

DATE: February 15, 2024

SUBJECT: Public Comments Regarding Request to Amend Indiana's Family Supports 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 IDD 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 Family Supports 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 appreciate the state's decision to create a priority category 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 would be more appropriate due to their likely higher level of need. We also recommend that this priority category be extended to individuals on the TBI Waiver who meet eligibility criteria for a Family Supports Waiver or CIH Waiver.

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 also appreciate the state clarifying some of the proposals set forth in the November 2023 amendment request such as vehicle modifications having a 10 year cap, not a lifetime cap and behavior support services allowing but not requiring individuals to address behaviors in the workplace as an option under this service.

There are several areas of the Family Supports Waiver proposed amendments that cause us concern.

We are very concerned that the state is only increasing the number of Family Support Waiver slots by fewer than 2,000 new slots each year. The advent of the BDS Gateway portal to allow individuals to apply for services online has been a great success, and the Bureau of Disability Services has acknowledged that approximately 7,500 people have applied through the portal each year since the online portal's implementation. This discrepancy between 7,500 new applications each year and only providing fewer than an additional 2,000 slots each year will lead to substantial waits for needed services and supports.

We recommend that the number of slots set aside for the priorities categories of 18-24 year olds who have finished school, and the children of active duty service members and veterans are inadequate as proposed. In the last 10 years, the state has made substantial improvements in reducing waiting times prior to the pandemic. We do not want the state to regress in these efforts going forward.

We encourage that the approved services 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 these assessments when it is 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 current Aged and Disabled Waiver and proposed Health and Wellness and PathWays for Aging Waiver offer a service called Caregiver Coaching. 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 recommend adding this service to the Family Supports Waiver.

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 lower that to age 13. Individuals who are 13 years old are teenagers and should be learning appropriate independence skills. In addition, most childcare providers and childcare agencies provide care through age 12. While remote supports are not meant to act as childcare, age 13 is a developmentally appropriate age to begin to encourage and facilitate greater independence. Eligibility for remote supports would help facilitate this process.