2015 Minnesota Statewide Brain Injury Needs and Resources Assessment

Executive Summary

JANUARY 2016

Prepared by:
Wilder Research

For the:
Minnesota Department of Human Services
Summary

Concussions sustained by athletes and military personnel in recent years has increased public awareness of brain injury. These commonly talked about injuries are traumatic brain injuries, or TBIs, which are sustained from a blow or other penetrating injury to the head. TBIs are a subset of acquired brain injuries (ABI), which are made up of all brain injuries sustained after birth, including brain injuries from strokes, chemical use, and surgery.

While there are no good estimates of the frequency of ABI, the Minnesota Department of Health estimates that about 2 percent of the state’s population—roughly 100,000 people—lives with long-term effects of TBI. In 2014 alone, more than 12,300 people in Minnesota were hospitalized or treated in an emergency department for a TBI. This number does not include individuals who did not seek care after getting a TBI or those who got care at a doctor’s office or urgent care center. It also does not include people whose TBI was not diagnosed.

Given the number of people who are affected by brain injury, it is important to understand the needs of this population and the resources they use and want. The Minnesota Department of Human Services contracted with Wilder Research to conduct the 2015 Statewide Brain Injury Needs and Resources Assessment to determine the capacity of Minnesota’s local service system to meet the needs of people with brain injuries. The assessment included interviews, focus groups, and surveys with brain injury survivors, caregivers, service providers, and county and tribal representatives. It also included analysis of data from the Minnesota Hospital Association and Wilder Research’s Statewide Homelessness study.

This report is intended to inform state agencies, stakeholders, advocates, people with brain injuries, as well as their family members or caregivers about the current state of services in Minnesota. It provides information that can be used to inform policy, service development, and future research.

What populations are at high risk for brain injury?

Rates of TBI are highest among youth age 11-17 and older adults age 81+. In 2014, 524 out of every 100,000 youth age 11-17 and 507 out of every 100,000 older adults were treated in a hospital for a TBI. Other populations that are at especially high risk include people experiencing homelessness, incarcerated people, military personnel or veterans, and American Indians.

- Wilder Research’s statewide homelessness study data shows that 34% of Minnesota’s homeless population has either been told by a doctor or nurse that they have sustained a TBI, or their history indicates that they are likely to have had a TBI. Rates
of significant mental illness, chronic health conditions, and substance abuse were found to be especially high among homeless people who have had a TBI.

- The Minnesota Department of Corrections found that 82% of all offenders that went through intake during a study period had a history of having sustained one or more TBIs.
- The effects of TBI on our military troops has been widely publicized in recent years, however we do not have current data on the frequency of brain injury among Minnesota’s veterans.
- Recent estimates from the Minnesota Department of Health show that American Indians experience non-fatal TBIs at twice the rate of other racial and ethnic groups – approximately 165 per 100,000.

### Key findings

**How well do persons with brain injuries feel service providers understand their injury?**

Brain injuries can be complex and may present with very different symptoms across different people. It is common for people with brain injuries to feel that service providers do not have a very good understanding of their injury. Figure 1 displays how people with brain injuries, or their caregivers, responded when asked how well their service providers understand their brain injury. Fifty percent of survey respondents said their service providers have some understanding of their brain injury, but it could be better. Nearly a quarter (23%) said their service providers do not understand.

<table>
<thead>
<tr>
<th>Service providers’ understanding of brain injury (N=140)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>They have a very good understanding (26%)</td>
<td></td>
</tr>
<tr>
<td>They have some understanding, but it could be better (50%)</td>
<td></td>
</tr>
<tr>
<td>They do not understand (23%)</td>
<td></td>
</tr>
<tr>
<td>Don't know (1%)</td>
<td></td>
</tr>
</tbody>
</table>

**Source:** Gaps Analysis Consumer Survey

Over one-quarter of survey respondents said it took at least a year for their brain injury to be diagnosed. This delay may be because individuals did not seek care during that time frame or because a health care provider was not able to diagnose the injury – greater awareness on all fronts would help to shorten the time between injury and diagnosis. People with brain injuries indicated a need for greater awareness and education among
service providers. One respondent said they want greater “education within the health care provider world about brain injury” and another wished that “…doctors would be more aware of basics of brain injuries.”

What do key brain injury stakeholders think about the quality and availability of services for people with brain injuries?

