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

**Performance Oversight Hearing:
The Department on Disability Service
Fiscal Year 2022**

**Councilmember Janeese Lewis George
Committee on Human Services**

February 16, 2023

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. 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 from year to year.

My testimony will summarize some highlights from FY 2022, both the challenges encountered, and progress made by DDS in its role as the central player in the District's decades long effort to improve supports and services for people experiencing intellectual and other developmental disabilities. In several meaningful ways last year was a transitional year. While not completely behind us, the most serious outcomes of Covid-19 pandemic receded and became much more manageable. Likewise, a few key initiatives long in the making became official as the year ended.

The three years beginning in March of 2020 will be remembered primarily for the Covid-19 pandemic. A once in a generation public health emergency resulted in significant support disruptions. Thankfully the extremely dangerous outcomes from Covid-19 began to wane last year. A key metric used to measure the most serious effects of the pandemic is deaths. There were 81 deaths in 2020, in 2021 it dropped to 57, and last year the number was 39, which is in keeping with norms over the past at least ten years. According to DDS as of November of 2022 only 38 deaths from Covid have been confirmed since March of 2020. The remaining 100 deaths are above the statistical average for those two years. The number of non-Covid related deaths from 2020 & 2021 are still a concern. We are awaiting a report from DDS on what possible causes can be attributed to the elevated numbers. Other measures such as hospitalizations attributable to Covid, and the number of people supported and Direct Support Professionals receiving a positive test also diminished as the year progressed.

As noted, the pandemic did cause significant disruptions, but the work of creating a 21st century system of supports in the District of Columbia continued, nonetheless. The leadership team at DDS, led by Director Reese deserves credit for continuing system reform initiatives while also managing the Covid-19 pandemic. Here are a few high points.

- The Developmental Disability Eligibility Reform Amendment Act of 2021 (DDERAA) took effect on October 1st, so technically this year, but the effort of so many people to get it over the finish line occurred last year. The DDERAA expands eligibility for DDA services to people with developmental disabilities, not just intellectual disabilities. The passage of the DDERAA - something almost twenty years in the making - will usher in fundamental changes that will shape services in the decades ahead. It is not an overstatement to say that as FY 2023 begins, the system for providing supports and services to people with intellectual and developmental disabilities (IDD) in DC is being profoundly altered. The significant advancement realized in the new law through the collective efforts of people with disabilities, their families, government, providers, and community advocates demonstrated that positive change can be driven by a shared vision for the future. Our hope is that these collective efforts will be carried forward while the never-ending work of changing hearts and minds continues in FY 2023, and beyond.
- Concluding a long period of planning and execution undertaken during the pandemic, DDS/DDA received approval for a renewal of the IDD Waiver and an amendment to the IFS Waiver in the fall of 2022. The IDD and IFS Waivers are DC's primary funding sources for community-based, long-term supports for people with IDD. While similar day and employment, as well as health and wellness services, are available under both Waivers, residential services outside a person's natural or family home are only available under the IDD Waiver. There is also a \$75,000 annual limit on services available under the IFS Waiver. For individuals who want to manage their own services, self-direction is only available under the IFS Waiver. The introduction of self-direction in the IFS Waiver, though somewhat limited in scope is an important step in enhancing the enhancing the power of people with disabilities as they negotiate with providers and government to create supports and services they need. **SHAWN-SHOULD WE POINT OUT THE DISCONNECT IN THE REGS WITH DDS STATEMENTS HERE?**
- Likewise, we hope implementation of new policies and procedures designed to meet the mandate of the new Settings Rules directive from CMS will further strengthen people's ability to separate the services they need from providers in what is now a take it or leave it approach where people must accept the requirements of providers or service category types in order to get the supports they want.
- And finally, emphasis in each newly approved Waiver on innovative ways to utilize technology to reduce reliance on the traditional provider approach should, in the long term, offer some people more freedom without their having to compete for what will no doubt become limited slots within the HCBS Waiver.

