Introduction and Background

The direct support workforce provides an array of critical supports making it possible for people with intellectual and developmental disabilities (IDD) to live, work and thrive in their communities. These professionals perform multiple tasks, at any given time during the course of their work, which may be similar to those of teachers, nurses, psychologists, occupational therapists, physical therapists, counselors, dieticians, chauffeurs, personal trainers, and others. There is no Bureau of Labor Statistics occupational classification for direct support workers and they are often categorized with home health aides, personal care assistants, certified nurse assistants, and others. Providing home and community-based supports for people with IDD, however, requires specialized skills and competencies that are not reflected by the low wages due to underfunded Medicaid-reimbursed rates, limited access to benefits, and lack of respect afforded to this essential workforce.

The shortage of direct support workers is well documented. Over 50% left their positions in 2018 with one-third leaving in the first six months of employment and vacancy rates are near 15% for full-time and 18% for part-time positions (National Core Indicators, 2019). As a result, many direct support workers, supervisors and other staff consistently have to work overtime to provide supports, yet sometimes people with IDD go without supports. Family members are called upon to provide these supports which affects their availability to maintain employment. With the pandemic, social distancing guidelines and stay-at-home orders have negatively affected the lives of people with IDD and the supports they need. As such the University of Minnesota and National Alliance for Direct Support Professionals collaborated to lift up the voice of the direct support workforce. The aim of this study was to gather evidence about the experiences of the direct support workforce during the COVID-19 pandemic and to inform efforts to better prepare for future waves of this pandemic.

A direct support worker was defined as an employee who spends at least 50% of their time providing supports for a person with IDD. Almost 9,000 direct support workers from the U.S. completed the survey between April 23-May 27, 2020. At least one survey was received from every state. Nearly 60% of respondents were employed in the direct support workforce as their primary job for more than 36 months and 18% were employed less than one year. A little over 60% worked in agency/facility sites, 39% worked in individual or family homes, and 17% worked in day program or employment services. While 96.8% self-identified as an essential worker, when the pandemic hit in the U.S., states were slow to identify direct support workers as essential.

Wages and extra pay

- 74% are primary wage earners in their household
- $13.63 average wage of DSP before pandemic
  *This is higher than the national median wage of $12/hour due to most respondents having worked in their positions for more than 3 years.
- 24% are receiving extra pay due to COVID-19 risks

Of those receiving extra hourly pay:

- 21% received more than $3.01
- 19% received $1.00 or less
- 45% received $1.01-$2.00

Additional hours worked per week

- 29% 1-15 hours
- 10% 16-30 hours
- 15% 31+ hours

Respondents experienced significant schedule changes

- 34% working more hours
- 18% working fewer hours
- 30% working different shifts
- 29% working in different settings
- 26% reported they were more short-staffed than before the pandemic

Pandemic effects on DSP turnover

- 42% knew someone in the DSP workforce who left their job due to the pandemic. Of those:
  - 34% feared becoming infected
  - 25% had childcare issues
  - 13% feared infecting others
  - 9% left after testing positive for COVID-19

Other reasons for leaving included caring for family members, being furloughed or laid off when a program closed, having hours cut, mental strain, or receiving more income from unemployment as compared to working.
Moving Forward – What is Needed

Comprehensive, organized and funded response plans at national and state levels for additional waves of COVID-19 and future pandemics. This workforce needs to be officially identified as essential and have access to PPE to protect their health and safety. Establishing a standard occupation classification for direct support workers would aid these efforts.

Wage increases for essential workers commensurate with the increased level of exposure. Direct support depends largely on human interaction, placing workers at increased risk for contracting COVID-19. Only 24% respondents indicated they were paid higher wages during the pandemic and many employees were working a high number of overtime hours.

Access to career ladders. 74% of respondents indicated they were primary wage earners in their household, earning an average of $13.63 per hour. This workforce should have access to career ladders and credentialing programs that result in increased wages and access to benefits.

Increased training on health and safety. 27% of new hires during the COVID-19 pandemic were reportedly not getting typical orientation and preservice training. Comprehensive safety training needs to be provided at the onset of a public health crisis.

Access to childcare and support if schools or daycares close. Ensuring essential worker status specific to this occupation would prioritize childcare availability for these families in most states.

Professional recognition of direct support. Direct support workers have always provided critical, essential supports. The average wage of $13.63 per hour prior to the pandemic is not reflective of the skilled nature of the work.

People with IDD need education and training on handwashing, hygiene, and social distancing. This should be ongoing.

Ensure access to technology for people with IDD that allows social interaction with others Invest in technologies that help people have greater control over their lives.

Develop evidence-based strategies for teaching people with IDD to use telehealth. Work with the medical community to eliminate disparities and ensure people get the healthcare they need.

Review of policies to ensure person- and family-centered practices with informed decision-making regarding social contacts during a pandemic. People with IDD and their families should be involved in decisions affecting them.

Reference
Please contact Jerry Smith with questions at smith495@umn.edu. The full report will be available in August 2020 at z.umn.edu/dsp-covid19.
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### DSP access to personal protective equipment (PPE)

<table>
<thead>
<tr>
<th>Type of PPE</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>84% gloves</td>
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<tr>
<td>53% homemade masks</td>
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<tr>
<td>46% medical-grade face masks</td>
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<tr>
<td>10% home-repair style masks</td>
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Many reported they had access to “other” types of PPE such as face shields, gowns/lab coats/ponchos, goggles/eyewear, shoe covers, hair/beard covers, bandanas for masks, and garbage bags for gowns. Some reported they were given money by their employer to purchase their own PPE.

### Safety measures put in place by employers

<table>
<thead>
<tr>
<th>Measure</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>72% posted signs on proper handwashing</td>
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<tr>
<td>66% took employee temperatures</td>
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<tr>
<td>66% provided training on health and safety</td>
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<tr>
<td>59% posted signs on social distancing</td>
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<tr>
<td>10% provided COVID-19 testing</td>
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### Social distancing practices of people supported

- 60% good/very good
- 24% fair
- 16% poor

### Allowed to see their family or friends in person

- 64% never
- 16% seldom
- 10% sometimes

### Consequences of isolation on people supported

- 80% boredom
- 57% mood swings/depression
- 52% increased behavior issues
- 48% loneliness
- 47% sleeping more than usual