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March 18, 2026

Public Comments Submitted by The Arc of Indiana

Traumatic Brain Injury Waiver Proposed Amendments

Opening Comments

The Arc of Indiana is a state-wide organization that advocates for the issues important to people with intellectual and developmental disabilities (IDD) and their families. Our mission is to ensure that people with IDD realize their goals of living, learning, working, and fully participating in their communities. With 41 local chapters covering 65 counties and a strong statewide membership, The Arc of Indiana has been a cornerstone of advocacy since its founding in 1956 by parents seeking a better and more accepting world for their children. Today, our combined efforts at the local, state, and national levels make The Arc the largest national community-based organization leading this work.

We are proud to be celebrating our 70th Anniversary. With over seven decades of experience and insight, we have learned valuable lessons that offer context to our comments on the proposed amendments to the Traumatic Brain Injury (TBI) Waiver.

While we understand that the state administration is concerned about the growth of Medicaid spending, Hoosiers, including those with disabilities, are living longer. This demographic reality requires intentional long-term planning and investment. While plans should already have been put in place to address this growing, vulnerable population, amendments to Indiana's Medicaid Waiver program provide an opportunity to "get it right."

The Arc is committed to ensuring that people with IDD have access to services in their local communities and are not forced into institutional care. When Indiana committed to closing state institutions and investing in home and community-based services, it absolutely made the right decision. We need to build on what we know is best for people with IDD and their families. This amendment should reinforce, not weaken, that commitment. We cannot go back. We must move forward.

Throughout our comments, you will see that The Arc strongly believes there is room for improvement in all areas of Medicaid oversight. There is a need for transparency by both the state and provider network so that those utilizing services can be good stewards of those services and the overall Medicaid program.

The Arc of Indiana is an organization that advocates not just for those receiving services in our state, but also for the thousands of people now on Medicaid Waiver waiting lists. We support the philosophy of people utilizing the services they need to meet their goals and desired outcomes, rather than being encouraged to choose services that maximize their waiver budget but may not add true value to their daily lives. A value-based, person-centered approach should guide all waiver decisions.

This approach will take time, and everyone involved in Medicaid will need to play a role. The Arc of Indiana is committed to being a partner in this effort.

The state also needs to recognize FSSA's current bandwidth to administer these programs. The state has not invested in growing human resources to meet the demand for services over the last three decades. The Arc strongly recommends an assessment of the manpower needed to create person-centered efficiencies, rather than broad-based cuts or elimination of services. This will make the program more effective for those who rely on it. The state must update its infrastructure so that the full cost of caring for people is known. Without this, policy decisions risk being driven by incomplete or inaccurate data. The state must partner with families, people with disabilities, advocates, and quality providers to include their recommendations on where true efficiencies lie.

With these thoughts in mind, The Arc of Indiana submits the following comments on the proposed TBI waiver amendments.

Waiver Alignment

As the Health & Wellness and Traumatic Brain Injury waivers have transitioned to the Bureau of Disabilities Services, we appreciate the steps the state has taken to align services and philosophies to ensure consistency and avoid confusion.

We appreciate the state defining terms such as "relative" and "own home" the same way across all waivers. We appreciate aligning service definitions so they are consistent across waivers.

We appreciate the state's dedication to ensuring services and supports are person centered and focused on helping individuals achieve their vision of a good life. By incorporating the LifeCourse Framework and the Person Centered Individualized Service Plan (PCISP) into the TBI Waiver, the state reinforces a consistent, person-centered approach across waiver programs.

We are happy to see the waiver ombudsman added to the TBI Waiver. The ombudsman serves a critical role in helping individuals and families navigate complex systems, resolve concerns, and ensure their voices are heard. This addition will provide meaningful support to waiver participants and their families.

Case Management

We appreciate the expanded role case managers will play under this amendment. Case managers have the unique ability to provide objective oversight to ensure individuals receive the services they want, ensure they are provided appropriately and in compliance with regulations, and ensure changes to services and supports are facilitated as needed.

Although the primary role of a case manager is to serve the waiver participant, they also play an integral part in preventing waste, fraud, and abuse, and should report such actions appropriately.

Case managers need to ensure waiver participants and their families fully understand individual waiver services, including what is and is not allowable under that service, as well as available alternatives.

Waiver participants and their families also need a better and more thorough understanding of the full array of waiver services available to move toward their vision of a good life. Case managers are essential to this effort.

We also appreciate the expanded role case managers will play in investigating incident reports, complaints, and grievances. With their increased participation, it is our hope that individuals and families feel respected and supported in difficult situations.

Case managers are also tasked with monitoring Medicaid redeterminations and facilitating redeterminations as needed. We recommend an expansion of that role. Many waiver participants do not have people in their lives who can help with Medicaid redeterminations, SNAP, and other benefits. Many individuals need more hands-on assistance to complete these processes to maintain eligibility, including support in filling out applications and in gathering and submitting information. Many individuals do not understand and are confused by Medicaid's expectations. Case managers should take a more active role in helping waiver participants maintain their Medicaid and other public benefit eligibility.

