# Iowa State Plan for Brain Injury

## 2018 - 2021

IDPH
Iowa Department of Public Health

Advisory Council on Brain Injuries

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# Introduction

Brain injury significantly affects the lives of thousands of Iowans each year. Approximately 27,500 traumatic brain injury-related emergency department visits, hospitalizations and deaths occurred each year in Iowa from 2011 to 2016. While brain injury can cause physical challenges, the cognitive, emotional, behavioral and social challenges caused by brain injury are often the most disabling and they are also very difficult for the public to understand. This is one of the primary reasons brain injury is referred to as the "Silent Epidemic."

In addition to injury-related challenges, individuals and families experience difficulties and stresses associated with navigating, accessing, receiving and paying for services. Iowa's developing, yet fragmented brain injury service system can be impoverishing, overwhelming and unbearable. Adjustment to disability after brain injury is extremely difficult. Without appropriate care management, rehabilitation and long-term services and supports, survivors and family members frequently experience unemployment, social isolation, re-occurring hospitalizations, institutionalization and homelessness. To address these and other issues, Iowa's Advisory Council on Brain Injuries (ACBI) is charged with:

- Improving the rehabilitation and long-term services and supports system;
- Building a skilled brain injury workforce;
- Promoting brain injury prevention strategies; and
- Making recommendations to the governor for developing and administering a state plan to provide services for persons with brain injuries.

The Iowa State Plan for Brain Injuries has been updated every four years since 1997. To prepare the ACBI State Plan Task Force for the 2018 planning process, five listening sessions on brain injury were hosted across the state of Iowa to gain public input. During these sessions, individual survivors of brain injury and their families shared their experiences, opinions and recommendations. Additionally, the Iowa Association of Community Providers and the Brain Injury Alliance of Iowa conducted needs assessments. Collected information reflected the current state of the brain injury services system in Iowa as encountered by individuals, families, professionals and service providers. Three themes emerged from these initiatives and they provide the foundational focus areas for the ACBI's 2018 plan recommendations: 1) Individual and Family Service Access, 2) Service System Enhancements and 3) Prevention of Brain Injuries.

The plan is intended to provide statewide guidance for the design and implementation of brain injury related policy and programs in Iowa. The identification of responsible parties, partnerships and timelines is not included in the plan; however, the Advisory Council on Brain Injuries provides this implementation framework, along with evaluation of progress, at their quarterly meetings.

## Focus Area 1: Individual and Family Service Access

*Iowans report that appropriate services can be extremely difficult to locate and to access. Outcome data support that has been shared by individuals with disabilities and their family members during listening sessions and needs assessments; access to information about brain injury, assistance with systems navigation, and care coordination are vital to healing, maximizing recovery and reestablishing quality of life following brain injury. Research on the impact of Iowa's waiting list indicates "short wait times (<6 months) appear to substantially reduce the risk of long-term nursing home use" (Peterson, 2014).[i] As of January 2018, wait time for brain injury waiver services funding was 26 months from date of application, compared to two months from the date of application just 10 years ago.*

*Service needs following brain injury are unique from person to person and family to family. For individuals who access services for a particular symptom of their injury (e.g., mental health struggles or substance use), it is important their services be adapted to address the cause of their symptoms (i.e., their brain injury). Increased awareness and person-centered planning leads to increased service success, reduced recidivism and reduced costs both to the individual and to the State of Iowa.*

**Goal #1: Increase awareness of brain injury and increase utilization of Neuro-Resource Facilitation Services in Iowa**.

Action Step 1.1: Identify underserved or inappropriately served populations for targeted outreach utilizing data driven processes.

Action Step 1.2: Develop and disseminate awareness materials, to include reports, fact sheets and other brain injury information and resources[ii].

Action Step 1.3: Expand the number of Iowa Brain Injury Resource Network partners[iii] through targeted recruitment efforts, particularly those supporting underserved areas or populations.

Action Step 1.4: Notify individuals on the Medicaid Home and Community Based Services Brain Injury Waiver[iv] waiting list of the availability of Neuro-Resource Facilitation Services[v].

Action Step 1.5: Develop formal agreements with Mental Health and Disability Services Regions[vi] to increase referrals to Neuro-Resource Facilitation Services.

