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

**Performance Oversight Hearing:  
The Department on Disability Service  
Fiscal Year 2018**

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

**February 21, 2019**

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 (DD) 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).

It has been two years since the *Evans* case was concluded. There are now approximately 2400 people who depend on DDS/DDA supports. DDS has continued to implement various initiatives focused on strengthening the service delivery system. To name just two:

- A Home and Community Based Waiver (HCBS) waiver renewal application submitted by the District in 2017, was approved by the Center for Medicare and Medicaid Services (CMS) in 2018, and is now being utilized by approximately 1400 people
- The Disability Services Reform Amendment Act (DSRAA) of 2018 became official law on May 5, 2018. The implementation of this law moves the District forward in respecting the rights and dignity of all its residents, by reforming civil commitment, recognizing Supported Decision-Making Agreements across the lifespan, and requiring the DC Department on Disability Services to create a formal complaint process that can be accessed by people receiving services from the Developmental Disabilities Administration

Fundamental changes of this kind require regulatory and policy changes as well. We encourage DDS to continue to work with their stakeholders on the changes that are needed to sustain system reforms into the future. DDS funding must be effectively utilized to support people today and in the future. As more people enter the system, appropriate utilization of both Medicaid and local dollars will become an ever-higher priority.

As noted in prior testimony, growth in the HCBS waiver over the past ten years has been a major achievement in the District of Columbia. There is no other way to maximize the

expenditures necessary to meet the needs of new applicants seeking DDS services going forward. Not only will requests for DDS services increase year after year, but we can identify at least two groups likely to require intensive support:

- former residents of Forest Haven as they continue to age, and
- people with intellectual disabilities who also have autism.

The highly specialized services required to assist these two groups (one predominately nursing, the other behavioral health in nature) share a common thread: they are expensive. That is why it is so important that other people whose needs are less extensive are not overserved. The ability of DDS to effectively assess people's needs and ensure effective services and supports for each is vital to the long-term viability of the system.

Ensuring access to quality and effective health care is a concern for everyone. It will be essential for former residents of Forest Haven as they age. Our monitoring data indicate that basic health care standards are being maintained for most people most of the time. We are in the beginning stages of a monitoring project that will help us look more closely at services and supports for people who go to the hospital unexpectedly. Such emergency hospital visits continue to be the most frequently reported serious incidents within the DC DD system. In addition, since the closing of Providence Hospital, QT staff members have heard concerns expressed by providers regarding hospitalizations. One provider nurse stated that a person she supported who was hospitalized at Washington Hospital Center (WHC) was being discharged before he was ready. He has since experienced a third hospitalization. The nurse expressed apprehension that so many people who previously went to Providence are now going to WHC. Another provider nurse complained about care from Holy Cross Hospital. She mentioned that the person she supports was discharged, even though she told them that the person was not well and not ready to go home. Holy Cross proceeded with the discharge and, within twenty-four hours, the person was re-hospitalized. We call on DDS/DDA and DHCF to closely examine how people who previously supported by Providence will be accommodated through emergency hospital visits to ensure people in the DC DD system are receiving the health care they require.

Many times, the kinds of issues that bring people to request advocacy from QT are rooted in dissatisfaction with the service and support experience at DDS. While much laudable work has occurred at the policy level, there are still numerous instances where people are not getting what they require, in the way they want, and with the urgency they need it. The disconnect between policy and practice was the cause of many requests for QT advocacy during FY 2018. Lack of urgency, problems with coordination and communication, and poor follow through by DDS service coordination and providers were the factors that drove most of our work in Fiscal Year 2018. For example:

- One person we met came to QT shortly before she was due to transition from special education into adult services. She was found eligible for DDA services at the beginning of July and was due to exit special education services in mid-December. DDS assigned a Service Coordinator in September. DDS held an ISP meeting in October and submitted the HCBS Waiver application package shortly after. Unfortunately, that waiver package remained pending eligibility when QT was contacted for advocacy support in November. This young woman had an active seizure disorder that required monitoring when her mother was at work, so she had an urgent need for in-home services the day after she exited school. This was a deadline of which the DDS Service Coordinator was aware, but had taken little urgent action to meet. When QT staff asked the DDS Service Coordinator to elevate the issue to his supervisor, she was told that he already had and that emergency services would not be approved. It took QT staff elevating this issue to the DDA Deputy Director to request interim funding be provided to meet this person's immediate health care needs upon her exit from school.

