



May 4, 2021

The Honorable Elizabeth Warren
United States Senator
309 Hart Senate Office
Washington, DC 20510

Dear Senator Warren:

On behalf of the American Network of Community Options and Resources (ANCOR), I write to express appreciation for the Equitable Data Collection and Disclosure on COVID-19 Act of 2021 (S.512), and also to share some thoughts on the disability-focused data collection. We are grateful that the legislation explicitly calls for disability-specific data, and share some insights we compiled from our members, and self-advocate and state groups [in this document](#). We hope you find it a useful resource as you work on these issues.

ANCOR is a national, nonprofit trade association representing more than 1,600 private community providers of services to people with intellectual / developmental disabilities (I/DD). Combined, we support over one million individuals with disabilities, and work to shape policy, share solutions and strengthen community. The Direct Support Professionals (DSPs) our members employ have been on the frontlines of the pandemic. DSPs help people with disabilities remain safe at home rather than in congregate settings where they are more likely to contract COVID-19, by assisting with essential tasks such as grocery shopping, daily hygiene and making good health decisions.

We appreciate that S.512 gives a seat on the proposed Commission on Ensuring Data for Health Equity to the Chairperson of the National Disability Council, which is knowledgeable on many cross-disability issues. We also appreciate that the Commission's duties include collecting data on access to vaccines, as when COVID-19 vaccines first became available many of our members flagged that they had difficulties getting their states to prioritize people with intellectual / developmental disabilities for vaccination, despite this population being more likely to die if they contract the COVID-19 virus than the general population.

We would like to bring your attention to the challenges and health care inequities caused by the absence of electronic health records systems in Medicaid disability programs. Reliance on paper records has broad ramifications for data collection, as well as health care delivery and quality of life for people with disabilities. We delve into some of those in the aforementioned document. Additionally, because of the intimate nature of some Medicaid disability supports, the well-being of DSPs cannot be separated from the well-being of people with disabilities. This workforce is largely comprised of women and minorities, so as you consider future data collection policies, we encourage you to consider DSP-specific data as well as it could enhance policy-makers' understanding of the challenges both in the disability community and larger population groups.

We are happy to further discuss these issues with you and thank you again for your work on behalf of the disability community. Please contact me at smeek@ancor.org should you have any questions.

Sincerely,

A handwritten signature in black ink that reads "Sarah Meek". The signature is fluid and cursive, with the first name "Sarah" and last name "Meek" clearly legible.

Sarah Meek
Senior Director of Legislative Affairs

Cc: Senate HELP Chair Murray
Senate HELP Ranking Member Burr
Sen. Baldwin
Sen. Blumenthal
Sen. Booker
Sen. Kaine
Sen. Klobuchar
Sen. Markey
Sen. Merkley
Sen. Rosen
Sen. Stabenow
Sen. Van Hollen
Sen. Wyden