

Testimony of Quality Trust for Individuals with Disabilities

Public Oversight Hearing: "The Public Health Element of the District's COVID-19 Response"

Councilmember Vincent C. Gray, Chairperson The Committee on Health

October 28, 2020

Quality Trust 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 needed by people are receiving or who may seek 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 first want to recognize the overall leadership from DC Health in responding to an unprecedented pandemic situation with strategies intended to manage and minimize the spread of the COVID-19 virus. Communications from the Offices of the Mayor and Director Nesbit have been critical to organizing and coordinating the community response in support of people with IDD in DC. We have greatly appreciated and relied on their education about expectations and practices regarding Personal Protective Equipment (PPE) and guidance about specific application of more generalized Centers for Disease Control and Prevention (CDC)recommendations to specific groups and situations. We are pleased that DC Health staff regularly participate on the weekly calls DDS holds with the stakeholder community.

However, as we have moved into the recent months of this pandemic, we have become increasingly concerned that the DC Health guidance provided does not clearly address the specific needs of the group of people with IDD supported by DDA. Even in the face of the disproportionate impact on people with IDD, we not aware of a concerted effort by DC Health to uncover the reasons for this impact so that required and recommended interventions are fully informed, and evidence based. Nor have we seen evidence of DC

Health reaching out to the provider and stakeholder community to gather information or ensure efforts to address needs are effectively coordinated with DDS.

Instead, DC Health's guidance has layered additional restrictions on some people receiving DDA supports, even when the general "stay at home" provisions of the Mayor's Order 2020-063 have been lifted for other DC residents. Troubling examples of this stigmatizing and outdated approach for serving people with IDD can be found in DC Health's Phase Two Guidance for Intermediate Care Facilities (ICFs)¹ We, along with other disability rights advocates and organizations, raised our deep concerns regarding this Guidance with Deputy Mayor Turnage and Director Nesbit on September 8, and just received a written response late yesterday morning.

Although DC Health revised their ICF guidance in response to some of our concerns – with new guidance² on indoor visitation released and dated as of yesterday– there was no direct contact with us about these changes until the response we received by email one day prior to this hearing. While we appreciate the investment of time and care that must have been given to these revisions and preparing the response to our concerns and comments, we respectfully suggest that direct dialog around these issues before DC Health issued its revised guidance may have been more productive to ensure a more thorough consideration of the important human rights issues involved. The transmittal email did indicate that DC Health was now "available to discuss" its response, which we will pursue.

Our remaining concerns include the following issues:

- It is important to recognize the community-based nature of DC's service system for people with IDD. Any guidance that adopts an institutional tone and imposes requirements not tailored to small, community-based settings is unacceptable. Unlike other jurisdictions, DC ICFs are in community neighborhoods and limited in size to 4 to 6 residents. They are more akin to residential habilitation homes than nursing homes. We must not shift backward and turn these homes into institutions.
- We have questions regarding the October 27, 2020 ICF guidance on indoor visitation. We hope that it represents an intention to no longer restrict indoor visitation to primarily compassionate care situations. Continuing to sequester people residing in ICFs absent anyone in or working at the home being exposed, symptomatic, or positive for COVID-19 will not only negatively impact their emotional health; it also eliminates external checks by their friends, family members, and other supporters, making them more vulnerable to abuse and neglect. The October 27 guidance also disincentivizes ICF providers from initiating indoor visitation, as it requires, as a prerequisite, for them to commit to having a sufficient supply of PPE to respond to an outbreak without depending

¹ Originally issued on August 5, 2020, this guidance was revised in October 2020 and is currently available at:

https://coronavirus.dc.gov/sites/default/files/dc/sites/coronavirus/page_content/attachments/COVID-19_DC_Health_Guidance_for_ICF_Phase_Two_2020-10-1.pdf.

