion about rules governing eligibility for the many programs housed in multiple agencies, and indeed report receiving inconsistent information from public service providers regarding services. When a system becomes too complex, it is not reasonable to expect either consumers or service providers to master it. These issues are made more intense for individuals with cognitive deficits who may not process information quickly or remember instructions and appointments. Also, these individuals are likely to need a more diverse set of services than most consumers.

Wisconsin provides an example of a state attempting to create such a long term care system. In 1999 Wisconsin piloted the Family Care model in nine counties to serve three target populations: 1) frail elderly, 2) adults with physical disabilities, and 3) adults with developmental disabilities. Two new organizations were created at the local level: 1) Resources Centers to offer "one stop shopping" for the wide range of services available, and 2) Care Management Organizations which help to arrange and manage services in five counties for eligible clients. Managed care principles, including capitated payments, are used to control costs. Having two local organizations plus the required use of independent enrollment consultants separates intake and service provision functions thereby reducing incentives to restrict care or limit eligibility. An evaluation of Wisconsin's Family Care model by the Lewin Group (Alecxih et al., 2003) finds that a number of project goals have been met (although it is too early to determine progress towards others). Access to, and use of, community-based services has increased in Wisconsin's pilot areas. The report also notes significant challenges for the future.

Recommendation # 2: In order to address the needs of individuals with moderate to severe TBI-related impairments, *in the medium term,* Michigan should consider creating a TBI specific Home and Community Based Medicaid Waiver as 25 other states have done.

Federal law allows states to create Home and Community Based (HCBS or 1915(c)) Medicaid Waiver Programs to provide long-term home and community-based services for a limited number of people who would otherwise be at risk of institutionalization. The waivers must demonstrate cost effectiveness in comparison to hospital or nursing home care. Broad federal guidelines are in place for waivers, but states are allowed to administer several variables of the program including, eligibility criteria, type of program, duration, scope of services, and rates (Spearman et al., 2001).

A redesign of Michigan's long term care system requires study and careful planning. *Pending such change*, an interim Waiver program would be a great benefit for individuals with TBI. Even so, Medicaid Waivers have drawbacks that should be mentioned: they are targeted towards those with severe impairments, and they are by definition exclusionary in that they are aimed at specific populations while leaving others out.

Currently twenty-five states have TBI specific Waivers in place or approved (NASHIA, 2003). Data from 2001 show that Minnesota spent the largest dollar amount, $17 million, followed by New Jersey, $14.5 million, and Wisconsin, $14.4 million. More typical are Colorado, Connecticut, Illinois, and New Hampshire which reportedly spent $5 to $5.8 million during the same year (NASHIA, 2003). Cost variation from state to state varies with the number of individuals served and services available.

The number of people reportedly served ranged from a low of 23 (Idaho) to a high of 1,400 (Illinois).[2] In addition to Idaho, the following states serve less than 100 individuals in the reporting year: North Dakota, Nebraska, Delaware, New Hampshire, and Kentucky. Kansas, Florida, Indiana, Iowa, and Connecticut serve between 118-160 individuals in a year. Wisconsin, New Jersey, and Colorado served 225-284 individuals. Mississippi, South Carolina, and Minnesota served 400-500 individuals. After Illinois the next largest TBI Waiver in terms of numbers served was New York (1,000 individuals).

In terms of services available through TBI waivers, data presented in 2001 (Spearman et al.) compared services provided by 20 states and noted the frequently offered services (number of states offering in parentheses):

- Specialized medical equipment and supplies/assistive technology (the only service *provided through all 20 waivers*)
- Personal care/attendant services (provided in 18 of the 20 TBI waivers reviewed)
- Psychology and counseling support (17)
- Home modifications (17)
- Respite care (17)
- Day programs (16)
- Home and community supports (14)
- Employment services (13)
- Non-medical transportation (13)
- Residential habilitation (12)
- Service coordination/case management (12)
- Independent living skills training (11)
- Occupational therapy (11)
- Speech therapy (11)

Michigan's TBI Waiver should address all the service areas identified in Figure 7.1 and in particular have staff to assist them with care planning, interagency coordination of services, advocacy, and follow-up (such as a case manager).

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[2] Some states reported service numbers for 2002, others reported them for 2001.

Sustainability

Recommendation # 3: The Governor or the MDCH needs to appoint a TBI Services and Prevention Council to monitor and advise regarding the implementation of services for persons with TBI and the promotion of prevention efforts which would lessen the incidence and cost of TBI in Michigan.

In order to improve Michigan's TBI service delivery system and prevent increases in TBI-related injuries and deaths (which drive up the cost of services to the State in Michigan); and in compliance with the federal TBI grant program; the Governor or the MDCH should designate a council comprised of representatives of state agencies, advocates, consumers, and private providers. The body would be responsible for monitoring and advising on the implementation of the recommendations in this report and furthering efforts to improve both the public and private TBI service delivery systems. It would also have the responsibility for monitoring the efforts of state departments to coordinate with each other to improve existing services and enhance the data gathering efforts. Annually, it shall provide recommendations to the MDCH or the Governor for improvements in service delivery and prevention efforts. It shall work with state departments in efforts to obtain additional funding and resources through grants and contracts with non-state entities. The Council will study the feasibility of expanding the scope of its charge to include other forms of brain injury (for example, anoxia, infection, stroke).

Recommendation # 4: The MDCH should designate one full-time equivalent position to oversee the implementation of the report and staff the activities of the TBI Services and Prevention Council.

The Federal TBI Act of 1996 requires each state that receives federal TBI grants to have designated FTE to oversee the state's TBI efforts. Designation of a position would open up the possibility of further federal funding to assist Michigan's TBI efforts and support the ongoing efforts of the TBI Services and Prevention Council. The position would coordinate inter-departmental efforts and continue to monitor ongoing project activities operated by outside vendors.

Recommendation #5: MDCH should provide continued support for ongoing collection, analysis, and reporting of injury and service use data; and for the development and measurement of service outcomes for individuals with TBI.

Data presented in Sections 2 and 3 should be monitored over time to detect trends and gauge the effectiveness of prevention efforts. The Michigan Emergency Department Community Injury Information Network (MEDCIIN) emergency department surveillance system provides a rich and unique source of information. It is because of the analysis of MEDCIIN data that the project was able to count the high incidence of TBI among children. Despite its value, the MEDCIIN database lacks a stable source of funding.

Analysis of service use data is important to show who TBI programs will need to serve. Moreover, the TBI Services and Prevention Council will need to have objectives that can be accurately measured. Data analysis activities should support the Council in monitoring the extent to which service objectives are met. *Michigan is the leading state in the country in terms of its ability to link and summarize service use data about individuals with TBI* (Susan Connors, personal communication, July 14, 2004[3]). These data activities should be supported so that Michigan can continue to be an example to other states.

Prevention

The scope of this report is primarily public service delivery following a TBI event. Clearly, the high cost of services for individuals with TBI is best met by preventing such catastrophic injuries from occurring. Analysis presented in Section 3 shows that at least 65% of *identified* Medicaid FFS costs for services with a TBI diagnosis are associated with acute inpatient care provided by hospitals. This amounts to nearly $29 million spent on 2,300 individuals during the four years studied. The project does not see that any savings can be accrued on these acute costs other than through prevention.

Recommendation # 6: It is essential that the State of Michigan and local communities continue to support and promote prevention efforts. Areas and ways to address TBI prevention include:

a. **Maintenance of Michigan's motorcycle helmet law**

Data from states that have repealed motorcycle helmet laws find that upon doing so: the wearing of helmets falls dramatically, deaths from motorcycle crashes increase by 29%, and rates of nonfatal serious injuries with resulting short or life-long disability also increase 67% (National Highway Traffic Safety Administration, 2003). Maintaining Michigan's motorcycle helmet law makes sense in terms of preventing both deaths and serious injuries and thereby saving costs. Motorcyclists are not covered by Michigan's no-fault automobile insurance system and are therefore more likely to need public services following debilitating injury.

b. **Education of students, parents, coaches, physical education teachers, and playground monitors in public schools, local recreation programs, and health clubs about concussion and other sports-related TBI**

Sports-related activities are a common cause of concussion, and less frequently, severe injury. Individuals with a history of concussion seem more susceptible to effects of subsequent head injuries (Collins et al., 2002). It is therefore important to take each individual concussion very seriously. Moreover, coaches and teachers need to be able to provide sports participants with information about head injury and they need to know when an injury is severe enough that treatment should be sought.

c. **Support for injury prevention efforts, especially as related to transportation, violence, and falls**

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[3] Susan Connors, Executive Director of the National Association of Head National Association of State Head Injury Administrators, spoke at the July 14, 2004 meeting of the Project Advisory Council.

Primary prevention of TBI is an important goal of public health efforts. Achieving this goal requires attention to each of the major external causes of these injuries as outlined in Section 2 of this document: transportation, violence, and falls.

