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## Preparing for the Next Disaster: Lessons Learned From the Early Experiences of Autistic Adults During the COVID-19 Pandemic

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# Preparing for the Next Disaster: Lessons Learned From the Early Experiences of Autistic Adults During the COVID-19 Pandemic

## Abstract

**Purpose:** Disasters, such as the worldwide COVID-19 pandemic, create significant disruptions for individuals and their communities. Understanding these disruptions is a first step towards planning for future events and disaster recovery. This research aims to explore how the initial COVID-19 restrictions, including lockdowns, impacted adults with Autism (ASD). **Method:** Using semi-structured interviews to understand how individuals with ASD experienced the early months of the COVID-19 pandemic, twelve participants were interviewed: six individuals with ASD (ages 20-38), three parents of individuals with ASD, and three support staff for individuals with ASD. **Analysis:** Grounded theory methods were used to analyze the impacts of COVID-19 based on the knowledge, challenges, activities, resources, and support needs of individuals with ASD. **Results:** Interviews were coded. The questions generated three themes with eleven subthemes 1) COVID Knowledge: Understanding COVID, Preventative behaviors, Information resources; 2) Pre-COVID activities: social, work/day-program/school, environment, physical activities, and 3) During COVID activities: social, work/day-program/school, environment, and physical activities. **Conclusion:** Individuals with ASD's understanding of COVID-19 is similar to the general public and display adequate, timely knowledge. They adopted new behaviors, including transitioning from structured physical schedules to less structured virtual schedules. Caregivers and support staff expressed concerns about preventative behaviors in the community.

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### ABSTRACT

**Purpose:** Disasters, such as the worldwide COVID-19 pandemic, create significant disruptions for individuals and their communities. Understanding these disruptions is a first step towards planning for future events and disaster recovery. This research aims to explore how the initial COVID-19 restrictions, including lockdowns, impacted adults with Autism (ASD). **Method:** Using semi-structured interviews to understand how individuals with ASD experienced the early months of the COVID-19 pandemic, twelve participants were interviewed: six individuals with ASD (ages 20-38), three parents of individuals with ASD, and three support staff for individuals with ASD. **Analysis:** Grounded theory methods were used to analyze the impacts of COVID-19 based on the knowledge, challenges, activities, resources, and support needs of individuals with ASD. **Results:** Interviews were coded. The questions generated three themes with eleven subthemes 1) COVID Knowledge: Understanding COVID, Preventative behaviors, Information resources; 2) Pre-COVID activities: social, work/day-program/school, environment, physical activities, and 3) During COVID activities: social, work/day-program/school, environment, and physical activities. **Conclusion:** Individuals with ASD's understanding of COVID-19 is similar to the general public and display adequate, timely knowledge. They adopted new behaviors, including transitioning from structured physical schedules to less structured virtual schedules. Caregivers and support staff expressed concerns about preventative behaviors in the community.

**Keywords:** autism, COVID-19, emergency response preparedness

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## INTRODUCTION

Emergency preparedness can be defined as an individual's ability to respond and recover from an emergency or disaster situation.<sup>1,2</sup> In recent history, many significant emergencies and disasters have occurred: 9/11 (2001), Indian Ocean Tsunami (2004), Hurricane Katrina (2005), London bombings (2005), Fukushima Daiichi nuclear disaster (2011), Hurricane Sandy (2012), Paris attacks (2015), and numerous others. Research has found that persons with disabilities are particularly vulnerable to the consequences and conflicts associated with emergencies and disasters.<sup>3,4</sup> Vulnerability was defined by The World Health Organization (WHO) as "the degree to which a population, individual or organization is unable to anticipate, cope with, resist and recover from the impacts of disaster."<sup>5</sup> Individuals with Autism Spectrum Disorder (ASD) are considered vulnerable because of challenges they experience with communication, socialization, and executive functioning differences that are inherent in the diagnosis and its common co-occurring conditions (e.g., anxiety disorder, intellectual disability).<sup>6</sup>

During the most recent COVID-19, public health crisis information regarding safe behaviors and mitigation was distributed on an ongoing basis. This information needed to be processed and responded to quickly -- a difficult challenge for individuals with ASD.<sup>7</sup> Rapid responses to a crisis can often decrease catastrophic effects and are crucial for best outcomes,<sup>8</sup> but individuals with ASD experience expressive communication challenges, leading to difficulty communicating pain, symptoms of illness, or emotional distress.<sup>9,10</sup> As a result, many individuals with ASD may find it necessary to increase reliance on their families, caregivers, or other staff to communicate important pandemic information to them or observe symptoms of potential illness. While research is growing, little is known about the real-time, self-described experiences of the autism population to the emergency response.<sup>11</sup> Filling the knowledge gap is necessary to assure better preparedness of and supports for an already vulnerable population.

Governmental and non-governmental organizations that support people with autism were not prepared for the emergence and global impact of the COVID-19 pandemic. On March 13, 2020, a national emergency was declared in the United States due to the novel Coronavirus.<sup>12</sup> Shortly after that, restrictions on activities to only life-sustaining and essential businesses were declared, impacting society throughout the United States. These included school closures and restrictions to numerous occupations that were deemed non-essential.<sup>12</sup> Work choices were often limited to virtual home or remote locations or being furloughed or laid off. These choices were particularly prevalent in services such as recreation, leisure, education, and social participation. The COVID-19 restrictions impacted everyone.<sup>13</sup> The entire population was trying to comprehend and understand the impact of the pandemic while also acclimating to the new restrictions. The changes impacted routines, social interaction, and physical activity and thus affected health and well-being.<sup>14</sup> Significant and sustained disruptions to daily routines increased stress significantly and perhaps more profoundly impacted persons with ASD who already faced challenges.<sup>15</sup>

ASD is a developmental disability manifested through significant social, communication, and behavioral challenges.<sup>16</sup> The prevalence of ASD has increased from approximately 1/1000 in the 1980s to 1/150 in the early 2000s to the current rate of 1/54.<sup>17</sup> A significant portion of individuals with ASD falls within that umbrella's Intellectual Disability (ID) segment.<sup>18</sup> Individuals with ID have 4-5x higher rates of co-occurring mental health conditions.<sup>19</sup> In addition, individuals with developmental disabilities (IDD) have been identified to have 3.5x the odds of suicidal ideation compared to their peers without disabilities.<sup>20</sup> The mental health challenges of these individuals create a strong need to identify interventions that remove some of the barriers to community participation and transitioning to adulthood.

