



4301 CONNECTICUT AVENUE NW | SUITE 310 | WASHINGTON DC 20008
(202) 448-1450 | (202) 448-1451 FAX | WWW.DCQUALITYTRUST.ORG

**Testimony of
Quality Trust for Individuals with Disabilities**

**Performance Oversight Hearing:
The Department on Disability Service
Fiscal Year 2019**

**Councilmember Brianne K. Nadeau
Committee on Human Services**

February 11, 2020

Good morning, my name is Jimi Lethbridge. I am the Deputy Director of Programs for Quality Trust for Individuals with Disabilities (QT). QT is an independent nonprofit advocacy organization. Our mission is to help people with developmental disabilities in the District of Columbia solve problems, achieve personal goals, and meaningfully contribute within their community. One way we do this is by advocating for safeguards for people who may seek or are receiving services and supports through the Department of Disability Services (DDS), including the Developmental Disabilities Administration (DDA). We also serve as an independent monitoring organization assessing the quality of services to people receiving assistance from DDA. Both activities inform our opinions about the performance of DDS over the past year.

A lot has happened since I testified before you last February. DDS continues to engage in several activities intended to improve outcomes and control costs, while also maintaining services at current levels. For instance, the long overdue formal complaint system, developed as part of the grievance component of the Disability Services Reform Amendment Act of 2018, became operational in January. Formal changes to policies and procedures needed for implementation of the Home and Community Based Services (HCBS) Settings Rule began to take effect slowly throughout the year. Developments such as these are encouraging; however, since they are still in the early stages of implementation, their true impact is currently unknown. We also are pleased that DDS reports that both the HCBS waiver featuring self-direction and a family supports waiver option for people living at home are slated for submission to CMS and implementation this fall. Once approved, these options will go a long way toward moving away from the “one size fits all” model of services that has defined the DDA system in the District for decades.

While we are pleased that there is continued focus on ongoing improvement at DDS, there remain facets of the current DDA service system that cause us concern.

Strengthening Supports for People with Autism: We have noted for a few years now that Autism is the fastest growing developmental disability. Providers with specialized skills and specifically

structured service models are required to effectively meet the needs of many people who live with Autism. It is disappointing that for the second year in a row DDS cannot answer the question about how many people with intellectual disabilities currently receiving DDA services also carry this diagnosis. While we are sensitive to the notion that people should not be defined or characterized by their diagnoses, we also believe that understanding the extent of the current need is important as a foundation for projecting future needs. In addition, we have heard from providers that more expertise in supporting people with autism is needed. We are not aware of a DDS focused plan to outreach to and recruit new providers to address this need.

Expansion of DDA Services and Supports -- For far too long, the District of Columbia has not made the investment needed to make the “Developmental Disabilities” Administration live up to its name. Currently, DDA only serves DC adult residents who have intellectual disabilities, which is but one kind of developmental disability and is characterized by a low IQ score and limitations in two or more adaptive life skills. That leaves behind adults with other kinds of developmental disabilities – such as autism, cerebral palsy, and muscular dystrophy – who do not meet the IQ cut-off for an intellectual disability, but still need services and supports to maintain and build the life skills necessary to live safely in the community. Quality Trust regularly receives calls from DC families whose family member with developmental disabilities are approaching or have reached adulthood but do not meet the current eligibility requirements for support through DDA, even though they require significant support to live successfully in the community. While some of these people may be eligible for the Elderly and Persons with Physical Disabilities (EPD) waiver through the DC Department of Aging and Community Living, that waiver does not provide the comprehensive array of community-based services and supports that DDA provides, such as individualized day supports, in-home support services, behavioral support services, long-term employment support services, and respite, among others. As we have testified in the past, the Council, Mayor, and DDS must engage in the budget, legal, and programmatic reforms necessary to expand access to DDA services and supports to all District residents with developmental disabilities that meet the intermediate care facility level of care required to qualify for HCBS waiver services. The time to act is now. One starting point could be to require DDS to establish a slot-limited pilot waiver program for adults with developmental (but not intellectual) disabilities. That way, the Council and Administration could gauge first-hand what the fiscal and personal impact of expanding access to this broader population is, and then move forward from there.