Child safety seats and safety belts are a child's best line of defense in a motor vehicle crash. The following actions are recommended to help protect our young passengers: support passage of a booster seat law for children ages 4-8; remove exemptions that compromise child passenger safety in Michigan's law; and support state efforts for child passenger safety education.

To help prevent TBI, helmets should be promoted at all times when riding on the following wheeled equipment: bicycles, roller blades, skateboards, scooters, ATVs, and motorcycles. Helmets should also be worn when participating in the following activities: football, hockey, horseback riding, skiing, and sledding.

Violence is a leading cause of TBI, especially among males. Violence with firearms is the leading cause of TBI-associated death. Effective programs designed to decrease the occurrence of interpersonal and self-directed violence would help address this issue.

Fall injuries are the greatest cause of TBI in very young children and the elderly. A consumer education campaign should address: installation of handrails on stairways, avoidance of babywalkers, use of child safety gates at the top and bottom of stairs, use of safety straps to secure children in strollers, shopping carts, and infant carriers, wearing shoes with non-slip soles, and use of a step-stool and grab bar to reach objects on high shelves.

Work begun by the Injury Prevention Section within MDCH should be continued to address fall injury prevention in adults 65 and older through the development, implementation, and evaluation of hospital-based geriatric fall prevention clinics. In addition, other state public health efforts should be supported, including: fall risk assessments administered to targeted elderly populations, referrals to evidence-based services, educational modules, senior exercise programs, and home safety programs.

This list of injury prevention efforts promoted by the State of Michigan is no doubt incomplete. Service delivery, rather than prevention, was the major focus of the MDCH TBI Project. Nevertheless, prevention is of critical importance and should be a major focus of TBI efforts in the future. Moreover, all public education prevention efforts advocated above should adhere to federal standards on providing access to individuals with limited English proficiency.

Identification of TBI and Application of TBI Specific Knowledge

In order to serve individuals appropriately, TBI needs to be identified and service providers need to have some knowledge about TBI, and available appropriate services. Recommendations in this section address screening, provider training, and local coordination.

Recommendation # 7: Departments, organizations, and agencies must adopt effective screening procedures to identify clients who may have TBI-related impairments. These

include, among others: FIA, CMHSPs, Substance Abuse AARs, public schools, MRS, MI Choice Program, and the Michigan justice system.

In addition to the wide diversity of outcomes, another common characteristic of TBI is its ‘invisibility’ – i.e., the fact that individuals who sustain a brain injury may not display obvious signs of disability in a simple interview. Service providers therefore may not recognize TBI as a source of their clients’ problems. Even consumers and their family members may not fully understand. Two consumers profiled in Section 4 did not obtain prompt treatment of their injury and remained undiagnosed until their lives had spun out of control.

A major difficulty in obtaining appropriate services is that few agencies in Michigan ask clients whether they have a TBI-related disability when presenting for services. Feedback from providers as presented in Section 4 is that identification of TBI is important, but typically is not something that is determined at intake.

Currently, there is no single brief screening tool that enjoys widespread use and acceptance. Public agency personnel need a tool that is easy to understand and score, not time consuming to administer, and reasonably accurate in flagging those persons whose care needs to be monitored and who may need further assessment.

To promote identification, correct diagnosis, and appropriate services for this population, the TBI Project adapted and tested a seven-item TBI screening questionnaire in participating pilot agencies. Approximately 70% of current users of the tool surveyed said it would be worthwhile to permanently adopt the HELPS screening tool (see Section 5). Responses were mixed as to whether pilot screeners thought any of their clients benefited from the screening. This was partly due to the discomfort a number of them expressed screening for a condition for which no services were available. Also, there was large variation from agency to agency in the proportion of positive to negative screening results. Therefore, the Project recommends that further development and testing of a screening tool is needed. Moreover, care needs to be taken to undertake screening at the most appropriate time in each agency. For some it might be important to identify TBI during intake, in other agencies it may be more important to identify TBI later during the care planning process.

Finally, it is important to distinguish screening from assessment. Screening is a method for identifying individuals who may need to be further assessed in order to obtain an accurate diagnosis and/or identification of TBI-related impairments. Agency workers need clear instructions on how to respond to a positive screening result.

Recommendation # 8: Michigan public human service providers, as well as staff in other public systems (such as the justice system), must be educated about TBI and the issues surrounding TBI. Materials for this training were developed and evaluated by the TBI Project.

Public service providers surveyed reported a great lack of information to serve clients with TBI. Lack of knowledge was the most often cited barrier to achievement to coordinated services for clients with TBI in provider surveys as summarized in Section 4. They lack knowledge of how to recognize TBI-related disabilities, successful strategies for interacting with such individuals, service needs, and available community services. These survey results are described in detail in Section 4 of this report.

The TBI project has developed, tested, and evaluated public agency training sessions and a host of supporting educational materials. Full six hour and abbreviated two hour trainings are available for intake and case management providers in state agencies. Reviews of these trainings by attendees were very positive. Educational materials developed include materials with information about the brain and TBI-related impairments and guidelines for accessing state services. Materials developed, and a summary of evaluation results, are described in Section 5 and Appendix D of this report. The project recommends that this training be offered statewide to staff in: FIA, CMHSPs, MI Choice Program, Public Schools, and MRS. Since survey results find that jails and the justice system are a common referral agency for individuals with TBI, staff in this system would also benefit from training.

For individuals in public agencies who provide direct therapeutic care or education to individuals with TBI, a more in-depth training should be offered. Such materials have been developed by other states and professional agencies and are available for use in Michigan. Michigan is rich in professionals who could present such information. Finally, all provider trainings should promote culturally competent service provision.

Recommendation # 9: Local interagency teams of public service providers should be created and authorized to take referrals of individuals with TBI and identify and advocate for appropriate local services.

As described above, Michigan’s public service system is confusing for anyone with complex and multiple needs and much more so for individuals with memory and other cognitive impairments. Service providers also report a lack of knowledge of available services for individuals with TBI offered by other agencies.

Currently, there is a community interagency model that brings together staff to identify and coordinate appropriate services for children and families with severe and multiple needs at risk of placement. The model is called “Wraparound” and exists in approximately 75 of Michigan’s 83 counties. As described in Section 5 of this report, TBI Project pilot sites implemented similar Interagency Care Coordination Teams to take referrals and find services for difficult to serve clients with TBI. It should be noted that there was variation in the extent to which pilot areas were able to come together and accomplish interagency care coordination goals. To implement this model, project resources were provided to the volunteers on the pilot committees to support a period of consensus and capacity building. Pilot committee members express the desire to continue their activities. Many stated that such a group *had the potential* to be very helpful. This potential was based on a belief that staff need not spend a lot of time and effort trying to track down information for consumers. Instead, as staff became familiar with TBI and the TBI resources available across multiple agencies, they could connect consumers to services and programs in a more expedited and efficient manner.

The creation of interagency teams is presented as a short-term rather than long-term solution because it is difficult to guarantee accountability for the desired change if no specific agency is identified as responsible for providing services. Thus, over the medium and long term, interagency teams are often less efficient. Ultimately it will be important to establish “local” (in many areas, this will mean across multiple contiguous counties) case managers with experience working with brain injury cases, who become involved as early as possible in the recovery process and ensure individuals receive services. Nevertheless, having local teams that are knowledgeable about TBI and who can identify local resources will mean that more service decisions can be made at the local level. As illustrated by one of the case histories, such appeals waste valuable time during which progress made in rehabilitation can be lost.

Removing Barriers to Services

The final set of recommendations focuses on ways to improve access to existing services for persons with TBI.

Recommendation #10: Medicaid reimbursement rates for neuropsychological examinations should be increased.

Neuropsychological examinations can be essential for identification of cognitive deficits that service providers will need to understand and work with when serving clients with TBI (Hanks et al., 1999). While Medicaid will cover such examinations when ordered by a physician, TBI pilot site participants have found that the reimbursement rate is so low that few providers in Michigan will agree to perform an examination for a Medicaid customer. The exceptions tend to be in university-affiliated clinics and hospitals where students or residents in training will perform examinations for Medicaid rates.

Recommendation # 11: The State of Michigan should establish a licensing category for AFC providers that have obtained accreditation and/or certification to care for individuals with TBI.

Currently AFC providers can be recognized by MDCH as specialists in caring for individuals with a DD or MI. Providing a new specialty to include the skills needed to work with individuals with TBI in order to gain positive behaviors and provide reinforcement for use of cognitive aids, etc., would be very helpful. A nationally known training/certification program is available in Michigan for those who provide care for individuals with TBI. The program is titled: American Academy for the Certification of Brain Injury Specialists, and is supported by the Brain Injury Association of America. Additionally, Commission on Accreditation of Rehabilitation Facilities provides accreditation for Medical Rehabilitation Facilities, including those serving individuals with brain injury.

Recommendation # 12: The MDCH should review reimbursement policies related to AFC facilities licensed to provide TBI services to support services needed, and/or allow additional reimbursed services to be offered in such facilities.

