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Rhonda Workman
Director of Federal Programs
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Via Email Only: Rhonda.Workman@maryland.gov; wfb.dda@maryland.gov

Dear Ms. Workman:

Disability Rights Maryland (DRM) is the federally mandated protection and advocacy system for people with disabilities in Maryland. We appreciate the opportunity to comment on the proposed DDA Waiver amendments. Our concerns are outlined in brief below, and in general, applicable to the relevant sections of both the Community Pathways and Community Supports waivers. We would welcome further opportunities to discuss these and other issues prior to the waiver amendment's finalization.

1. Respite Care Service Changes

DDA is proposing a drastic reduction in the availability of respite services to participants who are not interested in, or not able to attend, congregate camps. The new cap on non-camp-based respite amounts to 15 days. Prior to 2018, individuals and families had access to up to 45 days of respite. It makes no sense to slash respite in a system that relies heavily on family supports, because it significantly increases the risk of crisis and burn-out and creates a higher likelihood that individuals will lose family-based housing. We also expect to see a significant overlap between individuals at risk of crisis and individuals who are inappropriate for, or rejected by, camp providers. We caution DDA not to create a scenario that discriminates against individuals with more severe disabilities in access to respite services.

Relatedly, it is inappropriate to prohibit behavioral support services while in respite care. To the extent that it could inhibit individuals who need behavioral supports from accessing respite, this change may also constitute impermissible discrimination based on type and/or severity of a disability.

2. Community Development Services (CDS) Requirements

CDS should be made available in the participant's home as well as outside of the home. The definition of "community" to exclude the participant's home restricts the ability of the participant to choose online classes, skills development, and employment development activities that are readily accessible at home and not necessarily so in an external location.

Relatedly, striking "competitive employment" from the definition of CDS is problematic, especially given the time restrictions on "Discovery" in the new provisions on employment services. CDS allows for the development of skills related to community integration, including "promoting positive growth and developing general skills and social supports necessary to gain retain or advance competitive integrated employment

opportunities.” Participants should be able to use this service to gain networking and business development skills directed at both competitive employment and community integration.

DDA excludes apprenticeships from Employment Services other than the 90-day Discovery period. We wonder where in the waiver DDA intends to accommodate participants’ desire to engage in apprenticeships. DDA should allow adequate time for to support individuals in meaningful apprenticeships, which according to the U.S. Department of Labor, require at least 2,000 hours of on-the-job learning. 29 CFR 29.4. This could also be handled under CDS.

3. Transitioning Youth

It would be helpful to see the data on which DDA is basing its estimates of reserved capacity for Transitioning Youth (325 slots) and DHS Foster Kids Age-Out (10 slots). No meaningful comment can be made without access to that data.

4. Transportation Billing

Removing transportation billing as a separate item and including it within an already strained rate structure will compromise participants’ ability to retain qualified staff and access services as desired in the community, contrary to DDA’s responsibilities under the Statewide Transition Plan. This has already happened in the behavioral health context around the country, with deleterious effects on community services.

5. Personal Supports

As DDA knows, 1915(c) waivers are intended to provide comprehensive habilitative supports that are unavailable under the State Plan in scope, nature, and provider training. Waivers exist for the purpose of supporting a person to stay in the most integrated community setting and avoid more restrictive, institutional, and isolating settings.

Personal Supports are the critical habilitative supports that are “designed to assist participants in acquiring, retaining, and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings.” CMS Technical Guidance (Jan. 2015) p. 146. They include “personal assistance and protective oversight and supervision.” Under the current Service Definition and its implementation, Personal Supports have been impermissibly restricted to skills development, ignoring the crucial goals of maintenance or retention of skills. Therefore, the Service Definitions should read “Participant needs support for community engagement (outside of meaningful day services) or home skills development *or maintenance*.”

By focusing solely on skills development rather than on true habilitation, DDA has denied participants Personal Supports hours and increasingly forced them to apply for and/or exhaust State Plan (including Community First Choice (CFC)) services in order to receive so-called “nonhabilitative” personal assistance. In reality, personal assistance is just one aspect of habilitative development and maintenance. It also needs to be delivered seamlessly by individuals trained to support individuals with developmental disabilities.

This attempted bifurcation is causing real harm. DRM has received reports of and had clients lose critical staffing. The loss and reduction in Personal Supports hours and the shifting of hours to CFC has jeopardized Waiver participants’ health and safety, and forced their families, providers, and staff to attempt to pick up the pieces. We view the requirement for “cost-effectiveness” attached to Personal Supports as part of this ill-

advised attempt to require participants to obtain personal assistance from often less qualified and lower paid staff, instead of focusing on individualized, person-centered planning to determine participants' needs.

DRM is now hearing widespread stories of providers forced into discriminatory, antiquated judgments about whether or not a participant has the *ability to learn*. Personal assistance in the context of a DD Waiver is *virtually always* a habilitative service. Some examples include:

- Teaching the participant grooming and self-care, regardless of whether or not he is “doing” the activity.
- Assuring the participant that her overnight toileting and health and safety needs are met, which promotes her functioning and independence in the rest of her life.
- Creating a reliable structure and routine for a participant with behavioral needs, that can weave seamlessly around rest of his day and prevent crises and emergencies.

Finally, limiting Personal Supports to a default of 82 hours per week, without providing a meaningful mechanism for obtaining ongoing supports in excess of that cap, places individuals at serious risk of institutionalization and threatens the ability of individuals to live and receive services independently in their own homes. There are 168 hours in a week. Many people who need 24/7 care are not appropriate for supported or shared living and should not be forced to give up control of their homes and services. In order to avoid more restrictive levels of care, those individuals need hours authorized above the cap.

6. Self-Determination

DRM shares the Self-Directed Advocacy Network (SDAN)'s concerns about the direction DDA is moving in with respect to self-determination and criteria for accessing self-directed services. We welcome further dialogue on those issues.

7. Exhaustion Policy

DDA should explain to its stakeholders that its new policy of exhausting State Plan services was not required by CMS. We view this policy as inconsistent with the purpose of 1915(c) waivers, which is to provide comprehensive habilitative services through an individualized and person-centered planning process to individuals for whom State Plan services are inadequate, not to force individuals into inadequate State Plan services cobbled together in a piecemeal fashion with waiver services.

Participants are now at serious risk of lengthier institutionalizations, because during discharge planning they are denied waiver services if they might be covered under CFC, but given no mechanism for requesting CFC before they actually get out. When DDA denies coverage, the person is stuck.

We look forward to a productive discussion and resolution of these issues in the near future.

Sincerely,

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