

DATE: February 16, 2024

SUBJECT: Public Comments Regarding Request to Amend Indiana's TBI Waiver

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

The Arc of Indiana is a state-wide organization that advocates for and with people with intellectual and other developmental disabilities (IDD) and their families. It is our mission to ensure people with developmental 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 supports 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 pleased 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.

We applaud the state's proposal to increase 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.

While we recognize the state's need to pause rate indexing after the forecasted Medicaid shortfall, we strongly encourage the state to include language that allows rate indexing to go into effect when Indiana's fiscal situation permits this without having to seek another amendment and that also includes allowances to make up for the period of time when the index was paused.

We applaud the state's decision to give individuals more choice in service providing agencies by allowing them to choose a service providing agency in which their family may have an ownership stake.

We appreciate the state clarifying that the cap on vehicle modifications is a 10 year cap, not a lifetime cap.

We also appreciate the state's announcement on January 26, 2024, to allow the legal guardians of adults to provide up to 40 hours per week of paid Attendant Care or Home and Community Assistance.

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 can 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.

Many individuals and families are wary of the transition of the TBI Waiver from the Division of Aging to DDRS. In the November TBI Waiver proposal, the state outlined a detailed plan to ensure continuity of service for TBI Waiver participants as they transitioned from the Division of Aging to DDRS. This plan was important because it focused on maintaining continuity of services with minimal disruption, provided multiple meetings for "warm handoffs" if providers need to change, and provided extensive monitoring of needs to quickly address any changes individuals may experience during this transition.

We also appreciated the state's focus on ensuring individuals had back up plans for services to proactively address problems, including workforce issues, and offered full, transparent information, during the transition. The transition plan also committed to keeping plans consistent for 180 days to allow for a more seamless transition unless the individual requested changes. In the newest proposal, that detailed plan to ensure continuity of care and services seems to have been removed, and we are highly concerned by that change. All allusions to plan transitions now also limit the continuity of services to 90 days instead of 180 days. Waiver participants, case managers, service providers, contracting agencies, and state officials will be learning new systems, procedures, and regulations, and 90 days does not afford enough time to facilitate a transition this substantial. FSSA spent quite a bit of time developing the initial proposals submitted in November.

For the benefit of all involved, we highly recommend that the state reimplement the transition proposal initially submitted in November, including the 180 day transition.

The severe shortage of Direct Support Professionals, including skilled professionals, has risen to crisis levels. While the state is working with various entities to develop a plan to address this workforce crisis, it will take time to develop an adequate workforce to meet individuals' needs. In the spring of 2023, the state reassured individuals and families on the TBI Waiver that Legally Responsible Individuals would continue as paid caregivers for their loved ones with disabilities, in part due to this workforce crisis. The November waiver proposal solidified the state's intent to allow LRIs to continue as paid caregivers. After the December 2023 Medicaid forecast was announced, the state reversed its decision to allow LRIs to be paid as caregivers. We strongly disagree with this decision. The workforce shortage is still at a crisis level. LRIs have been shown as a responsible and reliable workforce to meet the needs of individuals with TBIs. We recommend that the state continue to allow LRIs to serve as paid caregivers for Attendant Care and Home and Community Assistance under the NASDDDS Extraordinary Care Provisions with appropriate hours, support, and respite to ensure the individual's health and safety.

The state has added Structured Family Caregiving (SFC) as an option under the TBI Waiver, and the state is allowing LRIs to be paid for providing SFC. While the state is encouraging this option for individuals, especially minors on the TBI Waiver, we have serious concerns about the current structure.

Currently, there is not a pediatric assessment tool that appropriately recognizes the needs of pediatric patients. Providers are reluctant to accept pediatric clients. Also, SFC was not designed for individuals with high medical needs, and the payment structure does not reflect the additional care needed for individuals who are medically complex. Under the current proposal, SFC is the only service that provides compensation for LRIs providing care. While we strongly recommend that the state continue allowing LRIs to serve as paid caregivers for Attendant Care and Home and Community Assistance, SFC could be an option for some *if* changes are made to the proposed SFC model. Currently, SFC provides payment based on one of three levels. We recommend adding a level 4 and level 5, with higher reimbursement rates for the provider agency and the caregiver, to compensate caregivers for the substantially increased efforts to care for individuals who are medically complex.

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 (ICF-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. We also encourage the state to include individuals with Traumatic Brain Injuries in the priority category for the FSW, with consideration for the CIH Waiver, when they no longer meet Nursing Facility Level of Care but meet ICF-ID Level of Care.

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.

The current Aged and Disabled Waiver and proposed Health and Wellness and PathWays for Aging Waiver offer a service called Caregiver Coaching. This service can provide valuable support for families and other caregivers and help them adjust as an individual's needs change over time. While a family may not need Caregiver Coaching when services begin, as needs change, this coaching could be valuable, extend caregiver resilience, and help caregivers best meet their loved ones needs. We recommend adding this service to the TBI waiver.

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 caseload, 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 caseload of 45 individuals. We recommend the TBI waiver adopt that limit.

As noted earlier, the TBI waiver is not well known, and individuals have struggled trying to apply for 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.