

DATE: December 14, 2023

SUBJECT: Public Comments Regarding Request to Amend Community Integration and Habilitation 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.

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.

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 IDD should be making those determinations, and their choices should be recognized, honored, and respected.

Following are our comments regarding proposed changes to Indiana's Community Integration and Habilitation (CIH) Waiver.

We fully support many of the new services being proposed, particularly regarding competitive, integrated employment. 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 IDD may need assistance in the workplace, their value to their employer and the state's economy outweigh those needs.

We applaud the state's efforts to assist people with IDD in gaining meaningful employment. Career Exploration and Planning will allow individuals to learn about a variety of careers and give them more choice in becoming employed in an area that is based on their talents and interests.

We support the state's efforts to interrupt the school to workshop pipeline by excluding 18-24 year olds from sheltered employment at subminimum wage. This will give transition age students more opportunities to explore competitive, integrated employment.

We appreciate the supports available through Extended Services, Prevocational Services, and Workplace Assistance which will allow individuals to customize the supports they may need to obtain and maintain community based employment. We believe that the expanded employment supports being proposed for waiver recipients will help encourage employment and independence, expand employment choice and opportunities, and recognize the dignity and equality of individuals with disabilities.

We do have concerns about some of the proposed CIH Waiver changes.

The state continues to perpetuate a Supported Group Living (SGL) first approach before granting a Community Integration and Habilitation (CIH) Waiver. Supported Group Living settings licensed as Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID) are institutional settings which limit individuals' choice, freedom of movement, financial opportunities, and more. The state should prefer and promote integrated, community based options over institutional placements.

While the CIH Waiver is designed to be an emergency based waiver, we are concerned by how few slots the state is allocating. The state's proposal delineates how many slots it is setting aside for each emergency category, making only 525 – 600 slots available depending on the year, with 250 – 325 of those slots dedicated to moving people out of SGL settings. This is not adequate to meet the critical needs of Indiana's IDD community and will lead to more admissions to institutional placements. Individuals often are not given a meaningful choice in whether they get a CIH Waiver or are forced into SGL. Individual choice should be prioritized.

We are also puzzled by the added requirement and incurred expense to the waiver budget for a separate home modification assessment. This additional step by a separate company will add additional time to the process, delaying needed home modifications. Assessments have always been required, and we recognize that need. However, requiring and billing separately for an independent assessment may cause more harm by the delays and loss of other services than it helps. It is also unclear why this service, and very few others, prevents Powers of Attorney, Health Care Representatives, or guardians from providing this service.

We encourage that the allowable activities for Psychological Therapy include evaluations and assessments. From time to time, individuals need updated assessments to determine current levels of abilities, but these evaluations and assessments can be difficult to obtain and harder to obtain insurance or Medicaid coverage for when these assessments are for updates. While private insurance and state plan funding to cover the cost of evaluations and assessments should be pursued first, evaluations and assessments should be added as an allowable activity under this service.

Individuals with autism have difficulty accessing Applied Behavior Analysis (ABA) services, especially through state plan funding, due to long provider waiting lists, limited providers in many parts of the state, and provider implemented age limits. In addition, ABA services are only available under the state plan for individuals on the autism spectrum and no other disabilities despite the help it can provide individuals with other disabilities. We encourage the state to allow Intensive Behavioral Intervention (IBI) services for individuals of all ages and disabilities. We encourage the state to allow these services when individuals may be on waiting lists for ABA services and to supplement ABA services when those services are limited. We also encourage the state to allow these services based on the individual's behavioral needs, not a specific diagnosis. This will allow individuals who may not have an autism diagnosis to receive the services and supports they need.

The state's proposal for remote supports specifically mentions providing services to 14-17 year olds in addition to adults. We encourage the state to change that to include 13 year olds as well. Individuals who are 13 years old are teenagers and should also be learning appropriate independence skills. In addition, most childcare providers and childcare agencies will provide care through age 12. While remote supports are not meant to act as childcare, age 13 is a more age and developmentally appropriate transition and should be eligible to use this support as an option to encourage and facilitate greater independence.

Finally, parents and guardians of minor children were allowed to act as paid caregivers as part of the flexibilities put in place during the pandemic. This helped address the severe workforce shortage and ensured children received the care and support they needed. Because this was a pandemic based flexibility, the ability to pay parents of minor children has expired. Unrelated to the pandemic, the parents and guardians of minor children on the Aged and Disabled (A&D) Waiver were also allowed to become paid caregivers. Again, this addressed the severe workforce shortage. It ensured children with substantial medical needs received appropriate and consistent care, reduced hospitalizations, and decreased costs. It also provided increased economic stability for families. Because this was not a pandemic related flexibility, paying the parents of minor children on the A&D Waiver, soon to be the Health and Wellness Waiver, will continue.

The Arc of Indiana will monitor the continued success and impact of paying the parents of minor children on the Health and Wellness Waiver. We will also monitor the impact of ending payments to the parents of minor children on the Family Supports and Community Integration and Habilitation Waivers to determine if it is appropriate to reauthorize this payment structure.