Disability Rights
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Washington's protection and advocacy system

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Evelyn Perez
Assistant Secretary
Developmental Disabilities Administration
Department of Social and Health Services

Dear Assistant Secretary Perez,

Thank you for the opportunity to provide comments to the proposed amendments to the Home and Community Based Services (HCBS) waivers administered by the Developmental Disabilities Administration (DDA). As detailed in these comments by Disability Rights Washington, the Arc of Washington State, the Developmental Disabilities Council, Sirianni Youtz Spoonemore Hamburger, and Northwest Justice Project, we have concerns that the proposed amendments will result in harm to waiver participants' health and welfare and place them at increased risk of institutionalization. We are writing to urge reconsideration and explain why these proposed amendments should not be adopted.

During the Summer of 2018, many stakeholders across the state participated in meetings with DDA regarding these proposed amendments. The DDA presentations about proposed changes to the waiver suggested changes to replace Positive Behavior Support and Consultation (PBSC) with four distinct services: 1) Specialized Habilitation, 2) Extended Behavioral Health, 3) Protective Community Services, and 4) DDA Stabilization Services.[1] DDA noted that stakeholders requested that DDA ensure Specialized Habilitation Services be available on the Core Waiver.[2] However, in its proposed waiver amendments, DDA did not incorporate this feedback, or include all of the new services that DDA presented to stakeholders. Although the proposed amendments will phase out PBSC from all waivers, these amendments do not include Specialized Habilitation for the Core waiver as stakeholders recommended, and do not include Extended Behavioral Health services that were presented in the Summer Stakeholder meetings. The proposed amendments to the CIIBS waiver also include a new individual cost limit, which DDA also did not discuss in the Summer 2018 presentations.

These proposed amendments to phase out PBSC should not be approved due to DDA's refusal to add Specialized Habilitation services to the Core Waiver, exclusion of Extended Behavioral

[1] *See* "DDA Home and Community Based Services (HCBS) Waiver Amendments Stakeholder Input," attached hereto as Exhibit 1 at p. 4.
[2] *See* "Summary of Stakeholder Input." available online at https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/Stakeholder%20Input%20Summary%20to%20HCBS%20Waiver%20Amendments%20August%202018.pdf (last visited 2/13/19).

Health services from all waivers, and the new individual cost limitation. These changes will increase the risk of institutionalization and the demand for out of home placement resources that are already all too scarce and difficult for many individuals to access. Even with available funding, the out of home and crisis provider capacity is too limited to even satisfy the current demand. [3] If approved, these proposed amendments will reduce access to the services that many individuals rely upon to live safely in the community, thwarting the fundamental purpose of the HCBS waivers.

Core and CPP Waivers Exclude Specialized Habilitation Services.

If PBSC is phased out from all waivers, excluding Specialized Habilitation as a non-crisis service from Core and CPP waivers will jeopardize the stability of participants on these waivers. Without PBSC, some Core waiver participants will have no access to ongoing non-vocational[4] related habilitative services to help them continue gaining skills to be more independent in everyday activities. Although many Core waiver participants may be receiving residential habilitation services, the Core waiver eligibility requirements also allow enrollment for individuals who are at risk of out of home placement.[5] Without Specialized Habilitation services or PBSC, individuals living at home with family or other natural supports will not be able to access direct services to assist them in learning various social and independent living skills unless they are enrolled on one of the other waivers. Enrolling on a different waiver that would offer Specialized Habilitation services may not be a suitable solution because the other waivers, unlike the Core waiver, include or, are proposed to include cost limitations. Thus, individuals with more intensive or longer term needs that exceed the service amount caps will be at even greater risk of needing out of home or crisis services to meet their needs.

In addition, even if the scope of Specialized Habilitation services is similar to the scope of Residential Habilitation, the current Core and CPP waivers have no restrictions that limit access to PBSC by individuals receiving Residential Habilitation.[6] Additional habilitative supports provided under the current PBSC services that supplement Residential Habilitation services should continue to be available to address the needs that the residential providers may not be equipped to meet. Providers have repeatedly stressed that the current rates are inadequate to

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[3] The lack of available crisis and residential resources has been well documented in reports by Office of Developmental Disabilities Ombuds (ODDO): "Diverting Crisis – Maintaining housing and supports for people with developmental disabilities" (hereinafter "Diverting Crisis") available online at https://ddombuds.org/wp-content/uploads/2018/05/Diverting-Crisis-Final-5.8.18.pdf (last visited 2/13/19) and "Stuck in the Hospital," available online at https://ddombuds.org/wp-content/uploads/2018/12/DD-Ombuds-Hospital-Report-12.10.18-Final.pdf (last visited 2/13/19).