**Goal #2: Decrease delays experienced in accessing the Medicaid Home and Community Based Services (HCBS) Brain Injury Waiver.**

Action Step 2.1: Host a "Medicaid HCBS Brain Injury Waiver Summit," convening individuals with brain injury, family members, providers, state agency representatives, stakeholders,

advocates and legislators, to identify barriers to waiver access and to develop a plan to eliminate identified barriers.

**Goal #3: Increase brain injury screening, assessment and service coordination across systems of care that address multi-occurring conditions often experienced by individuals with brain injury.**

Action Step 3.1: Host a "Brain Injury Multi-Occurring Conditions Summit" to select a brain injury screening tool for use across pediatrics, geriatrics, mental health, substance abuse, corrections and other settings.

Action Step 3.2: Identify processes with service system partners for individualized training and screening implementation.

Action Step 3.3: Train service system partners on the use of the *Mayo Portland Adaptability Inventory-4*[vii] for assessment and service coordination.

Action Step 3.4: Develop recommendations for enhanced person-centered[viii] planning to address multi-occurring conditions.

## Focus Area 2: Service System Enhancements

*In recent years, Iowa has made significant strides in meeting the needs of individuals with brain injury related to treating neurobehavioral symptoms, increasing treatment outcomes and reducing out-of-state placements. However, individuals with brain injury, their families and many providers continue to report a variety of unmet needs, which include training of professionals and para-professionals to increase knowledge and capacity required to address the unique needs and challenges individuals with brain injury and their families' experience. Additionally, in order to adequately and equitably provide needed services across the state, the system requires continued fiscal evaluation and appropriate funding growth.*

**Goal #4: Develop service recommendations to meet the needs of Iowans currently served out-of-state.**

Action Step 4.1: Evaluate the service needs of Iowans with brain injury currently served out-of-state.

Action Step 4.2: Utilize available data sources to determine the scope and costs related to services received by individuals within out-of-state placements and in-state institutional settings, including corrections and community-based neurobehavioral rehabilitation services.

Action Step 4.3: Analyze available data, including Medicaid Home and Community Based Services waiver claims, to determine service distribution and gaps across Iowa.

Action Step 4.2: Develop and disseminate identified recommendations to the governor and policy makers.

**Goal #5: Develop a well-trained and competent workforce for current service providers and for the jobs of tomorrow.**

Action Step 5.1: Design and implement a direct support professional brain injury training curriculum, leading to voluntary credentialing or certification.

Action Step 5.2: Design and implement a pre-service curriculum for postsecondary students in health and human services programs, aimed at increasing knowledge and capacity to effectively provide services to Iowans experiencing brain injury.

Action Step 5.3: Develop a proposal to establish enhanced reimbursement rates for utilizing credentialed or certified brain injury direct support professionals.

Action Step 5.4: Design and implement a brain injury training for hospital-based discharge planners and Medicaid-based case managers.

**Goal #6: Evaluate fiscal formulas to ensure services are adequately funded.**

Action Step 6.1: Reformulate the Medicaid Home and Community Based Services Brain Injury Waiver reimbursement structure to reflect current and actual costs.

Action Step 6.2: Survey funding needs for acute, post-acute and community-based services and supports and make recommendations for improvement as identified.

Action Step 6.3: Adequately fund the Brain Injury Services Program (BISP) to ensure staffing (e.g., programmatic, epidemiological and evaluative) and resources for program services (e.g., neuro-resource facilitation and training), to position the Iowa Department of Public Health for accessing federal funding opportunities.

**Goal #7: Enhance the diversity of the Advisory Council on Brain Injuries to ensure the concepts of person-centered programming, self-advocacy and self-directed care are included in system enhancement initiatives.**

Action Step 7.1: Work with Iowa's governor to align the diversity of the Advisory Council on Brain Injuries[ix] to reflect the Administration on Community Living's recommendations for state brain injury advisory councils.

Action Step 7.2: Expand the number of partners and advocates collaborating with the Advisory Council on Brain Injuries through targeted recruitment.

## Focus Area 3: Prevention of Brain Injury

*To reduce the burden of brain injury on individuals, families and all Iowans, it is critical to focus prevention efforts, both the prevention of the actual injury and the prevention of conditions that may increase the severity of long-term impact of the injury, by using best practices and evidence-based strategies.*

**Goal #8: Reduce falls in Iowa**

Action Step 8.1: Identify populations, including individuals with brain injury and other disabilities, and occupations at high risk of falls in Iowa.

Action Step 8.2: Adapt existing falls prevention awareness and evidence-based strategies for targeted populations, as needed.

