

BrainStorming March 2025



As Brain Injury Awareness Month comes to a close <u>now is the time to contact your U.S.</u> <u>Congressional representatives</u>. The U.S. Department of Health and Human Services (HHS) announced a restructuring, which may dramatically impact or even dissolve critical brain injury programs. BIAA and NASHIA have put together a campaign linked below to make it easier for you to make these contacts today!

FILL OUT THIS FORM TO CONTACT YOUR MEMBERS OF CONGRESS AND GOVERNOR TODAY

EDUCATE YOUR ELECTED OFFICIALS: PROTECT BRAIN INJURY PROGRAMS AMID HHS RESTRUCTURE!

On march 27,2025, The Secretary of Health and Human Services, Robert F. Kennedy, announced sweeping structural changes to the Department of Health and Human Services. These changes cold **dramatically impact or even dissolve critical brain injury programs** that millions of Americans rely on.

Our partners at the Brain Injury Association of America have created a campaign for you to contact your Governors and Members of Congress. For those of you with individual relationships with your Governors and Members of Congress, please email them directly and urge them to protect and preserve vital brain injury programs and funding using the outline below in addition to filling out the campaign from BIAA. These programs are not optional they are **lifesaving**, **life-changing**, **and essential** to individuals, families and communities here in Iowa and across the country.

What is at Stake?

CDC's Heads Up Program: A national initiative that provides education, training, and resources on youth concussions and return-to-learn protocols to keep students safe and supported after injury.

CDC's Return to Work Program: Guidance and resources to help adults with brain injuries successfully transition back into the workforce with the supports they need.

Programs within the Administration for Community Living (ACL): Crucial programs that empowers people with disabilities and older adults to live independently, participate in their communities, and access needed services and supports. **Programs executed by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR):** Programs that fund **civilian brain injury research**, including the **TBI Model Systems**, which provide critical data and treatment innovation for long-term recovery.

These programs are **irreplaceable pillars of care, research, and includes** the brain injury community. Cutting or consolidating them would roll back decades of progress and harm millions.

Contact your lawmakers today and urge them to ensure that brain injury programs are protected and preserved in any future structure of the U.S. Department of Health and Human Services.

EMAIL TEMPLATE BELOW FOR YOU - MAKE SURE YOU SHARE YOUR STORY!

- Find your US Congress members at: <u>https://www.congress.gov/contact-us</u>
- Contact the Office of Governor Kim Reynolds at: <u>https://governor.iowa.gov/contact-office-governor</u>

I'm writing in response to the March 27th announcement from the U.S. Department of Health and Human Services (HHS) regarding its proposed agency restructuring. While we support efforts to streamline services and improve care for individuals with chronic and mental health conditions, we urge you to ensure that critical brain injury programs are protected and preserved in any restructuring process.

We share Secretary Kennedy's concern about the unsustainable costs associated with managing chronic health conditions—costs our current system often struggles to manage effectively. Traumatic Brain Injury (TBI) has long been recognized by the Centers for Medicare & Medicaid Services (CMS) as a chronic condition due to extensive clinical evidence showing that brain injury is not a one-time event, but an evolving and lifelong condition that changes over time.

The restructuring proposal suggests moving key aging and disability programs, including the federal brain injury program, out of the Administration for Community Living (ACL) and into other agencies. While we appreciate the Administration's recognition of these programs' importance, we strongly urge that the TBI programs remain housed within ACL.

ACL's federal TBI State Partnership Program is a lifeline for thousands of Americans living with brain injury, enabling states to build service infrastructure, support survivors and their families, and reduce costly institutionalization and emergency care. Research shows that people living in states with ACL-funded TBI programs experience better long-term outcomes than those without.

Likewise, the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)—also located within ACL—administers the TBI Model Systems, the nation's leading longitudinal research initiative for understanding the long-term effects of brain injury. These efforts are essential to improving the evidence base for care and maximizing the return on investment in this population.

The proposed dissolution of NIDILRR further compounds the harm caused by Congress's decision to eliminate funding for the Congressionally Directed Medical Research Programs (CDMRP) in the March 2025 Continuing Resolution. The CDMRP has historically invested millions of dollars into advancing traumatic brain injury (TBI) research, supporting studies aimed at improving acute and chronic care, developing diagnostic tools, and understanding the long-term effects of TBI on cognition, mental health, and neurological function. Eliminating both NIDILRR and CDMRP funding in such close succession represents a major setback for the brain injury community and threatens the progress we have made in research, rehabilitation, and quality of care for TBI survivors across the country.

ACL was created in 2012 to bring together aging and disability programs under one roof, improving coordination, administrative efficiency, and service integration. Dispersing these programs across multiple agencies risks undermining their effectiveness, reducing efficiency, and disrupting critical services.

Finally, we are deeply concerned by the Administration's proposal to significantly reduce the workforce at the Centers for Disease Control and Prevention (CDC). As restructuring moves forward, it is essential that CDC's brain injury work—including its concussion education efforts, return-to-play guidelines, and national TBI surveillance initiatives—remain intact and fully supported.

We respectfully urge you to:

- Advocate for the continued housing of TBI programs and NIDILRR within ACL;
- 2. Oppose any restructuring that fragments or dilutes the mission of the Administration for Community Living;
- 3. Protect the CDC's brain injury programs from cuts or displacement during this transition.

These programs are essential to ensuring brain injury survivors receive the support, research, and resources they need to recover, live independently, and thrive.

Thank you for your consideration and leadership on this critical issue.

