# Iowa State Plan for Brain Injury

## 2013 - 2017

# DRAFT

A product of the Iowa Department of Public Health

(Iowa's Lead Agency for Brain Injury)

In cooperation with

Brain Injury Alliance of Iowa
Iowa Advisory Council on Brain Injuries
Iowa Association of Community Providers
Iowa Brain Injury State Plan Task Force
University of Iowa Center for Disabilities and Development.

## Introduction

Traumatic Brain Injury (TBI) impacts the lives of thousands of Iowans each year. TBI is often described as the "silent epidemic", because oftentimes disabilities resulting from the injury are not visible to others. The effects of brain injury are cognitive, emotional, social and can result in physical disability. In addition to the overwhelming challenges individuals with brain injury face, families also share the difficulties, especially related to navigating the service delivery system which can be confusing and frustrating.

This state plan is intended to provide guidance for brain injury services and prevention activities in Iowa.

## Methodology

This is the fourth Iowa State Plan for Brain Injury. In addition to a statewide needs assessment, development of this plan included recommendations made by the Mental Health and Disability Services Redesign Brain Injury Workgroup.

In the 2011 Iowa legislative session, language was passed that established a redesign of Iowa's Mental Health and Disability Services System (MHDS.) Senate File 525 tasked the Iowa Department of Human Services (DHS) to form seven workgroups, including a workgroup focused on Brain Injury. Stakeholder input was important throughout the workgroup process; DHS requested volunteers to serve on the workgroups. There were over 150 volunteers, with 100 being chosen representing geographic diversity and various stakeholder groups to achieve balance and adequate representation. DHS made a special effort to assure consumer and family participation in each workgroup as well.

The MHDS Brain Injury Workgroup had 12 members, including staff from the Iowa Department of Public Health (IDPH), which is the lead agency for brain injury services in Iowa. Members from the Governor's Advisory Council on Brain Injuries (ACBI) were represented and five of the 12 Brain Injury Workgroup members were survivors and family members of survivors. The rest of the workgroup was made up of service providers and representatives of state and county agencies that serve individuals with brain injury.

The Brain Injury Workgroup held five meetings that were open to the public. Additional work sessions were held to draft language to take back to the full work group for feedback. DHS established a website where all agendas, meeting materials and minutes were archived for public and work group access. Time was given at the end of each meeting for public comment. A facilitator led each meeting to ensure meetings stayed on task.

Stakeholders were provided with the opportunity to attend nine regional stakeholder forums. These forums were well attended and provided survivors, consumers, families, providers, county officials and staff, advocacy groups and other interested stakeholders an opportunity to provide feedback on recommendations that came from each of the workgroups.

In addition to the work done with the MHDS Redesign, planning documents from other organizations and groups with an interest in brain injury were reviewed and included in this plan. These included the IDPH Falls Coalition and the *Healthy Iowans: Iowa's Health Improvement Plan 2012-2016*. Needs assessments were completed by the Brain Injury Alliance of Iowa (BIAIA) and the Iowa Association of Community Providers (IACP) to identify needs related to brain injury services and provider education

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and support. A draft of this state plan was distributed to interested parties and posted on the ACBI website to allow the public to provide feedback on this plan prior to publication.

# Traumatic Brain Injury in Iowa: An Analysis of Core Surveillance Data

## TBI numbers and rates

For the first time in the history of TBI surveillance in Iowa, the numbers and rates of TBI deaths are decreasing. Although deaths are decreasing, hospitalizations and emergency department (ED) visits resulting from TBI are steadily increasing.

From 2008 to 2010, there were, on average, 334 (compared to 545 in 2006-2008) TBI-related deaths per year. For every death from TBI in Iowa, there were three Iowans hospitalized and 32 who sought services in an emergency department. During the reporting period, on average, 33% of Iowans who lost their lives to injury (1,672), 10% of those hospitalized (16,289) or 7% of those who visited the emergency department visits (258,660) because of injury, did so because of TBI.

Iowa's TBI age-adjusted mortality rate is consistent with the national rate. The mortality rate stayed close to 18 deaths per 100,000 Iowans with an age-adjusted rate of 17 per 100,000. The age-adjusted mortality rate for counties with less than 10,000 was 27 per 100,000 and was 74% higher than in counties with more than 50,000 people (13.9 per 100,000).

TBI mortality and morbidity cases were predominantly Caucasian males. Individuals over the age of 65 were more likely to die from or be hospitalized for TBI. For ED visits, the age distribution displayed a bimodal distribution in the form of a U-shape with a higher peak among people 24 years and younger.

## Leading causes of TBI

Nearly 70% of TBI deaths and over 80% of the TBI hospitalizations and ED visits were due to unintentional injuries. Intentional injuries, including suicide attempts and assaults, constituted 34% of TBI deaths, five percent of TBI related hospitalizations and eight percent of TBI related ED visits.

