Disability Rights Arkansas

Dignity. Respect. Advocacy.

Tom Masseau, Executive Director

May 27, 2022

Melissa Weatherton, Director
Division of Developmental Disabilities Services
Arkansas Department of Human Services
Via E-mail: ORP@dhs.arkansas.gov

Re: Comments regarding proposed amendments to the CES Waiver

Dear Director Weatherton,

Disability Rights Arkansas, Inc. (DRA) is the federally authorized and funded nonprofit organization serving as the Protection & Advocacy System for individuals with disabilities in Arkansas. DRA is authorized to advocate for and protect human, civil, and legal rights of all Arkansans with disabilities consistent with federal and state law.

I am writing on behalf of DRA to submit this letter with our comments to the State's proposed amendments to its 1915(c) Home and Community-Based Services Waiver.

Some of the amendments, we appreciate, particularly the clarification of supervision and monitoring as a necessary and reasonable service that will permit individuals to live in community settings. However, we are very concerned about the expansion of group home settings from four bed to eight beds. Given that it is purportedly in response to pandemic-related needs, we question whether such a permanent solution is necessary or positive for individuals otherwise eligible to live in community settings. We regret the lack of strict parameters to ensure such a move is justified and extremely limited and believe this could impair individuals from exercising a meaningful choice to live in community settings in its current form.

The comments are organized into three parts. The first part concerns overall clarity of the amendments and possible formatting errors that could create confusion. The second part goes through the delineated modifications that are identified on page 1 of the amended application. The final part addresses areas not identified on page 1 but are modified by the proposed amendment. For ease of reference, when page numbers are identified in this document, it refers to the pagination of the waiver amendment document that shows tracked changes.

Comments overall regarding formatting and clarity:

The modifications to the waiver application in some places are formatted in a way that is unnecessarily confusing.

One example is the Level of Care Criteria. Delineating the level of care criteria as it appears on page 38-39 of the amendment that each of numbers 1-12 apply to every individual in every case; however, that is inconsistent with how DDS regulation 1035, the federal regulations, or the state law define eligibility. Some of the elements apply only to individuals who have not been diagnosed with one of the categorically qualifying diagnoses but have been diagnosed with a condition that causes similar impairments to intellectual or adaptive functioning as an intellectual disability. As a result, it overcomplicates eligibility and level of care determinations in a way that governing laws and regulations do not permit.

At various places throughout the application, the boxes do not display all of the text. This complicates the opportunity to review and comment on what text is being modified. An example of this is on page 53, Appendix B-7.a. In other locations, boxes have apparently been modified to display text that would otherwise disappear, such as on page 55, Appendix C, "Service Definition" for "Caregiver Respite." In the current state of the proposed amendment, we are unable to ascertain what else has been excised from sections, if anything. Public comment would be best served by permitting individuals to see the entire scope of proposed changes to the waiver application before modifications.

Finally, perhaps simply an editing error, numbering throughout the application is inconsistent and confusing. An example of this is page 60, Appendix C, "Other Standard" for "Supported Employment." The proposed language as written reads:

> "Must be:
> Credentialed by the PASSE to provide HCBS services to persons with Developmental Disabilities and Behavioral Support Needs.
> (4) Permitted by the PASSE to perform these services.
> (5) Cannot be on the National or State Excluded Provider List.
> Individuals who perform respite services for the PASSE must pass a drug screen, a criminal background check, a child maltreatment registry check, and an adult maltreatment registry check, and
> 3) Have a high school diploma,
> 4) Have at least one year of experience working with persons with developmental disabilities or behavioral health diagnoses; or complete a session on incident reporting, abuse and neglect identification and reporting, overall training on IDD diagnosis, as well as client specific training on diagnosis and behavioral support needs.

3)Be certified to perform CPR and first aid"

Clarity and transparency of modifications is extremely important to allow for adequate constructive notice. Further, clarity in the final application is not without regulatory effect. It is extremely important that individuals be afforded some measure of predictability in areas such as eligibility for both the waiver program and the individual services it authorizes. Please modify the application to ensure clarity and consistency where possible and extend the opportunity for public comment when those changes are made.

