

Presentation to the

**Institute of Medicine**

**Committee on Traumatic Brain Injury**



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# Project Goals

- Meet requirements of TBI Act & Federal Grant
- Develop ongoing population based surveillance system for planning, evaluation, and system change.
- Identify systems gaps and develop intervention and outcome strategies.
- Provide data, recommendations, tools, and implementation strategies to policy makers in order to allow funding and systems change to take place.

# Michigan's System Problems

- **No single point of entry for services.**
- **Fragmented provider system.**
- **No agency with designated responsibility for TBI.**
- **Very little public funding for TBI rehabilitation.**
- **Structural budgetary problems, and potential cuts to Medicaid services.**



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# Questions Posed

## What is the significance of TBI in MI?

What is the incidence of TBI in MI?

What are the risk factors for TBI?

What is the cost?

## How many and where are TBI cases in the public system?

How many individuals with TBI are being served in each system:

- Medicaid: FFS & Managed Care
- MI Choice Waiver
- Community Mental Health Services Programs
- Department of Human Services - Home Help Services

How do providers and consumers perceive public services for TBI in Michigan?

How do consumers with TBI enter and get referred throughout the system?

To what extent are services effectively coordinated across agency lines?

What are barriers to effective interagency coordination on behalf of consumers with TBI?

# Michigan's Population Based Surveillance

## •Population:

- Mortality data (for fatal TBI cases from 1999 to 2002)\*
- Michigan Inpatient Database (nonfatal hospitalized cases from 1999 to 2002)\*
- MEDCIIN (emergency department injury surveillance – for nonfatal and nonhospitalized TBI cases in 2001)

## Cost and Services:

- Data on cost and services (from FY1999 to FY2002)\*
- Medicaid\* - used CDC accepted ICD-9 & 10 Codes.
- Community Mental Health Services Providers (46)\*
- Home Help (a Medicaid funded program administered by the MI Department of Human Services).
- Blue Cross/Blue Shield of Michigan

## •Point of Care Information:

- Stories from consumers.\*
- Focus groups.\*
- Feedback from providers.\*
- Results of pilot testing service improvements in three areas of Michigan

\* *Information available to every State.*

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# Limitations Encountered

## Confidentiality:

- Had to use Privacy Rule exceptions for the project:
  - 1) The Public Health exception, and
  - 2) The Health Research exception with IRB/privacy board approval of a waiver of authorization (based on the 3 waiver criteria)
  - 3) Had to develop business associate contracts with some project partners

## Registry Limitations:

- Enforcement of reporting – nearly impossible to have 100% compliance.
- Quality of data.
- Legislative mandates and sunset imposed on registries.
- Cost of maintaining registry.
- Legal impediments to establish a registry – HIPAA & privacy.

## Data Limitations:

- We had no standard TBI definitions in Michigan.
- No standard data sets.
- Inability to crosswalk systems.



# Methodological Challenges/Barriers: Issues Encountered

- Accuracy of TBI case identification and changes in operational definitions (e.g. use of 959.01, 950.1-950.3, 995.55 and S04.0)
- Incomplete and delayed data
  - E-coding is incomplete for hospital discharge and ED databases, and cause of injury information was not available in some databases in MIDB and MEDCIIN (important for identifying cause and intent of injury).
  - Race, ethnicity and other data limitations
- Inflexibility of data systems
- Lack of standardization of data items
- Overwhelming volume of data to be managed
- Data cleaning, sorting, and merging data files.

## Overall Findings

**Analysis of Michigan vital statistics and inpatient data has revealed that between 1999 and 2002 there were on average:**