The three leading causes of TBI deaths were, by order of magnitude, fall, firearm and motor vehicle crash (MVC.) Suicide and homicide (Intentional injuries) averaged 162 deaths, surpassing MVCs with an average of 140 in the causation of TBI deaths. Fall was the leading cause of TBI deaths, hospitalizations and ED visits. The leading cause of TBI death among Whites was MVC followed by fall, whereas in Blacks the leading cause of TBI related death was firearm followed by MVC.

MVC was the main cause of TBI deaths for Iowans under the age of 35, followed by firearm. The proportion of deaths due to MVC equaled the proportion of firearm deaths in Iowans between the ages of 35 and 54. Among those 55 to 64 years old, firearm was the leading cause of TBI related death in Iowa. Males were more likely than females to die, be hospitalized or visit the ED because of motor vehicle crashes and "being struck by or against."

## TBI outcomes: discharge location and length of stays

From 2008 to 2010, 56% of hospitalized TBI cases were discharged home, 18% to long term care facilities (including skilled nurse facilities, hospice care), six percent were transferred to another inpatient hosptial, and 11% to rehabilitation services. About seven percent died during hospitalization. The proportion of cases discharged to long-term care and rehabilitation programs, which increased from 24% to 30%, illustrates the severity of cases that were hospitalized.

The average length of stay (LOS) for TBI hospitalizations overall (all events), was 5.6 days (5.1 for first encounters only). The LOS for the two leading causes of TBI – Fall and MVC – was 6 and 4 days, respectively. In terms of magnitude, Fall had a higher total number of hospital stays compared to MVC.

## TBI related hospital charges

The three-year average total TBI related hospital charges for all cases amounted to $82 million with a mean of $40,000 (Median: $18,800). If MVC hospitalizations were typically charged to private payers, in this reporting period, Fall hospitalizations were mostly billed to federal programs such as Medicare and Medicaid. The MVC and Fall payment ratio (federal vs. private) were equally at 3:1 ratio. For ED visits, MVC-related TBI were still generally charged to the private sector while Fall were billed to federal and private payers (ratio less than 2:1).

## Conclusions

Although this report shows a stable trend of traumatic brain injury rates in Iowa and even decreasing trends because of the reduction of MVC, improved hospitalization protocols may have resulted in better triage with the worst cases reserved for hospitalizations. The true cost of TBI is not limited to hospital charges due to the proportion of cases that require ongoing care, services and supports including long-term care, which is significantly increasing over time.

Full report available at the Iowa Department of Public Health and the ACBI website at http://www.idph.state.ia.us/ACBI.

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# Vision

Iowa will have a comprehensive, coordinated and seamless service system for persons with brain injury that:

- Provides easy access to information and resources
- Collaborates and partners with all stakeholders in the system to reduce barriers and improve services and supports
- Creates and maintains a comprehensive base of needs assessment and service delivery data
- Actively and consistently pursues needed funding and legislative change
- Respects the individuality and dignity of the survivor and their family
- Continuously improves the outcomes for individuals with brain injury and their families for living, learning, working and recreating in communities of their choice

# Brain Injury: The Future

### *Focus Area 1: Individual and Family Care Access*

The most important support in the lives of individuals with brain injuries are families. A "natural support" in the life of a survivor, a family is often under-appreciated in all the work and care they provide. Brain injury affects survivors and their families both emotionally and financially, and because of that, the first area of focus was dedicated to the enhancement of their lives.

## Goal 1: Eligibility will be determined at the time of application for the Medicaid Home and Community Based Brain Injury Waiver.

- Develop an eligibility screening based on fiscal, functional and diagnostic criteria
- Immediately refer applicants to Neuro-Resource Facilitation (NRF) regardless of eligibility

## Goal 2: Individuals will be screened for brain injury at all access points in the service delivery system.

- Adopt and distribute a standardized brain injury screening tool
- Identify organizations to implement screenings, to include, but not limited to: all agencies as required by 225C.23, domestic violence shelters, mental health centers, substance abuse treatment centers, emergency rooms, homeless shelters, senior centers, schools, correctional facilities and non-profit or community based organizations providing human services
- Train staff on screening tool

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### Goal 3: Expand Neuro-Resource Facilitation services to accommodate increase in utilization.

- Align Iowa caseloads to national averages
- Develop and publish detailed reports on NRF utilization to include information on caseloads, average number of contacts per client, etc.

## *Focus Area 2: Service and Support Availability*

The service delivery system for individuals with brain injury and their families can be difficult to navigate. Service providers are in need of on-going training in order to most effectively provide services. Oftentimes the fragmented system leaves both individuals and providers unaware or misguided regarding services available and/or eligibility requirements.

### Goal 1: Decrease expensive and untoward medical outcomes and associated conditions related to a break in services.

- The State of Iowa will provide funding to eliminate any waiting period for eligible individuals within the Home and Community Based Services Brain Injury Waiver.

