

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

**Performance Oversight Hearing:
Department on Disability Services
Fiscal Year 2023**

**Councilmember Janeese Lewis George
Committee on Facilities and Family Services**

February 23, 2024

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. We 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 on 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 from year to year.

My testimony summarizes our assessment of DDS' performance in some key areas over FY 2023. DDS remains at the center of a complex system including multiple government agencies, private providers, attorneys, advocates, families, and most importantly people who have intellectual and developmental disabilities. Progress was made in beginning to realign the way services are provided but challenges persist.

Multiple factors are coming together which will alter how services and supports will be provided, financed, and used by the people supported by DDS in the decades to come. With implementation of the Developmental Disability Eligibility Reform Amendment Act (DDERAA) beginning on October 1, 2022, we anticipated we would see a bigger increase in people entering the system than the number provided by DDS in their pre-hearing answers. We also thought we might see an increase in enrollment into the Individual and Family Support (IFS) waiver, as well as the use of self-directed services contained in that waiver. As we noted in our annual monitoring report for last year, though, we did not see significant changes in these areas. As noted in DDS' answers to the Council's questions, significant vacancies remain in both waivers. DDS also noted that over the past two years, there has only been a net increase of 120 people entering the system. So, while we still expect significant change in the years to come, we did not see it last year.

This year was the first year the HCBS Setting Rule was expected to be fully implemented in all states throughout the country. As the Rule made clear, development of a system of services and support based in professionals and providers making decisions for people with intellectual and developmental disabilities is an outdated paradigm. States were challenged to develop structural changes that would ensure more autonomy and opportunity for real community inclusion for people receiving services through the HCBS waiver model. What we found was despite new expectations for community-based services, there was little change in the day-to-day lives of the people we met. In that sense FY 2023 was a continuation of top-down decision-making that has defined service delivery for decades. The choice of where and with whom one lives is still the product of decisions made by others much more than people themselves. It is clear changes of this magnitude will take time.

When it comes to where and with whom people live, the continued practice of filling vacancies creates a limited pool within which people vie for what is available. The spirit of the HCBS Settings Rule has yet to be realized. We did encounter people who had their own room, but not a key they controlled to ensure privacy. Likewise, people have the use of their own debit cards, but not autonomy to control how and when they use it. Finally, most of the people we met who receive supported living have lease agreements with their provider relating to the apartments in which they live - a key element in the District's approved plan to implement the Settings Rule - but the provider maintains control over the lease with the management company. When we asked Direct Support Professionals what they understood the lease agreements to mean, many were unclear, and some were not aware of the document. For the many people who have never been able to exercise true autonomy, this reality goes unheralded. They simply go about their day-to-day lives in the manner they always have. Some people, especially those who have entered the system in the past few years, however, exercise their choice by coming and going from their homes on a schedule and for reasons of their own preference rather than that of providers, guardians, and government officials. The challenging work of giving people methods to create the wealth and true autonomy necessary to control their own leases is still years away.

The District of Columbia has come an exceptionally long way in developing a rational and cohesive system of services and supports for people with developmental disabilities. Despite all the challenges of COVID-19, and the changes and new mandates created at the federal level, we have seen real improvements to DDS's Incident Management and Service Coordination units. For example, DDS now collects data to inform system improvement. However, as we have learned through the Creating A Culture of Quality initiative, sorting that data, eliminating duplication, and streamlining it has proved elusive. Ironically, the purpose of the HCBS Settings Rule was to question and upend the assumptions that have governed the provision of community-based supports. In that sense the system that DDS created over the past decade must be reinvented. To give people more autonomy, government and providers must retain less. That change will be slow and difficult.

For over twenty years, Quality Trust has remained steadfast in our belief in the inherent dignity of everyone we meet. Since 2001 we have stood beside people with disabilities. As the nature and structure of community living changes, we will continue to stand with people as they aspire to live their best lives.

Thank you for the opportunity to testify this morning. Quality Trust appreciates your ongoing commitment to the struggle of people with intellectual and other developmental disabilities to assume their rightful place in the city. I will be happy to answer any questions you might have.