

Brain Injury Advisory Committee Report

Presented to the Iowa Health & Human Services (HHS) Council

Date: November 20, 2025

ACTION ITEM: Advisory Committee Membership

An application process was developed to capture interest from potential new members for the 2026 Brain Injury Advisory Committee. Applications were sought specifically from:

- ▶ Individuals with lived experience, including survivors of brain injury and their care partners
- ▶ Brain injury service providers
- ▶ Other individuals with relevant expertise or interest

The call for applications began in September 2025, with applications accepted through early November. Eleven applications were received, in addition to interest from existing committee members for continued participation. The applicants represent two individuals who are brain injury survivors, four family/unpaid care partners, and five brain injury professionals/service providers.

A list of recommended appointees is included in Attachment A for the HHS Council review and approval.

Committee Meeting Summary

The Brain Injury Advisory Committee convened on October 20, 2025, to review results of the recent Brain Injury Needs Assessment surveys and discuss next steps for updating the Iowa Brain Injury State Plan. The group met again on November 6, 2025 to begin the planning process. Meeting dates, agendas and subsequent notes are posted at [Iowa HHS Brain Injury Advisory Committee | Health & Human Services](#)

Brain Injury Needs Assessment Activities

The Committee reviewed results from the statewide survey conducted as part of the brain injury needs assessment. Three surveys were launched, one for survivors of brain injury or their proxy, one for unpaid care partners, and one for paid providers, advocates and other professionals supporting individuals after brain injury. A summary of results is provided in Attachment B.

2026–2030 Brain Injury State Plan Development

The Committee began meeting for the 2026–2030 Iowa Brain Injury State Plan development process, using facilitation support from the Iowa HHS Strategic Development Team. The current timeline is to have a draft plan completed by the February 2026 HHS Council meeting for review and feedback.

Attachment A:

2026 Brain Injury Advisory Committee: Membership Recommendations

Guided by [42 USC 300d-52: State grants for projects regarding traumatic brain injury \(TBI\)](#) and Administration for Community Living funding requirements (HHS-2021-ACL-AOD-TBSG-0070), the following recommendations for community member representatives on the advisory committee are presented to the Iowa HHS Council for consideration.

Recommendations reflect brain injury experience and align with requirements for majority (50%+) lived experience, family, and other interested parties, with consideration for statewide balance where possible.

Individuals with lived experience:

- Tia Clark*, Ankeny
- Eric Lietsch*, Burlington
- Jordan True*, Des Moines
- Sandra Corn, Clive
- Kelly Wise, Cedar Rapids
- **Open**, Individual with lived experience
- **Open**, Individual with lived experience
- **Open**, Individual with lived experience

Unpaid care partners/family members:

- Andrea Gomez*, Shenandoah
- Brenda Easter*, Winterset
- Brandie Richman, Iowa City
- Laura Jess, De Witt

Professionals/providers:

- Jim Torner*, PhD. Iowa City. TBI Researcher at University of Iowa College of Public Health
- Shamika Carmen, Dubuque. Mental health therapist at Life Connections

**2025 committee member*

Agency and Organization Representation: The following recommendations align with the cited requirements and are unchanged from 2025.

- Statewide Independent Living Council Executive Director
- Developmental Disabilities Council Executive Director
- Disability Rights Iowa Executive Director
- Brain Injury Alliance of Iowa Executive Director
- Iowa Department of Education Director, or designee
- Iowa HHS Aging & Disability Services Administrator, or designee
- Iowa HHS Long Term Care Ombudsman, or designee
- Iowa HHS Medicaid Director, or designee
- Iowa HHS Public Health Director, or designee
- Iowa Vocational Rehabilitation Services Administrator, or designee

Attachment B

Brain Injury in Iowa: 2025 Survey Results

In September 2025, staff from the Iowa Department of Health and Human Services' (Iowa HHS') Brain Injury Program conducted a survey of community members across Iowa about life after brain injury. A total of 130 responses were received from individuals with lived experience or their proxy, family members or other care partners, and paid professionals who support people after brain injury. The following themes were produced from the surveys.

What services or support have been **most useful** for individuals who have experienced brain injury?

Survivors (N=30)	Care Partners (N=45)	Paid Professionals (N=50)
<ol style="list-style-type: none"> 1. Rehabilitation services 2. Counseling/mental health support 3. Government assistance 4. Information about brain injury 5. Support groups 	<ol style="list-style-type: none"> 1. Rehabilitation services 2. Financial assistance 3. Government assistance 4. Information about brain injury 5. Home and community-based services 6. Counseling/mental health support 	<ol style="list-style-type: none"> 1. Rehabilitation services 2. Government assistance 3. Financial assistance 4. Counseling/mental health support 5. Employment support and job training

What services or support do you feel are **most lacking**?

Survivors (N=31)	Care Partners (N=43)	Paid Professionals (N=48)
<ol style="list-style-type: none"> 1. Financial assistance 2. Government assistance 3. Counseling/mental health support 4. Support and advocacy for accessing services 5. Employment support and job training 	<ol style="list-style-type: none"> 1. Social or recreational opportunities 2. Home and community-based services 3. Counseling/mental health support 4. Financial assistance 5. Government assistance 6. Affordable and accessible housing 	<ol style="list-style-type: none"> 1. Government assistance 2. Counseling/mental health support 3. Affordable and accessible housing 4. Social or recreational opportunities 5. Home and community-based services 6. Financial assistance

What **barriers/challenges** have you encountered?