Research that examines the construct of community participation defines it as "active involvement in activities that are intrinsically social and either occur outside of the home or are part of a nondomestic role."<sup>21(p. 771)</sup> The broader focus on individuals with ASD in disasters is the concept of community participation and inclusion, which includes essential supports and services.<sup>21,22</sup> However, previous research found that the supports and services are deficient for community participation and inclusion under normal conditions for persons with.<sup>23,24</sup>

The COVID-19 pandemic may have had a disproportionate effect on the community participation and mental health of autistic people.<sup>11</sup> Information about the impact of the COVID-19 restrictions, including lockdowns, on the mental health of this population is limited. For the general population, prolonged periods of isolation can have an impact on mental health.<sup>26</sup> The ASD population is even more vulnerable.<sup>27</sup> Little is known about the impact of lockdown measures on autistic adults, their families, and support staff. A recently published study showed a decrease in essential and non-essential community mobility and community participation for individuals with ASD.<sup>28</sup>

Natural emergencies will continue to be an ongoing public health issue as we address current and future threats.<sup>29-33</sup> Even though a COVID-19 vaccine has been developed, there is a need to engage in preventative practices due to unknown vaccine effectiveness, emergence of new variants, delayed distribution, resistance to vaccination, and future pandemics.<sup>34,35</sup> Understanding how to quickly inform and support individuals with ASD is relevant beyond the COVID-19 pandemic Demographic and

environmental issues such as a growing population, urbanization, and climate change increase our risk for future pandemics.<sup>36</sup> Increased population and population density enable viruses to spread more quickly. Climate change has been known to affect the temperature and conditions within which new viruses thrive.<sup>37</sup> Global travel increases exposure and expands the distribution of widespread viruses.<sup>38</sup> Civil conflict and national and international policies may expose more people to viruses and exhaust limited resources that could otherwise slow the spread.<sup>39</sup> National and international policies could exacerbate consequences by providing inappropriate guidance and inadequate response strategy.<sup>40</sup>

### **Study Rationale**

There are currently many different approaches to handling disasters and responses to events at multiple time points. This study sought to explore the experiences of individuals with ASD during the initial shutdown phase of the COVID-19 pandemic. The study aimed to identify what knowledge, preparedness, and community participation disruptions these individuals experienced. First, it is essential to identify what knowledge individuals with ASD had about COVID-19 and preventative behaviors. Second, it is vital to identify information gaps. This knowledge would develop strategies to help ensure the needs of the ASD community are met during future immediate disaster responses. To understand how community participation was disrupted from the perspectives of the individual themselves and to identify areas that could be improved with a more rapid response when a future disaster occurs, we asked the following question: 1) What knowledge do you have about the COVID-19 pandemic?, 2) How are you getting your information about COVID-19?, and 3) How has the pandemic in real-time affected your community participation?.

Twelve participants were interviewed: six individuals with ASD, three support staff for individuals with ASD, and three parents of individuals with ASD. All the individuals with ASD were directly affected by the immediate responses to COVID-19. Therefore, it was important to recognize if any similarities existed among individuals with ASD. It was also essential to have the individuals represent their experiences immediately after COVID-19 restrictions were in place.

## **METHODS**

### **Approach**

Adults with ASD, their parents, and support staff were interviewed to better understand how individuals with ASD experienced the COVID-19 pandemic. This study explored the knowledge, challenges, resources, and support needs of autistic adults and their caregivers during the early months of the pandemic. A qualitative phenomenological design was the primary approach used to help understand the knowledge, challenges, resources, and support needs autistic adults and their caregivers identified about their experiences in the early months of the pandemic. A qualitative phenomenological design allows us to understand the person's firsthand perspectives through lived experience<sup>41</sup>.

Participants' interview data and observations determined themes that were relevant and important to prioritizing needs. Understanding the perception of changes in everyday life activities (works, school, social) and community participation for individuals with ASD is essential. It is also essential to identify if individuals with ASD understood and could implement the preventative behaviors required. The gaps identified helped inform future research and the development of accessible emergency materials.

One-on-one semi-structured interviews were conducted with individuals with ASD, parents of individuals with ASD, and support staff. All the interviews were conducted separately and privately to ensure the participants' confidentiality.

### **Ethics**

Temple University's Institutional Review Board approved the research study in April of 2020. This research was part of a more extensive study on travel training and community mobility. Required informed consent occurred virtually and through emails. Additionally, verbal consent was reaffirmed at the beginning of each interview. Interviewees were reminded that their participation in the April 2020 interviews was optional to the overall study and voluntary. Interviewees were also informed multiple times that they could end the interview at any time without impacting their participation in the overall research study.

