Voices from Academia

A Needs Assessment of COVID-19 Guidance for Adults with Developmental Disabilities

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ABSTRACT

People with intellectual and developmental disabilities (IDD) have been identified as particularly vulnerable to the COVID-19 virus. Besides susceptibility to viral threats, adults with IDD often find it difficult to make the changes in behavior and routine that are necessary to minimize risks of exposure and infection. The Centers for Disease Control and Prevention (CDC) is concerned that individuals with developmental disabilities receive vital guidance in a format they could understand. The CDC engaged the team at Georgia Tools for Life at the Center for Inclusive Design and Innovation at Georgia Tech to conduct a rapid assessment as to whether current CDC guidance addressed the unique communication differences that such individuals may require and to suggest ways to improve this communication.

A Rapid Needs Assessment study was conducted that involved interviews with six adults with IDD. These sessions asked them to interact with CDC's COVID-19 materials. The team collected feedback on ease

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of reading, comprehension ability, formatting, and use of images. In addition, a set of group interviews with four care providers was completed, collecting feedback on the same issues and materials.

When shown a CDC COVID-19 webpage, individual participants with IDD reported having difficulties reading and understanding the content due to unfamiliar vocabulary, lengthy and complex sentences, and dense text. Both caregivers and individuals with IDD suggested that documents should present simpler words and less text and raised questions regarding the effectiveness of use of images in such guidance. Individual comments helped researchers shape recommendations for production of more appropriate documents.

Keywords: intellectual disability, developmental disability, COVID-19

A NEEDS ASSESSMENT OF COVID-19 GUIDANCE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

The National Assessment of Adult Literacy (NAAL) suggests that more than 56 million adults in the United States read at levels below what is considered basic reading ability (White 2003). Lesgold and Welch-Ross (2012) assert that there has been little improvement in recent years. Comprehension of reading remains the area of poorest academic performance for virtually all adults with disabilities. This is most pronounced among adults with IDD (Wagner et al., 2006). Studies suggest that by middle school, the reading skills of students with intellectual disabilities stabilize at levels below a 3rd grade reading ability (Schulte et al., 2016). Nash, Clark and Karvonen (2016) suggest that only 20% of this group can read with comprehension at any level. Assistive Technology (AT) has been used with individuals with IDD to help them manage reading tasks in the context of school, workplace, and daily living (Davies et al., 2001; Lee et al., 2011; Wehmeyer et al., 2004).

The efficacy of AT use is linked to accessibility in the context of internet activity— particularly for people with IDD. The Web Content Accessibility Guidelines (WCAG 2.0, 2008) rests upon four central principles of accessibility: Web applications should be perceivable, operable, understandable, and robust. Of particular importance to individuals with IDD is the principle of being "understandable." This suggests that the readability of text and the efficacy of images and other visual presentation is central to a reader's ability to derive meaning from the content of the site or the app (Bunning et al., 2010).

While technology use has become more prevalent within society, challenges accessing content persist for people with IDD (Agren et al. 2020; Alper & Goggin, 2017; Chadwick et al., 2013; Clark, 2020; Karreman et al., 2007). Individuals with disabilities can use AT devices and supports to get on the internet and navigate to a site. However, if the content is not "understandable" then an impediment has been created and the individual's right to accessibility has not been fully addressed (Agren et al, 2020; Bunning et al., 2010; Chadwick, 2013; Ellcessor, 2015; Lazar et al., 2015). Greg Vanderheiden (2008) observed that true accessibility would be within our reach when we exchange our emphasis on trying to "provide access to the interface" for a focus on "providing access to the underlying function" (p.6).

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The well-being of persons with IDD could be at risk if guidance pertaining to the COVID-19 virus was not received and applied effectively. As the pandemic unfolded in 2020, the Centers for Disease Control and Prevention (CDC) took special concern that their guidance would be properly understood, and acted upon, by people with IDD, their families, and their care providers. The CDC had set a goal to provide information about COVID-19 in a format that followed the Plain Language guidelines (Plain Language Action and Information Network, 2011). Research suggests that Plain Language guidelines do not result in text that is simple enough to meet the needs of the entire population of adults with very low literacy skills, especially individuals with intellectual and developmental disabilities (Leroy et al., 2013). With regard to written instructions and guidance pertaining to health and safety, advice that is presented in language that is too complex for the intended audience is unlikely to be understood or followed.

