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Introduction
The COVID-19 pandemic has combined a severe concern for public health with a disruption in supply chains, resulting in shortages and public anxiety. For people with disabilities, the adversity has been compounded as the pandemic has made it even harder for them to meet their personal care and medical needs. Although it is undeniable that these hardships exist for individuals with disabilities, the specific effects have not been measured. In an effort to quantify, address and create next steps, the Adult Advocacy Centers (AACs) surveyed 134 individuals with intellectual and developmental disabilities regarding the impact that COVID-19 has had on their lives. It is the hope of the AACs that organizations who serve people with disabilities will use this information to better plan for future emergencies and disasters. Summaries of the survey responses are listed below, followed by a conclusion and suggested next steps.

Acknowledgements
The Adult Advocacy Centers would like to thank consultants Shari Cooper and Adonna Wilson-Baney for their work on this project. We are also grateful to the many self-advocacy groups who helped us spread the word about the survey and to all of those individuals who took the time to participate and give us the best possible data.

Survey Questions

**Question 1**
Have your services been disrupted?

![Pie chart showing percentages of respondents who answered 'Yes', 'Somewhat', and 'No' to the question.]

**Summary:**
Forty-eight percent of respondents answered that their services have been disrupted as a result of COVID-19. Specific information regarding service disruption are examined in the next question and associated graphic.
**Question 2**
What service disruptions did you experience due to COVID-19, and how has this impacted you?

Summary:
The majority of respondents answered that the closure of their day program was the most impactful service disruption. Loss of social interaction, decreased income, and finding extra staff to fill the void created by day program closures were the most frequently cited effects.

**Question 3**
Have you experienced problems with your staff being able to come to work?

Summary:
Approximately 70% of respondents answered that they have not experienced major problems with staff coverage. More than 30% of respondents answered that they have experienced significant problems with staff coverage. Although 30% is a minority, it is a troublesome number because nursing and personal care could lead to significant negative health outcomes.
**Question 4a**
Have you had problems being seen by your physician?

**Summary:**
Approximately 70% of respondents stated that they had not experienced issues seeing their physician when needed. Physician services mostly consisted of tele-medicine and were considered adequate. Approximately 31% of respondents reported that they experienced delayed or cancelled medical appointments or bloodwork.

**Question 4b**
Have you had problems getting your medications?

**Summary:**
Nearly 70% of respondents stated that they had not experienced difficulty in getting their medication. Approximately 30% of people reported that they had difficulties receiving their medications. Difficulties included problems receiving a written prescription or filling their prescription.
Question 5
If you receive services from a Personal Care Attendant (PCA), what additional precautions are being used?

Summary:
Most respondents reported that PCAs were taking precautionary actions, such as increased handwashing, temperature taking, frequent sanitizing of surfaces, and wearing gloves.

Question 6
What necessities have you had problems getting?

Summary:
Sanitizer was the most difficult item for respondents to find. Other items in short supply included disinfectant wipes, supplements, over-the-counter medication, and thermometers.
Question 7
How has social distancing impacted you?

Summary:
This question elicited many responses that included feelings of depression, anxiety and isolation. The closure of day programs was frequently cited as having the biggest impact for respondents.

Question 8
What are you doing to keep yourself occupied?

Summary:
Responses indicated that people were being resourceful in finding ways to keep busy while practicing social distancing. Many people were watching television/movies, listening to music, and playing games. Respondents also mentioned other activities including meditation, using social media, arts and crafts, phone calls, taking walks, exercising, organizing photographs, virtual meetings, housework, car rides, spending time with pets, gardening and baking.
Question 9
What are your biggest worries?

Summary:
Responses indicated that the biggest worry was associated with meeting health care needs. Respondents also expressed anxiety about meeting their daily care needs, lack of socialization, and loss of income and socialization due to the closure of day programs.

Question 10
Do you know who to contact for help?

Summary:
Approximately 83% of respondents said they knew who to contact for help. Of the 17% who did not know who to contact, many people did know they could contact law enforcement, but they did not always know who else they could call that might be more suitable for their situation.
**Question 11**
If you contacted people for help, were they helpful?

<table>
<thead>
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<th>Yes</th>
<th>Somewhat</th>
<th>No</th>
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<tr>
<td>67%</td>
<td>21%</td>
<td>12%</td>
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**Summary:**
Sixty-seven percent of respondents stated that they reached out and received appropriate help or services. Twenty-one percent of respondents stated that their call for help was met with a partially helpful response, and 12% of respondents stated that they did not receive a satisfactory response.