[4] Vocational habilitation services are highly limited in amount and scope, and do not address the skill sets targeted by PBSC or Specialized Habilitation services, which focus on improving social skills and promoting higher levels of functioning in any environment.

[5] The current Core waiver includes individuals who "require residential habilitation services ***or live at home*** but are at immediate risk of out of home placement due to one or more of the following extraordinary needs: *The individual has extreme and frequently occurring behavior challenges resulting in danger to health or safety or *Has had 18 or more days of inpatient psychiatric care in the past 12 months or *The individual lives in an ICF/IID and requests community placement or *Requires daily to weekly one-on-one support, supervision and 24-hour access to trained others\ to meet basic health and safety needs." October 15, 2018 Core Waiver Application at p. 35 (emphasis added).

[6] October 15, 2018 Core Waiver Application at pp 128-129; CPP Waiver Application at 104-105.

address many client needs currently assigned to them.[7] Expecting residential habilitation providers to meet additional complex behavioral support needs that currently could be better supported through supplemental PBSC amounts to an expectation for additional uncompensated supports that providers will not realistically deliver.

There is already a severe problem of DDA clients having services terminated by residential providers.[8] Removing PBSC as a resource for Core and CPP waiver participants without making an adequate substitute available will only make this crisis worse.

All Waivers Omit Extended Behavioral Health Services.

The proposed amendments to all waivers also omit the Extended Behavioral Health services that were discussed during the Summer 2018 stakeholder meetings. According to the presentations given this summer, DDA recognized that PBSC were meeting behavioral health needs that are unmet under the state plan. DDA explained that it would be adding a new service, "Extended Behavioral Health" to "focus on rehabilitation" and would be "[f]illing in the Gap if a person is not eligible for State Plan Benefits."[9] These services would include individual and group therapies, as well as other mental health treatments that would otherwise be unavailable on the state plan.[10]

In the proposed waiver applications, DDA continues to identify the gap in behavioral health services in the state plan for individuals with needs associated with intellectual/ developmental disabilities (I/DD) rather than mental health diagnoses. According to these proposed applications:[11]

> Most Medicaid mental health services in Washington are provided through a 1915-B waiver, which clarifies Access to Care criteria for those individuals needing more intensive mental health supports. Community mental health services through the waiver are provided through Behavioral Health Organizations or Managed care Organizations, which carry out the contracting for local mental health care. ***Access to Care criteria excludes the DSM diagnoses classes that include intellectual disabilities; learning, motor skills and communication disorders; and pervasive developmental disorders***. Individuals with primary diagnoses and functional impairments that are only a result of these diagnoses are not eligible for mental health waiver services. ***As a result, individuals with these issues must display an additional covered diagnosis in order to be served through the mental health system***, must be able to benefit from the intervention, and their unmet needs cannot be met more appropriately by another formal or informal

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[7] *See e.g.* "Supported Living: A System in Crisis." Available online at http://www.crsa-wa.com/legislative-advocacy/supported-living-a-system-in-crisis/ (last visited 2/13/19); "Wage Parity for Direct Support Staff." Available online at http://www.crsa-wa.com/legislative-advocacy/keep-30-cent-increase-for-sl/ (last visited 2/13/19)
[8] *See* "Diverting Crisis" at p. 22; "Stuck in the Hospital" at pp. 2, 4.
[9] Exhibit 1 at p. 5.
[10] *Id.* at p. 6.
[11] Proposed IFS Waiver at p. 177; Proposed CPP Waiver at p. 147; Proposed Core Waiver at p. 172; Proposed Basic Plus Waiver at p. 177 (emphasis added).

> system, such as the Developmental Disabilities Administration or community natural supports.

However, the proposed amendments do not include the "Extended Behavioral Health" services DDA presented to stakeholders. This is a significant and substantive difference that DDA has failed to identify or address in any of its communications about these proposed amendments and comment period. The "Summary of Stakeholder Input" does not include any statements that would suggest that this is in response to stakeholder feedback, nor is there any reason to believe the omission of these services would serve the interests of waiver participants. If the state plan will not cover behavioral health services, it is unclear from the waiver applications how waiver participants' needs for these types of services will be met if the participants do not have a qualifying additional diagnosis. Even so, MCO's may not have sufficient provider capacity for behavioral health services by clinicians with expertise in treating individuals with I/DD. If DDA is anticipating that it will take several years to transition from waiver PBSC to state plan ABA therapy due to network adequacy concerns, DDA should not assume that other behavioral health services for individuals with I/DD will be readily available through MCO's or BHOs that have not historically served this population.

Individuals who cannot access rehabilitative behavioral health therapies will be at greater risk of needing crisis stabilization services, which are insufficient to even meet current needs.[12] To the extent crisis stabilization services are inadequate and/or unavailable, individuals who cannot access behavioral health services to prevent decompensation will be at increased risk of hospitalization and institutionalization.