Modifications identified by State's page 1:

The application indicates it is adding new services of both "HCBS Supervision and Monitoring" as well as "HCBS Enabling Technology"

HCBS Supervision and Monitoring:

We are grateful for clarification of the vital role that supportive living services can provide through supervision and monitoring. We have seen individuals experience a reduction in authorized supportive living due to a misunderstanding of whether supportive living may provide overnight assistance while a beneficiary is asleep. As a result, individuals were potentially exposed to dangerous circumstances. That said, we would appreciate clarification regarding this service. On page 88, the service is defined as permitting delivery within a beneficiary's "own home," which is a home that is not licensed or operated by another entity. This is extremely unclear. How can a home not be operated by another entity? An entity other than what? Does this definition exclude delivery of this service to an individual who lives in an apartment owned by an HCBS provider?

In the same box, the definition permits assistance with "evening and nightly routines." This service originally was proposed to offer overnight assistance; however, "overnight" is deleted in the final proposal. Is there a reason monitoring and supervision cannot assist with daily or morning routines if the service is not restricted to overnight?

The definition also allows support to be provided either one-to-one or in a group. Is there any limit on how large the group should be? We are concerned that the effectiveness of the service could be drastically reduced if left with this ambiguous description. When reading this in conjunction with the following sentence authorizing the use of technology with this service, it would seem to permit a single support staff to provide this service to an entire apartment complex at one time through remote monitoring. Some limitation on how many individuals may be served would provide more clarity and predictability in the authorization of this service.

There is also no distance requirement for the provision of technology supporting monitoring and supervision. Would this permit an individual to monitor a service recipient from a remote location or even from another state? We believe this would greatly reduce the positive impact of this service and create potentially unsafe conditions for individuals.

Finally, the definition requires an "Assessment for Remote Support Services." The assessment is not defined or otherwise described in this document. Is this a standardized assessment to be uniformly used by the PASSEs when evaluating this service? Who administers this assessment? Why is there no other mention of it in the entire waiver application?

HCBS Enabling Technology:

This service has both good and bad potential. On one hand, it would be a valuable way to provide an individual with more opportunities for independence. We are aware of individuals who do not want staff in their home every hour of every day. If able to safely do so, this would permit some individuals with privacy they might not have previously experienced. However, the service would be improved with clarity regarding preference.

There are two different sets of requirements that are similar. Does enabling technology differ from monitoring technology? Is monitoring technology a form of enabling technology? We appreciate the apparent opportunity for the member to veto the use of enabling technology; however, its importance is minimized by placing the member's preference in parentheses within another requirement. Is a guardian permitted to authorize the use of this technology over a member's objection? What if the individual is not able to express a preference?

Meanwhile, if it is a different service, monitoring technology must be the least restrictive option and "the person's" preferred method to meet an assessed need. Logically, "person" should refer to the "member" or "someone who receives HCBS waiver services" or any other way a waiver participant is described in the application. Does this permit an individual's guardian to reject the use of enabling technology if it is not their preference? Would they be permitted to do so over the member's objection? Why does this section refer to "person" instead of something more descriptive?

The service also requires providers to treat the data collected by technology consistent with HIPAA but does not otherwise restrict how much of this data may be collected by the PASSEs or providers. Further, what happens to data gathered, if any, by such monitoring?

Finally, the addition of this service fails to address the recent study commissioned by the state which showed the state has about 110,000 underserved households when it comes to broadband, which translates to huge swaths of the rural areas of the state. While the governor has suggested addressing this in a special session in the next couple of months it will still take time for that infrastructure to be put in place, which will delay implementation of a lot of the enabling technology initiatives.

Removed restrictive language on who can receive Respite and where.

We are not sure why the state removed restrictions on where respite services may be provided. Is there a particular place that was not previously authorized that is targeted by this modification? If so, could that have been achieved by adding those places to the list without removing all restrictions on locations?

"Respite services are not to supplant the responsibility of the parent or guardian," is a sentence that should be modified. Natural supports must be voluntary pursuant to 42 C.F.R. § 441.540(b)(5). The suggestion that parents or guardians bear responsibility for support when staff are not available is equivalent to authorizing natural support under duress - that is not voluntary.

Permanently adding training requirements for direct support professionals in lieu of one year experience

The alternative to one year of experience proposed by the state is unclear. Under the alternative, one must "complete a session on incident reporting, abuse and neglect identification and reporting, overall training on IDD diagnosis, as well as client specific training on diagnosis and behavioral support needs." What is a "session?" Who will provide this session? Is it an online module the state offers, or an in-person class taught by a service provider? Are there qualifications for who may conduct this session?