Nursing homes may be completely inappropriate for young individuals with TBI, beyond the sub-acute rehabilitation phase. Yet persons with 24-hour care and/or supervision needs have difficulty finding appropriate residential placement in the Adult Foster Care system because their care needs so exceed services provided and reimbursed. Moreover, regulation currently does not allow for additional Medicaid services to be provided in licensed facilities, with the exception of Home Help for persons with TBI. These barriers to appropriate placement need to be removed.

Recommendation # 13: Home Help Services accessed through FIA should be provided to those who need supervision to accomplish activities of daily living, in addition to those who need "hands on" assistance.

This recommendation will require a change in the Medicaid State Plan, and therefore approval by the federal agency, Centers for Medicare and Medicaid Services. Individuals with TBI often suffer cognitive impairments that can include short and long-term memory loss, impulsivity, poor judgment, impaired ability to process information, trouble concentrating or paying attention, adynamia (poor initiation capability) and inability to do more than one task at a time. These cognitive impairments can substantially limit a person's ability to live at home safely and hold a job. Eligibility requirements to access Home Help include the provision that the client needs "hands on" assistance to accomplish ADLs. This means that individuals who are physically capable of accomplishing ADLs, but nevertheless are unable to do it without reminders and supervision, are not eligible for services. As reported by providers in Section 4 of this report, Home Help is an excellent way to help individuals with TBI remain in an independent setting.

Recommendation # 14: Medicaid should consider funding cognitive aids as durable medical equipment when warranted in terms of cost effectiveness and medical necessity; *in addition*, the definition of "Medical Necessity" should be expanded to include consideration of abilities and independence so that individuals can remain in the community and have full access and independence.

Medicaid covers durable medical equipment (DME) items that are medically necessary for beneficiaries with a wide range of physical disabilities and some severe behavioral issues. Medicaid does not provide funding for AT devices for cognitive disabilities, (such as notebooks, voice recorders, timers, etc.) that address memory and other cognitive deficits. The definition of medical necessity should be expanded to include consideration of function and independence. These recommendations are made with the understanding that federal regulations governing Medicaid will be thoroughly reviewed.

Recommendation # 15: The Physical Disability Services (PDS) Fund needs to include the provision of assistive technology for cognitive disabilities as well as physical disabilities.

The PDS Fund is designed to provide funds to increase community independence for individuals with physical limitations, that other resources will not cover. The requirements to obtain money need to be changed to include cognitive disabilities, as well as physical disabilities. AT devices for cognitive disabilities can increase community independence.

Recommendation # 16: Transportation issues are of great importance in many areas of Michigan and must be addressed.

a. Michigan's Medicaid Program should consider increasing Medicaid reimbursement for transportation to medical appointments.

Transportation is an issue for many Medicaid consumers. Particularly affected are those individuals with brain injury who are unable to drive due to a seizure disorder, motor coordination problems, visual perceptual or spacial orientation problems, and judgment or impulsivity problems. Transportation was the most frequently mentioned service gap for individuals with TBI in provider interviews as listed in Section 4. Medicaid covers transportation expenses for medical care. However, consumers report that few transport providers accept the current Medicaid rate.

b. Access to transportation by individuals unable to drive due to TBI requires further study.

Medicaid funding for transportation is only part of the solution to rectify this service gap. In some areas of Michigan there are no transportation providers. A solution to this issue requires further study, and possibly an interagency solution.

Conclusion

The emphasis of the policy recommendations as presented here is on providing services that promote rehabilitation and independence. While the CMH system and the MI Choice Program currently employ this model of service provision, individuals with TBI may not have access to these programs. A long term care system with a rehabilitative emphasis for persons with TBI would have the following characteristics: 1) better identification of persons with TBI who would benefit from targeted services, 2) provision of post acute rehabilitation, 3) trained staff knowledgeable about how to have effective interactions with individuals with TBI, 4) case management, and 5) local coordination of long term care services and supports that aim to keep individuals in the most appropriate independent settings. TBI rehabilitation, identification of TBI, and staff training on TBI are all lacking in Michigan's public system. While some pieces of a long-term support system for individuals with TBI are present, coordination across programs is lacking, and eligibility rules may act to restrict access to services for this population.

Another factor in planning a service system for individuals with TBI is consideration of the wide variation of impairments. Impairments for individuals who sustain a mild to severe TBI may range from no impairments to impairments affecting cognition, behavior, and/or mobility. The specific combination of impairments may also vary from one individual to another. A TBI can even lead to opposite effects in different individuals: some individuals with TBI may be unable to initiate activities and therefore do nothing, while others have poor impulse control and are unable to check inappropriate behaviors. Individuals whose injury is considered "mild" with impairments that "only" affect their ability to think, plan, and organize may be least able to qualify for services and yet could potentially be productive and independent with the appropriate supports.

Policy recommendations made here prioritize policy change that would make services for persons with TBI more flexible, more accessible, and less fragmented, while considering ways to reduce or stabilize cost to the Medicaid system.

An intermediate recommended step is to create a Home and Community Based Medicaid Waiver for individuals with TBI, as 25 other states have done. Such Waivers are subject to the limitations discussed above, but would nevertheless be of significant benefit to those who could qualify for services.

Other recommendations that should be implemented regardless as to whether the long-term strategy is a redesigned system or a TBI specific waiver, have been made in regards to sustainability, prevention, training, screening, and Medicaid policy modifications.

A final caveat relates to the definition of TBI. While this project has focused on TBI, there may be other groups who are similarly excluded from Michigan’s public service system and would benefit from the changes recommended here. Some other groups that might benefit include: individuals with other types of brain injury (such as stroke, anoxia, brain tumors or infection) and other non-progressive or slowly progressive neurological conditions like Multiple Sclerosis, Parkinson’s, and epilepsy. Careful consideration of appropriate services for these diagnosis groups should be part of the next level of planning for policy change.

It is the position of the TBI Project team that treating individuals and providing supported living settings in the community naturally provides the impetus to be as independent as possible, while institutionalization naturally supports dependence and ultimately higher costs to the state.

APPENDIX A:
LIST OF ABBREVIATIONS & GLOSSARY

List of Abbreviations

AAA	Area Agency on Aging
AAR	Access, Assessment and Referral Agencies
ADLs	Activities of Daily Living
AT	Assistive Technology
BIAMI	Brain Injury Association of Michigan
CDC	Centers for Disease Control and Prevention
CIL	Center for Independent Living
CIS	Consumer and Industry Services
CMH	Community Mental Health
CMHSP	Community Mental Health Services Programs
CSHCS	Children's Special Health Care Services
CWP	The Children's Waiver Program
DD	Developmental Disability
DME	Durable Medical Equipment
DMO	Devices for Memory Organization
DOC	Department of Corrections
DSM- IV	Diagnostic and Statistical Manual of Mental Disorders: Fourth Edition
ED	Emergency Department
FFS	Fee For Service (Medicaid)
FIA	Family Independence Agency
FY	Fiscal Year
HCBW	Home and Community-Based Waiver
HRSA	Health Resources and Services Administration
HSW	Habilitation Supports Waiver
IADLs	Instrumental Activities of Daily Living
ICD-9-C	International Classification of Diseases, Ninth Revision, Clinical Modification
ICF/MR	Intermediate Care Facility for the Mentally Retarded
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Program
ISD	Intermediate School District
LRE	Least Restrictive Environment
LTACHs	Long Term Acute Care Hospitals
MATCH	Michigan Assistive Technology Clearinghouse
MCCA	Michigan Catastrophic Claims Association
MCHB	Maternal and Child Health Bureau
MDCH	The Michigan Department of Community Health
MDE	Michigan Department of Education

MDRC	Michigan Disability Rights Coalition
MEDCIIN	Michigan Emergency Department Community Injury Information Network
MHA	Michigan Health and Hospital Association
MHP	Medicaid Health Plan
MI	Mental Illness
MI Choice Program	Michigan's Medicaid Home and Community Based Waiver for Elderly and Disabled
MIDB	Michigan Inpatient Database
MPCB	Multipurpose Collaborative Body
MPHI	Michigan Public Health Institute
MRS	Michigan Rehabilitation Services
OSA	Office of Services to the Aging
PDA	Personal Digital Assistant
PIHPs	Pre-Paid Inpatient Health Plans
RESNA	Rehabilitation Engineering & Assistive Technology Society of North America
SE	Southeast Michigan
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Social Security Income
SW	Southwest Michigan
TBI	Traumatic Brain Injury
UP	Upper Peninsula
VRS	Vocational Rehabilitation Services

Glossary

Acute – in reference to healthcare for TBI, describes the medical procedures undertaken to stabilize a patient; care that is provided on a short-term basis for an immediate need, usually right after the injury occurred

Administrative – of or related to the method of attending to (especially business) matters

Appropriate residential placement – helping a person with disabilities find a place to live that meets their needs and preferences to the extent possible

Assistive Technology – any technology that enables someone to do something that they normally cannot do; a special device which assists in the performance of self care, work or play/leisure activities or physical exercise

