

DATE: December 14, 2023

SUBJECT: Public Comments Regarding Proposed Health and Wellness 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.

We are dedicated to ensuring individuals with IDD are provided every opportunity to live the lives they want to live and engage fully in the community. We believe people with IDD deserve dignity, respect, and full participation in society, and we are committed to ensuring they have the resources and supports for that full inclusion.

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 the proposed Health and Wellness Medicaid Waiver.

The Arc of Indiana recognizes the monumental task the state took on when separating the Aged and Disabled Waiver into two different programs, one for individuals 60 and older and one for individuals 59 and younger. We recognize and appreciate all of the efforts the state made to engage a variety of stakeholders in the development of these programs. In addition, the state requested extensive information and consulted with other states to make these changes successful. We appreciate the deliberateness of the state's actions. We especially appreciate the efforts the state has made to include individuals who participate in services and their families in the development of these new programs.

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 disabilities should be making those determinations, and their choices should be recognized, honored, and respected. Individuals with disabilities 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 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 them to extend the use of the LifeCourse principles to individuals with disabilities and introduce these principles to a new community, including the Health and Wellness service providers.

With the transition of the Aged and Disabled (A&D) Waiver from the Division of Aging to DDRS, many individuals and families are nervous. We applaud the state's focus on maintaining continuity of services with minimal disruption, multiple meetings for "warm handoffs" if providers need to change, and extensive monitoring of needs to quickly address any changes individuals may experience during this transition. We also appreciate the state's focus on ensuring individuals have back up plans for services to proactively address problems, including workforce issues.

We appreciate the new emphasis on health and wellness and quality of life with the renaming of the A&D Waiver to the Health and Wellness (H&W) Waiver. We also appreciate the deliberate efforts and time the state and care managers will take to help individuals who will transition from the H&W Waiver to the PathWays for Aging Waiver when they become age 60.

We also recognize the A&D Waiver eliminated its waiting list several years ago. We highly encourage that as the A&D waiver transitions to the H&W and PathWays for Aging Waivers that the state continues to avoid a waiting list so individuals can receive services and supports as quickly as possible.

We are very pleased that Caregiver Coaching is included as a service on the H&W Waiver. This provides valuable support for families and unpaid caregivers. The supports this service offers can make a huge difference in the quality of life for waiver participants and their families.

Given the great value of this service, we recommend adding Caregiver Coaching to other home and community based programs, including Structured Family Caregiving. While a Structured Family Caregiver may not need Caregiver Coaching when services begin, as needs change, for example from a stroke, the onset of cognitive decline, etc., this coaching could extend caregiver resilience and help the caregiver provide better care.

We do gently recommend renaming the service Caregiver Coaching, rather than Caregiver Coaching and Behavior Management. Other BDS waivers include Behavior Management services that are directly for the waiver participant. The commonality in names with very different functions may cause confusion.

We are concerned that the services proposed for the H&W Waiver will not provide the array of supports individuals with disabilities need to fully engage in the community. We encourage the development of new services or expansion of existing services to address this important issue.

The proposed H&W waiver specifically prohibits independent care managers from assisting people in the initial application process for H&W 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 to monitor appropriateness of services. This waiver is different because it offers some limited opportunities for self-directed care. We appreciate the state's focus on ensuring self-directed care is appropriate and that the participant is adequately able to manage their self-directed care. We encourage the development of technical assistance support for those using self-directed care, especially for some of the more administrative issues such as taxes and issues more commonly considered by human resource departments. We will monitor self-directed supports to see if those options should be expanded to other services and to other portions of the state rather than the four zip codes in which it is currently available.

We encourage the state to include employment related services in the H&W Waiver. Individuals with disabilities are incredible employees. Studies have shown that businesses that employ people with disabilities 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 has proposed adding several employment related services to the Family Supports Waiver and Community Integration and Habilitation (CIH) Waiver, including Career Exploration and Planning, Extended Services, Prevocational Services, and Workplace Assistance. We believe that including employment supports in the H&W Waiver will encourage employment and independence, expand employment choice and opportunities, and recognize the dignity and equality of individuals with disabilities.

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 to and inclusion in the community.

We also encourage allowing transportation services to be used to purchase bus passes in the same way it is allowed for the Family Supports and CIH Waivers. 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 clarify as a 10 year cap.

Person Directed Home Care Services is only available to individuals over age 21 in this proposal. While it is likely a small number of individuals are affected, 18 year olds are legal adults and may be living on their own. Because 18 year olds can live on their own and these services are not covered by the Medicaid State Plan, this service should be adjusted to be available for individuals 18 and older.

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 also concerned that H&W 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 H&W 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.