Action Step 8.3: Expand falls prevention awareness and evidence-based strategies for older Iowans and caregivers of young children.

**Goal #9: Decrease the incidence of traumatic brain injury[x] related to motorized and non-motorized vehicle crashes.**

Action Step 9.1: Increase the availability of information related to the importance of helmet use in brain injury prevention across multiple, motorized and non-motorized, risk areas.

Action Step 9.2: Increase the availability of bicycle helmets to youth.

**Goal #10: Increase awareness and utilization of best practices for concussion prevention and management.**

Action Step 10.1: Increase the distribution of concussion awareness and prevention materials to parents, Iowa educators, athletic personnel, healthcare providers, freestanding youth sports organizations and other targeted groups.

Action Step 10.2: Increase the distribution of concussion awareness and prevention materials among the public.

Action Step 10.3: Include a concussion section to the annual surveillance report, *Brain Injury in Iowa*.

**Goal #11: Reduce preventable acquired brain injury.**

Action Step 11.1: Develop and disseminate material regarding acquired brain injury[xi] health risk factors, behaviors and exposures (e.g., obesity, substance abuse, physical activity, nutrition, toxic exposure) among targeted populations.

Action Step 11.2: Adapt evidence-based programs for reducing health risk factors, behaviors, or exposures, for the inclusion of people with brain injury and other disabilities.

Action Step 11.3: Recommend a policy that requires a brain injury prevention plan for individuals receiving publicly funded long-term services and supports.

# Acknowledgements

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**To learn more about the meetings and activities of the Advisory Council on Brian Injuries, please visit http://idph.iowa.gov/brain-injuries**

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# Appendix

[i] Peterson, G., Brown, R., Barrett, A., Wu, B., & Stone Valenzano, C. (2014). *Impacts of waiting periods for home and Community-Based Services on consumer and Medicaid long-term care costs in Iowa.* Retrieved from https://aspe.hhs.gov/basic-report/impacts-waiting-periods-home-and-community-based-services-consumers-and-medicaid-long-term-care-costs-iowa

[ii] The Iowa Department of Public Health routinely publishes reports and other products. The most current information available can be downloaded from the Iowa Department of Public Health's Brain Injury Services Program webpage at http://idph.iowa.gov/brain-injuries

[iii] To learn more about the Iowa Brain Injury Resource Network, and locate partners near you, visit https://idph.iowa.gov/brain-injuries/resource-map

[iv] The Iowa Medicaid HCBS Brain Injury waiver information packet can be accessed at https://dhs.iowa.gov/sites/default/files/Comm510.pdf If you need assistance, please contact Iowa Medicaid Member Services at 1-800-338-8366.

[v] Neuro-Resource Facilitation is a fee-free service offered by the Brain Injury Alliance of Iowa to help people with brain injury and their families, caregivers, and community navigate medical and general life challenges after brain injury. To speak to a neuro-resource facilitator, call 1-855-444-6443 or email info@biaia.org

[vi] Mental Health and Disability Service Regions are Iowa's community-based, person-centered mental health and disability services system which provide locally delivered services, regionally managed with statewide standards. For more information, including a map of the regions, visit https://dhs.iowa.gov/mhds-providers/providers-regions/regions

[vii] The Mayo-Portland Adaptability Inventory (MPAI) was primarily designed to assist in the clinical evaluation of people during post-acute (post-hospital) period following acquired brain injury and to assist in the evaluation of rehabilitation programs designed to serve these people. This tool is publicly available and has been designed for possible completion by professional staff, people with brain injury and their families. http://www.tbims.org/mpai/

[viii] Person-centered planning allows individuals to be engaged in the decision making process about their options, preferences, values, and financial resources. For more information about person-centered planning, visit https://www.acl.gov/programs/consumer-control/person-centered-planning

[ix] The Advisory Council on Brain Injuries is a governor appointed board as established in *Code of Iowa 135.22A*. The council meets quarterly and meetings are open to the public. Individual's interested in serving on this council should submit an application at https://openup.iowa.gov/

[x] Traumatic brain injury (TBI) is a type of brain injury which is caused by an external force, such as a bump, blow, jolt or a penetrating object. Concussions are a type of TBI.

[xi] Acquired brain injury (ABI) is the umbrella term for brain injuries which includes injuries caused by a variety of factors, including stroke, medical conditions, TBI, and toxic exposure or overdose.