**Question 12**
What plan could have been in place to make this crisis easier for you?

<table>
<thead>
<tr>
<th>Not sure</th>
<th>Backup plan for nursing and personal care services</th>
<th>Plan to ensure people have food and other needed supplies</th>
<th>Provision of day programming</th>
<th>Increase technology and assistance using technology</th>
<th>Creation of a safety or disaster plan for people with disabilities</th>
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<td>3%</td>
<td>29%</td>
<td>6%</td>
<td>17%</td>
<td>6%</td>
<td>3%</td>
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**Summary:**
Almost 40% of respondents were unsure of what could be done to lessen the ramifications of the COVID-19 pandemic. Approximately 30% of respondents reported that having a backup plan for nursing and personal care would ease the effects of the pandemic, and 17% reported a plan for ensuring needed food and supplies would be the most helpful.
Summary:
Approximately 40% of respondents expressed that people with disabilities should be treated better during the pandemic. Twenty percent of respondents expressed sincere gratitude for the family, friends, neighbors and staff who have provided care and assistance.
Conclusion and Next Steps

While this survey was specific to the effects of COVID-19, the outcomes may be applied to any disaster or emergency. Survey results validated that individuals with disabilities and their families face unique challenges. Although these challenges exist, they could be minimized with some systemic planning, services and resources. Below are some recommendations for next steps.

Access to the News

Ensuring access to current events and the news will help people know what to do to stay healthy and safe. This information can be gathered through accurate and reliable sources on the television, radio, social media or a newspaper. People can also ask a trusted neighbor or friend.

Safety Planning

One of the most important takeaways of the survey is the need to plan for safety. In response, the AACs have created a Self-Directed Safety Planning Guidebook and an Assisted Safety Planning Guidebook. These guidebooks provide a step-by-step process to help people with disabilities create their safety networks. Links to these important guides are listed below:

Self-Directed Safety Planning Guidebook:

Assisted Safety Planning Guidebook:
Stockpiling

Stockpiling is the act of gathering things that may be needed in the future. Stockpiling certain items now may help an individual stay healthy and safe during a disaster or emergency. Below are some examples of things that may be wise to have stockpiled. This list should include a reasonable number of items and should be customized based on individual need.

- Alcohol-based sanitizer
- Vitamins
- Garbage bags
- Soap
- Toilet paper and paper towels
- Hygiene supplies

Collecting Medical Supplies

Having medical supplies on hand may also be helpful. It is recommended that individuals consult their physician, specialist or nurse to design a list that best fits their needs. Some examples are listed below.

- First aid kit
- A three-month supply of prescribed medications, if possible and advisable
- Thermometer
- Over-the-counter pain relievers, and cold and cough medicines
- Masks
- Gloves

Creating a Long-Term Food Pantry

Purchasing and storing a reasonable amount food that has a long shelf-life may be helpful if there is an emergency or disaster. Food should be gathered keeping individual diet needs and preferences in mind. Some examples of food that will last a long time are listed below.

- Rice, dried beans or lentils
- Protein bars, granola bars, trail mix, nuts or dried fruits
- Canned soups, beans, fruit and vegetables
- Jars of peanut butter and jelly
- Coffee, tea, hot chocolate or powdered drink mixes
- Dried jerky, canned meats or bouillon cubes
- Pasta, flour, pancake mix, cereal or crackers
- Dried, shelf stable, evaporated or condensed milk
- Olive, vegetable or other oil for cooking
Other Useful Resources

- Your local health department:
  odhgateway.odh.ohio.gov/lhdinformationsystem/Directory/GetMyLHD

- The Ohio Department of Health’s call center:
  1-833-427-5634

- Best practices for hand washing
  cdc.gov/handwashing/index.html

- Social story providing information about testing for COVID-19

Report Abuse, Neglect and Theft

- Ohio Department of Developmental Disabilities
  - To report a major unusual incident, find your county board of developmental disabilities at: dodd.ohio.gov/wps/portal/gov/dodd/your-family/all-family-resources/4-find-your-county-board
  - DODD abuse/neglect hotline: 1-866-313-6733
    Online reporting form: ocf.prodapps.dodd.ohio.gov/

- Disability Rights Ohio
  - Intake line: 800-282-9181, option 2
  - Online intake form: disabilityrightsohio.org/intake-form

- Your local law enforcement agency

Call 911 if you are experiencing a life-threatening emergency or are in immediate danger!