

DATE: December 14, 2023

SUBJECT: Public Comments Regarding Request to Amend TBI Waiver

RESPECTFULLY SUBMITTED: Kim Dodson, CEO, The Arc of Indiana

The Arc of Indiana is a state-wide organization that advocates on issues important to people with intellectual and other developmental disabilities (IDD) and their families. It is our mission to ensure people with disabilities realize their goals of living, learning, working and fully participating in the community.

The Arc of Indiana has 46 local chapters throughout the state covering 68 counties and over 30,000 members. We were established in 1956 by parents of children with IDD who joined together to build a better and more accepting world for their children. Today, the combined strength of The Arc at the local, state and national level makes The Arc the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families.

Following are our comments regarding proposed changes to Indiana's Traumatic Brain Injury (TBI) Waiver.

The understanding, treatment, and supports for individuals with Traumatic Brain Injuries (TBI) has changed substantially since the TBI waiver was created. More effective treatment and interventions are now available, and the outlook for individuals with TBI has greatly improved. Individuals impacted with a TBI do not need to be relegated to an institutional setting. They can live in the community successfully with appropriate access to supports. Because individuals who have sustained a TBI have similarities to individuals with IDD due to the cognitive impact of TBIs, we applaud the state's decision to move administration of the TBI waiver to the Division of Disability and Rehabilitative Services (DDRS) and the Bureau of Disability Services (BDS). We believe this will allow individuals with TBIs to receive more appropriate support for their needs.

One of our highest priorities is ensuring individuals with disabilities have real choice. Individuals should be able to determine the lives they want to live including where to live, how to spend their days, with whom they choose to spend time, what supports they need and want, how those supports will be provided, and who will provide those supports.

Individuals with TBI should be making those determinations, and their choices should be recognized, honored, and respected. Individuals with TBI should also have the support and inclusion of others of their choosing, and we are glad to see the state also wants to honor individuals' choices about including others in their support network in the waiver process.

We are also happy to see the state's emphasis on ensuring services and supports are person centered. DDRS has embraced the LifeCourse Framework, including the LifeCourse principles, philosophies and tools, for use with their clients. We encourage DDRS to extend the use of the LifeCourse principles to individuals with TBI and introduce these principles to the TBI community, including TBI service providers.

With the transition of the TBI Waiver from the Division of Aging to DDRS, many individuals and families are nervous. We applaud the state's focus on continuity of services. We appreciate the efforts they are taking to keep things as consistent as possible for individuals in waiver services and ensuring individuals have appropriate supports, including full, transparent information, during this transition.

We applaud the state's proposal to increase the income limits for individuals on the TBI waiver from 150% of the maximum SSI amount to 300% of the maximum SSI amount. This brings the TBI Waiver in line with other waiver programs. It opens the door to more individuals who may be over the 150% threshold due to higher Social Security Disability Insurance payments, and it makes it easier for individuals with TBI to work in competitive, integrated employment without jeopardizing services.

We do have recommendations regarding this proposal for the state to consider. We want individuals with TBI to access and fully engage in the community. The current services that exist and are proposed in this waiver do not provide support for that community engagement. We encourage the development of new services or expansion of existing services to help ensure people with TBI are able to access and fully engage in the community.

This proposal specifically prohibits independent care managers from assisting people in the initial application process for TBI Waiver services. The Arc of Indiana embraces the No Wrong Door approach, and we want to eliminate any barrier to accessing supports. We encourage the state to eliminate this prohibition.

We support the state's efforts in monitoring appropriateness of services. This proposal acknowledges that the state investigates if Intermediate Care Facility for Individuals with Intellectual Disabilities (IFC-IID) level of care should be used if the brain injury was sustained prior to age 22. We encourage the state to talk with individuals in those situations about other waivers they could qualify for so the individual can choose which program would service them best and help them achieve their vision of a good life.

If an individual is getting close to no longer meeting the appropriate level of care for TBI Waiver services, we encourage care managers to begin those discussions early to prepare the individual. As part of those discussions, care managers should discuss other services and resources, including other waivers for which the individual may qualify, that may be available to support the individual if they no longer meet TBI Waiver Level of Care.

Individuals with IDD are incredible employees. Studies have shown that businesses that employ people with IDD have higher productivity, higher job satisfaction, lower absenteeism, and lower turnover rates. While employees with disabilities may need assistance in the workplace, their value to their employer and the state's economy outweigh those needs. The state is proposing to add several services to the Family Supports Waiver and Community Integration and Habilitation (CIH) Waiver to assist people with IDD in employment. We encourage the inclusion of these services in the TBI Waiver proposal as well.

Career Exploration and Planning, Extended Services, Prevocational Services, and Workplace Assistance will allow individuals to customize the supports they may need to obtain and maintain community based employment. We believe that the expanded employment supports in the TBI waiver would help encourage employment and independence, and expand employment choice and opportunities

We also encourage some modifications to existing services in this proposal. For example, interpreters have been included as an option under Specialized Medical Equipment, but it limits the circumstances in which someone can use interpretation services. We encourage expansion of interpretation services and supports to provide individuals with greater access and inclusion in the community.

We also encourage allowing transportation services to be used to purchase bus passes, as allowed for individuals on the Family Supports Waiver and CIH Waiver.

We also ask for clarity on the Vehicle Modifications service. The proposal refers to a "lifetime cap," but it also refers that this service is available every 10 years. This is confusing. We recommend clarifying if this is truly a lifetime cap or a 10 year cap, with preference being to provide a 10 year cap.

At one point, the term "mental retardation" was the official diagnosis for an individual with an IQ of around 70 or below. However, colloquialism coopted that term and it became an insulting slur used against people. We respectfully ask that the term "mental retardation" be removed from this proposal and replaced with "intellectual disability."

We are very concerned that this proposal only provides 200 waiver slots for individuals with TBI each year. We believe this is inadequate. With the proposed expanded income limits, more individuals will be eligible for this waiver. This waiver has also historically been underpublicized and difficult to access. With corrections to those struggles, we expect more individuals will apply for services and 200 slots will not be enough to support Hoosiers with TBIs.

We are also concerned that TBI Care Managers can have caseloads of up to 65 people. This is an incredibly high amount, especially with the required interaction care managers must have with waiver participants. Case managers on the Family Supports and CIH Waivers can only have a maximum case load of 45 individuals, and we recommend the TBI waiver adopt that limit.

Family members, Powers of Attorney, Health Care Representatives, and legal guardians have successfully served as paid caregivers for waiver participants on the Family Supports and CIH waivers. This helped address the severe workforce shortage and ensured individuals received the care and support they needed. If an individual with a TBI wishes to have a family member, Power of Attorney, Health Care Representative, or legal guardian serve as their paid caregiver, that should be allowed. As with the Family Supports and CIH Waivers, this should be done with the oversight of an agency and the Individual Support Team to ensure this is appropriate. A company's ownership should not be a factor in that decision. This should be directed by the individual's comfort and choice with appropriate safeguards in place.

As noted earlier, the TBI waiver is not well known and individuals have struggled trying to apply for and access services. We encourage increased publicity about this and all other waiver services and application processes so individuals in need of services know what supports are available and how to access them.