In-depth key informant interviews were conducted with three key community and agency leaders who could provide system-level perspectives on gaps in services for people with brain injuries. The key informants indicated that many professionals lack an understanding of the complexity of brain injuries. They also said there was a need for additional training and education for professionals who work with individuals with brain injuries, both those who provide direct services and those who assist people seeking access to services. The need for improved understanding and recognition of brain injury has been a concern that has been stated in all past brain injury needs and resources assessments.

Do people with brain injuries feel their services and supports meet their needs?

Every brain injury is different. There is no standard for rehabilitation, treatment, or necessary supports for people with brain injuries. Furthermore, people with brain injuries commonly have co-existing conditions. For example, 65 percent of survey respondents with brain injuries, or their caregivers responding on their behalf, indicated that they also had a mental health condition. As such, it is important for an individual’s services and supports to be tailored to meet their specific needs. Figure 2 shows how brain injury survivors, or their caregivers responding on their behalf, responded when asked whether their complete array of services met their needs. Most survey respondents (71%) felt that their services and supports met some but not all of their needs.

2. How persons with brain injuries feel their services and supports meet their needs (N=142)

- The help meets all of my needs (24%)
- The help meets some of my needs (71%)
- The help meets none of my needs (1%)
- Don't know (4%)

Source: Gaps Analysis Consumer Survey
Among those who did not believe their needs were completely met, a common concern was that services were not accessible enough. One brain injury survivor stated that they would like “to make choices about my care and services instead of "bundling" services so I can only get certain services along with other services or only get services from specific providers.” A caregiver stated, “A lot of the burden falls on parents to fill in the gaps in their child's care when it is needed. Transportation, housing, appointments, arranging medical care, finances, etc. Services don't necessarily meet all the needs in these areas.”

Focus group and interview respondents also commonly expressed that their services and supports were not able to meet all their needs. These respondents described services as not being an appropriate fit for them and not being flexible.

It’s not an additional service, but I would like to see a little more flexibility in the services.

It feels like the approach is everybody fits this little category. You have a brain injury…therefore you fit into this group of people with cognitive disabilities and these are the services we are going to provide and this is the direction we are going to encourage you to go. It just doesn’t fit well. …They just don’t know what to do with people with a brain injury.

What are the most significant service gaps?

People with brain injuries, and their caregivers, most commonly expressed that they needed, but were unable to get, caregiver or family training or support, respite care, chore services, personal support or companion services, and supported employment or help finding a job (Figure 3).

3. Top services persons with brain injuries feel they need but are not able to get (N=81)

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver or family training/support</td>
<td>22%</td>
</tr>
<tr>
<td>Respite care</td>
<td>20%</td>
</tr>
<tr>
<td>Chore service</td>
<td>17%</td>
</tr>
<tr>
<td>Personal support/companion services</td>
<td>15%</td>
</tr>
<tr>
<td>Supported employment or help finding a job</td>
<td>14%</td>
</tr>
</tbody>
</table>

Source: Gaps Analysis Consumer Survey
County and tribal representatives and service providers were both asked to indicate the services that had the largest or most significant gaps in capacity to serve people with disabilities, including people with brain injuries. Similar to the feedback provided by people with brain injuries, these respondents commonly ranked respite care services (specifically out-of-home respite care and crisis respite care) among the services with the largest or most significant shortages. Furthermore, both county and tribal representatives and service providers ranked foster care, behavioral programming, and non-medical transportation among the services with the largest or most significant gaps. Providers further indicated that PCAs, chore services, and supported employment had significant gaps in capacity to serve people with disabilities, including people with brain injuries.

**What barriers do people with brain injuries face when accessing services?**

It is not only a question about whether individuals are receiving the services they need, but also how accessible the services are and what barriers they face in obtaining the services. When brain injury survivors, or their caregivers, were asked how easy it was to access their most valuable service, 39 percent said it was difficult (Figure 4).

<table>
<thead>
<tr>
<th>4. How easy it is for persons with brain injuries to access their most valuable services (N=146)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very easy (22%)</td>
</tr>
<tr>
<td>Somewhat easy (38%)</td>
</tr>
<tr>
<td>Difficult (39%)</td>
</tr>
<tr>
<td>Don't know (1%)</td>
</tr>
</tbody>
</table>

*Source: Gaps Analysis Consumer Survey*

When brain injury survivors, or their caregivers, were asked about the barriers they faced in accessing the service they needed most but could not get, 29 percent said they could not afford it (i.e., high copays, no sliding fee) (Figure 5).
5. **Most common barriers to accessing most needed services among persons with brain injuries (N=79)**

