The Arc
Maryland

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Senate Finance Committee
SB 796: Developmental Disabilities Administration - Program Changes and Required Reports
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Position: Support with Amendments

For many years, The Arc Maryland has worked with the Developmental Disabilities Administration along-side fellow advocacy organizations and people with disabilities and we have collaborated on change. There was a shift a few years ago in the conversation and collaboration, however. The tone is now more one of- *this is what we are doing and we need your feedback on how to fix it when it doesn't go smoothly*- and less of- *what do people with disabilities and families actually want and how can* ***we*** *develop and implement a plan for change*.

Although I suppose administrations may decide to lead and push change differently, the difference here is that the change was and continues to be communicated to stakeholders as what families and people with disabilities stated they wanted. In my communications with families and people with disabilities, I have not heard enough that supports this position, and in fact, I am hearing that many of the changes are in direct conflict with what people who receive services want and need with only a few exceptions.

DDA is mandated to obtain stakeholder feedback for guidance. Over the past few years, they have held listening and feedback sessions across the state and The Arc Maryland has had representatives attend most of them. What DDA says they heard and have put into the new waivers as "what people want" is not what we heard in those forums and in direct conversations with people. The feedback is collected by DDA is either not truly considered, or it has been considered but largely rejected. Trust has eroded to a point with families that they are afraid to sign-in at a meeting because they don't know how their signature is going to used. It has been used by DDA in the past two waiver amendment applications to CMS to show stakeholder feedback was obtained, and it is assumed to represent agreement for the changes DDA has proposed in those applications.

The Arc Maryland is a large statewide advocacy organization with an expansive membership. We recently held 8 listening sessions across the state in December and early January to hear directly from families and self-advocates about what they want and what they are experiencing. Themes of these discussions can be summarized as devastation, confusion, fear, and gratefulness for service providers and other personnel who help them.

We also received confirmation that families and self-advocates feel they did not ask for much of the changes DDA has made or is in the process of making, nor do they understand where all the ideas are coming from. They don't understand the need for service definition changes such as designations of "small group" versus "large group" activities, or "daily" versus "hourly" billing, "shared living" versus "supported living" or "regular supports" versus "enhanced supports". Families and people with disabilities only know they communicated a desire for choices of activities in their days of support; to work and recreate or attend school, they want to be able to live with friends, and have high quality caregivers to help them. They could often get this flexibility prior to all the changes, but now there are so many constraints and guardrails around the new service definitions, many feel they have less flexibility. They are now worried about service denials and disruptions.

People with developmental disabilities and their families have found it more and more difficult to keep Coordinators of Community Supports (CCSs) in their lives as the turnover in that essential and KEY position has exploded. Finding qualified staff to provide Direct Care is also a constant struggle, and just when a person gets used to a Direct Support Professional, they leave- often for better pay and working conditions. It is difficult enough to allow a caregiver to provide intimate direct care and to develop trust to the extent that that care is comfortable. Now they must adjust to a new person every few months.

The changes that have been proposed are confusing and they are not communicated consistently to all stakeholders, or in a way that families and people with disabilities can understand. Without a guide for families, and written/available policies, procedures and guidelines, DDA often relies too heavily on to CCS's to deliver the messages. Somethings this reliance impacts negatively on the relationship between the CCS and individual/their family, especially when the message changes. Even the CCSs will tell you they do not have the breadth of knowledge needed to communicate changes or help a family navigate through those changes.

With all of the changes and the impacts they have had on DDA operations, including changes to service definitions, an active push to move people to CFC services and exhaust then before accessing DDA services, regional office processing delays for authorizations for needed services, etc. we no longer feel we have a stable system upon which people can rely and yet DDA is moving forward with additional changes.

The results:

- People in services are not getting needed services and supports in a timely manner.
- People are losing services they rely on because their services have been written out of the waiver as a covered service, or are being forced to exhaust CFC (considered an inferior service due to an inability to use it in the community) before they are authorized DDA services.
- People who need to access DDA services are facing unprecedented delays to accessing services.
- Families are stressed. Some people are going into Self-Directed Services by default instead of by choice as providers, also stressed by the changes, are declining to expand.
- Some parents are quitting their jobs to stay home and care for their adult child which is contributing to high family stress and loss of economic contributions.

Families and about 16,000 people with intellectual and developmental disabilities in the state rely on DDA service provider organizations and another approx. 1000 people self-direct their DDA services.

Providers are already struggling after years of insufficient funding. I believe you have seen our graphs over the years which show how the funding for DDA services has eroded, not keeping pace with the costs of doing business in Maryland. I know of at least two families who have recently told me their DD provider has not been picking up their adult children from their home for day services, due to direct support professional vacancies. I also know of a provider organization has exhausted their line of credit with the bank and is selling a building but even with those efforts, they do not believe they will be able to scrape together enough to make payroll in less than 4 weeks. I am terrified as I think about these situations and wonder how many other situations like these we don't know about.

If things don't change and DDA is not mandated to slow the transition until all are ready, perhaps one of the groups that will suffer the most are the Transitioning Youth (TY). For years, we have watched the slow decline of TY admissions to DD adult provider organizations, often for reasons of "capacity." It isn't that providers don't have space or vacancies. Capacity, I have found, relates to a provider's inability to make new commitments to support people when they feel they cannot meet the commitments they have already made to care for existing people in their programs. The situation has continued to deteriorate year after year.

I spoke with a father in Anne Arundel county last month whose son graduated from high school in June 2019, just this past year. Prior to graduation, he and his wife went to 10 different providers and all declined to support his son, many citing his son's need for diabetes management and a lack of nursing funding and provider expertise to properly support the young man. After graduation, this father and his wife spent about a month more trying to find a provider before being forced to consider Self-Directed services for their son. It is not what they wanted but they were out of options. They developed the Self-directed services budget and submitted it but as of last month, they were still waiting for that budget to be finalized. His wife had to quit work. She had no choice since their son cannot be alone for any great length of time and they were well out of protected time to take off.

This bill requires DDA to delay implementation of the new service definitions and transition of providers to the new system (LTSS) until such time as the department can meet certain benchmarks and produce assurances that neither people with developmental disabilities nor providers will be adversely impacted in the transition.

Among other important things, the bill (as amended) will ensure that people who act within 90 days to appeal a loss of their Medicaid eligibility will maintain their DDA services during the appeal process.

The bill also requires several reports from DDA to the General Assembly to ensure that the system, rates, communication, back-up plans and training are all in place in order to facilitate a smooth transition.

We need a written plan from DDA; with milestones instead of due dates; with true stakeholder feedback and engagement; and with assurances that system components are in place and working before that plan is executed.

Respectfully submitted, Ande Kolp, Executive Director