Augment (also augmentative) – to make greater, such as an increase in size, ability, extent, quality

Beneficiary – the person named to receive benefits

Capitated – a term relating to Managed Care contracts indicating the fixed amount to be paid per enrolled member

Claims records – a line of information in a database (such as Medicaid) detailing services performed for a beneficiary or enrolled member, and the amount charged and paid for services

Cognition – refers to functions of the brain and how one thinks or reasons

Community living supports – a range of services provided to assist people to live in the home of their choice

Compensatory techniques – strategies or approaches used by a person to offset or counterbalance a disability

Coordination and planning of services – the act of planning an array of resources and supports that complement each other and meet the needs of a beneficiary, and helping a beneficiary obtain access to those services

Cost-effectiveness – efficient in terms of amount of good or service received for amount of money spent

Data-based – conclusions or findings that are supported by relevant information and data

Data Warehouse – the MDCH Data Warehouse is a system for sharing most data collected and stored by MDCH in a centralized and accessible form

Demographic – selected characteristics of a population, such as age, race, sex, employment status for social study purposes

Denominator – the expression written below the line in a common fraction that indicates the number of parts into which one whole is divided

Diagnostic codes – system of symbols (as letters or numbers) to represent the mark or symptom by which one health condition is known or distinguished from others

Durable medical equipment – doctor-ordered, reusable medical items for use in the home; examples include canes, walkers, and ventilators

Electronic records – computer file documents providing evidence or information about past events

Encounter – in reference to a database, “encounter” means a record or description of the service provision – usually during a single visit

Entitlement program – a government program that guarantees and provides benefits to a particular group

Ergonomic – equipment design intended to reduce worker fatigue, discomfort, and possible repetitive use injury

Executive functions – the ability to direct and organize behavior, including planning, making decisions, setting goals, reflection

Fiscal – having to do with finances or money; “fiscal year” means a 12 month accounting period: October 1 – September 30 in Michigan

Incidence – in reference to TBI data, “incidence” refers to the number of a given type of events in a year

Intervention – service or program intended to address a problem or issue

Managed care – an arrangement for health care in which an organization (such as an HMO) works between a person seeking care and a physician

Mean – average; calculated by adding up all the elements and dividing by the total number of elements

Median – a value in an ordered set of values below and above which there is an equal number of values or which is the arithmetic mean of the two middle values if there is no one middle number

Medicaid – a jointly funded, federal-state health coverage program for low-income people; “Medicaid Health Plans” are Medicaid managed care plans (HMOs) in which the plan is paid a capitated rate for providing a range of physical health services through network providers; “Medicaid Fee for Service” allows beneficiaries to seek approved care from any provider willing to provide it

Methodology – the technique or procedure used to determine results

Longitudinal study – study that involves the repeated observation or examination of a set of subjects over time

Orthotics – the use of specialized devices, such as a brace, to provide artificial support; not limited to physical disabilities

Percentage – parts per hundred

Person-centered planning – a process in which the individual is the central driving force in determining his or her future vision, goals, supports and services with the support of family and care givers

Personal care – the occupation of attending to the physical needs of people who are disabled or otherwise unable to take care of themselves, including tasks such as bathing and cooking

Protocol – a detailed plan or set of procedures for (in this case) providing services

Rates – the measure of a part with respect to the whole; for example, comparing the number of individuals with TBI to the total Michigan population

Relative risk – the probability of an event in one group compared to the probability of an event in another group

Rehabilitation – the return of function after injury or illness, often with the assistance of a variety of medical professionals

Screening method – an initial technique or tool used to identify those people who (in this case) might have disabilities or symptoms due to a brain injury; screening is not the same thing as a more thorough “assessment” which would rigorously determine a person’s needs and diagnosis

Severity – the degree of something undesirable

Standard deviation – a statistical measure of the amount by which a set of values differs from the average; equal to the square root of the mean of the differences’ squares

Statistically significant – indicates results that are unlikely to have occurred by chance

Stratified – to arrange the different parts of something in separate layers or groups

Stratified random sample – a way to chose a group of elements from a larger population, in which the elements are first put in groups, and then chosen at random from the groups; a statistically valid way to choose a group (or “sample”) of elements that will represent all the elements (the “population”) in predictable ways

Surveillance – close observation of a person or group

Universal design – development of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation

Unweighted – a mathematical term indicating that elements of a sample have not been assigned a “weight”. In the case of the MEDCIIN data, because of stratification (see above), some hospitals had a greater chance of being selected for study than others. This group (or “sample”) of hospitals can still represent the state of Michigan in valid and predictable ways, but only after data from each hospital are “weighted” mathematically. The mathematical process of “weighting” the hospital data was not finished at the time that this report was prepared. Final figures calculated from the MEDCIIN data will therefore be different from those shown here.

Vocational – related to, or being in training, for a skill or trade to be pursed as occupation or job

APPENDIX B: INCIDENCE AND RISK FACTOR ANALYSIS

Detailed Methodology

Case Selection

The Centers for Disease Control and Prevention recommended diagnostic codes were used for identifying deaths, hospital admissions, and ED visits involving a TBI. For mortality data, cases were identified if any of the following ICD-10 codes were included in the sequence of conditions contributing to death:

- S01.0 – S01.9 (open wound of the head);
- S02.0, S02.1, S02.3, S02.7– S02.9 (fracture of skull and facial bones);
- S06.0 – S06.9 (intracranial injury);
- S07.0, S07.1, S07.8, S07.9 (crushing injury of head);
- S09.7 – S09.9 (other and unspecified injuries of head);
- T01.0 (open wounds involving head with neck);
- T02.0 (fractures involving head with neck);
- T04.0 (crushing injuries involving head with neck);
- T06.0 (injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level); and
- T90.1, T90.2, T90.4, T90.5, T90.8, T90.9 (sequelae of injuries of head).

For hospital discharge and ED data, cases were identified if one or more of the following ICD-9-CM diagnostic codes were present in any of the diagnosis fields:

- 800.0 - 801.9 (fracture of the vault or base of the skull);
- 803.0 - 804.9 (other and unqualified multiple fractures of the skull);
- 850.0 - 854.1 (intracranial injury, including concussion, contusion, laceration, and hemorrhage); and
- 959.01 (head injury, unspecified).

Note that in both the inpatient and ED databases queried, cases were only present if the primary diagnosis was an injury diagnosis (TBI or other injury). Cases with late effect external cause of injury (E-codes) and visits for follow-up care as identified by V-codes were excluded.

Calculations

All rates are unadjusted, calculated as the number of cases in a given category divided by the estimated Michigan population in the same category. Rates presented for multiple years are calculated by adding the number of TBI cases during each year and dividing by the sum of the population during each year and multiplied by 100,000. Percentages presented for multiple years are calculated as the sum of cases in a given category for all years divided by the sum of all cases during the timeframe. Annual averages are the number of cases during the time frame divided by the number of years.

Definitions

Cause of injury is recorded using the ICD-10 coding system for deaths, and the ICD-9-CM coding system for hospitalizations and ED visits. Rates of cause coding for TBI cases in the various databases are: mortality data – 100%, inpatient data – 85-86%, ED data – 65%. Causes are summarized only for those cases with a code. It is unknown whether those cases without a cause of injury code exhibit the same patterns as those with a cause code.

Intentional versus unintentional injuries

ICD-9-CM and ICD-10 coding systems distinguish between intentional and unintentional injuries. Note that the key distinction is not who inflicted the injury, but whether the injury was purposefully inflicted or an accident. For deaths, intentional injuries are those classified as homicide and suicide. For non-fatal injuries, intentional injuries are coded either as assault or self-inflicted injury. All other cause of injury categories are considered to be accidents, or unintentional. To the extent that there are errors in the data, it is most likely that assault and self-inflicted injuries are under-identified and reported as unintentional.

Motor vehicle traffic

Motor vehicle traffic crashes are all crashes involving a motor vehicle in traffic, except bicycles. Injuries to bicyclists have been separated out for reporting purposes. Some of the bicycle-related injuries may involve cars and others may not. Motor vehicle traffic thus includes all car, truck, and motorcycle crashes occurring on a public roadway and involving drivers, passengers, pedestrians, or other bystanders outside the vehicle. Note that this category does not overlap perfectly with the class of injuries that can be covered through Michigan’s no-fault automobile insurance system. Automobile insurance does not cover motorcycles (unless a covered car or truck is also involved in the crash), but it may cover some crashes involving a motor vehicle that is not in traffic.

Unintentional struck by/against

This category of injuries includes situations in which a person was injured through impact with another object or person, other than in the case of vehicle crashes or falls, and so long as the injury was not reported as purposefully inflicted. Most sports injuries would come under this category.

County

Where death or hospitalization rates are presented by county, it is important to note that county is where the person lived. It is assumed that most injuries take place in the county in which the person resides, but this is not always the case. In terms of hospitalizations, the county data are not the same as where the person was hospitalized. It is likely that many people are hospitalized in counties other than the ones in which they live (or are injured).