**Ø1,566 TBI-related fatalities annually**

**Ø9,065 TBI-related non-fatal hospitalizations annually.**

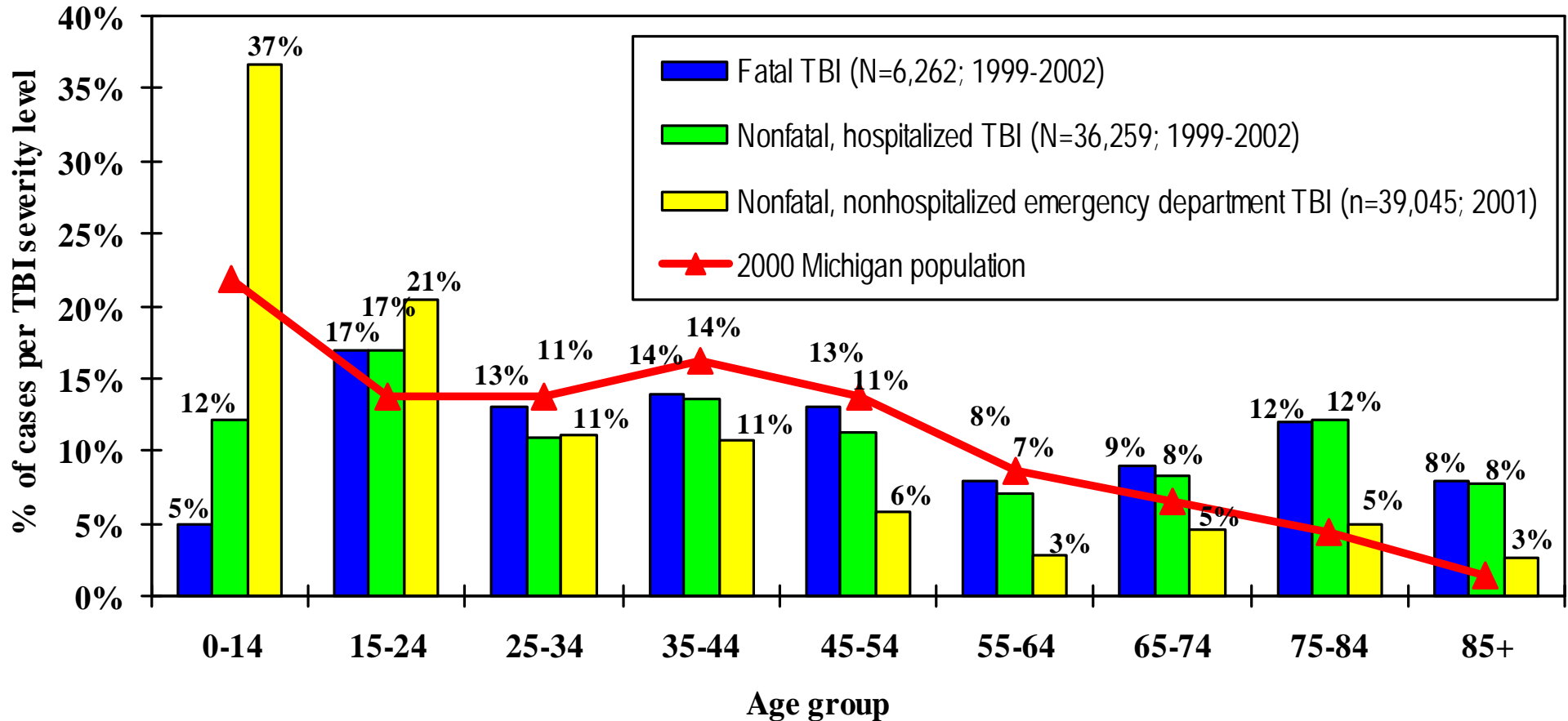
**Data from a weighted probability sample of Michigan emergency departments reveal an estimated:**