The semi-structured interviews were used to gain an in-depth description of the knowledge, behaviors, and experiences of individuals with ASD. Interviews and data collection were conducted virtually using recorded Zoom technology between April 22, 2020, and May 27, 2020. All participants agreed to have their interviews recorded so the interviewee could engage more in the interview. Analysts would later use their transcripts for quotes and extracting subthemes. Interviews were conducted by either a research staff member or a peer interventionist. The peer interventionist was an individual with ASD who previously worked with participants on an intervention travel study. Individuals, parents of an individual with ASD, and support staff of individuals with ASD interviewed had previous interactions with the interviewers. This study's interview was designed to assess specific experiences

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with COVID-19, including respondent's perceptions of COVID-19, how the participants understood safety procedures, and what changes to community participation the individual was experiencing.

### **Participants**

Participants needed to meet the following criteria: 1) Associated with an established travel training program and 2) 18 years or older with an ASD diagnosis or parent or support staff to an individual 18 years or older with ASD. Purposeful sampling was used to identify participants. The research team responded to an email gauging their interest and inviting them to participate. Individuals, parents, and staff with existing relationships who were engaged and reachable were invited to participate.

Table 1 summarizes the demographics of the study including participant ID, relationship to the adults with ASD, age, gender, race, education, living situation, employment, change in employment, and interview date. Twelve participants were interviewed for the study. This study consists of six individuals with ASD, three parents of individuals with ASD, and three support staff of individuals with ASD. The individual with ASD brings his/her lived experience, the parent of the individual with ASD brings parent observation and unconditional support, and the support staff brings a more objective and globally informed perspective. It is important to understand multiple perspectives to develop encompassing strategies. The age range for individuals with ASD was 20-38. Individuals' education ranged from high school to college graduate. The interviewed staff members included two working at a community organization established to build independence for individuals with disabilities in their home, job, and community.

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**Table 1** Participant Demographics

Participant	Relationship to Adults with ASD	Age	Gender	Race	Education	Living Situation	Employment	Change in Employment Situation During Covid	Interview Date
1	Self	20	Male	Mixed	HS Graduate	Home w/parents	Retail Services	No Change	5/2020
2	Self	25	Male	White	HS Graduate	Home w/parents	Janitorial Service	No Change	5/2020
3	Self	25	Male	White	HS Graduate	Home w/parents	Food Service	No Change	4/2020
4	Self	40	Male	White	HS Graduate	Renting Apartment	Food services	No Change	5/2020
5	Self	38	Male	Mixed	College Graduate	Home w/parents	Looking for Employment	Became employed	4/2020
6	Self	32	Male	White	College Graduate	Home Alone	Food Services/Service Provider	Unemployed/Unemployed	4/2020
7	Mother	55	Female	White	College Graduate	Home w/children	Food Services	No Change	5//2020
8	Mother	55	Female	White	College Graduate	Home w/children	Health Care	No Change	5/2020
9	Mother	56	Female	White	MD	Home w/children	Health Care	No Change	4/2020
10	Support Staff		Female	White	College Graduate	Home w/partner	HCBS*	No Change	5/2020
11	Support Staff	-	Female	White	-	-	HCBS*	No Change	5/2020
12	Support Staff	-	Female	White	-	-	HCBS*	No Change	5/2020

\*Home and Community-Based Services



One is working at an agency that supports young adults with disabilities to experience freedom and achieve independence goals. Previous qualitative research involving similar sample sizes has been considered adequate for addressing various research questions.<sup>42</sup>

**Interview Procedures**

Participants provided consent for the interview and permission for recordings prior to the interviews. During the consent process, all participants were given time to ask questions and request clarifications to ensure they had a complete understanding of the research study. The interviews were conducted in April of 2020, shortly after the pandemic began. All participants lived in Philadelphia and Southeastern Pennsylvania and were in a pandemic-induced lockdown starting mid-March 2020. The lockdown was still in place when the interviews were conducted. The participants' demographic information had been previously collected as they were part of another ongoing study. In addition, the parents completed an online Qualtrics survey to collect demographic information. The interviews were conducted and recorded remotely using the Zoom video conferencing program—the Zoom cloud audio recording allowed for a transcript to be created to the cloud. Transcripts were checked for accuracy. Participants provided consent via an electronic consent form prior to the interview. Participants were reminded that the interviews were being recorded and were voluntary, allowing them to stop the interview at any time.

Interviews ranged from 10 to 41 minutes with an average of 24 minutes. This is consistent with other ASD semi-structured interviews.<sup>42–45</sup> First, participants were asked about their general understanding of COVID-19 and where they receive their information. Next, they were asked how COVID-19 changed their community participation and what they considered positive and negative changes. Finally, they were asked about how their use of public transportation had changed. They were questioned on their current comfort level regarding future use of public transportation and what type of education would help them when they accessed public transportation again.

Table two summarizes the interview questions. Interviews were conducted by an autistic research team member and a neurotypical research staff member. An interview guide was used, and mock interviews were conducted as practice prior to recruitment. The autistic research team member facilitated the majority of the interviews with individuals with ASD to enhance rapport building and was present during the interviews with parents and staff. All interviews were conducted separately with participants.

**Table 2** Structured Interview Guide

Question Category	Question
COVID Knowledge	What do you understand about COVID-19? How do you get your information? What types of things do you need to do differently because of COVID-19? How can you prevent the spread of the virus? How can you keep yourself and others safe?
Everyday Life Activities Prior to COVID	What do you think of when we talk about community participation? Do you know what community participation means? Before this March and the virus caused us to change, what were some things that you did? What types of things did you enjoy doing before? How were you getting places?
Everyday life activities during COVID	How have things changed for you? What are you doing now? Are there any activities/things you are doing now that you were not doing before? Are you doing any activities/things that allow you to interact/see friends/families/neighbors? Is there anything you really enjoy about your new activities and routines? Is there anything that is really hard for you? How has COVID-19 changed transportation for you? How has it made it harder? Do you think it made it easier?