Additional Tables and Figures

Table B1. TBI-related deaths, by sex and year

Year	Sex	Number (N)	Percent (%)	Rate/100,000
1999	All	1,585		16.07
	F	429	27%	8.47
	M	1,156	73%	24.08
2000	All	1,591		16.01
	F	454	29%	8.96
	M	1,137	71%	23.33
2001	All	1,563		15.62
	F	412	26%	8.08
	M	1,151	74%	23.44
2002	All	1,523		15.15
	F	399	26%	7.80
	M	1,124	74%	22.78
CY1999-2002	All	1,566		15.71
(Average)	F	424	27%	8.33
	M	1,142	73%	23.41

Source: Michigan Vital Statistics, Calendar Years 1999-2002

Table B2. TBI-related nonfatal hospitalizations by sex and year

Year	Sex	Number (N)	Percent (%)	Rate/100,000
1999	All	8,612		87.31
	F	3,145	37%	62.11
	M	5,467	63%	113.90
2000	All	8,702		87.57
	F	3,228	37%	63.73
	M	5,474	63%	112.33
2001	All	9,275		92.69
	F	3,455	37%	67.79
	M	5,820	63%	118.54
2002	All	9,662		96.20
	F	3,689	38%	72.10
	M	5,973	62%	121.05
CY1999-2001 (Average)	All	9,065		90.94
	F	3,379	37%	66.43
	M	5,973	63%	116.46

Source: Michigan Inpatient Database, calendar years 1999-2002. Rates were calculated using population estimates from the US Census.
Note: Gender totals for each year will not necessarily add up to the ‘All’ category for that year. All categories also include the very small number of cases where no gender was specified (only 8 of these cases for the 4 year period).

Table B3. TBI deaths and nonfatal hospitalizations by county, 1999-2002

County	Deaths		Nonfatal Hospitalizations	
	Annual Average Number	Rate/ 100,000	Annual Average Number	Rate/100,000
Alcona	1.8	15.1	10.8	92.6
Alger	3.0	30.5	8.0	81.2
Allegan	16.3	15.2	96.3	90.0
Alpena	5.5	17.6	27.0	86.5
Antrim	4.5	19.3	18.3	78.4
Arenac	4.0	23.3	17.0	98.8
Baraga	1.5	17.2	9.8	111.7

Table B3. TBI deaths and nonfatal hospitalizations by county, 1999-2002

County	Deaths		Nonfatal Hospitalizations	
	Annual Average Number	Rate/ 100,000	Annual Average Number	Rate/100,000
Barry	11.5	20.1	56.3	98.5
Bay	22.8	20.7	115.5	105.1
Benzie	3.0	18.4	9.8	60.0
Berrien	27.5	16.9	135.5	83.5
Branch	11.8	25.6	41.3	90.0
Calhoun	24.0	17.4	120.3	87.0
Cass	12.8	24.9	43.5	85.1
Charlevoix	4.5	17.2	20.0	76.4
Cheboygan	6.5	24.4	19.8	74.2
Chippewa	6.5	16.8	17.0	44.0
Clare	9.3	29.5	31.8	101.4
Clinton	8.3	12.6	51.5	78.8
Crawford	4.5	31.2	10.0	69.3
Delta	6.3	16.3	27.5	71.5
Dickinson	5.3	19.2	30.8	112.2
Eaton	11.5	11.0	88.0	84.4
Emmet	6.5	20.5	28.8	90.6
Genesee	85.3	19.5	614.5	140.3
Gladwin	4.0	15.2	28.5	108.5
Gogebic	2.3	12.9	9.3	52.9
Grand Traverse	14.5	18.4	49.3	62.4
Gratiot	5.3	12.6	41.5	99.2
Hillsdale	9.5	20.4	34.3	73.4
Houghton	8.3	23.0	39.8	110.6
Huron	9.5	26.5	33.8	94.3
Ingham	30.0	10.7	231.8	82.7
Ionia	12.0	19.3	57.8	93.1
Iosco	5.0	18.4	21.5	79.1
Iron	3.8	28.9	20.5	157.9
Isabella	6.8	10.6	45.3	71.0
Jackson	24.8	15.6	134.3	84.4
Kalamazoo	37.3	15.6	197.0	82.3

Table B3. TBI deaths and nonfatal hospitalizations by county, 1999-2002

County	Deaths		Nonfatal Hospitalizations	
	Annual Average Number	Rate/ 100,000	Annual Average Number	Rate/100,000
Kalkaska	2.8	16.4	14.3	85.2
Kent	76.8	13.3	474.3	81.9
Keweenaw	0.5	-*	3.8	165.9
Lake	5.5	48.5	10.5	92.5
Lapeer	16.8	18.8	83.0	93.4
Leelanau	2.3	10.6	12.5	58.7
Lenawee	14.0	14.1	73.3	73.8
Livingston	20.5	12.7	100.8	62.6
Luce	1.0	-*	4.3	60.5
Mackinac	2.8	23.4	8.0	68.1
Macomb	100.8	12.7	688.3	86.5
Manistee	5.5	22.3	16.8	67.9
Marquette	14.0	21.7	43.0	66.9
Mason	6.5	22.8	26.8	93.9
Mecosta	7.5	18.4	33.0	80.9
Menominee	5.8	22.8	21.8	86.1
Midland	11.5	13.8	65.5	78.6
Missaukee	3.8	25.7	13.8	94.1
Monroe	13.5	9.2	147.3	100.1
Montcalm	14.3	23.1	63.5	103.0
Montmorency	3.0	28.8	8.3	79.3
Muskegon	30.3	17.7	162.8	95.4
Newaygo	8.8	18.1	46.5	96.3
Oakland	150.5	12.6	849.0	70.9
Oceana	5.3	19.4	24.8	91.5
Ogemaw	6.3	28.9	17.0	78.5
Ontonogan	1.3	16.1	11.8	151.2
Osceola	6.5	27.9	23.8	102.1
Oscoda	3.5	37.1	6.8	71.5
Otsego	5.0	21.2	15.3	64.7
Ottawa	33.5	13.9	162.8	67.5
Presque Isle	2.8	19.1	11.5	79.9

Table B3. TBI deaths and nonfatal hospitalizations by county, 1999-2002

County	Deaths		Nonfatal Hospitalizations	
	Annual Average Number	Rate/ 100,000	Annual Average Number	Rate/100,000
Roscommon	6.0	23.5	23.0	89.9
Saginaw	42.5	20.2	236.3	112.5
Sanilac	10.5	23.6	42.8	96.1
Schoolcraft	3.5	39.5	1.8	19.8
Shiawasee	15.0	20.9	71.8	99.8
St. Clair	22.3	13.4	138.0	83.4
St. Joseph	14.0	22.4	57.5	92.2
Tuscola	12.3	21.0	71.8	123.1
Van Buren	14.5	18.9	72.3	94.3
Washtenaw	33.0	10.1	188.3	57.6
Wayne	327.5	15.9	2296.8	111.6
Wexford	5.3	17.2	28.0	91.7

*Rates are not presented if there were fewer than 5 cases total during the 4 years analyzed.
Source: Michigan Vital Statistics, Calendar Years 1999-2002

Table B4. Average annual TBI-related deaths by age and sex			
	1999-2002 Average Number (N)	Percent (%)	(Rate)/100,000
BOTH SEXES			
<1	11	1%	8.51
1-14	66	4%	3.29
15-24	261	17%	18.82
25-34	208	13%	15.38
35-44	226	14%	14.15
45-54	200	13%	14.38
55-64	126	8%	14.22
65-74	144	9%	22.57
75-84	193	12%	43.85
85+	133	8%	89.40
All Ages (Total)	1566	100%	15.71
FEMALE			
<1	5	0%	7.75
1-14	23	1%	2.38
15-24	60	4%	8.77
25-34	44	3%	6.43
35-44	49	3%	6.03
45-54	45	3%	6.35
55-64	32	2%	7.02
65-74	39	2%	11.09
75-84	66	4%	24.73
85+	62	4%	59.46
All Ages (Total)	424	27%	8.33
MALE			
<1	6	0%	9.24
1-14	43	3%	4.16
15-24	201	13%	28.55
25-34	164	10%	24.39
35-44	177	11%	22.40
45-54	155	10%	22.65
55-64	94	6%	21.89
65-74	105	7%	36.47
75-84	127	8%	73.21
85+	70	4%	161.40
All Ages (Total)	1142	73%	23.41

Source: Michigan Vital Statistics, Calendar Years 1999-2002

Table B5. TBI-related nonfatal hospitalizations by age and sex			
	CY1999-2002 Average Number (N)	**Percent (%)**	**(Rate)/100,000**
BOTH SEXES			
<1	189	2%	142.62
1-14	911	10%	45.44
15-24	1545	17%	111.60
25-34	987	11%	73.16
35-44	1226	14%	76.86
45-54	1012	11%	72.82
55-64	642	7%	72.57
65-74	753	8%	117.93
75-84	1101	12%	250.72
85+	700	8%	472.31
All Ages (Total)	9065	100%	90.97
FEMALE			
<1	72	1%	111.26
1-14	336	4%	34.32
15-24	458	5%	67.22
25-34	269	3%	39.78
35-44	345	4%	42.96
45-54	293	3%	41.48
55-64	233	3%	51.13
65-74	328	4%	93.93
75-84	590	7%	221.89
85+	455	5%	434.64
All Ages (Total)	3379	37%	66.45
MALE			
<1	117	1%	172.51
1-14	576	6%	56.03
15-24	1086	12%	154.51
25-34	717	8%	106.65
35-44	881	10%	111.27
45-54	719	8%	105.11
55-64	409	5%	95.37
65-74	424	5%	147.00
75-84	511	6%	294.99
85+	245	3%	562.33
All Ages (Total)	5684	63%	116.48
Source: Michigan Inpatient Database, calendar years 1999-2002. Rates were calculated using population estimates from the US Census.			