Documentation

The Arc applauds the state's increased documentation requirements. While additional documentation can be burdensome, these standards are thoughtful and relevant. It will allow the state to more closely monitor services to ensure regulatory compliance, reduce inappropriate services and billing, and identify and deter bad actors. The additional documentation can be used to monitor and report progress.

In this amendment proposal, the state removes the requirement that providers document one positive event during the delivery of service. We very much liked that requirement as it helps focus on the individual's abilities and strengths. We encourage the state to reincorporate that requirement in the documentation standards. We also recommend that waiver participants, their families, and guardians regularly receive copies of progress reports and service utilization, including clear, understandable summaries of cost utilization.

Behavior Support Services

We appreciate the state allowing Behavior Support Services supervision while other direct services are being provided to ensure a full integration of services and supports.

Fiscal Responsibility

The Arc of Indiana recognizes the state's desire to provide high-quality services in a fiscally responsible, efficient, and sustainable manner. With that in mind, we recommend the following:

Billing Transparency

It is important to ensure that waiver participants are receiving the services they need and that those services are being provided in an appropriate manner. It is also important to ensure that the state is being billed correctly for the services being provided. Waiver participants and their families can help in the good stewardship of waiver dollars.

We recommend that waiver participants and their families receive monthly billing and service utilization reports in a format that allows them to meaningfully review and confirm services billed. Providing this information in plain language will be critical to ensuring it is usable and effective.

This oversight and stewardship will help reduce waste, fraud, or abuse. We also recognize mistakes can happen; providers should have a period of time to correct any inaccurate billing or provide additional information that may be appropriate in the situation.

Waiver Setting

The state has reported there have been situations in which a waiver service has been provided in settings or in a manner that is not allowed. While such situations may have been unintentional, they do need to be corrected.

We recommend that when such a situation arises, the waiver participant's entire Individual Support Team convene promptly to review the situation. This could include a clear determination of whether the issue was a compliance concern, a service delivery issue, or a misunderstanding. Further, the team should discuss what, if any, changes should be made to ensure services are in compliance and determine if a different service would be a more appropriate way to provide the support. This will help ensure compliance with state and federal regulations, and it will ensure waiver dollars are being used most appropriately and effectively.

Waiver Ombudsmen

We recommend that the Waiver Ombudsman Annual Report be made public with personally identifiable information redacted.

Electronic Visit Verification

Electronic Visit Verification (EVV) has been in place for several years, and it has helped reduce questionable service delivery. However, parts of Indiana are still quite rural and have unreliable internet access. Weather and emergencies can also inhibit EVV's efficacy. The state should develop an alternate verification system when EVV is unavailable.

Incident Reports, Complaints, and Grievances

When problems occur, and an incident report, complaint, or grievance is filed, the waiver participant must be at the center of any investigation, and the process should be timely and transparent. We highly recommend a slightly altered investigation procedure.

- State investigators should start by talking with the reporting party to make sure the state understands what is being reported and has the opportunity to ask clarifying questions.
- Next, we recommend the state, when appropriate, speak directly with the individual(s) at the heart of the report to hear the individual(s) perspective about what occurred and any impact the alleged incident may have had on the individual(s).
- After gathering those facts and perspectives, the state should engage the provider agency to understand its perspective on the situation, including any corrective action the agency may have taken to address the situation.
- The state should then follow up with the individual(s) and the reporting party to determine what happened and how the situation should be addressed.

- Finally, all relevant parties – including the reporting party, the individual(s), their legal guardians (if applicable), family members as appropriate, and the support team – should receive a clearly written summary of findings and outcomes.

Waiting List

The TBI Waiver did not have a waiting list until August 2025. With so few slots available on this waiver, it is even more important to reduce this waiting list as quickly as possible to ensure people are able to get the services and supports they need.

Waiting List Invitations – Timeline for Eligibility

When an individual is invited off the waitlist to begin receiving waiver services, they have 180 days to have Medicaid health coverage, case management, and an initial Notice of Action in place; otherwise, the individual's invitation onto the waiver will be rescinded.

When this limitation was put in place, it seemed like a reasonable requirement and timeline. However, since this was implemented, people have been experiencing more problems getting Medicaid health coverage in place in a timely manner.

Medicaid Health Coverage processes are taking longer to evaluate an individual's eligibility.

Due to the Special Income Limits that apply to waiver participants, errors in eligibility determinations have increased. An increase in administrative barriers is making this timeline requirement harder to satisfy. We agree that 180 days under normal circumstances would be sufficient; however, inadequate staffing and/or procedures are causing hardships. We recommend reviewing this and putting in place the appropriate resources. Individuals should not lose access to services due to administrative delays outside of their control.

We recommend either increasing or pausing this timeline until eligibility processing stabilizes. Individuals should not lose access to services due to administrative delays outside of their control.

Paid Caregivers

For more than a decade, HCBS services have experienced such a serious workforce shortage that it has been repeatedly referred to as a workforce crisis. Despite efforts to increase direct support professional (DSP) recruitment, create DSP career pathways, and professionalize DSP careers, Indiana still finds itself with a deficit of DSPs.

