

DATE: February 16, 2024

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 for and with 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.

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.

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 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 support 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 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. However, we recommend reinstating the 180 day plan continuance for this transition rather than reducing it to 90 days.

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 continue to avoid a waiting list so individuals can receive services and supports as quickly as possible.

We support the inclusion of Caregiver Coaching as a service on the H&W 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.

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 as we want to eliminate any barrier to accessing supports. We encourage the state to eliminate this prohibition.

Many individuals and families are wary about the transition of the H&W Waiver from the Division of Aging to DDRS. In the November 2023 H&W Waiver proposal, the state outlined a detailed plan to ensure continuity of service for H&W Waiver participants as they transitioned from the Division of Aging to the 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 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.

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 H&W 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 H&W 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, especially for minors on the H&W Waiver.

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 appreciate the state's decision to create a priority category for the Family Supports Waiver for individuals on the Health and Wellness Waiver who no longer meet Nursing Facility Level of Care but still meet ICF-DD Level of Care. This will allow for a better transition between programs while ensuring individuals do not go for extended periods of time without appropriate supports. However, in addition to being assessed for the Family Supports Waiver, we encourage the state to also assess these individuals to determine if a Community Integration and Habilitation Waiver is more appropriate due to their likely higher level of need.

If an individual is getting close to no longer meeting the appropriate level of care for the H&W Waiver, 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 H&W Waiver Level of Care.

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. Regarding people with IDD, assurances should be put into place to make sure that they, not their families, are directing their care. Assistance should be available to help in situations where they may need to stop utilizing a friend or family member as a caregiver. 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.

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.

We are also concerned that H&W 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 case load of 45 individuals, and we recommend the H&W waiver adopt that limit.