Preliminary Results from COVID-19 Survey for Adults with IDD

Christine Brown, Margaret Rosencrans & Andrew Buck
The Ohio State University Nisonger Center
Adults with intellectual and developmental disabilities (IDD) are at increased risk for:

- **poor mental health outcomes** (Cooper, Smiley, Morrison, Williamson, & Allan, 2007)
- **poor employment outcomes** (Butterworth, Hiersteiner, Engler, Bershadsky, & Bradley, 2015)
- **social isolation** (Abbot & McConkey, 2006)

*Increased risk before the COVID-19 pandemic*
Literature Review

Racial and ethnic minorities are at an increased risk of getting sick and dying from COVID-19 due to systemic health and social inequities/disparities:

- **Discrimination** (e.g., racism, chronic/toxic stress)
- **Healthcare access and use** (e.g., uninsured, transportation)
- **Education, Employment, and Income** (e.g., non/essential work, paid leave)
- **Housing** (e.g., living in groups or crowded conditions, homelessness) (CDC, 2020)
Literature Review

Family caregivers have reported more negative effects than non-caregivers:

- **Social Isolation**
- **Anxiety and/or Depression**
- **Fatigue and/or Sleep Disturbance**
- **Financial Hardship and/or Food Insecurity**
- **Worry about getting sick or being a vector to care recipient**
- **Interrupted access to care for self or care recipient**

(National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh, 2020)
Literature Review

Even greater negative impacts were reported by caregivers who identify as:

- Female
- Minority
- Younger
- Having less education and/or lower income
- Caring for persons with mental health or behavioral issues
- Living with the care recipient

(National Rehabilitation Research and Training Center on Family Support at the University of Pittsburgh, 2020)
Service providers of intellectual disability or autism have reported greatly reduced capacity due to COVID-19:

- **Transportation** (80% decrease in individuals served)
- **Community Participation Supports** (68% decrease)
- **Supported Employment, Small Group Employment** (40% decrease)
- **Turn-Over Rates** (56% between April – July 2020; 31% in June 2019)

(Pennsylvania Advocacy and Resources for Autism and Intellectual Disability, 2020)
Literature Review

Barriers reported by Direct Service Providers:

- **Risk to self or household members** (65%)
- **Wages** (42%)
- **Educating Children at Home** (40%)
- **Poor Health or Higher Risk** (37%)
- **Child Care** (36%)
Literature Review

Thus, COVID-19 may have a uniquely negative impact on individuals with intellectual and developmental disabilities (IDD):

How is COVID-19 impacting the well-being of adults with IDD?

To answer this question, we designed an online survey for adults with IDD to complete independently or with support.
Who are our survey participants?

- **471 individuals** participated, but not everyone completed the survey.

- **394 individuals completed the entire survey and provided an email for follow-up:**
  - 49% disclosed an intellectual disability and a developmental disability
  - 30% disclosed a developmental disability
  - 21% disclosed an intellectual disability

- 61% filled out the survey with support from a friend or family member
- 26% filled it out on their own
- 13% filled it out with support from a service provider or health professional
Who are our survey participants?

Types of Disabilities/Difficulties

- Deaf or Hard of Hearing: 7%
- Blind or Difficulty Seeing: 10%
- Difficulty with concentration, memory, or decision making: 65%
- Difficulty walking or climbing stairs: 25%
- Difficulty dressing or bathing: 34%
- Difficulty doing errands alone (visiting doctor or shopping): 78%
Who are our survey participants?

<table>
<thead>
<tr>
<th>States</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Ohio</td>
<td>50</td>
</tr>
<tr>
<td>Virginia</td>
<td>38</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
</tr>
</tbody>
</table>
Who are our survey participants?

Gender Identity

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Male</th>
<th>Female</th>
<th>Trans</th>
<th>Nonbinary</th>
<th>Prefer not to answer</th>
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<tbody>
<tr>
<td>52.10%</td>
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<td>46.60%</td>
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<td>0.20%</td>
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<td>0.20%</td>
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<td>1%</td>
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</table>
Who are our survey participants?