**Data Analysis/ Procedures**

The analysis used grounded theory methods to identify the impact of COVID-19 on community participation for individuals with ASD. Zoom recordings were transcribed using the software's cloud audio transcription tool and cross-checked against the recordings for accuracy by research staff and graduate students. Word clouds (Figure 1) were created from large amounts of qualitative transcript data to investigate patterns, phrases, and responses.<sup>46</sup>





**Figure 1** Word Cloud Derived from Qualitative Interviews

The review and word clouds allowed for identifying broad themes and subthemes. The transcripts were imported into the Dedoose software.<sup>47</sup> The researcher independently worked to identify themes present within each topic area through a process of open coding and investigator triangulation to increase the credibility of broad and subtheme development. Researchers used a list of codes developed in open coding to identify similarities across the guided question areas. Three general themes were identified. Next, the researchers separately conceptualized definitions for each theme and subtheme. A group of six researchers finalized conceptualized definitions through a consensus process. Upon coming to a consensus, frequencies and definitions of each concept were summarized into a single document (Table 3). Axial coding was completed by six researchers to examine and identify the relationship between subthemes. Similar subthemes were combined into larger groupings until three broad themes were identified across topic question areas.

To guard against contextual bias in the analysis process, bracketing was implemented by identifying preconceptions before and during data analysis to avoid contextual bias regarding strategy responses. For example, during data analysis bracketing was necessary when strategy responses reported were at odds with what the researchers viewed as a suitable strategy. Data saturation within broad themes occurred after all eleven transcripts were read. The quantitative analysis helped to calculate the frequency of responses in each of the themes and subthemes. The frequencies allowed the researchers to determine what areas of COVID-19 impact were most discussed.

## RESULTS

Interviews were coded, and responses were observed, which identified eleven subthemes under the three topic question areas 1) COVID-19 Knowledge 2) Pre-COVID-19 activities 3) During COVID-19 Activities. Table 3 encapsulates the themes and subthemes determined along with definitions. Table 4 illustrates the number of respondents that addressed the subthemes as well as the number of total references or unique comments to each subtheme.

**Table 3.** SubThemes with Definitions

Themes	SubThemes	Definition
COVID Knowledge	Understanding COVID-19	Defines and is familiar with COVID-19
	Preventative Behaviors	Familiar with safety behaviors like PPE, including masks
		Familiar with safety behaviors like social distancing
		Familiar with safety behaviors like hand/hygiene
Information Resources	Information on how COVID-19 is obtained – Traditional Media: television, newspaper Information on how COVID-19 is obtained – Social Media: YouTube, Facebook, Twitter Information on how COVID-19 is obtained - talking to trusted adults such as parents/staff	
Pre-COVID Lifestyle	Social	Social community activities
	Work/Day-Program/School	Work, day program, and school community activities
	Environmental	Technology adaptations
	Physical Activities	Activities that require the use of energy and body movement, some examples walking, running, cycling, exercise classes
During-COVID Lifestyle	Social	Transportation changes
	Work/Day-Program/School	Work, day program, and school activities during COVID
	Environmental	Technology and Technology adaptations
	Physical Activities	Activities that require the use of energy and body movement, some examples walking, running, cycling, exercise classes

**Table 4. SubThemes Frequencies**

Themes	Number of Respondents Discussed SubThemes	Themes Ratio to N	Number of References to SubThemes	Reference Ratio to N
Understanding COVID-19	8	0.667	10	0.833
Preventative Behaviors	12	1.000	37	3.083
Information Resource	9	0.750	13	1.083
Pre-COVID Social	9	0.750	16	1.333
Pre-COVID Work/Day-Program/School	5	0.417	5	0.417
Pre-COVID Environment	7	0.583	10	0.833
Pre-COVID Physical Activities	4	0.333	4	0.333
During-COVID Social	9	0.750	18	1.500
During-COVID Work/Day-Program/School	7	0.583	11	0.917
During-COVID Environment	11	0.917	59	4.917
During-COVID Physical Activities	4	0.333	9	0.750

### COVID-19 Knowledge

The first interview questions focused on the general knowledge of COVID-19 acquired by individuals with ASD a month into the pandemic. There were three subthemes identified under COVID-19 knowledge, including 1) perception/understanding, 2) preventative behaviors, and 3) information resources. The preventative behaviors and information resources had further subthemes. Preventative behaviors subtheme included masks, hand/hygiene, and social distancing. Information resources subtheme included hard news, social media, and conversations with parents/staff.

### Understanding COVID-19

The general understanding subtheme resulted in individuals providing definitions or an affirmative when asked about COVID-19. Individuals were asked to define and explain their familiarity with COVID-19. Individuals identified if they had an understanding of COVID-19. Some individuals provided information on the origin of COVID-19.

Participant 1 "Just like the Spanish by virus in 1918. When you get the flu and pass on to someone else, and it spreads the world."

Participant 4 "I never fully understood what it is or what to do."

Participant 11 "They understood COVID-19 and what it is."

Participant 6 "It started in China, and it came over to America. Some random mutation and people are now getting sick."

Participant 10 "I do think that most of them understand at least [the] seriousness of this."

Participant 5 "In general, it's just it's scary I'm personally. All right, but it's still [a] very, very scary situation."

### Preventative Behaviors

Individuals identified familiarity with safety behaviors like personal protective equipment (PPE), hand hygiene, and social distancing. They provided examples of PPE, explained how it was used and comfort levels. They also explained if they had ever heard of social distancing and what the term meant. If individuals did not describe any of CDC recommendations for preventative behaviors, they were prompted with examples of PPE, hand hygiene, and social distance to determine if they knew what these terms meant.

Participant 6 "I wash my hands. I put a face mask when I go to work."

Participant 1 "Say it's important to wear a mask so that you don't pass it on to someone else in the future, right."

