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The Arc Maryland seeks to create a world where children and adults with developmental disabilities and their families have and enjoy equal rights and opportunities.

**Comments on the DDA Medicaid Waiver
Submitted by The Arc Maryland
October 2014**

The Arc Maryland commends DDA's efforts to outreach state-wide to gain public input in the waiver renewal process that includes waiver participants and other stakeholders to share their thoughts, concerns, and recommendations.

Background

The Maryland Developmental Disabilities Administration's (DDA) application to renew its Community Pathways (CP) waiver has been approved by the Centers for Medicare & Medicaid Services (CMS), but there are several changes to the new CP waiver. The New Directions (ND) waiver is no longer a separate waiver, but is now included as part of the Community Pathways waiver, which allows both self-directed and provider-delivered services. However, Community Pathways does not include Low Intensity Supports and Services (LISS).

Recommendations

After listening to the concerns and suggestions of several waiver participants throughout the state, The Arc Maryland would like to share the following comments and recommendations:

1. We commend DDA for providing a wide variety of services under the waivers that have allowed people with disabilities to gain independence, learn new skills, and generally live more fulfilling lives.
 - Maryland offers a strong array and menu of supports to waiver participants.
 - Many waiver participants are living on their own for the first time, pursuing higher education, or succeeding at competitive employment.
 - Although some items are lacking and need strengthening, it is recommended that Maryland continue its array of waiver menu items with support to participants and their families to make informed choices.

2. Certain rules imposed by DDA undermine the effectiveness and purpose of the waivers.
 - Hospitalization: When a person in the Community Pathways waiver is hospitalized, community agencies are not paid to provide direct care staff once they are admitted to the hospital. Maryland Code of Annotated Regulation

[COMAR (10.09.06.05B (26))] stipulates DDA will not pay for services provided by a provider agency while an individual is hospitalized.

This is particularly problematic if an individual needs assistance with multiple activities of daily living and the Service Funding Plan calls for overnight, awake direct support staff because they require constant monitoring. There are often nursing shortages in hospitals, which limit nursing staff attentiveness to each patient. This reality forces many families to either pay out of pocket for an attendant all night, or risk leaving their family member unattended. There are many participants with no living family members.

- The Arc recommends revision of the regulations to allow payment to community providers to meet staffing requirements needed in accordance with the Service Plan during hospitalizations.

3. Supporting Individuals with Multiple and Intensive Needs:

The Community Pathways Waiver allows for day habilitation services, but many individuals who need one-on-one support because of their complex needs are being turned away by providers who assert that DDA does not provide sufficient funds to provide the necessary supports for an individual with that level of support.

In addition, deaf individuals report they are unable to receive supports with competent sign language staff, a violation of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. Community agencies state they do not receive sufficient DDA funding under the waiver to provide the required ASL competent staff and instead report they have been instructed to teach staff ASL. This is a clear violation of the ADA and S 504 that require reasonable accommodations; and a violation of the federal waiver regulations that require individuals receive ongoing supports to develop and maintain skills, including essential communication skills. Individuals with I/DD who are deaf are especially vulnerable to lack of opportunities to exercise choice and community options when there is no meaningful, skilled communication for and with them. In addition, deaf individuals should have access to certified sign language interpreters for key program planning meetings to ensure independent communication.

As individuals age, their needs may become more intensive. We urge DDA to provide the funding sufficient to enable individuals to age in place in their own home rather than be discharged to a nursing facility.

It is recommended DDA provide sufficient funding to meet its obligations under the waiver, ADA and Section 504 for the one-on-one and ASL supports required for individuals with multiple and/or complex needs to live in the most integrated setting in their community.

4. Personal Supports:

Under the Community Pathways waiver, people who are entitled to personal supports formerly called a “Community Supported Living Arrangement” (CSLA) are limited to y 82 hours per week of staff support, even though the waiver says DDA may approve

more. The 82-hour limit is arbitrary, greatly limits self-direction, and does not correspond with individual need or the enabling statute. The enabling state statute stipulated CSLA is for all individuals to ensure that all individuals have the opportunity to live in the most integrated setting, regardless of the nature or severity of their disability.

It is recommended:

- DDA should not limit these supports to 82 hours/week, and develop reasonable criteria for assessing need based on individual support needs.
 - The process for obtaining exceptions to this rule is long, arduous, and overwhelming for people with disabilities and their families. It is recommended DDA abbreviate and streamline the process.
 - The new Home and Community-Based Services (HCBS) Federal rule states that States must plan to allow people to have the option to live alone and to choose their roommates.¹ Therefore, DDA should provide the staff support people need to live in their preferred living setting in the most integrated setting per their individual needs and preference. The level or severity of their disability should not preclude them from enjoying equal access to integrated and independent housing situations with the supports they need.
5. In some cases, the new Community First Choice waiver has resulted in unintended consequences for several of its participants.
 - Some individuals state the Resource Utilization Group (RUG) scores provided under the waiver (which determine the amount of support they receive) greatly underestimates their actual needs.
 6. When confronted with problems, DDA has often suggested that several issues with the waiver are the result of the rules established by the Centers for Medicare and Medicaid Services (CMS), and therefore cannot be changed.
 - DDA has the authority to reasonably address these challenges with a focus on doing what is best for the individual and their needs.
 7. The waiver provides tremendous opportunities for those receiving services. However, there remain over 8,000 individuals on the DDA Waiting List for community supports. We urge DDA to work with stakeholders to develop a multi-year waiting list initiative.

The Arc Maryland appreciates this opportunity to share our comments and recommendations, and looks forward to working with DDA to improve the quality of life for people with intellectual and developmental in our state.

Thank you for your consideration of these recommendations.

¹ Source: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/HCBS-setting-fact-sheet.pdf>