Table B6. Nonfatal nonhospitalized TBI-related ED visits, unweighted sample		
	Number (N)	**Percent (%)**
BOTH SEXES		
<1	341	4.2%
1-14	2770	34.1%
15-24	1798	22.2%
25-34	906	11.2%
35-44	780	9.6%
45-54	496	6.1%
55-64	291	3.6%
65-74	266	3.3%
75-84	283	3.5%
85+	185	2.3%
All Ages (Total)	8,116	100.0%
FEMALE		
<1	153	1.9%
1-14	1,034	12.7%
15-24	718	8.8%
25-34	411	5.1%
35-44	385	4.7%
45-54	247	3.0%
55-64	163	2.0%
65-74	146	1.8%
75-84	192	2.4%
85+	152	1.9%
All Ages (Total)	3,601	44.4%
MALE		
<1	187	2.3%
1-14	1,736	21.4%
15-24	1,080	13.3%
25-34	495	6.1%
35-44	395	4.9%
45-54	249	3.1%
55-64	128	1.6%
65-74	120	1.5%
75-84	91	1.1%
85+	33	0.4%
All Ages (Total)	4,514	55.6%

Limitations

Mortality Data

Certain limitations are associated with using the cause of death data on death certificates to describe fatal TBI trends. Race/ethnicity data might be misclassified, as this information could be provided by different sources, e.g., funeral directors on the basis of next-of-kin or other informant communication or through observation. The accuracy and reliability of the TBI diagnostic codes are dependent on the accuracy of the diagnoses and on the care with which these diagnoses are recorded on the death certificates. It has been pointed out that the quality of medical certification on death certificates has not been evaluated fully. Additionally, because TBI-related deaths were selected where any one or more TBI diagnostic codes were included in the sequence of conditions leading to death, it is possible that some of the TBI-related deaths included in the analysis were not actually deaths immediately resulting from a TBI.

MIDB Data

The hospitalized TBI surveillance system relies heavily on the use of hospital administrative data sources. The accuracy of case identification and other critical information is dependent on the care and accuracy of information entered into each hospital’s database. Cause of injury coding was incomplete, ranging from 85-86% during the years analyzed. This means that actual rates and percentages of various causes of hospitalized TBI may vary somewhat from those presented here.

MEDCIIN Data

The MEDCIIN dataset is based on a sample of 23 hospitals throughout the state. The sample was conducted to allow weighting and estimation of accurate rates throughout Michigan. At the time of publishing this report, however, weighted data are not yet available. Therefore, unweighted data are presented. While not necessarily representative of the state as a whole, even the unweighted data give us a unique and valuable picture of the more mild end of the spectrum of brain injury. As with the hospitalized cases, the accuracy of case identification and other critical information from the ED injury surveillance system is dependent on the care and accuracy of information entered into each ED’s database. Case selection criteria are dependent on accurate coding of diagnosis, which is in turn dependent on clinical identification of TBI. It is believed that TBI might not be identified by ED staff when associated with more immediate comorbid conditions. Studies have documented limitations in the accuracy of diagnostic coding performed in hospitals, and the increasing use of codes denoting more specific and severe diagnostic categories with the increased use of prospective payment systems.

The reliance on E-codes limits the extent to which cause can be ascertained for the sample. E-coding rates vary greatly by hospital with a few hospitals accounting for most of the missing E-codes. Analyses of the MEDCIIN database are also limited by the lack of clinical details included in the electronic records such as Glasgow Coma Scale (GCS) scores, or the results of any other diagnostic tests conducted. Data on race and ethnicity from the EDs are almost always observed by hospital staff, rather than self-reported. Initial analysis of the MEDCIIN data also revealed the large proportion of missing information on patient's race. Thus, no attempts were made to calculate incidence rates by racial and/or ethnic grouping. Lack of clinical and race data is common to data systems using billing data and does not detract from the value of the MEDCIIN database.

The availability of only one year of weighted MEDCIIN data does not allow for evaluation of trends in TBI-related ED visits. The distributions of TBI by age, sex, and cause of injury tend to remain similar over time; however, because of the trend toward decreased hospital admission rates for TBI, rates for strictly ED visits may possibly have been increasing.

APPENDIX C: COST AND SERVICE USE ANALYSIS

Detailed Methodology

Medicaid FFS and MHP

Medicaid data is provided as claims files (FFS) or encounter files (MHP). A claims data file is one in which each line of the data file represents a claim or bill from a provider to Medicaid. There may be multiple such claims for each service event or visit. Each claim or encounter line has one or more diagnoses listed. Initially, only those claims lines with a TBI diagnosis, primary or secondary, were provided to MPHI by Medicaid.[1] The next task was to transform the data, summarizing each claim and event, so that each line of the data tells the story of an individual. This process was undertaken at MPHI using SPSS statistical software. MPHI was in contact with Medicaid technical staff to ensure that appropriate decisions were made in interpreting and summarizing data entries.

Once this was done, we had a list of Medicaid ID numbers of everyone on Medicaid who received a service in which TBI was one diagnosis during fiscal years 1999-2002. We knew which of these individuals had inpatient hospital care with a TBI diagnosis. The enrollment database was queried to determine which of these people hospitalized with a TBI was continuously eligible for Medicaid for two years following the inpatient care for TBI. These individuals were selected for further analysis. The Medicaid system was again queried to get *all* the claims and encounters (regardless of diagnosis) for these individuals. Some of these claims/encounters are not specifically related to having a TBI (annual physicals or treatment of diseases, for example). Nevertheless, to the extent that the person may be on Medicaid because of the TBI it is important to summarize the entire cost of caring for him or her. The individuals summarized may not be representative of the typical person with a brain injury as a result of the case selection criterion of two continuous years of eligibility and enrollment in Medicaid FFS (see Limitations, below).

Cost data and provider category are contained only in the FFS claims (since the MHP contracts are capitated and therefore bills are not submitted for each service). Therefore, most analysis centers on summarizing costs and provider categories within the FFS data. Provider category should not be confused with where the service occurred. For instance, nearly $29 million were identified as hospital inpatient costs. These are likely to exclude professional charges occurring during a hospital stay in cases where the professional submits a separate bill.

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[1] If, during the same visit, a person was also treated for broken ribs (for example), this would only be reflected if the TBI diagnosis was also listed on the record. Or, if a person with TBI enrolled in Medicaid due to impairments resulting from a TBI (but the initial event was covered while the person was still working and had insurance) – that person would only enter our statistical calculations if a medical provider specifically listed the TBI diagnosis on a claim. This is why cost estimations presented in Table 3.2 should be seen as a lower bound estimate. The actual cost of TBI to Medicaid Managed Care is certainly greater.

Home Help and CMHSP

The TBI Project matched the list of Medicaid ID numbers of individuals who received a TBI-related service through Medicaid FFS or MHP to Home Help beneficiaries receiving services during FY2000-FY2002 and to CMHSP beneficiaries during FY1999-2002. (The shorted time frame for the Home Help analysis was necessitated because earlier data had been purged from the Data Warehouse.)

A query of the Data Warehouse was used to sum yearly Home Help costs for those individuals with a TBI identified in the Medicaid FFS or MHP files. Cost data are not found in the CMHSP database. Rather, service categories were summarized. For both Home Help and CMHSP, data are presented for all individuals with any identified TBI service in Medicaid, as well as for those who sustained a TBI severe enough to result in hospitalization. It should not be assumed that individuals are enrolled in either of these programs because of a TBI. It could be the case that individuals already enrolled subsequently experienced a TBI.

Additional Tables and Figures

Table C1 shows the total number of Medicaid clients serviced by each CMHSP between FY99 and FY02, along with the number and percentage of individuals who received a TBI-related service through Medicaid during the same four years. Individuals with a Medicaid identified TBI who received a CMH service ranged from 3,557 (Wayne) to 35 (Barry). Saginaw (8.0%) had the highest percentage of CMH cases with a Medicaid-TBI followed by St. Clair, Genesee, Bay-Arenac, and North Central all of which had percentages in the seven percent range.