Participant 8 "Like we would go for a walk, and he wouldn't move to the side. And then you know when we were grocery shop people kind of REACH behind somebody to get something instead of waiting for them, you know and come around, but he's good now ok so just took a few reminders, and it was yeah exactly, and he is really good about remembering gloves and a mask before we go out."

Participant 5 "We have to social distancing like if you're outside, you should keep like I think it's six feet away from other people."

### **COVID Information Resources**

The subtheme COVID-19 information resource provided an opportunity for individuals to report what resources they used to learn about the COVID-19 virus. Individuals identified a variety of sources including old media and new media. In addition, families and organizations were identified as resources.

Participant 5 "I have been consuming a lot of news about it. Like sometimes, my parents are watching the news, and I will hear things. But other times I will read it for myself because I want that, you know, even though it's really scary. I do want to know more about it into be informed."

Participant 8 "Also interestingly get some information from watching YouTube, like some of the YouTube users that he follows that are also elevator enthusiasts."

Participant 2 "I get information from the news and from some from organizations that send it."

### **Pre-COVID Everyday Life Activities**

This broad question topic allowed individuals to identify what types of everyday life activities they participated in before the COVID-19 mitigation. The subthemes that were generated and identified included social activities, work/day program/school, environmental and physical activities.

### **Pre-COVID Social Activities**

Participants explained the types of social activities they were a part of before COVID-19. The majority of individuals identified as participating in social activities pre-COVID-19. These activities included family events, gym, work, community meetings, and school activities.

Participant 5 "I would sometimes visit with some family friends who live nearby."

Participant 11 "They went to the gym, grocery store, and farmer's market for occasional lunches out. They also served customers at [local community center] and held events for small children and their parents."

Participant 3 "My family on my dad's side usually gets together once a month for birthdays, ok."

Participant 12 "They are no longer meeting at [local community center] or going to [employment location]."

Participant 6 "So you're staying inside a lot more than you did before."

### **Pre-COVID Work/Day-Program/School Activities**

This subtheme allowed participants to explain the changes or new activities associated with work, day programs, and school. Individuals identified changes to their work and school programs. This was primarily discussed by the adults with ASD.

Participant 11 "Before the virus, participants and [provider agency] workers mostly worked at [local community center]."

Participant 4 "I go to work."

Participant 5 "I did have a job, I would have it would have to start on a volunteer basis first it was due to start. I think in late April. But now, that's all been pushed back. So I still feel good about it. I am concerned about the status of the job. You know, I'm not sure that it will still be there, but for the most part, I'm feeling good about it."

Participant 6 "I was walking dogs volunteer around town, and now they're saying no."

**Pre-COVID Environment**

This subtheme allowed participants to explain what their environment was like before COVID-19. This included their use of technology and transportation. Individuals identified using public transportation like the bus or train pre-COVID-19.

Participant 1 "Well, the only thing I have to do is to wait till after the public until before the public is open before I can start going back to public transportation."

Participant 5 "On public transportation, I took train to Philadelphia museum."

Participant 11 "Took the bus or train to work every day."

Participant 3 "Before I took the bus."

**Pre-COVID Physical Activities**

The WHO defines physical activity as bodily movements that result in expended energy. This includes walking, running, cycling, and many other forms. This was primarily discussed by the adults with ASD.

Participant 5 "I would go out into town. I would go to the gym."

Participant 6 "Walks and stuff."

Participant 1 "I sometimes go swimming."

**During COVID-19 Everyday lifestyle Activities**

This broad question topic allowed individuals to identify the impact COVID-19 restrictions had on them. The identified subtheme included social activities, work/day program/school, environmental and physical activities.

**During-COVID Social Activities**

Participants explained the types of social activities they were a part of during COVID-19. Individuals discussed social activities for instance virtual classes, virtual social activities and being with families. Individuals with ASD, parents, and support staff responded.

Participant 10 "They're like, oh, I can stay in my apartment all day and play video games like hosting virtual art lessons they've been drawing like cartoon characters and cartoon animals."

Participant 4 "I stay with family. I go from here and there." ..."[program] events like watch parties and cooking nights."

Participant 12 "Most of the [day program] participants never used Zoom before."

**During-COVID Work/Day-Program/School Activities**

This subtheme allowed participants to explain the changes or new activities associated with work, day program, and school. These activities included classrooms and programs transitioning to a virtual platform. All twelve study participants responded regarding this subtheme.

Participant 8 "He sits there in front of an assignment, and I don't know if he's kind of just distracted."

Participant 7 "They [day rehabilitation program] have been pretty. pretty great still."

Participant 10 "In terms of the people who are still working. We have two people working at Acme, one person working Wegmans, we have one person that works in a group home, so he's a direct support staff."

Participant 3 "Yes, I'm still working at [local] hospital."

Participant 1 "My school district has moved on to online classes for the rest of the year."

Participant 9 "Well, I mean he works with food and nutrition. So I guess he's considered essential in the hospital."

***During-COVID Environment***

This subtheme allowed participants to explain the changes to their environment as a result of COVID-19. The environmental analysis includes their use of technology and transportation. Individuals with ASD, parents, and support staff responded.

Participant 9 "I guess the biggest concern is, you know, prior to this [Participant 3] used to take the bus."

Participant 3 "Mom drives me to [a] brand new one hospital."

Participant 4 "I am not going back and forth as much; I get to stay here 24/7."

Participant 7 "Sharing information about the scheduling and what they're doing and making sure that they're still cleaning and that telling them telling him all that information would be something he does want right."... "Prevention techniques as well as what SEPTA [local public transit agency] is doing would be a benefit."

Participant 5 "It has changed that because I've been looking forward to using public transportation more."

Participant 1 "Well, I can't take a train if the coronavirus is still going on."