CIIBS Waiver Introduces New Individual Cost Limit.

In the Summer 2018 Stakeholder presentations, DDA did not specify that it would be adding a new individual cost limit for CIIBS services. Although there was information about separating funding into categories "to better track funds available, based on yearly amounts,"[13] the presentations were not explicit that this would entail introducing a new individual limit of $8,000 per year for any combination of some services, including the new Specialized Habilitation services, and a 125 hour service cap for any combination of other "auxiliary" services.[14] This too is a significant and substantive difference between what was presented to stakeholders and what is being proposed. Unlike the other anticipated changes that DDA explained were intended to resolve problems with the way PBSC was defined, DDA did not offer any explanations for why CIIBS services should be capped. No utilization information or data has been shared to demonstrate why DDA has determined $8000 and 125 hours are appropriate. Despite being major change in the CIIBS waiver, DDA offered no explanation for why introducing these limits is necessary, how DDA and HCA assessed what the limits should be, or how these cost limits intersect with the state's federal EPSDT obligations under the Medicaid Act.[15]

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[12] *See* "Diverting Crisis" at pp. 15-18.
[13] Exhibit 1 at p. 11.
[14] Proposed CIIBS Waiver at p. 26.
[15] 42 U.S.C. §§ 1396a(a)(43), 1396d(a)(4)(B), (r)(5); 42 C.F.R. § 441.61(b).

Without any information about why a cost limit is necessary, this change is particularly perplexing. Over the last decade, CIIBS has been highly successful in keeping countless young people in their own homes with their families. As one CIIBS parent explained, beginning to receive services available on the CIIBS waiver is when her son's "entire life changed." This CIIBS participant reportedly receives direct behavior supports three times a week that amount to over $6,000 per month. With these behavior supports and a combination of personal care, respite, assistive technology, and speech therapy, the parent of this young waiver participant states that his life transformed from being unable to leave his house due to significant safety concerns to being a "man about the town" who loves "going to the grocery store and helping pick out items, ordering and eating at restaurants, going to the movies (especially if there is popcorn), going bowling, rock-climbing (!), roller skating, and can even endure the dreaded clothes shopping trips that every kid dreads." Under the proposed cost limitation, these kinds of transformations will be no longer possible. If approved, the new proposed cost limitation would provide for barely more than a month of the services that this participant depends upon to safely live a full and successful life in the community.

In addition, there is a severe risk that children who have a potential to thrive will decompensate into crises that their families will be unable to safely manage, especially for participants with higher and more complex needs. The CIIBS participants who are most likely to need a greater amount and array of combined services are arguably most at risk of institutionalization. Setting a combined cost limit for services that children need to stay in their own homes will require many children to prioritize the services that are most essential to their basic functioning, may be insufficient to fully meet all of their needs, and risks an ultimate defeat of CIIBS waiver's purpose to support the children with greatest behavioral needs to remain safely in their homes. Specifically, the proposed methods for implementing the cost limit will increase the risk that children with the greatest needs and least amount of natural supports will lose their in-home services and be forced to seek institutional or out of home care through other waivers, state plan, or child welfare system.[16]

Revising Rather than Eliminating PBSC Would Better Serve DDA Clients.

In sum, the proposed waiver changes have a high likelihood of further straining an already strained service delivery system. For many waiver participants, PBSC has helped to prevent needs for crisis services or higher levels of more restrictive and more expensive services in institutional and hospital settings. People should not have to be in crisis to access services to "stabilize" them when there are proven services that help them maintain stability. Even so, crisis services and institutional placements are limited resources that are difficult to access.[17] The elimination of PBSC risks exacerbating the challenges in ensuring an adequate safety net of

[16]The remedies for addressing needs that exceed the scope and limits of waiver services rely on individual having natural supports or qualifying for an Exception to Rule in order to stay on current waiver. Because the other waivers have lower cost limits and the Core waiver does not include Specialized Habilitation, transferring to a different waiver would not be a viable way to support continued in-home placement for CIIBS participants whose needs exceed the cap. The only other option for getting needs met is institutionalization. *See* Proposed CIIBS Waiver at p. 28 (citing WAC 388-845-3085).

