Addressing Michigan's Public Service Gaps for Persons with Traumatic Brain Injury

Executive Summary of the Michigan Department of Community Health TBI Project Report - September 2004

Introduction

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 arising from blunt or penetrating trauma or from acceleration-deceleration forces, such as from a fall, car crash, or being shaken.[1] 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 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.

Michigan has become **the recognized leader** in data linkage and analysis regarding incidence and cost of TBI.[2] The **non-partisan, multiple-agency, consumer-involved, data-driven efforts** of this project have culminated in the compilation of this report.

Michigan Department of Community Health
MDCH
Jennifer M. Granholm, Governor
Janet Olszewski, Director

Brain Injury Association of Michigan
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5000 copies printed at $0.14 each with a total cost of $699. Paid through HRSA Grant # 6 H21 MC 00039-03-01.

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 knowledgeable about brain injury
- ✓ A screening method to identify people suffering from TBI-related injury so they do not remain misdiagnosed or undiagnosed
- ✓ A rehabilitation 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

For additional information regarding this report, contact:
Manfred Tatzman, State TBI Project Director, Michigan Department of Community Health, (517) 241-2534 or,
Michael Dabbs, President, Brain Injury Association of Michigan, (810) 229-5880.

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.

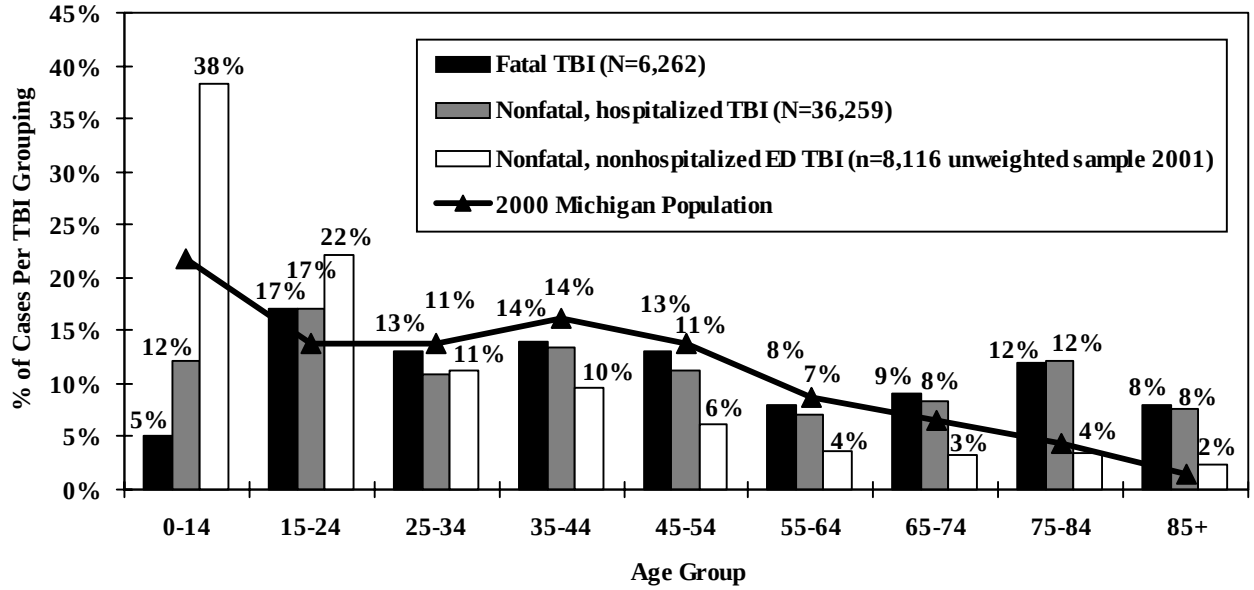
Interviews with **individuals with TBI, their family members, and public service providers** revealed that, from **their perspective**:

- 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.

TBI cases by age and severity, 1999-2002 [3]



[1] Thurman D.J., Sniezek J.E., Johnson D., Greenspan A., Smith S.M. (1994). Guidelines for Surveillance of Central Nervous System Injury. Centers for Disease Control and Prevention.

[2] Susan H. Connors, National Association of State Head Injury Administrators. 2004 Meeting of the Michigan TBI Advisory Council.

[3] Mortality data from MDCH Office of Vital Records based on death certificates – for fatal TBI cases, Michigan Inpatient Database (MIDB) – for nonfatal hospitalized TBI cases, Michigan Emergency Department Community Injury Information Network (MEDCIIN) – for nonfatal, non-hospitalized TBI cases.

Recommendations

In light of the findings contained in this brief, 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.

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.

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.

3. The Governor or the Michigan Department of Community Health (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.

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.

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.

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.

7. Departments, organizations, and agencies must adopt effective screening procedures to identify clients who may have TBI-related impairments. These include, among others: Family Independence Agency (FIA), Community Mental Health Services Programs, Substance Abuse Access, Assessment, and Referral Agencies, public schools, Michigan Rehabilitation Services, MI Choice Program, and the Michigan justice system.

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.

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.

10. Medicaid reimbursement rates for neuropsychological examinations should be increased.

11. The State of Michigan should establish a licensing category for Adult Foster Care (AFC) providers that have obtained accreditation and/or certification to care for people with TBI.

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.

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.

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.

15. The Physical Disability Services Fund needs to include the provision of assistive technology for cognitive disabilities as well as physical disabilities.

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.

This report was supported in part by Grant 6 H21 MC 00039-03-01 from the Department of Health and Human Services (DHHS) Health Resources and Services Administration, Maternal and Child Health Bureau to the Michigan Department of Community Health. The contents are the sole responsibility of the authors and do not necessarily represent the official views of DHHS.