



## CURRENT CHALLENGES IN COLLECTING DISABILITY COVID-19 DATA

- How COVID-19 cases are reported varies by state. Within states, it also varies by Medicaid program – for example, Home and Community-Based Services (HCBS) programs report COVID-19 cases to critical incident management agencies, while Intermediate Care Facilities report to state public health agencies. There is an additional level of variance within Medicaid programs based on settings (e.g. residential, living with family, etc.).
- Most COVID-19 case reporting focuses on the name of the individual, the location that was affected, and where the individual is quarantining – generally speaking, the reporting does not have demographic data.
- How disabilities are categorized and pathways to Medicaid eligibility also vary greatly by state, which greatly complicates attempts to aggregate data by type of disability or through disability proxies such as eligibility for certain Medicaid programs.
- Additionally, while we have an idea of the amount of people with disabilities eligible for Medicaid programs, that does not capture the full disability community, e.g. people not on state waiting lists, who are undiagnosed, or who simply do not interact with the Medicaid system.
- Finally, some states aggregate staff and individual supported data, making it even harder to understand the spread of the COVID-19 virus in different communities. This is also a challenge being encountered with reporting on vaccination roll-out.

NEEDED TO MEANINGFULLY STRENGTHEN POLICY-MAKING THROUGH DATA:

### **Federal investment to create an electronic health records (EHR) infrastructure for Medicaid disability supports.**

*Rationale:* Disability supports were largely left out of EHR systems developed through Medicare and the Affordable Care Act, and created data gaps which left Medicaid disability programs ill-equipped as the pandemic spread nationwide, and during COVID-19 vaccination deployment. Many states still maintain paper records for disability supports beneficiaries, which hindered tracking the spread of the disease in the community and affected states' ability to rapidly respond. In addition to allowing for tailored responses as the population becomes affected, an EHR system would provide access to case management and billing information, which contains valuable demographic information such as race, gender and type of disability. This would allow for more consistent analysis, overcoming data gaps caused by: large state variations in how disabilities are defined; different Medicaid eligibility pathways; and differences in COVID-19 case reporting mechanisms by state and by disability program.

*Potential case studies to further inform policy-making on this topic:* Two states – Pennsylvania and Missouri – had developed their own electronic health records that made their early pandemic response stand out. In the case of Pennsylvania, the state also has excellent protocols to facilitate vaccine roll-out. What would be needed to assist other states in creating similar systems?

### **A survey of additional areas of expenses created by the pandemic, to inform future policymaking and budget planning.**

*Rationale:* the pandemic created many unforeseen expenses, such as the need for personal protective equipment (PPE) in supports that traditionally did not employ them. As a result of these unforeseen expenses, many providers struggled to maintain their staff / service levels during the pandemic.



Developing an understanding of these expenses will be essential so federal and state policy / budget planners can develop appropriate funding mechanisms in future public health crises.

### **Financial support for providers to comply with data reporting.**

*Rationale:* In a typical I/DD supports agency, over 85 percent of staff consists of Direct Support Professionals (DSPs) who offer frontline support to people with disabilities to meet their everyday needs and keep them healthy and safe. Due to chronic vacancies and high turnover in this field, which has been exacerbated by the pandemic, DSPs typically work long hours. Their immediate supervisors are often also helping fill service gaps caused by vacancies. Particularly when supporting high-needs individuals, they have little time to fill out report forms, and agencies have little additional administrative staff to help with the process. This puts providers in the unenviable position of having to decide whether their frontline staff spend time supporting consumers or complying with reporting requirements. Policymakers should recognize the financial / administrative burden placed on providers as they cover labor costs related to additional reporting and allow providers to bill for that time and/or hire more administrative staff to assist with the process, as well as develop flexible and user-friendly reporting protocols / systems. Some issues to consider are lack of state infrastructure regarding data collection, and the need for providers and state systems to be compatible with each other.

### **A study of Direct Support Professional (DSP) mortality and health risk during the pandemic.**

*Rationale:* Many DSPs could not socially isolate from the individuals they supported during the pandemic because of the personal nature of the tasks with which they assisted. However, because state reporting requirements on staff varied or at times were aggregated with individual supported data, and because the DSP overall tends to be classified under the much broader home health aide workforce, it is unclear how at risk they were during the pandemic. Understanding this would assist with developing stronger guidelines on who qualifies as essential staff (which currently varies by state), who can obtain priority access to PPE, and other key pandemic response considerations. We strongly recommend that Direct Support Professionals be considered essential workers in future health crises.

RECOMMENDED IN ADDITION:

### **Research into best practices that reduced transmission rates during the pandemic.**

*Rationale:* Because the COVID-19 virus' high contagiousness led to supports having to rapidly and frequently change their protocols, many providers had to innovate to keep individuals supported and their staff safe and healthy. Understanding which practices helped curb transmission rates could help establish forward-looking best practices for future public health emergencies.

*Potential case studies to inform future policy-making:* Some ANCOR members shared that tracking the trends listed below helped them have a clear assessment of their ability to respond to crisis points.

- DSP vacancy rates;
- DSP availability at the shift level (e.g. day, evening and overnight shifts);
- Availability of PPE;



- Hospitalization and hospital visit trends. Specifically, one member noticed a decrease in frequency since the pandemic, so they are currently assessing what types of health services could be better delivered in the community.

We hope to get a preliminary sense of these trends in early 2022, when the 2020 National Core Indicators Survey will be released, as it included questions about staffing issues related to the pandemic.

In terms of external data tracking, one ANCOR member shared they were able to adjust their COVID-19 testing once they started receiving data from their county on the spread of COVID-19 in the region – they increased testing as regional cases increased, and decreased accordingly as well.

#### **Federal investment to survey program beneficiaries on their pandemic experience.**

*Rationale:* The perspective of disability supports beneficiaries on how the pandemic affected their quality of life, the ability of staff to adhere to individuals' person-centered plans, and more is irreplaceable. It will also be important to ensuring that programs are working as they should for the individuals who rely on them. However, there is little such COVID-19 specific data available at this time and this research would need a national scope to reflect differences in state Medicaid models, etc., justifying federal investment in and oversight of the research.

#### **Research identifying technology challenges and innovations that arose during the pandemic.**

*Rationale:* The pandemic prompted a large expansion of the use of telehealth, digital and/or phone technologies. However, due to variations in state regulations, differences in appendix K waiver applications, and infrastructure (particularly broadband access or lack thereof), not all states, localities, programs and providers were able to leverage that technology in the same way. Understanding and developing solutions for challenges that arose from technology during the pandemic, and scaling up innovations that improved outcomes for people with disabilities, will be important not only for any new public health emergencies but for the future of disability programs overall.

#### **An analysis of the overlaps, gaps and opportunities for cooperation between public health response and disaster relief agencies.**

*Rationale:* ANCOR members interacted with state emergency planning agencies to obtain PPE early in the pandemic, as well as the National Guard to assist with large-scale testing (e.g. an agency testing over 200 staff and individuals supported) and also obtain PPE. However, most did not in part because they were not even aware of disaster relief agencies' work on COVID-19 response, and because state reliance on disaster relief agencies varied. Many providers did not know where to turn to in their local area for assistance with emergency management (EMA). This variation contributed to disparities in pandemic response across the country. Understanding how public health and disaster relief agencies can cooperate will ideally lead to updated pandemic response frameworks for future crisis. Including providers in local emergency management plans is needed.