

DATE: February 16, 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 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.

We are dedicated to ensuring individuals with developmental 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.

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.

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.

Many individuals and families are wary of the transition of the Aged and Disabled (A&D) Waiver to a managed care program through PathWays for Aging. In the November PathWays for Aging Waiver proposal, the state outlined a detailed plan to ensure continuity of service for PathWays Waiver participants as they transitioned from the Division of Aging to Managed Care. 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 extremely 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.

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 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.

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 Aged and Disabled 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 to be a responsible and reliable workforce to meet the needs of individuals with disabilities. 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 PathWays Waiver, and the state is allowing LRIs to be paid for providing SFC. We recognize this may be a valuable option for some individuals and families. However, we have serious concerns about the current structure.

Currently, 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 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 older adults can 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 are also concerned that PathWays Care Managers can have caseloads of up to 65 people. This is an incredibly large 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 PathWays waiver adopt that limit.

Finally, we are now 135 days away from the implementation of the PathWays for Aging Waiver. At this point in time, current A&D case managers do not have adequate information on this program or the transition process to discuss with their clients to assist in the transition. Managed Care Entities (MCE) have not published medical provider networks or service providing networks. Individuals who are transitioning into this program do not have access to the information they need to make an informed choice about which MCE they wish to use, and yet, we are only 74 days away from the state auto-assigning MCEs. We encourage the state to expedite case manager information and training. We encourage the state to insist MCEs publish their provider networks as soon as possible, and we encourage the state to initiate a robust and meaningful outreach program to all individuals who will be affected by this transition.