



Kerstin Sjoberg, Executive Director of Disability Rights Ohio
Written Testimony for the Minority Health Strike Force
June 19, 2020

Disability Rights Ohio (DRO) appreciates the opportunity to provide written testimony to the Minority Health Strike Force regarding health disparities in the state. DRO is the state designated and federally authorized protection and advocacy system with the mission to advocate for the human, civil, and legal rights of people with disabilities in Ohio. DRO has been working on addressing the impact COVID-19 is having on people with disabilities. The pandemic has exacerbated issues that exist in our service systems disproportionately affecting people with disabilities.

Disability Rights Ohio applauds the Minority Health Strike Force for addressing the issue of systemic racism by using data and empirical evidence to find effective solutions to health disparities. False information that derives from racial stereotypes and tropes is dangerous and unhelpful. For people with disabilities, stereotypes and judgements about abilities or quality of life can impact service delivery and lead to discriminatory practices.

DRO would like to address three (3) themes for the Strike Force in this testimony:

1. Healthcare which includes **rationing care policies, visitation policies, and access to home and community-based services and supports;**
2. Data which includes increasing testing to capture **data on people with disabilities impacted by COVID-19** and specifically those in long-term care facilities; and
3. Education and outreach ensuring individuals and families have **access to information and services.**

I. **Healthcare**

a. Rationing Care

Distributing scarce resources should not be discriminatory towards people with disabilities. Specifically, hospital policies need to be clear, robust, statewide, and enforceable. People with disabilities can be penalized in rationing decisions for having disabilities unrelated to their ability to respond to COVID-19 treatment. Allocation of scarce resources should not be based on stereotypes, assessments of perceived quality of life, or judgments about a person's relative "worth" based on the presence or absence of disabilities or age.

Exclusionary criteria based on diagnosis that de-prioritizes people with certain diagnoses are particularly problematic. Individualized assessments, based on the best available objective

medical evidence to determine one's ability to respond to treatment and short-term survivability, is the standard that should be followed. References to "long-term survivability," which is notoriously difficult to predict, tend to discriminate against people with disabilities, as does language about de-prioritizing "older" or "sicker" patients and those who need more time or resources to recover, in favor of "young" or "healthy" patients.

Finally, to ensure transparency and accountability, hospitals should have an appeal process when life-saving care is denied due to rationing protocols.

b. Visitation policies

Currently, there are no statewide enforceable standards on visitation policies and many hospitals have strict no-visitor policies, as a protection against the spread of COVID-19. People with disabilities seeking care in a hospital may need exceptions to these strict policies to allow them to have a family member, caregiver, or provider present where necessary to ensure equal access to care and treatment. Patients with disabilities may need a support person in the hospital due to altered mental status, intellectual or cognitive disability, physical disability, developmental disability, communication barriers or behavioral concerns. The CDC has published guidelines regarding safe accommodations for essential visitors.¹

A common reason for needing a support person is to ensure effective communication with the person with a disability. Effective communication requires different supports for different people, depending on their communication needs (non-verbal cues, modeling words, information simplification, ASL interpreters, and use of assistive technology). Effective communication is necessary to ascertain pertinent medical information and histories, and secure informed consent. The lack of accommodations and effective communication can lead to sub-optimal clinical outcomes, the use of unnecessary physical and chemical restraints, and the risk of bias and misplaced assumptions and stereotypes influencing care decisions.

c. Access to home and community-based services and supports

It is critical for the state to maintain funding for home and community-based services and supports as congregate care settings become dangerous for people with disabilities. Currently, 70% of deaths reported due to COVID-19 are from long-term care facilities.² As you know, the home and community-based service systems were stressed before the pandemic and reducing funding to these services could force people into long-term care facilities, putting them at greater risk.

¹ The Centers for Disease Control and Prevention. *Management of Visitors to Healthcare Facilities in the Context of COVID-19: Non-US Healthcare Settings*. <https://www.cdc.gov/coronavirus/2019-ncov/hcp/non-us-settings/hcf-visitors.html>

² The Columbus Dispatch. May 21, 2020. 70% of Ohio coronavirus deaths have occurred in long-term care facilities. <https://www.dispatch.com/news/20200521/70-of-ohio-coronavirus-deaths-have-occurred-in-long-term-care-facilities>

Further, those receiving service in the community must be protected. Individuals with disabilities rely on direct service professionals to receive care in the community and access to PPE has been limited. Therefore, there is a need for additional funding to ensure PPE for direct service professionals.

The COVID-19 pandemic shifted how services are provided to individuals. The Ohio Department of Medicaid, through their 1135 and appendix K waivers, approved providing services via telehealth. However, not all people with disabilities have access to the internet or technology. Specifically, over 1 million Ohioans do not have access to broadband internet.³ To ensure individuals continue to receive services the state should consider providing additional funding for providers to 1) purchase technology for clients to access telehealth services; and 2) maintain in-person services for those unable to access and use technology.

Additionally, ensuring individuals have access to intensive case management services is critically needed, especially for those at-risk of institutionalization. As you know, social determinates of health include transportation, housing, and proximity to goods and services.⁴ Therefore, services should be streamlined and expanded in areas where access to housing, transportation, and goods and services are limited ensuring individuals can stay in their communities preventing placement into long-term care facilities.

II. Data

a. Testing

There is a need to ramp up testing in long-term care facilities and those receiving home and community based Medicaid services. This additional testing will help inform where the state needs to focus its efforts to protect people with disabilities.

b. Disability Data

The state should expand the information it gathers from its testing to see the extent that COVID-19 has impacted people with disabilities. The state should capture data on the number of individuals with disabilities who have died due to COVID-19. Again, specific disability data will help the state indicate areas of need to focus its supports.

c. Long-term care facilities data

The Ohio Department of Health captures cases and deaths in long-term care facilities but it does not break down the types of facilities and the number of deaths or cases in those facilities. The

³ Innovate Ohio. *The Ohio Broadband Strategy*.

<https://innovateohio.gov/wps/portal/gov/innovate/priorities/resources/broadband/>

⁴ Kaiser Family Foundation. May, 10 2018. Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity. <http://files.kff.org/attachment/issue-brief-beyond-health-care>

state should be showing a breakdown of that data and a total of cases and deaths per facility type.

III. Education and Outreach

Information regarding COVID-19 is distributed through the ODH website, but information about service system changes are often on other agency websites such as the Ohio Department of Developmental Disabilities. To ensure people with disabilities and their families have access, this information should be made available in plain language and distributed broadly throughout service systems. This would include working with providers and local behavioral health and developmental disabilities boards to get the information to individuals

Plain language information will help: 1) inform individuals and their families how to mitigate the spread of COVID-19; and 2) inform individuals and families on service options available and service changes occurring in the service systems

DRO appreciates the opportunity to provide written testimony to the Minority Health Strike Force and how the COVID-19 pandemic is impacting people with disabilities. If you have any questions or wish to discuss these issues further feel free to reach out to myself or Jordan Ballinger, Policy Analyst (614-466-7264 x135 or jballinger@disabilityrightsohio.org).