



October 27, 2014

Bernard A. Simons, Director
Developmental Disabilities Administration
201 W. Preston St.
Baltimore, MD 21201
By email to bernard.simons@maryland.gov

Re: DDA Medicaid Waiver

Dear Mr. Simons:

Maryland Disability Law Center (MDLC) appreciates this opportunity to comment on the Developmental Disabilities Administration (DDA) Medicaid Waiver. After working with many waiver participants, MDLC recommends the following:

Improved Public Information/Communication

1. People including applicants, waiver participants, families, professionals and others, need more information about the Medicaid waiver and support services including eligibility, access to the waiver, services and rights. DDA's communications with the public should be understandable to the average reader.
2. As DDA develops the Community of Practice model, it should provide information about how this model will operate with the Medicaid Waiver.

Eligibility

3. DDA continues to routinely deny eligibility to children who have professional documentation of developmental disabilities such as autism and intellectual disability. DDA typically reverses its decisions if MDLC becomes involved but most people don't have legal representation. In recent years, DDA sent flawed and misleading eligibility determinations that said the applicant was eligible for support services but did not say DDA was denying eligibility for the Medicaid waiver. DDA should correct the old, erroneous notices so these applicants can establish their eligibility before they turn 21 years old.
4. DDA should review its eligibility and level of care procedures. When people have a history of mental illness and professionals subsequently determine the person has an intellectual or developmental disability, DDA staff often deny eligibility. DDA eligibility staff lack adequate training or clinical qualifications to interpret the clinical assessments. This particularly affects youth in the foster care system who have experienced substantial trauma and have no system of support.

Planning and Resource Coordination

5. DDA should reconsider the targeted case management (TCM) service. When DDA was delivering resource coordination as a waiver service with no choice of providers, CMS required DDA to choose delivering the service under an administrative service model or as a waiver service with choice. Without informing the public what a change would mean, it asked for

public feedback about whether people wanted to be able to choose their resource coordination agencies and predictably, people did want choice. However, DDA failed to plan an orderly transition to TCM and many people, especially in Montgomery County, either went without the TCM service for months or had so many new TCM workers that service was not meaningful. TCM continues to be fraught with problems that we do not have space to discuss here. **We appreciate that you are taking a deeper look at TCM.**

6. People need more support from resource coordinators in planning their waiver services.
 - DDA should ensure person centered planning occurs as required by the new federal rule.
 - To ensure individual needs and desires are reflected in the individual plans, resource coordinators should be required to be trained in and use best practices in person centered planning including tools such as MAPS, PATH, etc.
 - Some resource coordinators are poorly informed about self-directed services and are unable to help people learn their options to self-direct.
 - DDA doesn't provide information about provider agencies, including OHCQ surveys and other relevant public information about quality.
7. People who do not speak English need more communication assistance and support.
 - DDA is refusing to provide interpreters to people with hearing impairments whose providers do not have signing staff. People with hearing impairments need signing staff, and until such staff are available, DDA should provide interpreters.
 - Staff should meet peoples' needs to maintain and/or learn and gain communication skills, whether through signing, devices or other means.

Adequate Array of Provider Agencies

8. DDA currently does not have an adequate array of provider agencies to meet the needs of people with more intensive needs. People with a higher level of need spend up to a year or more trying to find provider agencies willing to meet their needs. **DDA needs to create capacity for service providers to meet the needs of people who require a higher level of support for their health or behavior.** Currently, many DDA licensed provider agencies are refusing to serve people they would have served 5 years ago due to:

- Changes in DDA reimbursement policy for people who need "add-on" funding: DDA used to ensure ongoing "add-on" funding but now gives approvals in time-limited intervals.
- The absence day policy results in loss of reimbursement for a provider when a person doesn't go to the day program or is out of residential services for over 30 days. People with more health care issues are more likely to miss their day program or be hospitalized for longer periods of time, which results in a more frequent and higher loss of reimbursement for providers.

To help alleviate this capacity constraint problem, MDLC recommends removing "add-on" support services from the Request for Service Change process and that DDA and provider agencies cooperate to reach funding agreements for people with greater needs. People receiving services do not understand add-ons, nor are add-ons a waiver service: add-ons are a funding mechanism for waiver services. We recommend that individuals request waiver services and that once the services are approved, DDA work with the provider agency to develop a mechanism for funding the service. If the person's needs change to result in a need for more or less staff support, this can be noted in a team meeting or other documentation from

the provider agency, but DDA should not require individuals to attempt to understand how to request additional funding from DDA to pay for adequate staffing support.

Behavior Support Services

9. When DDA recently developed a contract for behavior support services, it did not solicit public input or even inform the public that it was developing a contract. The new contract ignored earlier recommendations of stakeholders to model DDA behavior support services along the lines of the Southern region's behavior support consortium. Instead, DDA placed all behavior supports under the administration of one provider, Humanim. Several years ago, DDA led a large group of stakeholders to make comprehensive recommendations for eliminating the use of restraints as well as developing a continuum of behavior support services and training. This work group was an ideal constituency to review and comment on a plan to change DDA's behavior support services.

10. People do not have a choice of providers of behavior support services as required by federal Medicaid waiver law. Currently, people either receive behavior supports from their provider agency, which is a conflict of interest, or they have only one regional contract waiver provider to choose from.