Increased the Group Home bed capacity from 4 to 8 to address trends in institutionalization we are seeing due to pandemic and workforce shortage.

We have great concerns about the state's reliance on institutional settings to meet individuals' needs. The state should be moving toward smaller settings, and this reflects a commitment in the opposite direction. Further, compliance with the settings rule might not be possible with some four-bed group homes, making it even less likely when increased to eight beds. The modification appears to permit current four-bed facilities to simply add beds without increasing space. We are concerned that this will happen against individuals' wishes and without faithful observation of individual preferences unless the state firmly and clearly requires it.

As it stands, the workforce needed to remedy the dearth of supportive living services in the state are able to work in lower demand, higher wage positions. Until the state expresses a commitment to remedying the problem causing the void that currently exists, it is of no consequence that the waiting list is eliminated. The state must commit to ensuring waiver support staff positions are attractive. Increasing the size of group homes should not be the solution. Further, permitting this permanent shift in response to the pandemic should be supplied with appropriate guardrails or a sunset if it is sincerely intended to be temporary.

The state must consider applying limits to when or why providers would expand from four beds to eight. It should require some evidence of knowing consent by the individual to live in that environment, how their individual needs will be met, and some way to ensure more individual choice or autonomy if forced into that setting. In addition, some individuals will naturally do far worse with more roommates, so additional protections should be considered to prevent larger settings from increasing the risk of institutionalization. More effort should be focused on protecting smaller settings where needed to ensure availability of such settings.

Finally, why isn't the state similarly devoting resources to increase the physical availability of more independent individualized settings at the same time? Expanding group home sizes does nothing to address staff shortages, without which the likely scenario is that people will be funneled into the group homes or other institutions. Further, eliminating the waiting list, while a worthy endeavor, will be meaningless if individuals are not provided the services, they need to live to live in community settings. The PASSEs have returned millions of dollars to the state that they have not spent on individual services. The state should consider how it is using the returned funds and whether it would better serve the community of waiver recipients to invest it into improving and increasing the workforce supplying these services.

With the state budget surplus expected to reach 1.47 billion dollars by the end of this fiscal year on June 30, now would be a great time to commit to things like funds to address the staffing shortage and broadband infrastructure to make use of enabling and other technology.

Streamlined "crisis plans, safety plans, behavioral support plans", in order to use consistent language across the PASSE program/Using the terminology Behavioral Prevention and Intervention Plans and clarifying that they are the responsibility of the Supportive living providers.

We understand that clarification was necessary regarding crisis planning, behavior support, etc.; however, we are concerned that the result does not resolve issues that will still exist.

On page 77 the proposed modification adds:

"The PASSE is responsible for developing a Risk Mitigation Plan for each client that outlines risk factors and action steps that must be taken to mitigate the risk. CES Waiver clients who are at risk of displaying behaviors that can lead to harm to self, and/or community members must have a Behavioral Prevention and Intervention Plan that is overseen and implemented by the client's supportive living provider. The goal is to keep the member in his or her place of residence and avoid an acute placement. Supportive Living Staff developing, overseeing, and implementing Behavioral Prevention and Intervention Plans must receive training in verbal de-escalation, trauma informed care, verbal intervention training,"

It also says: "Screening, assessing and developing positive behavior support plans; assisting staff in implementation, monitoring, reassessment and plan modification; allowable providers: psychologist, psychological examiner, Positive Behavior Support (PBS) specialist, and Board Certified Behavior Analyst (BCBA) within the scope of their practice area."

Now, on page 117, it says, "Supportive Living providers must develop and implement Behavioral Prevention and Intervention Plans to address behavioral risks identified in the client's Risk Mitigation Plan performed by the PASSE. The specific details of the Behavioral Prevention and Intervention Plan are outlined in the service description under the service Prevention, Intervention and Stabilization."

It would seem that these are two very different things. Are they exclusive of each other? Why are the supportive living providers not utilizing the professionals identified in the earlier section for developing behavior interventions?

<u>Areas not identified on page 1:</u>

We are concerned that modifications to the level of care criteria and significant reductions to provider obligations regarding the use of restraint and other interventions were not expressly identified as amendments to the waiver.

Level of Care Criteria

It is possible that the formatting of page 38-39, Appendix B-6.d. leads to a misunderstanding of this amendment; however, it its current form, it evidently modifies the level of care criteria from what it has consistently been in state and federal laws and regulations.