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I cannot afford it (high copays; no sliding fee)</td>
<td>29%</td>
</tr>
<tr>
<td>It is too hard to get it (lack of time, confusing process)</td>
<td>25%</td>
</tr>
<tr>
<td>It is not available near me</td>
<td>22%</td>
</tr>
<tr>
<td>There is a long waiting list for it</td>
<td>19%</td>
</tr>
<tr>
<td>I am not eligible for it</td>
<td>14%</td>
</tr>
</tbody>
</table>

**Source:** Gaps Analysis Consumer Survey

County and tribal representatives had a somewhat different perspective on the key barriers to accessing services. When looking at barriers identified by county or tribal representatives:

- 59% identified geographic location of providers or the distance to services as a significant barrier
- 54% identified access to transportation
- 34% identified lack of service availability on short notice or during crisis
- 32% identified lack of housing
- 23% identified lack of capacity to access service or navigate the system

**How do people with brain injuries learn about services?**

Finding out how brain injury survivors and caregivers learn about services provides insight into where state resources should be focused for training, education, and service coordination. When brain injury survivors, or caregivers, were asked how they learned about services:

- 48% said through a health care provider
- 40% said from family or friends
- 40% said from a case manager, care planner, or social worker
31% said via service or advocacy organizations, such as the Minnesota Brain Injury Alliance or Centers for Independent Living

**Do available transportation options meet the needs of people with brain injuries?**

Several respondents indicated that transportation was an important area of need.

- County and tribal representatives and service providers indicated that non-medical transportation was among the top service gaps faced by people with disabilities, including those with brain injuries.

- 36% of brain injury survivors, or their caregivers responding on their behalf, said there was at least one time in the past month when they could not get where they wanted or needed to go because they did not have transportation. They most often indicated that they were unable to get transportation for non-medical reasons such as running errands or social, spiritual, or recreational activities.

- Many focus group and interview respondents expressed frustration with their transportation options. Common themes for the frustration were unreliable transportation and a need for increased availability and flexibility of their transportation options.

**Do people with brain injuries feel they have appropriate choices about their living arrangements?**

Focus group and interview participants described housing as an important need. One respondent indicated, “There is a lack of appropriate housing for people who have similar needs,” and another stated “I wouldn’t be in this neighborhood if I was making my own choices.”

However, when survey respondents were asked about their agreement with a series of statements about their housing choices, the majority of brain injury survivors, or their caregivers responding on their behalf, felt they could:

- Choose where they live (57%)
- Choose who they live with (51%)
- Get the help they need to stay in or maintain the place where they want to live (57%)

Nearly half (47%) agreed that they had more than one choice of places to live when they were making their housing decision.
What do people with brain injuries need to help them feel better integrated into their communities and have improved quality of life?

In addition to improved supports related to housing, transportation, and employment, people with brain injuries and their caregivers indicated two additional areas where supports could be improved to allow them to be more integrated in their communities. These were a desire for more education and understanding in the community regarding brain injuries and more social opportunities that are appropriate for them.

When asked how the services they used could be changed to improve their quality of life, many people with brain injuries or their caregivers had positive things to say about how their services and supports affect their quality of life and expressed appreciation and gratitude for what they were receiving. Others offered suggestions for changes, including: having more knowledgeable staff to provide help and services, improving the accessibility and quality of assistance they receive, enabling better access to social and recreational activities that are appropriate for them, and having better housing options.

Additional notes about the report

Although the report covers many areas related to services for people with brain injuries and gaps in services, some important issues could not be addressed in the assessment and need further study. We encourage you to read the full report and think about how you can use and share the information it provides with policymakers, care providers, family, and friends. The figures in this summary are also included in the full report along with relevant source information. Additional data and information are provided in the Appendix to the full report.

This effort was supported with funding from federal Health and Human Services, Health Resources Services Administration (HRSA) Traumatic Brain Injury Program grant #H21MC17234. Information in the assessment was gathered from a number of sources, including Minnesota Hospital Association data, Wilder Research’s Statewide Homelessness study, and surveys, interviews, and focus groups associated with the 2014-15 Gaps Analysis study.

This project was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number #H21MC17234, TBI in Minnesota Correctional Facilities: Systems Change for Successful Return to Community, a Traumatic Brain Injury State Implementation Partnership Grant (Federal Funding Total: $990,385. No nongovernmental funding financed this project).

This information or content and conclusions included in this report are those of the author(s) and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS, the U.S. Government, or the Minnesota Department of Human Services (DHS).