**Ø39,045 TBI-related non-fatal and non -**

**hospitalized emergency department visits in 2001.**

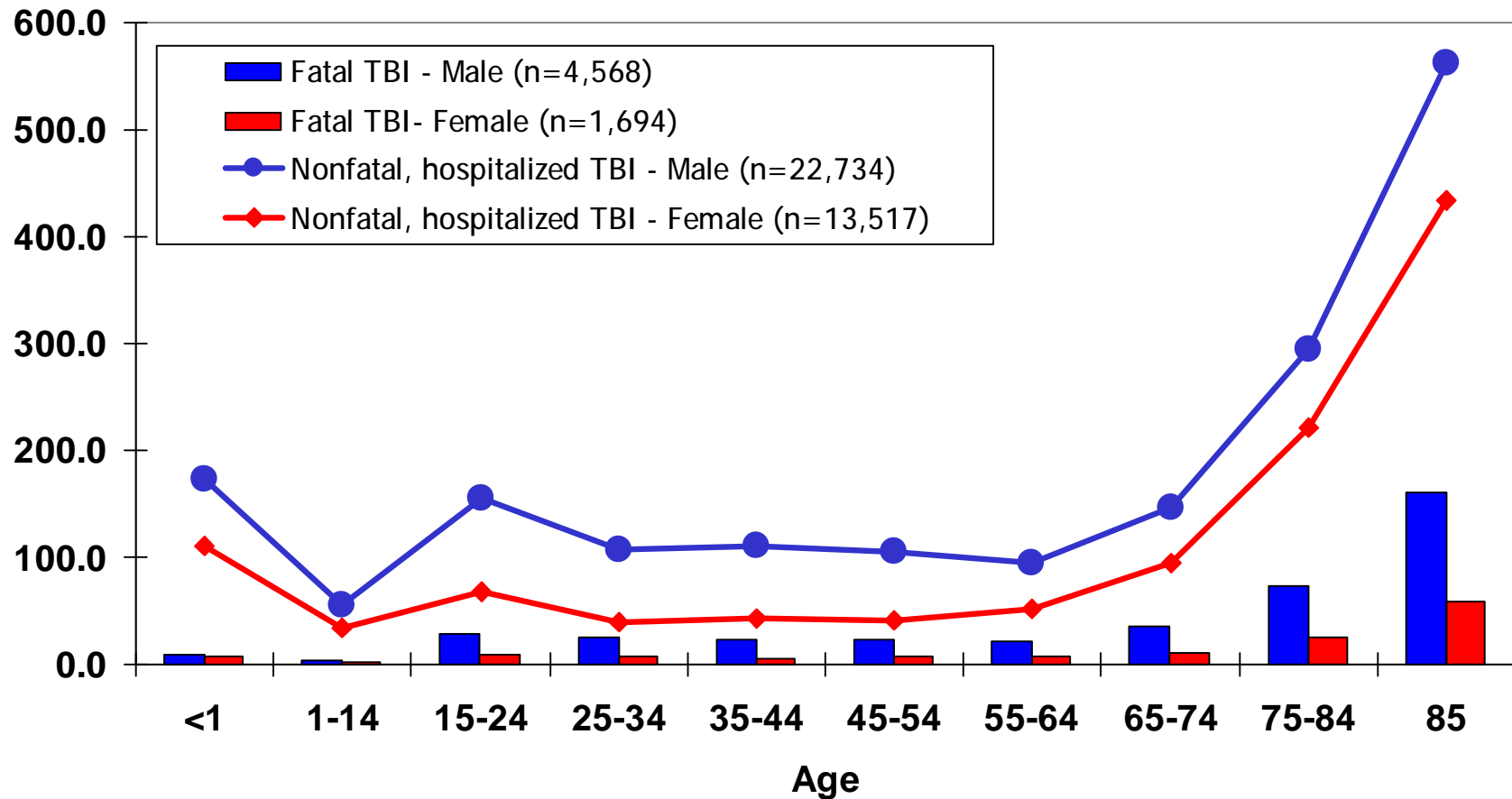
# Findings - Demographic Characteristics

## TBI in Michigan by age for three levels of TBI severity



Data are from the MDCH Office of Vital Records and Health Statistics, Michigan Inpatient Database and the Michigan Emergency Department Community Injury Information Network.

## Rates of Fatal and Hospitalized (Nonfatal) TBI by Age and Sex (1999-2002)



*Note: Rates are per 100,000 population in specified group, and are averaged over the 4 year period.*



## Leading Causes of TBI in Michigan (1999-2002)

| Rank | Fatal TBI<br>(N=6,262)          | Nonfatal TBI<br>Hospitalizations<br>(n=30,667) | ED Visits<br>(n= 5,299 cases in 2001<br>unweighted ED sample) |
|------|---------------------------------|--|---|
| 1    | Motor vehicle,<br>traffic (28%) | Motor vehicle, traffic<br>(39%)                | Unintentional falls<br>(41%)                                  |
| 2    | Suicide (27%)                   | Unintentional falls<br>(35%)                   | Unintentional struck<br>by/ Against (23%)                     |
| 3    | Unintentional falls<br>(16%)    | Assault (10%)                                  | Motor vehicle, traffic<br>(16%)                               |
| 4    | Homicide (12%)                  | Bicycle and Struck<br>by/Against (both<br>3%)  | Assault (12%)   |

Cause of injury coding varied across datasets with coding rates of 100% for deaths, 84% for hospitalizations, and 65% for emergency department cases.