Note that the numbers associated with each CMHSP would sum to a higher total than is found in tables in Section 3. This is because those tables include only unique individuals as identified in the entire accumulated data set over the four year range. In Table C1, if an individual received CMH services by more than one CMHSP during the reporting period, that individual is counted within each CMHSP that provided services.

Table C1. Medicaid-TBI and CMH cases by CMHSP, FY1999-2002

CMHSP	Total CMH Cases	CMH Cases with TBI	% of CMH Cases with TBI	CMHSP	Total CMH Cases	CMH Cases with TBI	% of CMH Cases with TBI
Allegan	1,943	103	5.3	Monroe	2,445	163	6.7
Antrim-Kalkaska	1,164	50	4.3	Montcalm	1,462	97	6.6
AuSable	2,408	162	6.7	Muskegon	4,769	311	6.5
Barry	971	35	3.6	Newaygo	1,501	102	6.8
Bay Arenac	3,956	290	7.3	North Central	3,277	230	7.0
Berrien	4,071	268	6.6	Northeast	2,617	137	5.2
CEI	8,707	584	6.7	Northern	2,970	152	5.1
Central Michigan	6,527	390	6.0	Northpointe	2,418	151	6.2
Copper	1,740	89	5.1	Oakland	11,005	642	5.8

Table C1. Medicaid-TBI and CMH cases by CMHSP, FY1999-2002

CMHSP	Total CMH Cases	CMH Cases with TBI	% of CMH Cases with TBI	CMHSP	Total CMH Cases	CMH Cases with TBI	% of CMH Cases with TBI
Genesee	11,651	882	7.6	Ottawa	3,092	170	5.5
Gogebic	1,013	44	4.3	Pathways	3,720	208	5.6
Gratiot	1,244	66	5.3	Pines	1,795	85	4.7
Great Lakes	2,815	127	4.5	Saginaw	5,016	402	8.0
Hiawatha	1,870	82	4.4	Sanilac	1,046	69	6.6
Huron	1,002	55	5.5	Shiawassee	952	54	5.7
Ionia	1,319	81	6.1	St. Clair	3,361	258	7.7
Kalamazoo	4,959	310	6.3	St. Joseph	2,231	109	4.9
Kent	13,621	786	5.8	Summit Pointe	6,928	372	5.4
Lapeer	1,027	65	6.3	Tuscola	1,398	88	6.3
Lenewee	1,418	86	6.1	Van Buren	1,942	112	5.8
Lifeways	5,420	364	6.7	Washtenaw	3,374	172	5.1
Livingston	1,513	59	3.9	Wayne	90,918	3,557	3.9
Macomb	8,263	449	5.4	West Michigan	2,262	149	6.6
Manistee-Benzie	1,677	79	4.7	Woodlands	1,246	66	5.3

Table C2 depicts summary information on the amount of services received by Medicaid CMHSP clients hospitalized for TBI. Data are summarized for one year only, October 1, 2000 – September 30, 2001. For comparison, the same information is presented for Medicaid CMHSP clients with no identified TBI. Data are presented only for services received by at least 10% of any service category of Medicaid CMHSP clients hospitalized for TBI. (Other services not likely to be accessed and thus not presented are: state inpatient, supported independent housing, outpatient partial hospitalization services, clubhouse programs, intensive crisis stabilization services, family support/skills-DD, family skills development-MI, community living equipment-DD, community living environmental modification-DD, community living medical supplies-DD, enhanced health care-pharmacy-DD, extensive observation beds-MI, and prevention services.)

Table C2. Quantity of frequently used CMHSP services received by Medicaid beneficiaries with TBI hospitalization, FY2001

Services (units summarized in parentheses)	**Medicaid CMHSP Cases with TBI Hospitalization**									**Medicaid CMHSP Cases - No identified TBI**								
	DD (n =97)			**MI Adults (n =430)**			**MI Children (n =66)**			**DD (n =24,696)**			**MI Adults (n =46,284)**			**MI Children (n =16,402)**		
	No.	**Ave.**	**S.D.**	**No.**	**Ave.**	**S.D.**	**No.**	**Ave.**	**S.D.**	**No.**	**Ave.**	**S.D.**	**No.**	**Ave.**	**S.D.**	**No.**	**Ave.**	**S.D.**
Mental Health Clinic (hrs)	21	8	8	350	12	53	46	9	12	4142	8	26	40524	8	21	13673	8	10
Emergency Services/Crisis Stabilization (encounters)	17	9	24	188	5	15	15	2	2	1855	4	15	10961	3	9	3096	2	4
Community Inpatient (days)	10	11	9	102	15	15	8	4	1	541	15	27	4688	14	23	1106	10	19
Supports & Services Coordination (contacts)	70	22	26	165	17	28	10	11	7	19509	20	25	18239	16	21	2698	9	16
ACTC (contacts)	3	-*	-*	51	38	43	1	-*	-*	146	55	69	4521	61	72	42	24	28
Crisis Residential (days)	2	-*	-*	31	10	13				122	15	21	1732	12	15	71	19	36
Specialized Residential (days)	25	255	120	37	165	137				7317	288	117	2426	196	149	165	132	116
Day Programs (hrs)	22	693	523	21	167	265				7096	775	494	1309	292	372	62	66	28
Community Living – Staff (hrs)	9	1787	2169	21	191	504				4390	1136	1972	2376	489	1416	213	67	85
Skill Building Assistance-Supported Integrated Employment (hrs)	14	157	266	8	26	58				4269	195	282	1928	138	248	19	34	48
Housing Assistance ($)	4	-*	-*	3	-*	-*				1084	3499	4292	799	2562	3586	25	2008	2101
Enhanced Health Care - Staff – DD (hrs)	59	21	27	7	301	795	1	-*	-*	16487	24	121	1139	18	158	334	28	192
Skill Building Assistance - All Other (hrs)	18	456	444	12	112	158	1	-*	-*	7340	491	479	1389	206	362	80	20	38
Home-Based Services (contacts)	3	-*	-*	6	14	9	12	40	49	231	21	27	570	18	20	2692	24	28
Respite Care (hrs)	15	287	294				3	-*	-*	3309	290	365	172	262	555	1671	215	276
Assistance for Challenging Behaviors – DD (hrs)	13	59	169							3878	6	36	97	3	4	30	4	7

* Means and standard deviations are not calculated when number < 5.

† Data are not presented because of apparent errors/unexplained values in the dataset.

Limitations

Limitations come from case selection criteria and potential incompleteness of diagnostic coding. To the extent that TBI is not listed as a diagnosis on medical claims, the number of people with TBI, the service provision, and the costs are underestimated. It is believed that hospital claims may have fairly accurate diagnoses because diagnosis is important for billing and receiving payment. Other types of claims, such as professional claims and long term care claims, are not reimbursed on the basis of diagnostic codes. Therefore, diagnostic information on these types of claims is almost certainly incomplete. Without a TBI diagnosis, the record would not be part of the available dataset. This leads to a bias in types of services summarized – more hospital services will be summarized and fewer professional and long term care claims. In addition, some people may be missed entirely to the extent that their acute hospital visit occurred before the time frame of analysis, or to the extent that it was paid for by a source other than Medicaid, and follow-up hasn't been identified with a TBI diagnosis.

Secondary analysis of hospitalized individuals was designed to overcome limitations associated with inaccurate diagnostic coding by selecting claims on certain individuals regardless of diagnosis. This analysis is also subject to limitations. First, individuals without a hospitalization are not included. This is appropriate since the majority of people with only outpatient visits will probably not have long-term impairments (although a minority will have substantial, lifelong consequences).

Secondly, requiring continuous Medicaid eligibility for a two year period following hospitalization and limiting analysis to Medicaid FFS beneficiaries only, limits the sample to those who have a long-term disability severe enough to prevent them from working or otherwise becoming ineligible for Medicaid.

The cases chosen for CMH and Home Help data analysis are those identified through the Medicaid analysis, therefore the analysis of CMH and Home Help data are limited by the same case identification issues affecting Medicaid analysis. Additionally, analyzing CMH data from this time period is difficult because the data were not in the form of encounters but rather in the form of yearly service summaries. Other than the fiscal year services were received, it was not possible to know dates of service. This leads to the problem of not knowing whether individuals were already in the CMH system and then suffered a TBI, or whether they had a TBI and then needed CMH services.

Finally, it should be pointed out that because TBI is so unpredictable in its consequences, it is not possible to know objectively what services individuals needed. While services received can be summarized, TBI Project staff are not able to determine whether these were the most appropriate ones for individuals. Future research needs to examine this question in the aggregate. For example, some states have registries and conduct follow-up research to determine the service use and needs of individuals with TBI. Using such data as benchmarks, future analysis could follow a sample with TBI in Medicaid to determine whether expected numbers were receiving services in various areas.

APPENDIX D: DETAILED SUMMARY OF TBI SERVICE PROVIDER TRAININGS

Provider Training Attendance

Each pilot site assumed responsibility for inviting staff to the provider trainings. Participating agencies included: CMH, FIA, School Districts, Hospitals, Area Agencies on Aging, Michigan Department of Career Development, and Centers for Independent Living. The table below (Table D1) summarizes the number of attendees for each training location.