***During-COVID Physical Activities***

This subtheme discusses the participants' physical activities practiced during the lockdown. As noted above the WHO's definition of physical activity was used for this subtheme. Primarily individuals with ASD and parents responded to this subtheme.

Participant 1 "If the weather is nice, I go for walks."

Participant 3 "Well, there's doing exercise videos while I work out at home."

Participant 6 "Places are just shuts down."

Participant 9 "I don't think he could stay home and not do anything."

**DISCUSSION**

The COVID-19 pandemic had a global impact that affected billions. Vulnerable populations were among those that were hardest hit, and that includes individuals with ASD. This study was designed to explore how the first few weeks of mitigation during the 2020 COVID-19 pandemic affected transitioning adults with autism. This research aims to identify what knowledge, preparedness, and community participation disruptions these individuals experienced. First, it was important to identify what knowledge individuals with ASD had about COVID-19 and preventative behaviors to determine information gaps. This knowledge is helpful with future immediate disaster responses. Second, it is equally important to understand how everyday life activities were disrupted from the perspectives of the individual themselves. Third, it is crucial to identify areas that could be improved with a more rapid response when a future disaster occurs. To accomplish the study goals, individuals answered questions about their knowledge, perception, and impact of COVID-19 during the first months when restrictions and lockdowns occurred.

It was important to collect information directly from the stakeholders to identify what initial understanding and knowledge individuals with ASD perceived. In addition, it was important to determine what preventative behaviors were understood and possibly being implemented. This research gives important real-time insight into how the everyday life activities of those individuals with ASD were impacted. It allows a better understanding of which interruptions were immediately interpreted as challenging and negative, as well as those that were embraced and turned out as positives. It facilitated a better understanding of the impact of COVID's transformative impact on those with ASD's daily life, routines, and understanding and perception of the pandemic.

Individuals with ASD were believed to be at greater risk of COVID-19 than the general public. Some of these fears were justified. Individuals with ASD often require face-to-face assistance from direct care providers. Under the best circumstances, they often have difficulties communicating symptoms and following new and dynamic safety instructions. The COVID-19 instructions were coming from the CDC. Some of the recommendations required social distancing practices, handwashing or hand sanitizing, and the use of personal protective equipment, which was soon followed up with the regional requirements for face masks.<sup>16</sup> In the past, individuals with ASD were not included in emergency planning and preparedness. This oversight was particularly impactful given the ASD community's diverse array of needs and supports. Individuals with ASD often have a greater need for information.

Individuals with ASD reported their lives, including everyday activities that create structure often necessary to maintain routine and order. The individuals with ASD said that before the COVID-19 pandemic, they participated in their communities in many different ways. They participated in social activities like bands, clubs, and outings. They would exercise at gyms and pools. They were a part of day programs, schools, and the workforce and often took public transportation to accommodate their activities. The COVID-19 pandemic disrupted all of the routines and schedules. Some of the interviewed individuals responded well to the changes in socialization. Some increased their physical activities, such as walking, during COVID-19, which was validated in previous research.<sup>28</sup> They even may have preferred using technology to socialize compared to in-person. In contrast, others identified that the changes were scary and not sustainable. The individuals used their preferred news source to learn about the virus. Some individuals even identified that they listened to their favorite YouTube for information. These insights can help with the future dissemination of critical emergency information. It also suggests a window of time that individuals with ASD might benefit from social activities that access technology to continue with normalcy and routine even if using a different platform.

The reported impacts of COVID-19 on individuals with ASD varied among all three categories – individuals themselves, parents, and support providers. Comments that reflected a positive outcome for individuals with ASD were identified in 19 percent (24 comments total) of the responses. Conversely, adverse outcomes were only identified in 9 percent of the comments (12 comments total). Thus, the findings indicate that individuals with ASD who had support systems and resources were able to adapt readily.

Parents and support reported many similarities to the individuals with ASD. When asked how their lives were impacted, all stakeholders identified the change from in-person to virtual platforms and the considerable disruption to the norm. Some parents and support staff believed individuals with ASD were negatively impacted by technology and lack of socialization. Still, there were individuals with ASD who found this a positive impact of the pandemic. Overall, the different participants believed individuals with ASD had an understanding of the COVID-19 pandemic. Parents and support staff seemed more concerned with the ability to uphold CDC recommendations properly. Individuals with ASD seemed to believe they would only move about when all government officials suggested it was ok. They were very compliant and listening to the information and following rules. The parents and stakeholders seemed to identify a need to find a "new normal" and determine how to live safely quicker.

Understanding how to prepare and inform individuals with ASD during emergencies is a crucial component and one that requires further research. However, quicker communication and limited disruptions can cause a better outcome for all.

### **Limitations**

The purpose of the study was to explore the immediate impact on individuals with ASD. The study participants lacked diversity and generalizability. The participants were all white males and in similar age groups. Additionally, all participants had been actively involved in the more extensive research study that involved community mobility. Also, adults with ASD who did not live at home received support services through state agency funding. Thus, the adults with ASD all had working pre-existing supports systems before the onset of the pandemic shutdown.

### **CONCLUSION**

There is limited information understanding the impact of pandemics and natural disasters on individuals with ASD. These semi-structured interviews showed how the COVID-19 pandemic immediately impacted individuals with ASD. COVID-19 added barriers and facilitators to everyday activities. In addition, the interviews identified where they were receiving information as well as how their community participation might change as future pandemics and natural disasters occur. Understanding how to best implement technology, supports, and socialization for individuals with ASD will better assist their management and overall health during difficult times.

Individuals with ASD had a level of understanding of COVID-19 similar to other populations. They identified COVID-19 as a virus that was impacting their lives and forcing new behaviors. Caregivers and support staff expressed concern with individuals with ASD implementing preventative behaviors in the community. Individuals with ASD went from a structured physical schedule to a less structured virtual schedule. It was impressive and unexpected to learn how well some individuals with ASD coped with the shift.