Ultimately, thanks to QT advocacy, DDS agreed to approve local funding to provide supports to this person until HCBS waiver services were approved. It is fortunate QT was involved, because, on the very first day of receiving adult services, this young woman experienced a seizure requiring intervention of the in-home support staff. Five months should have been plenty of time for DDS to engage in the planning necessary to ensure a timely and safe transition into adult services, had DDS staff appreciated the urgency of the situation.

- Another person came to QT in need of DDA residential services. His mother had completed the DDA application but was told by DDS Intake staff that the documentation she provided was not adequate. She disagreed and called QT for assistance. After some initial advocacy with intake staff, her son was approved. Once approved, finding a suitable placement was required. This person has autism and behaviors related to that diagnosis which are challenging, especially with unfamiliar people. He first moved into a respite situation because provider choices were limited. He then moved into a DDA-funded home with a roommate. That placement quickly deteriorated. Of significant concern to us were remarks made by the provider that they lacked experience working with people with autism. The police became involved during outings, and the provider decided that they could no longer support him. He then had to quickly move again. With the support of his mother, he chose another provider. Thankfully that placement has turned out to be successful. He also chose a day provider that could support him with the highly individualized support he needs. The amount of time required for success was seven months. Many of the barriers that caused the residential process for this person to take so long were avoidable. Two of these were the DDS/DDA rejection of documentation which clearly noted his intellectual disability and repeated delays in the process of finding a suitable residential provider. In the end, the QT advocate, not the DDS Service Coordinator, made calls and found the provider he and his mother chose. Developing his Behavior Support Plan (BSP) was also particularly problematic. Intensive follow through was required to ensure its timely development and staff training on its proper implementation. DDS must ensure existing providers receive enhanced training on supporting people with autism. We also urge DDS to proactively recruit more providers with proven success working with people with autism. Although DDS/DDA currently only serves people with a co-occurring diagnosis of intellectual disability and autism, our experience indicates that addressing the needs of this group of adults is not a current skill strength within DDS or the DDA provider community. We know that the number of people diagnosed with autism is increasing nationally.<sup>1</sup> According to the Autism Society of America, over the next ten years an estimated 500,000 people with autism will enter adulthood. DDS must be prepared to support that population within its DDA system.

DDS is making important changes in the structure of its DDA services and supports. The continuation of the efforts to become a Person-Centered Organization and numerous policy changes in the District are excellent examples of this progress. Our recommendations for the current Fiscal Year are that DDS:

- Acknowledge that such changes are disruptive and have negative impacts on the day-to-day lives of people with disabilities and their families.

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<sup>1</sup> According to the Center for Disease Control (<https://www.cdc.gov/ncbddd/autism/data.html>), 2014 surveillance data indicated approximately 1 in every 59 children was diagnosed with autism, while 2000 surveillance data indicated 1 in every 150 children had that diagnosis.

- Contentiously offer opportunities for the public – including people most affected by proposed policy changes – to provide informed and meaningful input into what change looks like in their lives.
- Redouble its efforts to establish an operating formal complaint process that people impacted by such policy changes can easily access to have their grievances heard. Proposed regulations for that process are long overdue – by over 8 months, according to the DSRAA.<sup>2</sup>
- Ensure Service Coordinators at DDA, Case Managers at RSA, and DD providers to do everything in their power to coordinate their efforts more closely, so that people supported by DDS experience positive life outcomes.

Thank you, and I am glad to answer any questions.

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<sup>2</sup> See D.C. Code 7-761.09 (a-2) (requiring the Mayor to issue proposed regulations within 45 days after the effective date of the DSRAA, which was May 5, 2019, and then submit them to the DC Council for review).