Investigation of SRIs on MTM transportation -- We are concerned by DDS’ plans to shift away from investigating serious reportable incidents (SRIs) – such as abuse, neglect, missing person, and serious physical injuries – that occur while a person receiving DDA services is using Medicaid-funded transportation through MTM. We are aware of people receiving DDA services and supports who have been injured, picked up very late, returned home hours late with no explanation why or where they have been, and in one tragic instance killed as a result of a car accident on MTM transportation. In its response to the Council’s oversight questions last year, DDA stated that it investigated such SRIs.¹ Now DDS states it will investigate such incidents only if they are not investigated by MTM.² In our experience, the Department of Health Care Finance, the DC Medicaid Agency, does not currently conduct investigations of SRIs on MTM

¹ See Council’s Question No. 61: “Does DDA coordinate with the Department of Health Care Finance to address issues or complaints against MTM, the Medicaid transportation provider? If so, please explain the coordination.” DDS’ response: “DDS has a dedicated staff person who forwards complaints that come into DDS to MTM, which then completes an investigation. The resolution may include a provider change. If the complaint reaches the level of a Serious Reportable Incident as defined by DDS, DDA also will complete an investigation. Outcomes are provided to DHCF.

² See Response to Council’s Question No. 73: “We will continue to work with DHCF on this project and ensure that incidents not investigated by MTM will be investigated by DDS to ensure the health and safety of people supported by DDA.”

transportation. Therefore, DDS change in policy means there will be situations in which no outside governmental entity is investigating SRIs on MTM transportation. If DDS no longer wishes to investigate such SRIs, then we recommend it must ensure there is another D.C. government agency that does, in order to appropriately safeguard the safety of people receiving DDA services.

Need for Further Agency Transparency: We continue to encourage the leadership at DDS to build stronger alliances with stakeholders. The lack of communication and outreach to the stakeholder community prior to the DDS decision not to extend the Georgetown contract created a significant breach of trust between the agency and stakeholders. In another example, despite assurances to the contrary at the March Budget Forum, in April of 2019, DDS began to institute several initiatives designed to limit the growth of services with the FY 2020 budget. Some of the changes were required in the HCBS Settings Rule, while others were instituted at the local level in order to control costs. While we understand reasonably controlling costs is a factor DDS must consider, the way in which this process was presented caused concern and anxiety for families and providers alike.

Due to our unique role as an external advocacy organization, DDS often invites us to sit on various stakeholder initiatives. We value the opportunity to offer our opinions in these venues. However, the timeframe provided for us to prepare and develop our official answers is uniformly minimal. It is not unusual for us to be given 72 hours or less to submit analyses of often complex material. Over the course of FY 2019, we received many calls from family members concerned by how little information was being shared when issues involving their loved one arose. Often what they are told by providers differed from what they heard from their Service Coordinator, which sometimes differed from what they heard from leadership within DDS -- resulting in differing answers to the same question. It is this dynamic that undermines trust and leads to heightened anxiety. This lack of trust often plays out around obtaining entry in or navigating within the DDS system. Whether it is related to services available, services offered or when services will begin, people supported, and their families need to trust that the information they receive is accurate

We see one of the activities DDS began in late FY 2019 as a good example of what is needed to build trust and collaboration within the stakeholder community. Director Reese has charged a work group of internal and external stakeholders to lead an initiative called "Creating a Culture of Quality." The process will involve a focused review of many of DDS's current activities to develop a better understanding what is and is not working. The work group will then make recommendations to Director Reese for changes that will improve systems and ultimately, outcomes for the people receiving support. This type of collaborative work and analysis is critically important and much needed.

We remain committed to working with everyone in our community to make life better for people with developmental disabilities and their families. Our community is stronger when everyone is respected and included in all aspects of community life. Thank you for your work to understand and support people with developmental disabilities in their quest to be active and contributing community members.