Sincerely,

Public Misconceptions About Brain Injury

New national survey shows public misconceptions about brain injuries persist and highlight the need for education. Below are the survey highlights: - 81% of adults in the U.S. do not recognize concussions as traumatic brain injuries. - While 70% of Americans say they are familiar with concussions, only about half report awareness of brain injuries more broadly.

- Fewer than one in five can correctly identify falls as the number one cause of traumatic brain injuries.

During Brain Injury Awareness Month, we want to make sure that our community is well-equipped with the information and resources they need to start the conversation about brain injury with their friends, families, and communities.

The Brain Injury Association of America has created a new <u>fact sheet</u> to help you share important statistics and information about brain injury, including information about who is most likely to be affected by TBI, common causes of brain injury, associated risks of brain injury, and more.

Iowa HHS Announces Intent to Award for Disability Access Points

Des Moines, IA – The Iowa Department of Health and Human Services (Iowa HHS) is announcing the intent to award seven individual contracts to entities that will serve as Disability Access Points (DAP) across the state. The full list of recipients can be found <u>here</u>.

Disability Access Points are district-level organizations that connect individuals with disabilities to providers who can provide the necessary services to meet their needs. DAPs provide information, assistance, person-centered planning, etc. to those who walk through their doors.

In May 2024, Governor Kim Reynolds signed into law HF2673, the historic behavioral health bill, which transfers the management of disability services from the local Mental Health Disability Services (MHDS) Regions to Iowa HHS's Division of Aging and Disability Services (ADS).

The state's overall management of this work allows for a streamlined focus on delivering systems of support, care and connection for all lowans and families with disability needs. In addition, the state will build relationships and leverage opportunities to get additional providers and organizations on board to support the needs and develop a statewide Aging and Disability Resource Center Network.

"At Iowa HHS, we have been fully committed to reimagining and overhauling our systems to ensure they are entirely centered around the individuals we serve," said Kelly Garcia, Iowa HHS Director. "While we've made great strides in many areas, one thing remains clear: Iowans want seamless, easy access to care, and they want to receive that care within their communities and ultimately, in their homes. It's equally important to make sure all aspects of our system—whether Medicaid, Public Health, or Behavioral Health—are interconnected and aligned."

The Disability Access Points will serve the same seven districts outlined in the Behavioral Health System. Iowa HHS will work collaboratively with the DAPs to coordinate and oversee access to long-term services and supports and ensuring for well-defined access points.

"Iowans with disabilities, their families and caregivers will now have the same opportunity to access the care they need whether they are in northwest Iowa or eastern Iowa...and every point in between," said Zach Rhein, Iowa HHS Aging and Disability Division Director. "We will work closely with our established network to enhance their reach and services, as well as our Technical Assistance and Call Center, so that any lowan has every opportunity to reach out and be connected to the services they need." The new Disability Services System will begin July 1, 2025, in conjunction with the new Behavioral Health System Alignment.

To learn more about the Disability Services System and Disability Access Points, visit <u>https://hhs.iowa.gov/initiatives/system-</u> <u>alignment/iowas-disability-services-system</u>

Participants Needed for a Traumatic Brain Injury Research Study

The Mindfulness, Exercise, Nutrition to Optimize Resilience (MENTOR) Program, is designed for people with physical disabilities and the study seeks want to understand how effective it is for individuals with TBI. While this is a research study, it also serves as a valuable tool for individuals after rehabilitation, serving as a continuation of care. Download flyer to learn more.

"We Want to Work" Survey Results Are In!

Disability Rights Iowa announced that the full report on barriers to employment for Iowans with disabilities is on their website. The report features responses to the 2024 State of and Barriers to Employment in Iowa Qualitative Survey as well as additional research and commentary. <u>View full survey report.</u>

Developing Brain Injury Resource Facilitation for Acquired Brain Injury: Indications and Unmet Needs

Members of the Service Access Subgroup of the 2023 Moody Galveston Brain Injury Conference (MGBIC) collaborated on a white paper featuring an overview of the current status of brain injury resource facilitation (RF) along with an analysis on the challenges and opportunities in brain injury RF for acquired brain injury. <u>Read more</u>.

Webinars

CEU opportunities available for these webinars! Visit our webinar page to learn more and register.



Period of PURPLE Crying:

An Effective and Memorable Abusive Head Trauma Prevention Program

Shantel Wakely, BS - PURPLE Program Director, National Center on Shaken Baby Syndrome



TUESDAY, APRIL 1, 2025 FROM 12:00-1:00 PM CST

info@biaia.org 🗰 www.biaia.org



April 10, 2025 12:00-1:00 PM CST



1-855-444-6443 info@biaia.org www.biaia.org

On With Life After Brain Injury: Occupational Therapy's Role in Restoring **Daily Function**

Monica W. Radcliffe Occupational Therapist - On With Life





Program Manager, Injury Prevention and Community Outreach Iowa Health Care, Stead Family Children's Hospital

May 20, 2025 12:00-1:00 PM CST

www.biaia.org info@biaia.org 1-855-444-6443



Brain Injury — Alliance —



Brain Injury Resource Facilitation



Brain Injury Resource Facilitators are available to serve lowans; to answer questions and connect those with a brain injury to resources and information. Learn more about this program. BIAIA is one call away.

BIAIA Satisfaction Survey



Our mission at the Brain Injury Alliance of Iowa is to create a better future through brain injury prevention, advocacy, education, research and support. Join us on our platforms to obtain the latest and most relevant information pertaining to brain

injury.