

Testimony of QUALITY TRUST FOR INDIVIDUALS WITH DISABILITIES

Human Services Public Roundtable "The Response to the COVID-19 Public Health Emergency"

Councilmember Brianne Nadeau, Chairperson
The Committee on Human Services

November 4, 2020

Good afternoon, Chairperson Nadeau and other members of the Committee on Human Services. My name is Morgan Whitlatch, and I am the Legal Director at Quality Trust for Individuals with Disabilities (QT). QT is an independent nonprofit advocacy organization. Our mission is to help people with intellectual and developmental disabilities (IDD) 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. As such, we have been actively monitoring the impact of the COVID-19 pandemic for people with IDD and advocating for changes where needed.

We want to start our testimony by acknowledging the actions of DDS leadership in response to this unprecedented pandemic and public health emergency. This pandemic has required the creation of new strategies and systems to communicate about requirements and essential activities. DDS Director Reese has been meeting weekly with stakeholders and has made himself and his leadership team available to address issues as they arise - although coordination with other agencies within the government is often required to achieve the outcomes desired by people with disabilities. Director Reese also has participated directly with the stakeholder community in efforts to increase awareness of individual rights issues during the pandemic and help ensure practices are in line with policies and law.

Last week, QT expressed our concern about guidance from DC Health that impacts people supported by DDA at the public hearing held by Councilmember Gray and the Committee on Health. We are disappointed that there is not a greater effort by DC Health to develop fully informed and evidence-based interventions specific to the needs of people with IDD. While we respect DC Health's public health expertise and authority, we would expect that the agency would have greater interest in collaborating with the community of advocates and families when developing such guidance, to ensure that it not only is informed by their own knowledge of public health practices, but also best practices in supporting people with IDD. A disability stakeholder coalition collaborated on a letter to DC Health in early September outlining our specific concerns and received a written response less than 24 hours before the Committee on Health hearing. QT has asked DC Health to schedule a time to talk with us and the provider and stakeholder communities to gather information and ensure efforts to address needs are effectively coordinated with DDS. The lack of communication, outreach, or collaboration between DC Health, DDA, and the stakeholder community is not a new concern or limited to this

health emergency. For many years, it has been an issue that has yet to be adequately addressed by this or other DC government administrations.

We are very concerned that, after eight months of this pandemic, many people supported by DDA are staying at home with little meaningful engagement and with limited or no in-person contact with anyone other than staff. As a result, they are solely reliant on staff to provide them with what activities they do manage to participate in at home. Many times, the types of activities provided involve watching television or participating in tabletop activities. Long-term deprivation of skill-building, interactive, and community-based activities places people with IDD at a real risk of regression - of unlearning skills that they could once do independently. Enhancing people's lives during the remainder of this pandemic will require an infusion of new resources, strategies. and creativity. One area that could help address this concern is expanded use of technology. Many people with IDD could benefit from having access to a laptop or tablet for communication, learning, or enjoyment. Some resources have been made available through grants and small initiatives, as well as recent amendments to the DDA IDD Waiver. However, much more is needed to assess and address the needs of the large number of people who have not previously used technology in their daily routines. This must be an area of high priority, given that, for many people receiving DDA supports, there is no end in sight for this public health emergency, because they are a member a group designated as being at higher risk.

Monitoring what is or is not happening for people receiving DDA supports is another area of concern. Quality Trust has been able to continue our regular monitoring activities using remote strategies. We also have focused in on specific areas when concerns about people are identified through incident reports or other available data. For example, we note that, in the month of October, incidents of abuse, neglect, and serious physical injury were significantly lower than one year ago. We wonder why we are seeing so little in the way of serious reportable incidents, when people with IDD are spending so much time within confined spaces with little different or engaging activities to do. Overall incidents decreased by 42% this October compared with October 2019. Incidents of neglect declined from 29 last October to 10 last month, a decline of 66%. Similarly, serious physical injuries fell from 23 to 7, a reduction of 70%. We expect that DDS/DDA is also continuing with its ongoing monitoring processes through Service Coordination, Quality Resource Specialist, and Incident Management Enforcement Units. We encourage DDS to share the results of this work with the community, so that data such as this can be understood in the light of the significant restrictions so many people receiving DDA supports have had to bear during the pandemic. It is critical to be open and transparent about the issues being identified through these monitoring processes, so that any indicators of concern are acted on as early and as quickly as possible.

Finally, it also is important to address the issue of contact with family and loved ones for the people receiving residential supports through DA – especially people living in ICF homes. Our colleagues at Georgetown have spoken about the potential for mental health issues related to this pandemic and the impact of segregation. We would add to this our concern about people with IDD having limited in-person contact with familiar people who could provide the most emotional care and comfort. While we understand the need for precaution around the spread of the virus, it also is important to recognize the potential harm from the lack of physical and emotional contact with loved ones over extended periods of time. In addition, the lack of regular visitation eliminates external checks by friends, family members, and other non-staff supporters, making people more vulnerable to undetected abuse and neglect.

¹ See https://www.webmd.com/lung/news/20200615/how-to-cope-when-covid-steals-loving-touch-hugs

In summary, the COVID-19 pandemic has had a serious and disproportionate impact on the physical health of people supported by DDA. Many people with IDD are at higher risk because they cannot avoid coming into close contact with others who may be infected, such as direct support providers, family, and friends who provide assistance with activities of daily living. Many also may be at risk of poorer health care outcomes because of underlying health conditions. Protecting their physical health and safety requires vigilance. However, measuring the cost of the pandemic on people with IDD is more complicated than their higher risk of and from catching this virus. Public health guidance intended to keep them safe is having the unintended consequence of returning their lives to institutional patterns of service delivery, restricting them from safely engaging in activities in and outside the home that would provide both emotional support and opportunities to retain and further build skills to support independence. We must all be vigilant in recognizing and balancing these competing costs and in monitoring the unique impact of this pandemic for each person supported.

We express our thanks to Chairperson Nadeau for this opportunity to highlight the issues important to people receiving DDA supports and services, and we are happy to answer any questions you might have. We also want to thank Chairperson Nadeau for her leadership in acknowledging that there is a population of DC residents with developmental disabilities who are not eligible for DDA supports and services and who should not be forgotten during this pandemic. As always, Quality Trust is committed to working in collaboration with the District government and others in the community to ensure that people with IDD in DC receive the best possible support.

Submitted by:

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