We are concerned that the proposed limitations on relatives and legal guardians as paid caregivers move in the opposite direction of addressing the ongoing workforce shortage.

With appropriate documentation, oversight, and case management, these caregivers can provide stable, high-quality supports and remain a key part of the workforce solution.

Family caregivers are often the most stable and reliable members of the workforce. Policies should recognize this reality rather than restrict it.

Live-In Caregivers

The proposed amendment would reduce the reimbursement rate for live-in caregivers. Live-in caregivers provide the same services and supports as non-live-in caregivers.

We understand that the rate methodology may appropriately account for differences in costs, including transportation, that are not incurred by live-in caregivers. To the extent live-in arrangements reduce certain provider costs, a differentiated rate may be justified.

At the same time, any rate adjustment should be carefully calibrated to ensure it does not unintentionally discourage live-in caregiving, which can provide stability, continuity of care, and strong outcomes for individuals.

We encourage the state to ensure that the rate remains sufficient to support recruitment and retention of qualified caregivers, including family caregivers, while appropriately reflecting differences in cost structure. Rates should be equally fair to a caregiver who lives in the home and a caregiver who lives outside the home.

Reasonable Accommodations and Supports

Individuals with disabilities can request and use a wide array of reasonable accommodations and supports aside from waiver services, including support in accessing resources, gathering information, and making decisions. We applaud the state's efforts to ensure individuals in waiver services are exercising self-determination. However, there are times when individuals need and request supports from trusted individuals, including those acting under a power of attorney (POA) or other supported-decision making. Current policy has led to denials of these requests.

While not directly related to the waiver amendments, this issue underscores the need to increase transparency in the waiver program. If an individual or their family believes it would be beneficial to have these supports, we believe the request should be honored. Among other things, it will provide an additional person who can be aware of service provision and appropriate billing. In addition, these supports are far less intrusive than guardianship. Rather than denying supports, efforts should be made to encourage supported decision-making in conjunction with the supports.

LRIs

On December 31, 2025, the state allowed Legally Responsible Individuals (LRIs), defined as a spouse of a waiver participant or the parent of a minor child waiver participant, to be a paid caregiver for certain services through the waiver if the waiver participant needed extraordinary care under that state's definition of extraordinary care. However, the current definition of extraordinary care only focuses on physical health needs. Behavioral health challenges can also lead to extreme need and prevent the individual from accessing supports or receiving supports or services due to extreme behavioral health needs. We recommend that the state adjust the definition of extraordinary care to include not only intensive nursing needs but also intensive behavioral needs.

Service Caps

Benefits Counseling was added as a waiver service option, but it has been capped at 6 hours per year. While this limit should be enough for most individuals, we recommend allowing additional hours as needed, with BDS approval when someone has experienced a change in employment.

MED Works

Individuals with disabilities are capable of many things, especially with appropriate supports. In particular, individuals with disabilities are incredible employees. They contribute to the economy, improve businesses, and increase production value. The state has rightfully adopted a variety of regulations and supports that make it easier for individuals with disabilities to work.

No program embodies that dedication to employment opportunities more than MED Works, a category of Medicaid for employees with disabilities. This program is a success under several metrics.

We are concerned that the waiver amendment references a 2-year lockout period for individuals on MED Works who do not pay their premiums.

Managing finances and paying bills is often a support that individuals with disabilities need, including supports to ensure MED Works Premiums are paid. We recommend adding Auto Bill Pay to MED Works as a reasonable accommodation and removing the two-year lockout. The lockout creates a barrier to employment, which is contrary to the purpose of the program.

We support additional service adjustments:

- Speech therapy should include general speech and communication issues, including but not limited to answering questions, working on multi-exchange conversations, etc.
- Home modifications should allow more than one exterior door modification, one ramp, and one door opener. This is a safety concern to prevent being limited to only one safe, accessible way in or out of a home, especially in fire emergency situations. Housing codes specifically require multiple modes of egress. This is a basic safety requirement. This should also include accessible entrances and exits to a home. In addition, individuals should also be allowed to upgrade from basic modifications at their own expense.
- Specialized medical equipment and supplies should also include electronics, subscriptions, exercise equipment, and recreational equipment if they provide therapeutic, life, or social benefit. Technology is constantly evolving. Many supports now rely on electronic platforms or subscription-based services. Waiver policy should reflect modern service delivery models. That support should be available on an ongoing basis, as part of an individual's regular budget, if the supports benefit the individual.
- Vehicle modification maintenance should be allowed regardless of the original funding source. If an individual received the original vehicle modification from another source, such as a community foundation, community fundraising, or some other source, the need for maintenance isn't tied to the original funding source. The need for maintenance is universal and directly impacts a person's ability to access the community and participate in life. Therefore, vehicle modification

maintenance should be available to waiver participants, with the existing limits, regardless of the original vehicle modification funding source.

Finally, we support adding the following services:

- Career Exploration and Planning
- Day Habilitation
- Family and Caregiver Training
- Music Therapy
- Recreation Therapy
- Workplace Assistance
- Services to help individuals access and fully participate in the community. These services should allow individuals to engage in self-advocacy, community engagement, civic engagement, and social and spiritual activities.