Introduction

- TBI is a leading cause of morbidity and mortality among children and young adults in the U.S.
- Each year, approximately 1.5 million Americans incur a TBI, of which about 230,000 are hospitalized.
- Annually, about 80,000-90,000 persons are permanently disabled from TBI in the U.S.
- Each year, approximately 50,000 Americans die from TBI, accounting for one-third of all trauma-related deaths.
- There are an estimated 5.3 million Americans living with a TBI-related disability.
- To examine the issue of TBI service access, a survey of persons with TBI in North Dakota was conducted to delineate the presence of barriers to needed services.

Hypotheses

The type and quantity of perceived barriers to service access significantly differ by:

- Geographic location of residence (urban versus rural)
- Race/ethnicity (Caucasian versus American Indians)
- Functional limitation (none, mild, moderate, severe)

Methods

- Mail survey
- Convenience sample of 425 North Dakotans with TBI
- Twenty-one invalid contacts were recorded
- 117 completed surveys (29% response rate)

Results

Demographics

- Gender: Male (62.8%); female (37.2%)
- Age ranged from 5 to 76 years with a mean of 43.8 years.
- Race: 75.7% were Caucasians; 18.3% were American Indians.
- Income: $5,000 to $24,999
- Functional Limitation: One-half (56.6%) needed no care, followed by ‘can be left alone for most of the day’ (21.2%), ‘left alone for a few hours’ (8.0%), and ‘cannot be left alone’ (14.2%).
- Cause of Initial TBI: Motor vehicle crash (69.9%); assault (10.8%); pedestrian incidents (9.6%).
- Number of TBIs: 12% had incurred more than one TBI.
- Years since Last TBI ranged from 0 to 44 years and averaged 14.1 years. About two-thirds (70.9%) indicated they incurred their last TBI more than 5 years ago.

Accessing Services, by Respondents’ Race

- Caucasian American Indian

Barriers to Services among Persons with TBI

- Medical necessity (50.0%)
- Inadequate knowledge of TBI services (46.2%)
- Inadequate financial resources (45.3%)
- Lack of individualization of TBI services (41.9%)
- Inadequate community support (38.5%)
- Lack of understanding of TBI by service providers (34.2%)
- Long distance to travel for services (33.3%)
- Lack of acceptance of having TBI (31.5%)

Conclusions

- Persons with TBI, regardless of geography, race or functional limitation, reported several obstacles for accessing services for North Dakotans with TBI.
- The most frequently cited barrier was related to poor advocacy efforts and a lack of information.
- Many of the cited barriers could be located or alleviated through increased state efforts to address the needs of persons with TBI.
- Much work needs to be done to increase access to needed care for North Dakotans with TBI.
- The next step toward achieving a comprehensive, coordinated system of care is to apply for and secure a federal TBI Implementation grant.
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- These funds will initiate and facilitate efforts to achieve the goals and objectives of the state TBI Action Plan and build upon the statewide momentum and interest in TBI issues generated by activities conducted in the Planning Phase.