## References

1. International Federation of Red Cross & Red Crescent Societies. Published online 2011.
2. Nelson C, Chan E, Chandra A, et al. Developing National Standards for Public Health Emergency Preparedness With a Limited Evidence Base. *Disaster med public health prep.* 2010;4(4):285-290. doi:10.1001/dmp.2010.39
3. Masten AS. Global Perspectives on Resilience in Children and Youth. *Child Development.* 2014;85(1):6-20.
4. Penrose A, Takaki M. Children's rights in emergencies and disasters. *The Lancet.* 2006;367(9511):698-699. doi:10.1016/S0140-6736(06)68272-X
5. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems (10th Revision.* World Health Organization; 2005. <http://www.who.int/classifications/apps/icd/icd10online>, 2007
6. American Psychiatric. ). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®).* American Psychiatric Pub; 2013.
7. Wallace GL, Budgett J, Charlton RA. Aging and autism spectrum disorder: Evidence from the broad autism phenotype: BAP and aging. *Autism Research.* 2016;9(12):1294-1303. doi:10.1002/aur.1620
8. Born CT, Briggs SM, Ciraulo DL, et al. Disasters and Mass Casualties: I. General Principles of Response and Management. *JAAOS - Journal of the American Academy of Orthopaedic Surgeons.* 2007;15(7). [https://journals.lww.com/jaaos/Fulltext/2007/07000/Disasters\\_and\\_Mass\\_Casualties\\_\\_I\\_\\_General.4.aspx](https://journals.lww.com/jaaos/Fulltext/2007/07000/Disasters_and_Mass_Casualties__I__General.4.aspx)
9. Hubbard K, Trauner DA. Intonation and Emotion in Autistic Spectrum Disorders. *J Psycholinguist Res.* 2007;36(2):159-173. doi:10.1007/s10936-006-9037-4
10. Rattaz C, Michelon C, Munir K, Baghdadli A. Challenging behaviours at early adulthood in autism spectrum disorders: topography, risk factors and evolution: Challenging behaviors at early adulthood in ASD. *Journal of Intellectual Disability Research.* 2018;62(7):637-649. doi:10.1111/jir.12503
11. Baweja R, Brown SL, Edwards EM, Murray MJ. COVID-19 Pandemic and Impact on Patients with Autism Spectrum Disorder. *J Autism Dev Disord.* Published online March 10, 2021. doi:10.1007/s10803-021-04950-9
12. White House. Proclamation on Declaring a National Emergency Concerning the Novel Coronavirus Disease (COVID-19) Outbreak. Washington DC. Source: [trumpwhitehouse.archives.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/](http://trumpwhitehouse.archives.gov/presidential-actions/proclamation-declaring-national-emergency-concerning-novel-coronavirus-disease-covid-19-outbreak/).
13. Fisher J, Languilaire JC, Lawthom R, et al. Community, work, and family in times of COVID-19. *Community, Work & Family.* 2020;23(3):247-252. doi:10.1080/13668803.2020.1756568
14. Lesser IA, Nienhuis CP. The Impact of COVID-19 on Physical Activity Behavior and Well-Being of Canadians. *IJERPH.* 2020;17(11):3899. doi:10.3390/ijerph17113899
15. Simpson N, Pérez R, Goldberg M. Semi-structured interviews on disaster and emergency preparedness for people with disabilities in two states in Mexico. *Nat Hazards.* 2021;106(1):1037-1064. doi:10.1007/s11069-021-04508-z
16. CDC. Coronavirus Disease 2019 (COVID-19). Centers for Disease Control and Prevention. Published February 11, 2020. Accessed October 4, 2020. <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/returning-to-work.html>
17. Hyman SL, Levy SE, Myers SM, et al. Identification, Evaluation, and Management of Children With Autism Spectrum Disorder. *Pediatrics.* 2020;145(1):e20193447. doi:10.1542/peds.2019-3447
18. Havercamp SM, Krahn GL, Larson SA, et al. Identifying People With Intellectual and Developmental Disabilities in National Population Surveys. *Intellectual and Developmental Disabilities.* 2019;57(5):376-389. doi:10.1352/1934-9556-57.5.376
19. Bennett AE, Miller JS, Stollon N, Prasad R, Blum NJ. Autism Spectrum Disorder and Transition-Aged Youth. *Curr Psychiatry Rep.* 2018;20(11):103. doi:10.1007/s11920-018-0967-y
20. Cassidy SA, Nicolaidis C, Davies B, et al. An Expert Discussion on Autism in the COVID-19 Pandemic. *Autism in Adulthood.* 2020;2(2):106-117. doi:10.1089/aut.2020.29013.sjc
21. Chang FH, Coster WJ, Helfrich CA. Community Participation Measures for People With Disabilities: A Systematic Review of Content From an International Classification of Functioning, Disability and Health Perspective. *Archives of Physical Medicine and Rehabilitation.* 2013;94(4):771-781. doi:10.1016/j.apmr.2012.10.031
22. Berry LL, Stuart B. An "Essential Services" Workforce for Crisis Response. *Journal of Public Policy & Marketing.* Published online May 28, 2020:074391562092811. doi:10.1177/0743915620928111
23. WHOQOL Group. Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). *Qual Life Res.* 1993;2(2):153-159. doi:10.1007/BF00435734
24. Myers E, Davis BE, Stobbe G, Bjornson K. Community and Social Participation Among Individuals with Autism Spectrum Disorder Transitioning to Adulthood. *J Autism Dev Disord.* 2015;45(8):2373-2381. doi:10.1007/s10803-015-2403-z
25. Orsmond GI, Shattuck PT, Cooper BP, Sterzing PR, Anderson KA. Social Participation Among Young Adults with an Autism Spectrum Disorder. *J Autism Dev Disord.* 2013;43(11):2710-2719. doi:10.1007/s10803-013-1833-8
26. Hawkey LC, Cacioppo JT. Loneliness and pathways to disease. *Brain, Behavior, and Immunity.* 2003;17(1):98-105. doi:10.1016/S0889-1591(02)00073-9
27. Rumball F, Happé F, Grey N. Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. *Autism Research.* n/a(n/a). doi:10.1002/aur.2306