Services Should Be Provided with Reasonable Promptness

11. People experience very lengthy delays in obtaining DDA services, both when people are enrolled in the waiver and when they request a change in services. For example, if a person is discharged from a hospital and needs a higher level of support for health care, it can take weeks or months after DDA approves services for the in-home support to begin. This lag puts enormous stress on families and their jobs and is a violation of the requirement to provide services with reasonable promptness.

12. Behavior support services are not provided with reasonable promptness. It can take six months to develop a behavior plan. While a behavior plan is being developed, an interim plan should be provided to help assure support to the person in need. The plan should be monitored and promptly adjusted as needed by the individual.

13. DDA does not provide services with reasonable promptness to transitioning youth with intensive needs. There is no process for such youth to receive the full array of services they need for their health and safety when their Medicaid waiver services begin. Instead, transitioning youth may only begin services with a basic day or supported employment program even if this means they are at risk of harm or family members are at risk of losing their jobs. DDA should help youth with intensive needs to safely transition into waiver services.

Waiver Services

14. Community Supported Living Arrangement (CSLA) services should meet individual needs.

- For people who live in their own homes with CSLA supports, DDA limits staff support to 82 hours per week, though the waiver says DDA may approve more. The 82-hour limit is arbitrary and does not correspond with individual need. DDA has no criteria or process for people to get more hours of needed support. DDA should not limit CSLA to 82 hours/week and needs reasonable criteria for assessing need.
- In response to people who ask for more CSLA hours of support in their homes, DDA has refused and suggested that they consider moving to provider agency residential

homes. The Americans with Disabilities Act requires DDA to provide services in the most integrated setting. Also, the new federal rule that says DDA must plan to allow people to have the option to live alone and to choose their roommates. DDA should support people need to live in their preferred living setting.

15. Community Pathways should include needed nursing services.

- In violation of the Supreme Court's Olmstead decision, several years ago, DDA stopped providing private duty nursing (PDN), which puts people at risk of institutionalization if they cannot get PDN from the Maryland Medicaid program. In its waiver application, DDA said it would study the issue of nursing and obtain input from stakeholders but this has not occurred. Advocates attempted to expand the Medicaid PDN program so it would include people who are currently barred for technical eligibility reasons (they receive Medicare and/or are in Medicaid through spend-down) but the Department of Health and Mental Hygiene vigorously opposed these efforts. DDA should include PDN as a Medicaid waiver service.
- Many DDA provider agencies will not serve people who receive PDN from the Maryland Medicaid program due to issues of liability and how to ensure there is a backup caregiver as the Medicaid program requires. DDA should work with provider agencies to resolve these issues and ensure people with Medicaid PDN services can live where they choose and avoid institutionalization.

16. Self directed services have been extremely difficult to obtain and saddled by extraordinarily dense rules. The rules are especially unclear about the mutual responsibilities of support brokers and resource coordinators. DDA should improve its staff support of self-direction and develop rules that will foster rather than inhibit self-direction.

Community Integration

17. To make community integration a reality, DDA should review provider and self-direction policies that limit opportunities for people to participate in community activities because they lack staff and transportation.

18. DDA should make integrated employment and integrated day support opportunities available to all waiver participants. DDA has no rules or rate structure for Community Learning Services, an integrated day service, six years after it was added to the waiver. Several DDA provider agencies deliver wholly integrated employment and day program services but DDA has no rates or regulations that encourage or permit this. In contrast, sheltered workshop participants rarely progress to integrated competitive employment. Many people still spend most of their time in segregated facilities with little meaningful activity. Programs do not document how much time is spent with nondisabled people in the community. People say they want more integration. The waiver should ensure this is an option for all waiver participants.

Support in Hospitals and Nursing Facilities

19. Waiver participants need specialized services while they are in hospitals and nursing facilities. In the hospital, people need support from family members or staff who know them and their needs, can communicate effectively with them, respond to their unique and special needs and avoid unnecessary trauma. DDA should investigate whether it can obtain Federal Financial Participation for services provided in the hospital setting. If not, DDA should still provide appropriate support in the hospital setting for those who need it.

20. For people in nursing facilities, DDA needs to review the federal PASRR requirements. First, for all persons with a developmental disability, DDA must review and determine whether a person may not be admitted to a nursing facility because their needs can be met in the community. It is MDLC's position that most people can return home with waiver supports and that waiver participants generally should not be admitted to nursing facilities. Second, although Maryland has not provided specialized services to many people with DD in nursing facilities, under recent CMS guidance, if a person with a developmental disability is admitted to a nursing facility, DDA is required to "provide individualized services and supports for the disability, as required to attain the highest practicable physical, mental, and psychosocial well-being." As far as we can tell, this is not currently occurring.

Additional Waiver Services Needed

21. DDA should help people use independent Social Security Representative Payees and consider adding this as a waiver service. Many provider agencies insist on being the representative payee for people they serve, which creates a conflict of interest. People in services should have independent, reliable representative payees.

22. DDA Medicaid waiver recipients continue to experience unnecessary pain and risk of infection due to a lack of dental care. Most adults on Maryland Medical Assistance are not entitled to dental care and may not know about the limited care available from some of the Managed Care Organizations. DDA should include dental care as a waiver service or ensure people have dental care, including helping people access medically necessary oral surgery.

Thank you for considering our comments as part of your review of the DDA Medicaid waiver.

Sincerely,



Nancy Pineles
Managing Attorney

Cc: Mary Sowers, Robin Cooper, Jeanine Zlockie
DD Coalition