![Age Distribution Chart]

- 18-30 years: 49.10%
- 31-45 years: 32.60%
- 46-60 years: 13%
- 61 or older: 5.40%

Age
Who are our survey participants?

**Living Arrangements**

- Living Alone: 18%
- Living with Non-family Members: 12%
- Living in Group Home: 4%
- Living at Parents': 58%
- Living at Family Member's: 7%
Who are our survey participants?

Race and Ethnicity

- American Indian or Alaska Native: 3%
- Asian American: 2.30%
- Black or African American: 12.20%
- Native Hawaiian or Pacific Islander: 0.40%
- White: 79%
- Latinx: 3.60%
- Other: 2.30%
- Prefer not to answer: 4%
Who was getting county or state services before COVID-19?

- Receiving services \( (n=368) \)
- Not receiving services
- NA
Of those who were receiving services (n = 368):

- Still getting county/state services (n=311)
- No longer getting services
- NA
Of those who were receiving services (n = 368), did anyone have problems accessing them?

- Yes (n=112)
- No
- NA
Of those who were receiving services (n = 368) - still getting waiver services during COVID-19?

- Yes (n=264) - 71.7%
- No (n=72) - 19.6%
- NA - 8.7%
Technology

78% of the sample is using technology to talk with others:

<table>
<thead>
<tr>
<th>Communication Method</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Phone calls</td>
<td>75%</td>
</tr>
<tr>
<td>Texting</td>
<td>63%</td>
</tr>
<tr>
<td>Emails</td>
<td>40%</td>
</tr>
<tr>
<td>Video Calls</td>
<td>78%</td>
</tr>
<tr>
<td>Social Media</td>
<td>46%</td>
</tr>
<tr>
<td>Forums</td>
<td>8%</td>
</tr>
</tbody>
</table>

How often?

- 33% (every day)
- 23% (1-2 days/week)
- 23% (several times/day)
- 20% (3-5 days/week)
Technology that participants wish they had since COVID-19:

- Desktop computer: 12%
- Laptop computer: 17%
- Tablet: 15%
- Smart phone: 11%
- Happy with my technology: 67%
Employment

- 41% (n= 181) reported having a job before COVID-19.

  - Of those who were employed before COVID-19 (n=181):
    - 54% *work less hours* since COVID-19
    - 50% *have been laid off* since COVID-19
    - 42% reported they have not gotten unemployment
    - 35% reported they did not find it easy to get unemployment
Employment

- Of those who were employed before COVID-19 (n=181):
  - 29% reported still having to go into work and be close to others
  - 10% reported having to work more hours since COVID-19
Health

- 97% reported that they have not had COVID-19
- 85% reported that they have not been exposed to someone with it
- 12% reported that they are not sure if they have been exposed to it
Health

- 60% reported knowing what to do if they were exposed to COVID-19
- 77% reported being able to get necessary medical treatment
- 80% reported being able to easily access protective gear
- Most reported using protective gear all or most of the time
Health

In-Person Providers Using Protective Equipment

- All the time: 53%
- Most of the time: 11%
- Some of the time: 7%
- Never: 1%
- NA: 30%
Health

Since the COVID-19 pandemic:

- 11% reported having more health problems
- 50% reported more mental health problems
Symptoms endorsed by those reporting more mental health issues (n=197):

- Worried: 70%
- Stressed: 66%
- Scared: 39%
- Nervous: 54%
- Sad: 56%
- Angry: 34%
- Annoyed Easily: 43%
- Impatient: 42%
- Tired: 43%
- Over-Excited: 8%
- Jumpy: 15%
- Problems Sleeping: 46%
- Other: 11%
- Prefer not to answer: 11%
How is mental health treatment during the pandemic?

- Great: 14%
- Good: 59%
- Fair: 21%
- Poor: 6%
Next Steps

- We will:
  - Review results with partners (DoDD, OOD, OSDA, Self-Advocates)
  - Make minor revisions to the survey based on feedback
  - Contact participants who provided emails to re-take survey (October)
  - Conduct a longitudinal analysis to compare/contrast results

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References