28. Pfeiffer B, Brusilovskiy E, Hallock T, et al. Impact of COVID-19 on Community Participation and Mobility in Young Adults with Autism Spectrum Disorders. *J Autism Dev Disord*. Published online May 14, 2021. doi:10.1007/s10803-021-05054-0
29. Mason DJ, Friese CR. Protecting Health Care Workers Against COVID-19—and Being Prepared for Future Pandemics. *JAMA Health Forum*. 2020;1(3):e200353. doi:10.1001/jamahealthforum.2020.0353
30. McVeigh K. Experts warn world 'grossly unprepared' for future pandemics. *The Guardian*. <https://www.theguardian.com/global-development/2019/sep/18/a-deadly-virus-could-kill-80-million-people-in-hours-experts-warn>. Published September 18, 2019. Accessed October 8, 2020.
31. Pearce JM. A review of open source ventilators for COVID-19 and future pandemics. *F1000Res*. 2020;9:218. doi:10.12688/f1000research.22942.2
32. Rice D. Scientists are seeing an “acceleration of pandemics”: They are looking at climate change. USA TODAY. Published September 10, 2020. Accessed October 4, 2020. <https://www.usatoday.com/story/news/nation/2020/09/10/climate-change-covid-19-does-global-warming-fuel-pandemics/5749582002/>
33. Wolfe N. COVID-19 Won't Be the Last Pandemic. Here's What We Can Do to Protect Ourselves. Time. Published April 15, 2020. Accessed October 4, 2020. <https://time.com/5820607/nathan-wolfe-coronavirus-future-pandemic/>
34. McFadden SM, Malik AA, Aguolu OG, Willebrand KS, Omer SB. Perceptions of the adult US population regarding the novel coronavirus outbreak. *PLOS ONE*. 2020;15(4):e0231808. doi:10.1371/journal.pone.0231808
35. Tyson A, Johnson C, Funk C. U.S. Public Now Divided Over Whether To Get COVID-19 Vaccine. Pew Research Center Science & Society. Published September 17, 2020. Accessed October 7, 2020. <https://www.pewresearch.org/science/2020/09/17/u-s-public-now-divided-over-whether-to-get-covid-19-vaccine/>
36. Lafferty KD. The ecology of climate change and infectious diseases. *Ecology*. 2009;90(4):888-900. doi:10.1890/08-0079.1
37. Wu X, Lu Y, Zhou S, Chen L, Xu B. Impact of climate change on human infectious diseases: Empirical evidence and human adaptation. *Environment International*. 2016;86:14-23. doi:10.1016/j.envint.2015.09.007
38. Madhav N, Oppenheim B, Gallivan M, Mulembakani P, Rubin E, Wolfe N. Pandemics: Risks, Impacts, and Mitigation. In: Jamison DT, Gelband H, Horton S, et al., eds. *Disease Control Priorities: Improving Health and Reducing Poverty*. 3rd ed. The International Bank for Reconstruction and Development / The World Bank; 2017. Accessed December 10, 2020. <http://www.ncbi.nlm.nih.gov/books/NBK525302/>
39. Espejo W, Celis JE, Chiang G, Bahamonde P. Environment and COVID-19: Pollutants, impacts, dissemination, management and recommendations for facing future epidemic threats. *Sci Total Environ*. 2020;747:141314. doi:10.1016/j.scitotenv.2020.141314
40. Srinivas H, Nakagawa Y. Environmental implications for disaster preparedness: lessons learnt from the Indian Ocean Tsunami. *J Environ Manage*. 2008;89(1):4-13. doi:10.1016/j.jenvman.2007.01.054
41. Pfeiffer B, DeRita J, Giacomucci E, et al. Barriers and Facilitators to Public Transportation Use for Individuals with Intellectual and Developmental Disabilities. *Occupational Therapy in Mental Health*. 2021;37(1):1-14. doi:10.1080/0164212X.2020.1832013
42. Doak J, Katsikitis M, Webster H, Wood A. A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Research in Developmental Disabilities*. 2019;93:103428. doi:10.1016/j.ridd.2019.103428
43. Calder L, Hill V, Pellicano E. 'Sometimes I want to play by myself': Understanding what friendship means to children with autism in mainstream primary schools. *Autism*. 2013;17(3):296-316. doi:10.1177/1362361312467866
44. Cridland EK, Jones SC, Caputi P, Magee CA. Being a Girl in a Boys' World: Investigating the Experiences of Girls with Autism Spectrum Disorders During Adolescence. *J Autism Dev Disord*. 2014;44(6):1261-1274. doi:10.1007/s10803-013-1985-6
45. Crane L, Batty R, Adeyinka H, Goddard L, Henry LA, Hill EL. Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *J Autism Dev Disord*. 2018;48(11):3761-3772. doi:10.1007/s10803-018-3639-1
46. DePaolo CA, Wilkinson K. Get Your Head into the Clouds: Using Word Clouds for Analyzing Qualitative Assessment Data. *TECHTRENDS TECH TRENDS*. 2014;58(3):38-44. doi:10.1007/s11528-014-0750-9
47. Dedoose. <https://www.dedoose.com/resources/articledetail/dedoose-desktop-app>