[17]According to ODDO, there are only eleven diversion beds in in the entire state, and even RHC placements can be difficult to access. *See* "Diverting Crisis" at pp. 13, 16-17.

crisis stabilization services because the needs for these crisis services will expand without services that prevent crises from arising. As a result, these amendments will create an increased risk of institutionalization in violation of the "integration mandate" set forth under the Americans with Disabilities Act (ADA).[18]

Rather than eliminating PBSC and attempting to meet these needs with a more limited and less comprehensive set of services, DDA should be working with stakeholders to distinguish PBSC from ABA therapy and other state plan services in a way that will fully address all of the needs that PBSC currently meets. We believe this approach is both feasible and preferable under Washington's long-standing policies. As described the attached chart, other states have 1915(c) waivers that include Positive Behavior Supports (PBS) that DDA and stakeholders could review and compare to what DDA waiver participants in Washington need in order to maintain stability. Although PBS grows out of ABA theory, it involves a different therapeutic approach.[19] Moreover, DDA has endorsed PBS, rather than ABA, as the preferred behavioral intervention for children and youth with challenging behaviors:

> The Developmental Disabilities Administration (DDA) has formally endorsed positive behavior support as the systematic approach for intervention and prevention of challenging behaviors. The literature indicates that positive behavior support with parental and/or caregiver involvement and technical support is an effective intervention for children and youth with developmental disabilities, including autism and other disorders, and can significantly prevent and reduce severe challenging behaviors.[20]

The difference is more than therapeutic. ABA therapy is regulated differently from PBS and must be delivered by a licensed provider or someone operating under the supervision of a licensed provider.[21] There is no such limitation on PBS. Thus, providers who are not licensed as BCBAs may provide PBS therapy to Medicaid recipients. Those providers, however, are not permitted to provide ABA therapy to their patients. DDA's assumption, implicit in the waiver application, that a PBS provider can also provide ABA services covered by private insurance, is without any factual support.

Also, the proposed waiver amendments do not recognize that the services covered by the state Medicaid plan or private coverage in theory may not be actually available to waiver participants, or that participants may not be able to navigate the MCO and private health insurance system sufficiently to access the services. The proposed amendments do not recognize that there is a

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[18] Under the ADA, 28 C.F.R. § 35.130(d); *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999); *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003); *A.H.R. v. Washington State Health Care Auth*., CASE NO. C15-5701JLR, 2016 WL 98513(W.D. Wash. Jan, 7, 2016).

[19] *See* Carr, E. *et al.,* "Positive Behavior Support: Evolution of an Applied Science," Journal of Positive Behavior Interventions, Vol. 4, No. 1, pp. 4-20 (Winter, 2002). Available online at https://orbehavioranalysis.files.wordpress.com/2014/01/carr-et-al-2002.pdf (last visited 2/14/19).

[20] DDA Policy 5.19 Positive Behavior Support for Children and Youth, p. 1. Available online at https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/policy/policy5.19.pdf (last visited 2/14/19). *See also* DDA Policy 4.06, p. 1. Available online at https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/policy/policy4.06.pdf (last visited 2/14/19) (same).

[21] *See generally* RCW 18.380.

severe network adequacy issue for mental health treatment in much of Washington State. The pool of providers who take private insurance and who serve persons with I/DD is even smaller. In addition, the new waiver services do not provide for intensive behavioral support provided by PBSC practitioners in areas of the state where licensed mental health or ABA providers are unavailable.

PBS has been a way to ensure that waiver participants continue to receive the intensive outpatient behavioral treatment they need, when there is a lack of in-network licensed providers through their MCO or private coverage. Eliminating this critical behavioral health service from the waiver does not eliminate the need for this service among waiver participants. Nor are the needs of waiver participants for PBS fully addressed by the proposed replacement services. Unless and until there is evidence that MCOs in Washington have an adequate network (including in rural areas of the state) to meet the need for intensive outpatient behavioral health services for DDA waiver participants, PBSC should not be removed. For waiver recipients at risk of institutionalization, the waivers must provide the safety net services needed to continue to live outside of an institution while the pre-authorization review, and appeals process occurs for these services at the MCOs and private coverage. Advocates know of at least one waiver participant who decompensated as a result of the loss of his PBS services, resulting in a request for an emergency placement at a RHC.

Despite its claim that "DDA conducted live stakeholder meetings across the state to discuss proposed service changes and receive feedback from participants prior to proposing these changes in this amendment," DDA presented anticipated changes that are substantively different than these proposed amendments. The proposal to eliminate PBSC should not be approved because alternatives to PBSC are inadequate substitutes that are not even equivalent to the "solution" that DDA presented last summer.

All of the undersigned would be happy to meet with DDA and other stakeholders to craft a solution that will improve rather than weaken the DDA service system. Please let us know a time you or your staff could be available and we will look forward to further discussions. You may respond to Susan Kas at Disability Rights Washington (DRW) at susank@dr-wa.org or 206-324-1521.

Sincerely,

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Disability Rights WA

For Elizabeth Landry, Attorney
Northwest Justice Project

For Eleanor Hamburger, Attorney
Sirianni Youtz Spoonemore Hamburger

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CC: Cheryl Strange, Secretary of Department of Social and Health Services

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