Experiences of Direct Support Professionals Supporting Adults with Intellectual Disabilities in DC During the Early Phase of the COVID-19 Crisis

Caitlin Schille Jensen, MPH; Tawara D. Goode, MA; Deborah F. Perry, PhD; Vivian Jackson, PhD; Robin Shaffert, JD; Joan Christopher, JD

Purpose and Background

Our purpose was to gather information about the lived experiences of DSPs during the early phase of the COVID-19 pandemic in the District of Columbia to inform our training, technical assistance, research, and advocacy at the Georgetown University Center for Excellence in Developmental Disabilities (GUCEDD). Per recent data from the DC government, 345 direct support professionals (DSPs) have tested positive for COVID-19, and 8 have passed away, representing a large cohort of minimum wage staff in DC.

Methods

- Mixed methods approach
- Rapid response environmental scan to quickly attain timely and needed information
- Brief web-based survey and qualitative semi-structured interviews with DSPs

Sample Description

- The 162 survey respondents were predominantly Black or African American (89%) and Female (74%)
- The 20 interviewees were sampled from survey respondents
- Interviewee characteristics were similar to survey respondents, indicating a representative sample

Results of Survey and Qualitative Interviews

Survey Results

- 65% had to miss work/stop working due to COVID-19 infection, fear of COVID-19, fear of infecting others, transportation, child care, other family issues, or other reasons
- 84% are the primary wage earner in their household
- 68% have worked as DSP for more than 3 years
- Nearly all worked in small (2-6 person) residential habilitation settings, supported living, intermediate care facilities, and/or natural home settings

Interview Exemplary Quotes

“I’m 59 years old. I’m almost senior myself. Exposing me to COVID would not be good.”

“It’s very taxing, when you get home your kids cannot hug you, your husband cannot touch you.”

“I wish that the government sees us like a valuable person, just like they see our government workers, nurses, doctors, policeman, firemen.”

“I don’t use the front door to get into my house. I have to immediately take a shower…while I’m at home, I always make sure I have my mask on around my kids so I don’t expose them or my family members.”

Discussion and Implications

Results highlighted the juxtaposition between how dedicated DSPs are to their work, and how little they are compensated and feel respected for their essential work. Many DSPs spoke about how much they worry about and care for the people with ID they support. Another emerging theme was how the pandemic has increased the complexity of DSPs’ work, as people were unable to participate in their normal community-based activities.

Acknowledgements

Funding provided by the GUCEDD core grant provided by the U.S. Department of Health and Human Services, Administration for Community Living. Special thanks to Ian Paregol at the DC Coalition of Disability Service Providers for distributing the survey.