Survivors (N=31)	Care Partners (N=44)	Paid Professionals (N=48)
<ol style="list-style-type: none"> 1. Lack of direct care providers with brain injury knowledge 2. Insurance coverage issues 3. Long wait to access brain injury waiver 4. Cost of services 5. Difficulty with paperwork/processes to get services 	<ol style="list-style-type: none"> 1. Lack of brain injury specialists 2. Lack of direct care providers with brain injury knowledge 3. Lack of primary care providers who have experience with brain injury 4. Long wait times to access services 5. Long wait to access brain injury waiver 	<ol style="list-style-type: none"> 1. Long wait to access brain injury waiver 2. Insurance coverage issues 3. Lack of mental health or substance use treatment providers with BI knowledge 4. Lack of transportation

What could **improve the lives** of individuals with brain injury in Iowa the most?

Survivors (N=29)	Care Partners (N=45)	Paid Professionals (N=49)
<ol style="list-style-type: none"> 1. Increased funding for brain injury services 2. Increased availability of brain injury specialty services 3. More services and/or financial support closer to time of injury 4. More support for caregivers and families 	<ol style="list-style-type: none"> 1. More support for caregivers and families 2. Increased funding for brain injury services, like the waiver 3. Increase availability of brain injury specialty services 4. More options for community-based support services 5. Access to time-limited financial support 	<ol style="list-style-type: none"> 1. Increased funding for brain injury services, like the waiver 2. More options for community-based support services 3. Access to time-limited financial support needs related to brain injury 4. Increase availability of brain injury specialty services

Themes from comments shared at the end of survey.

Survivors of brain injury:

Access to Care & Services

- Limited number of doctors and facilities trained in brain injury care.
- Survivors often face overwhelming paperwork, eligibility barriers, and challenges of transportation.
- Need for statewide access to support programs (e.g., *On With Life*, peer groups, and therapies).

Continuity of Support

- Therapy programs end too soon — recovery takes longer and progress can be slower.
- Calls for more flexible and survivor-focused services, including online (Zoom) and multiple time options. More training/education for survivors than just caregivers.

System Navigation & Coordination

- Services are siloed — a single, easy-to-navigate “one-stop” resource hub is needed.
- Greater awareness of available services and advocacy support (e.g., hospital-based social workers).

Justice & Understanding

- Courts should recognize the behavioral effects of brain injury (e.g., aggression linked to CTE) when sentencing.

Mental Health & Family Support

- Depression and motivation loss are major challenges.
- Family support is crucial but not available to everyone — more community-based emotional support is needed.

Family members and other care partners

Access to Care & Services

- Major delays and gaps between hospital discharge and approval for rehab or home supports — families left without safe options.
- Long waitlists (up to 9+ years) for Brain Injury Waivers; limited respite and medical daycare options.
- Private insurance and Medicaid often fail to cover needed therapies, equipment, or modifications.

Healthcare System Challenges

- Inadequate training for doctors, nurses, and medical staff on brain injury care.
- Few providers accept Medicaid; shortage of specialists.
- Early recovery windows missed due to poor coordination and lack of timely follow-up care.

System Instability & Bureaucracy

- Confusion and inconsistency within DHHS and HCBS waiver programs.

- Difficulties accessing approved waiver funds for essential items (e.g., lifts, car mods).
- Families report feeling lost in red tape and abandoned by systems meant to help.

Housing & Support Gaps

- Limited options between full independence and group homes; stigma and shame create additional barriers.
- Centralized intake for housing and support is slow and ineffective.
- Care Partner Strain
- Family caregivers face exhaustion and lack of respite.
- Need for education, emotional support, and practical resources for long-term caregiving.

Education & Public Awareness

- Public misunderstanding of brain injury limits compassion and opportunities for survivors.
- Broader education needed - from healthcare to law enforcement to sports organizations - to prevent and respond appropriately.

Transportation & Dignity

- Transportation services are unreliable and sometimes degrading; access impacts participation in care and community life.

Paid professionals

Financial and Insurance Support

- Survivors and families struggle with grief and financial stress while adjusting to a “new normal.”
- Stable funding and insurance coverage are critical so individuals can focus on recovery, not affordability.

Long-Term and Community-Based Care

- Lack of appropriate long-term care options for adults ages 30–50.
- Need for more flexible day treatment and support programs — adult day care alone is often not suitable.
- Community-based social workers should provide consistent, lifelong case management rather than one-time referrals.

Personalized, Human-Centered Support

- Survivors want face-to-face engagement with social workers who meet them where they live.
- Families need more hands-on support navigating services, funding for assistive technology, home modifications, and caregiver pay.

Prevention & Public Safety

- Rising injuries from e-scooters, ATVs, and unhelmeted riders highlight the need for stronger helmet laws and public education to prevent traumatic brain injuries