Table D1. Training attendees by location

	Location	# of attendees	Month
1	Marquette	16	October 2002
2	Lawrence	25	October 2002
3	Battle Creek	30	October 2002
4	SW (in Kalamazoo)	33	November 2003
5	Houghton	15	September 2003
6	Marquette	16	September 2003
7	Sault Ste. Marie	31	September 2003
8	Washtenaw (WCHO)	57	February 2004
9	Lenawee (in Adrian)	47	May 2004
10	Monroe	36	May 2004
11	Livingston	34	May 2004
	TOTAL	**357***	

*This number does not equal the number of completed evaluations

Each pilot site was responsible for inviting attendees to the trainings. Table D2 below summarizes the number of attendees from each agency represented at the pilot site trainings.

Table D2. Training attendees by agency

	CMH	FIA	Waiver	Schools	Other
UP pilot site trainings	37	10	5	11	15
SW pilot site trainings	32	14	14	11	17
SE pilot site trainings	30	5	12	16	111

At the end of each training, attendees were asked to comment on the content and presentation of each section.

Evaluation of First Round of Provider Trainings: UP and SW, Fall 2002

Training attendees found the information to be helpful. Using a 5 point scale in which Excellent = 5, Very Good = 4, Good = 3, Fair = 2, and Poor = 1, average ratings by attendees were as follows:

1. Increased your knowledge of brain injury: 3.9
2. Usefulness of material: 4.1
3. Organization of material: 4.0
4. Presentation by trainer: 3.9
5. Trainer knowledgeable about material: 4.4
6. Length and pace of presentation: 3.6
7. Adequate time for questions: 3.8
8. Quality of handouts: 4.3

Overall 4.0

A series of questions measured knowledge about TBI, how best to serve people with TBI, and public services for people with TBI. These questions were administered prior to training on a pretest, and after training on a posttest. The mean pre-test score for the three pilot sites was 70.0%. The mean post-test score for the three pilot sites was 83.0%. The mean positive difference between the pre- and post-tests was 13.0%. This improvement in scores was statistically significant (t value of -6.5, p< .001).

On the posttest, attendees were also asked to write in suggestions for improvement to the training. Comments included: make the presentation more organized, provide more information on available services, and provide training geared towards particular service providers (e.g., teachers, mental health, etc.). It was suggested that at future trainings descriptions of each agency and their roles be included. Overall attendees felt the TBI training was useful and necessary.

Follow-up Survey Results

A follow-up survey with the same knowledge questions as the pre and posttests was sent to all training participants approximately three months after the trainings. A second mailing of the follow-up surveys was sent one month later to participants who had not yet returned the survey. Seventy-nine pre-tests were completed, 74 post-tests were completed and thirty-one follow-up surveys were completed and returned. The overall averages were as follows: pretest = 70%, posttest = 83% and follow-up test = 75%.

Nineteen training participants completed all three tests. Mean scores based on these 19 respondents were as follows: pre-test = 66%, post-test = 81% and follow-up test = 75%. Of the individuals who completed all tests, the average improvement between the pretest and the follow-up survey was 9.5%.

The follow-up survey included questions on how the training has helped participants in the work place, and how useful the training materials have been. Questions regarding barriers to service coordination and possible solutions were also included.

Evaluation of Barriers to Service Coordination and Solutions

Twenty-five people responded to the open-ended question regarding barriers to service coordination. The following barriers to service coordination between agencies were ranked among the top 3 barriers with the following frequencies: lack of funding (23), heavy workloads (18), inability to assess and diagnose TBI (8), lack of flexibility to provide a variety of services to meet needs over time (8), lack of available information about services offered by other agencies (7), too much paperwork (7), and lack of cooperation from other agencies (5).

Twenty-seven people responded to the question regarding changes/activities that might be useful for coordinating services. The following changes that would be useful to help coordinate services with other agencies were ranked among the top three: inclusion of TBI specific questions on assessment forms to aid in identification of TBI (15), a local TBI ombudsman available for advice and referral (15), implement TBI training into agency training program (14), form interagency TBI committees (12), standardization of consent to share information forms among all agencies (11), and standardization of intake and assessment form among FIA, CMH, waiver agents, and schools (8).

Evaluation of Second Round of Provider Trainings: UP, SW and SE, 2003-04

In response to feedback from the first round of provider trainings held in 2002, the curricula were modified. As noted in Section 5 of this report, the second round of training contained an additional module: screening and care coordination protocols being implemented by participating local agencies. Section 5 presents a summary of evaluation results of this second round of training. In addition to rating specific aspects of the trainings, attendees were invited to include open-ended comments that could be used to improve the trainings. Comments received included:

- Great program, very much needed in order to identify TBI people and provide services they need to improve quality of life. We often get information on causes, but not to do with afterwards - lots of information in this area is great.
- Should include cross training between departments. FIA to train programs and present guidelines, CMH the same, Waiver programs, etc. Lack of knowledge about one another's programs hinder us in referral steps. People who don't come close to meeting requirements are referred and turned away, which greatly increases frustration on everyone's part.
- Services may be in place, but the funding isn't, so I would like to see a more realistic approach to the issue of TBI and funding issues.
- I believe doctors need to be educated more. My daughter had a TBI 8 years ago and any doctor I took her to thought she was "faking." I believe this is why TBI is virtually unknown. TBI needs to be listed in the DSM IV.
- More TBI trainings need to be made available to our county.

APPENDIX E: HELPS BRAIN INJURY SCREENING TOOL

Consumer Information: ______________________________

____

Agency/Screener's Information: ______________________________

____

H Have you ever **H**it your **H**ead or been **H**it on the **H**ead? ☐ Yes ☐ No

Note: Prompt client to think about all incidents that may have occurred at any age, even those that did not seem serious: vehicle accidents, falls, assault, abuse, sports, etc. Screen for domestic violence and child abuse. A TBI can also occur from violent shaking of the head, such as whiplash or being shaken as a child.

E Were you ever seen in the **E**mergency room, hospital, or by a doctor because of an injury to your head? ☐ Yes ☐ No

Note: Many people are seen for treatment. However, there are those who cannot afford treatment, or who do not think they require medical attention.

L Did you ever **L**ose consciousness or experience a period of being dazed and confused?

☐ Yes ☐ No

Note: While significant in helping to determine the extent of the injury, many people with minor brain injury may not lose consciousness, yet still have difficulties as a result of their injury.

P Do you experience any of these **P**roblems in your daily life? ☐ Yes ☐ No

Note: Other problems may include: visual, auditory, sensory impairments, paralysis, weakness of any extremity, balance problems, fatigue, apathy, silliness, impulsivity, mood swings, irritability, decreased self-awareness, decreased ability to learn new information or retrieve old information, shift from one topic to another, set goals or plan tasks, monitor own behavior and difficulty with abstract thinking.

- ☐ headaches
- ☐ dizziness
- ☐ anxiety
- ☐ depression
- ☐ difficulty concentrating
- ☐ difficulty remembering
- ☐ difficulty reading, writing, calculating
- ☐ poor problem solving
- ☐ difficulty performing your job/school work
- ☐ change in relationships with others
- ☐ poor judgment (being fired from job, arrests, fights)

S Any significant **S**icknesses? ☐ Yes ☐ No

Note: Traumatic brain injury implies a physical blow to the head, but acquired brain injury may also be caused by medical conditions, such as: brain tumor, meningitis, stroke, heart attack, seizures, high fever, etc. Also screen for instances of oxygen deprivation such as near drowning or near suffocation.

Scoring the HELPS Screening Tool

For this TBI screening to be considered positive, the following **3** items must be identified:

1. an event that could have caused a brain injury (yes to H, E **or** S) **and**
2. a period of loss of consciousness or of being dazed and confused (yes to L) **and**
3. the presence of **2** or more problems listed under P.

Note: Positive answers to these questions are not sufficient to suggest the presence of a brain injury. It is recommended that positive responses be placed within the context of the person's self-report and documentation of altered behavioral and/or cognitive functioning. This information in along with your judgment can be used as a basis for further inquiry, e.g. referral to a physician, further evaluation, clinical observation, etc.

Refer to the *Instructions for Use of the HELPS Brain Injury Screening Tool* for administration instructions and follow-up.

The original HELPS TBI screening tool was developed by M. Picard, D. Scarisbrick, R. Paluck, 9/91, International Center for the Disabled, TBI-NET, U.S. Department of Education, Rehabilitation Services Administration, Grant #H128A00022. The Helps Tool was updated by project personnel to reflect recent recommendations by the CDC on the diagnosis of TBI. See http://www.cdc.gov/ncipc/pub-res/tbi_toolkit/physicians/mtbi/diagnosis.htm.

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APPENDIX F: LITERATURE CITED

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Appendix G: Current Workgroup Members

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CRHOP
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