### Goal 2: Reduce the need for out of state placement and increase ability to bring people back to Iowa from out of state placement.

- Increase availability of post-acute inpatient and outpatient neurorehabilitation skilled nursing facility level of care in Iowa.

### Goal 3: Expand the availability of Medicaid funded intensive neurobehavioral/neuro-rehabilitation services in both residential, community, and home environments.

- Support providers to expand services to include neurobehavioral services

### Goal 4: Develop telehealth services for Iowans with brain injury.

- Expand ~~mental health~~ telehealth services to include services for individuals with brain injury and multi-occurring disorders.

### Goal 5: Expand opportunities to engage survivors of brain injury and their families.

- Develop on-going education opportunities
- Expand peer-support services
- Provide mentoring and advocacy opportunities

### Goal 6: Develop and deploy a web-based, searchable, comprehensive brain injury resource.

- Include a directory to services and resources

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## *Focus Area 3: Service System Enhancements*

Building Iowa's capacity to serve individuals with brain injuries requires continued funding growth and public awareness campaigns that draw attention to the impact of brain injury. Enhancements to the current delivery system will help Iowans with brain injury and their families' access services more easily.

### Goal 1: Continue to determine initial and ongoing eligibility for state brain injury services.

- Replace current assessment tools for the brain injury waiver with a more sensitive, standardized tool.
- Include assessments for cognitive, psychosocial and functional abilities and needs.
- Implement a uniform brain injury assessment process and tool across all regions as established by MHDS redesign.

### Goal 2: Expand services and increase access to the Iowa Brain Injury Resource Network (IBIRN).

- Require administrative hubs (as established by the MHDS redesign) to participate as IBIRN sites.
- Provide adequate funding for regional resources materials (i.e., Brain Injury tote bags, NRFs).
- Develop and deploy a follow-up outreach service for individuals served by the IBIRN.

### Goal 3: Increase timely access to information, services and supports for brain injury.

- Reduce lag time for receipt of information regarding brain injury services associated with letters generated from the Brain Injury Registry.
- Develop a follow up service to individuals receiving brain injury registry outreach letter.

### Goal 4: Iowa will expand services for Iowans with Brain Injury.

- Develop specialized brain injury case management within DHS and in independent settings.
- Expand the scope of the Residential Care Facilities specialized licensure (IAC 481-63.47(135C)) to include Brain Injury.
- Develop acute inpatient neurobehavioral treatment programs to prevent out of state placements for Iowans with brain injury and multi-occurring disorders.
- Increase flexible, reliable and affordable transportation services for rehabilitative, medically necessary care and community integration.
- Adequately fund unfunded portions of the Brain Injury Services Programs.

### Goal 5: Expand brain injury training and education opportunities in Iowa.

- Develop brain injury training for crisis intervention programs.
- Develop brain injury competency in jail diversion programs through training and education.
- Continue and expand specialized brain injury training and consultation for direct service providers across the service array to include but not limited to human services, rehabilitation, nursing, skilled nursing, home health agencies, assisted livings

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## Goal 6: Expand the scope of brain injury advisory groups in Iowa.

- Elevate Governor's Advisory Council on Brain Injuries to the Brain Injury Services Commission and expand current scope to include identifying it as the state policy making body for the provision of services to Iowans with Brain Injury.
- Form and support a state of Iowa interagency, intergovernmental brain injury coordinating committee to meet quarterly to continue deploying best practices for brain injury services.
- Develop a statewide brain injury consultation team, composed of individuals from the fields listed to serve as brain injury consultants: medical (i.e. MD, RN, MSW, CBIST), education, vocational, judicial, law enforcement, mental health, substance abuse, domestic violence shelter staff, homeless shelter staff, correctional facilities, community-based organizations providing human service provision.

### *Focus Area 4: Brain Injury Prevention*

To prevent and reduce the burden of traumatic brain injury, it is critical to focus efforts on changing the factors that increase the risk of its occurrence in the first place. These goals address three of the most common causes of brain injury: falls, no helmet use, and motor vehicle crashes.

## Goal 1: Decrease by 10%, the death rate related to falls for those aged 55 and older.

- ACBI members will participate in the IDPH Iowa Fall Prevention Coalition.
- Promote fall prevention activities and programs.

## Goal 2: Decrease TBI in youth by requiring helmets for moped and motorcycle riders under the age of 17.

- Educate lawmakers and the public about the importance of helmet use in youth.

## Goal 3: Expand the Graduated Driver's License system to protect novice drivers, their passengers and other road users.

- Include requirements surrounding night time driving restrictions
- Increase the time a novice driver has to practice behind the wheel to master critical driving skills.

## Goal 4: Decrease the number of TBIs caused by falls off of bicycles.

- Promote helmet use in all populations especially children.
- Promote correct helmet fitting and use.

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