First, the amendment adds the requirement that an individual "would be institutionalized in an ICF/IID in the near future, but for the provision of CES Waiver

services." This is not apparent in any of the cited policies, regulations, or laws from which it purports to derive. This is an extremely ambiguous and subjective phrase that could be used to exclude individuals simply because they or their families are committed to living in a community setting. It is unnecessary, extraneous, and should be removed.

Second, as discussed previously in these comments, DDS regulation 1035, the federal regulations, and state law define eligibility differently. As currently written, eligibility would require every individual to consistently exhibit scores of intelligence two or more standard deviations below the mean.

If this is the intent, it does not rely upon criteria and standards for ICF/IID facilities admission. According to federal regulations applying to ICF/IID facilities, a developmental disability includes a related condition defined as "[a]ny other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of [individuals with intellectual disabilities], and requires treatment or services similar to those required for these persons." 42 C.F.R. § 435.1010 (emphasis added).

Arkansas Code Annotated, § 20-48-101, which is cited in the Request, is consistent with these federal regulations. This statutory section includes a definition of developmental disabilities that includes not only the five categorically eligible diagnoses but also includes an "other" category for a condition that is closely related to an intellectual disability that results in "an impairment of general intellectual functioning or adaptive behavior similar to that of a person with an intellectual and developmental disability or requires treatment and services similar to that required for a person with an intellectual and developmental disability." (emphasis added).

Like Federal law, Arkansas state law does not require that an individual have both a categorically qualifying diagnoses and significant adaptive behavior deficits. DDS Policy also does not define eligibility criteria as narrowly as what is described and proposed in this amendment. DDS Policy 1035 provides that an individual with an impairment in intellectual functioning or adaptive behavior can be eligible.

What appears to be missing from this section is the clarification that exists in DDS Policy 1035, which states:

> "In the case of individuals being evaluated for service, eligibility determination shall be based upon establishment of intelligence scores which fall two or more standard deviations below the mean of a standardized test of intelligence OR, is attributable to any other condition found to be closely related to an intellectual disability because it results in

impairment of general intellectual functioning or adaptive behavior similar to those of persons with an intellectual disability, or requires treatment and services similar to those required for such persons."

We would appreciate consistency in this description, as it could greatly impact access to services for children with traumatic brain injuries or other conditions that might result in significant deficits in adaptive behavior, but who might have borderline intelligence scores. The state should modify this section to reflect DDS Policy 1035, Arkansas Code Annotated, § 20-48-101, and 42 C.F.R. § 435.1010.

Use of restrictive interventions and restraint

We are particularly concerned about the quiet removal of the following language from pages 145 and 148:

> "DDS requires that, before a provider may use any restrictive intervention[1], they must have developed alternative strategies to avoid the use of those interventions by developing a behavior management plan which incorporates the use of positive behavior support strategies as an integral part of the plan. The plan must:
>
> 1. Be designed so that the rights of the individual are protected,
> 2. Preclude procedures that are punishing, physically painful, emotionally frightening, involve deprivation, or puts the individual at medical risk,
> 3. Identify the behavior to be decreased,
> 4. Identify the behavior to be increased,
> 5. Identify what things should be provided or avoided in the individual's environment on a daily basis to decrease the likelihood of the identified behavior,
> 6. Identify the methods that staff should use to manage behavior, in order to ensure consistency from setting to setting and from person to person,
> 7. Identify the event that likely occurs right before a behavior of concern,
> 8. Identify what staff should do if the event occurs,
> 9. Identify what staff should do if the behavior to be increased or decreased occurs, and
> 10. Involve the fewest interventions or strategies possible."

[1] As on page 148; on page 145, "restrictive intervention" is replaced by "physical restraint."

The removal of this is not clearly identified on page 1, unless it is an intended part of streamlining 'crisis plans, safety plans, behavioral support plans' or clarifying that behavior plans are the responsibility of supportive living providers.

While we understand the need to clarify or assign responsibility for such plans, we do not understand why the state would eliminate the specific elements that must exist in such plans. Further, the elimination of specific plan requirements does not require the state to eliminate the obligation to develop a plan before using restrictive interventions or physical restraint. We would greatly appreciate the state maintaining these or similar requirements of providers.

Conclusion

Strengthening and improving access to HCBS services must be a priority in Arkansas to ensure that the State is not only serving but adequately serving individuals with developmental disabilities who desire to live in the community as opposed to institutions.

Sincerely,

Tom Masseau
Executive Director