https://coronavirus.dc.gov/sites/default/files/dc/sites/coronavirus/page_content/attachments/ICF_Indoor_V isitation_2020.10.27_FINAL.edited%20%282%29.pdf

on any public health stockpiles. Financially supporting safe visitation for residents in ICF should not fall solely on the shoulders of providers; it is the District's responsibility, too. While we fully recognize the importance of using universal precautions and PPE, we do not believe the need for these precautions should prohibit the ability for individual decision-making about visitation on a person by person basis. For some of the people in ICF's, the use of electronic communication cannot adequately address their need for contact with people who are most important to them. Our data indicate the number of people testing positive and dying from COVID 19 throughout the system has been decreasing since May and the last recorded death linked to COVID 19 was in August. We strongly encourage DOH to actively engage and work with DDS and the stakeholder community to develop any further guidance. The goal should be to effectively balance implementation of recommended precautions while also addressing individual needs for both physical and emotional well-being since we expect that we will all be implementing these guidelines well into the foreseeable future

- The October 2 revised guidance does not allow for individualized community activities for people living in ICFs other than medical appointments and nonmedical personal service activities. The allowable activities are strongly discouraged and the requirements for effective implementation are significant which is likely to result in effective limitation. While we fully understand the need for precautions, we also believe that individual decision-making must play a much larger role in determining what is and is not possible, since this guidance will be implemented for an extended period. The unintended result of people receiving these services in their home is a return to institutional patterns of service delivery, limited engagement in meaningful activities and an increase in the potential for abuse and neglect for the people living in these homes.
- The October 2 revised guidance requires universal eye protection to be worn by all direct care staff "in 1) care areas, and 2) any staff areas where 6 feet of distance is unable to be maintained. We are perplexed by the fact that this guidance is issued when there has been a significant decrease in the number of positive tests among people in ICF. Further, "care areas" is not defined, and we are concerned that would include community outings. Requiring eye protection during all times staff are supporting people with IDD seems to indicate a high degree of potential for transmission from people with disabilities to their staff – when in fact, the opposite is far more likely. Again, we find this guidance institutional in nature and stigmatizing to the people living in ICF's.
- The issuance of ICF and other guidance from DC Health that impacts people supported by DDA raises concerns regarding lack of interagency coordination between DC Health and DDS/DDA. DDS/DDA should be actively involved in developing and reviewing any guidance implemented within its system. DDS/DDA leadership knows how its community-based system of services supports works and how best to ensure practices are person-centered as much as possible during this public health emergency. Any disparate treatment of people with IDD who live in ICFs or any other Medicaid funded setting must be grounded in a human rights framework, fully informed by the unique residential

structure in the District, evidence-based, and consistent with best practices in the IDD field.

Along similar lines, during the time of general COVID-19 hospital visitor bans, we remain concerned that DC Health is not effectively ensuring that all hospitals it licenses are complying with their responsibilities under federal law to reasonable accommodate patients with disabilities who require in-person supporters while hospitalized in order to ensure their equal access to health care. A patient with a disability may require an inperson supporter to ensure effective communication, informed consent, and/or physical and behavioral support while in the hospital. The DC Hospital Association's current guidance^[1] to hospitals is not sufficient, as it is not characterized as mandatory and does not expressly apply to people with all types of disability who may need such inperson supporter if the patient with a disability is COVID-19-positive. DC Health instead should issue a notice modeled on the more legally sound one recently issued by its counterpart in Maryland^[2] on "Access to Support for Patients with Disabilities in Health Care Settings" (Sept. 24, 2020).

We recognize that the Mayor and DC Health, as the state public health agency in the District, have the authority to place restrictions on the DC community during this unprecedented COVID-19 pandemic. However, that authority is not unlimited, even during a pandemic. Under federal law, including the American with Disabilities Act, they are still barred from discriminating against people with disabilities and may not impose unjustified restrictions on people simply because they receive DDA-funded residential services and supports.

We thank Chairman Gray for organizing this public hearing to ensure the voices of all stakeholders are heard. We remain committed to working in collaboration with the District government to ensure that people with IDD in DC receive the best possible support.

Respectfully Submitted:

Tina Campanella, CEO Morgan Whitlatch, Legal Director Jimi Lethbridge, Deputy Director of Programs

^[2] <u>https://phpa.health.maryland.gov/Documents/2020.09.24.01_MDOD_MDH_Notice%20-</u> %20Access to Healthcare Facilities.pdf