All of these innovations are needed because the effect on staffing in all services-but in particular residential services- has reached a crisis- not just in the District but across the country. The Arc of the United States shares on its website "[W]ith an average annual turnover rate of 45 percent, an average wage of \$10.72 an hour, and an average vacancy rate of 9 percent, the needs of people with disabilities, their families, and the workers themselves are not being met."¹ While

¹ The Arc of the United States, "Direct Support Professionals: Why It Matters." Accessed at <https://thearc.org/policy-advocacy/direct-support-professionals/> on 12/29/22.

these are national figures and DC pay rates are slightly higher, DC has not been immune to the direct support professional (DSP) workforce crisis. Ian Paregol, Executive Director of the DC Coalition of Disability Service Providers is quoted in a 2021 Washington Post article, “The industry now is saddled with a *minimum wage* job where a prospective DSP [direct support professional] applicant is *more likely to contract COVID-19 than in virtually any other industry* coupled with a continually *ticking clock of attrition* (emphasis in the original).”²

- An increasing number of people being eligible for and seeking access to long-term IDD services in DC along with chronic shortages of staff could lead to the development of waiting lists in a city that has not previously experienced this situation. However, most states have been contending with such lists for years, if not decades. What, then, will the post-COVID, workforce crisis, new eligibility for supports and services District of Columbia look like?
- Two states have promoted one possible answer to meet the new reality by creating a growing role for remote supports and assistive technology. A report on Ohio Technology First, an initiative of the Ohio Department of Developmental Disabilities, notes that “Remote supports can be used by a variety of people, including those who have complex needs...Even if a person has restrictive measures, technology can be used to increase the person’s opportunities to live, learn, work, and thrive in their home and community.”³ An Impact article describes several examples from two Minnesota providers on how they’ve used technology, including sensors and adapted call devices, to create opportunities for more independent living. The article describes how “technology keeps staff informed of when individuals come and go, take medications, are in or out of bed, have an activated smoke detector, and so forth. The technology is also used to provide reminders and prompts directly to the person, only involving staff if the matter isn’t resolved.”⁴
- Use of these types of approaches will not only positively impact the workforce shortages currently confronting IDD providers, but as it reduces reliance on direct human support, it might also increase autonomy and freedom for some people receiving supports. In the District there is potential for use of technology for recipients of services and supports in both HCBS waivers beginning in FY 2023.

While many positive outcomes characterized FY 2022 at the systemic level, as the results of our monitoring work demonstrated things were uneven at the level of people receiving services and supports. As we have noted for the past three years three components of provider services continue to be problematic. They are communication, coordination, and documentation. Too often we encounter situations where due to the above medical diagnoses, current medication information and need for medical follow up are misunderstood, forgotten or otherwise not

² Vargas, Theresa, “Help (desperately) wanted: One low-wage job has become harder to fill during the pandemic, despite the nation’s high unemployment rate,” The Washington Post, February 27, 2021. Accessed at https://www.washingtonpost.com/local/help-desperately-wanted-one-low-wage-job-has-become-harder-to-fill-during-the-pandemic-despite-the-nations-high-unemployment-rate/2021/02/27/5f9d0b82-786f-11eb-948d-19472e683521_story.html on 12/29/22.

³ Ohio Department of Developmental Disabilities, “Technology First and the DSP Workforce Crisis: Ohio’s Future Paved By Technology,” August 2022. Accessed at https://dodd.ohio.gov/wps/wcm/connect/gov/5bba191b-519b-4675-9219-483dc6474f43/DSP+Workforce+Crisis+Data+%282%29.pdf?MOD=AJPERES&CONVERT_TO=url&CACHEID=ROOTWORLDSPACE.Z18_K9I401S01H7F40QBNJU3SO1F56-5bba191b-519b-4675-9219-483dc6474f43-od260Do on 12/29/22.

⁴ Henry, SandraLee, “New Technology Means New Options for People Needing Supports: A Minnesota Story,” *Impact*, Volume 31, (Number 1), Winter/Spring 2018. Accessed at <https://ici.umn.edu/products/impact/311/Technology/#Technology> on 12/29/22.

effectively conveyed between nursing and direct care staff. It is concerning that this continues to be a problem despite the numerous monitoring visits completed by DDS and DHCF.

Unless there is a significant re-imagining of the provider-based community living model that has been in place for decades, there is little reason to expect significant change. We believe that, in increasing models of autonomy enhancing supports for certain people will provide better results.

On a final note, the makeup of the IDD system in DC is complicated by the fact that there is an increasing number of young people who have never experienced institutionalization, and a decreasing number of older people who did. The needs of younger people now entering the system will need to become the focus for the system in the future. At the same time, the needs of older people cannot be minimized. Just one of many questions facing leadership is what the best course of action is to address both dynamics in a city whose healthcare system has been so dramatically altered by the Covid-19 pandemic.

Thank you for the opportunity to testify this morning, Chairwoman Lewis George. As we have since our founding in 2001, we look forward to working with you and all other stakeholders to navigate the new and, we hope dynamic system of services and supports on behalf of all people who experience developmental disabilities in the District of Columbia. I will be happy to answer any questions you might have.