

DATE: December 14, 2023

SUBJECT: Public Comments Regarding Proposed PathWays for Aging 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 disabilities 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 PathWays for Aging 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.

We know healthcare costs have skyrocketed, and the state has an interest in controlling healthcare costs. In an effort to control those costs, Indiana has decided to pursue managed care for both medical costs and home and community based services for individuals over age 60 in institutional settings and on Medicaid Waivers. We know Indiana has consulted with other states who have transitioned their home and community based services to managed care. We have also spoken with users in managed care states, individuals receiving services, families of those receiving services, and providers of those services. Some states have been more successful than others at this transition.

The Arc of Indiana's priority is ensuring individuals retain choice – choice in service type and quantity, choice in providers, and choice in managed care entities. We want to ensure that if individuals are not getting the services they are supposed to receive or if the provider is not meeting the individual's expectations, the individual can change provider agencies to better meet their needs. While we recognize the need for consistent managed care entities, limiting changes without due cause, we want to ensure individuals can change provider agencies as they deem fit. We are glad to see the state has a disenrollment procedure to allow individuals to change managed care entities. Individuals should be fully informed when making such a decision including the impact such a change would have on providers, service plans, and existing prior authorizations.

We also want to ensure a robust grievance process if a managed care entity denies or limits a service and that a robust appeals process outside of the managed care entity exists so individuals can have a neutral party making decisions if the individual and managed care entity cannot resolve their conflict. Because this program is providing services to individuals who may have more unique needs and may need more specialists, we also want to ensure a robust grievance or appeals process for seeing medical specialists who may be out of network or when in-network specialists are inappropriate due to distance, waiting lists, or contentious past history. Because this also deals with medical care and with services to keep people out of institutional settings, we encourage an expedited grievance and appeals process when a delay in medical treatment could cause harm or increase the likelihood of institutional placement.

We recognize that individuals enrolled in the PathWays for Aging program are at increased risk of hospitalization and medical issues that may require temporary admission to a rehabilitation facility. We want to ensure the managed care entities prioritize providing enough and focused rehabilitation services to allow the individual to return home as quickly as appropriate, if the individual chooses, to avoid permanent admission to an institutional setting such as a skilled nursing facility.

We appreciate the extensive assessments the managed care entities will use to determine the services and supports individuals will receive. We want to ensure individuals' requests, preferences, and experiences are heavily weighed in those decisions. We also recognize the efforts the state is putting into this transition to ensure continuity of care for PathWays participants.

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 also want to ensure that there is an emphasis on services and supports being person centered. DDRS has embraced the LifeCourse Framework, including the LifeCourse principles, philosophies and tools, for use with their clients. We encourage the state, managed care entities and PathWays care managers 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 a managed care program through PathWays for Aging, 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 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 quickly receive services and supports.

We are very pleased that Caregiver Coaching is included as a service on the PathWays 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 have recommendations regarding this proposal for the state to consider. We want individuals with disabilities 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 disabilities and older adults are able to access and fully engage in the community.

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 allow individuals great access 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.

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 PathWays 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 PathWays 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 disability or an older adult 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.