# Number of Individuals Receiving Michigan Medicaid Services with a TBI Diagnoses

|  | <b>FY1999</b> | <b>FY2000</b> | <b>FY2001</b> | <b>FY2002</b> | <b>Average no. cases per year</b> |
|--|---------------|---------------|---------------|---------------|-----------------------------------|
| No. Medicaid beneficiaries                                     | 1,315,958     | 1,409,998     | 1,484,637     | 1,578,494     | 1,447,272                         |
| No. receiving services for TBI                                 | 15,704        | 15,758        | 18,807        | 22,431        | 18,175                            |
| TBI cases per 1,000 Medicaid enrollees                         | 11.93         | 11.18         | 12.67         | 14.21         | 12.56                             |
| No. beneficiaries with Medicaid-reimbursed TBI hospitalization | 1,272         | 1,385         | 1,512         | 1,733         | 1,476                             |

## FY2002 Cost of TBI Treatment Services Medicaid - Fee-For-Services Only!\* (n = 8,285)

|                                 | Total amount paid    | % of total |
|---------------------------------|----------------------|------------|
| Hospital – Inpatient            | \$ 6,698,726         | 59%        |
| Hospital – Outpatient           | \$ 645,488           | 6%         |
| Hospital - Long term care units | \$ 719,554           | 6%         |
| Professional Services           | \$ 473,922           | 4%         |
| Nursing homes                   | \$ 2,191,532         | 19%        |
| Home health agency              | \$ 210,431           | 2%         |
| Ambulance service               | \$ 160,140           | 1%         |
| Other                           | \$ 208,613           | 2%         |
| <b>Total</b>                    | <b>\$ 11,308,406</b> |            |

• Fee-For-Services. Is approximately 33% of entire Medicaid program. Remainder is a capitated Managed Care program.





## Surveys: Service Provider Feedback

- Mailed surveys to CMHSPs, DHS offices and MI Choice program agents, n=115
- Telephone interviews with 20 service providers in participating agencies

- Majority of providers surveyed do not think TBI is adequately addressed by their agency
  - They believe that TBI is often not identified in their clients
  - They would like more education about TBI, and services that are available and appropriate
  - There is no clear policy on which agency should take a lead role in providing services to people with TBI
  - Needed services do not exist or are insufficient
  - There is insufficient public funding to pay for services for people with TBI

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## Dissemination, Education, and Evaluation

- **Data** was used to drive recommendations in Final Report.
- **Disseminated** through presentations to human service networks – aging, mental health, educators, long term care groups, advocates, professional organization, and consumers.
- **Utilized** by State TBI Services and Prevention Council & policy makers for policy change and recommendations, e.g. Medicaid long term care issues, and identifying service gaps.
- **Utilized** collaboratively by TBI related networks, i.e, Protection & Advocacy, Brain Injury Association, state disability groups, and State agencies.

# Products Developed

- **Web-based Provider Training** – Developing first web-based TBI provider training.
- **Michigan Resource Guide – MRG** – Hybrid document between directory and teaching guide. Provides directions on how to seek help and basic advice. Audience is both professionals, survivors and support persons. 10,000 printed. Including Spanish and Arabic.
- **Access Guidelines** – Hybrid document also. Provides information about services and guides user through complex state government structure. Audience is primarily service providers at the front line or intake, but can be used by survivors & family caregivers.
- **Training Manual** – specific training tool to supplement the training for front line staff at public agencies.

# Recommendations:

- “Standard definition” of TBI which have been developed over the years keep changing with the addition of new Codes. In addition, there is still no uniformity among States about whether to include certain non-traumatic conditions (stroke, near-drowning, etc.) in how “TBI” is defined.
- Technical Assistance through NASHIA or CDC should be provided to states.
- States should be encouraged to seek out resources within each state – State epidemiologists and injury prevention programs, university researchers, NIDRR model systems, research institutes, and surveillance or state data bases.
- States need to be strongly encouraged to use partnerships in order to gather data from – both public and private sources. The current silos of services must be eliminated.
- HRSA should include funding support for population-based surveillance systems to expand the ability to gather information on non-fatal and mild TBI’s in states.

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# Acknowledgements

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