As the COVID-19 pandemic unfolded, the CDC became concerned that individuals with IDD receive and apply its guidance effectively. The nature of the guidance itself had become complex and difficult to simplify. It was with a sense of urgency that the CDC reached out to Georgia Tools for Life (GATFL) at the Center for Inclusive Design and Innovation at Georgia Tech. GATFL was asked to conduct a rapid assessment of current CDC guidance to determine whether it addressed the unique communication differences that such individuals may require and to suggest ways to improve this communication.

GATFL is the Assistive Technology Act (1988) agency for the state of Georgia and had partnered with the CDC Foundation on training projects in the past. GATFL is staffed by people with extensive experience in working with people with IDD and has many relationships with public and private agencies that the CDC believed could be leveraged to draw together a group of individuals with IDD swiftly for this purpose.

TARGET AUDIENCE AND RELEVANCE

The target audience for this paper includes those who support and care for individuals with intellectual and developmental disabilities: their care providers, families, and friends. It also includes the employers, therapists, teachers and administrators, transition coordinators, vocational rehabilitation counselors, and support coordinators who work with them. Clearly there are significant threats to health and safety wrapped up in our responses to the COVID-19 virus, so individuals with IDD should benefit from the application of these findings. Anyone who can and does help shape the behaviors and understanding of these individuals will benefit from reading and considering the lessons learned here.

LITERATURE REVIEW

People with intellectual and developmental disabilities (IDD) have been identified internationally as one of the most vulnerable segments of the population with regard to viral infections such as COVID-19 (Buono et al., 2021). Overall, disorders of the respiratory system have been considered one of the chief threats to health and longevity for individuals with IDD (O'Leary et al., 2018; Truesdale et al., 2021). This

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is particularly true of individuals with Down syndrome (O'Leary et al., 2018). Further, challenges related to intellectual disability, specifically the limited capacity to discern threats and evaluate risks, further exposes this group to dangerous complications (Biswas et al., 2010; Perera et al., 2020). These vulnerabilities have been brought into international focus in 2020 during the COVID-19 pandemic (Buono et al., 2021; Courtenay, 2020; Courtenay & Perera, 2020; Perera et al., 2020).

Heightened attention to the need for changes in behavior and observance of safety practices such as social distancing, frequent and thorough handwashing, and wearing facial coverings was considered especially significant for individuals with IDD. Health officials viewed minimizing risks by drawing attention to these safety practices as a priority for this group (Buono et al., 2021). The CDC was especially concerned for the safety of these individuals and sought ways to present its COVID-19 guidance most effectively. The CDC partnered with Georgia Tools for Life (GATFL) at the Center for Inclusive Design and Innovation (CIDI) at Georgia Tech to explore ways to make its guidance more accessible to people with disabilities including individuals who are blind (through Braille documents), have hearing impairments (via ASL videos), and those with IDD (through easy-to-read documents and videos).

The number of individuals with IDD in the United States is estimated to be between 2.6 and 4 million (Landes et al., 2020). IDD is comprised of a number of disabilities that affect an individuals' capacity in the areas of motor, communication, cognition, and behavior, and is lifelong in nature (Zablotsky et al., 2019). These disabilities include Down syndrome, cerebral palsy, and spina bifida, as well as less common disorders such as Fragile X.

Historically, the roles individuals from this group have played in the workforce would place them in such settings as warehouses, food service, supermarkets, and janitorial services (Hiersteiner et al., 2018). This suggests that a number of people with IDD have served in roles as essential workers in the early days of the pandemic (Thompson & Nygren, 2020).

Individuals with IDD have been found to experience poorer health outcomes than the general population (Buono et al., 2021; Helmsley & Balandin, 2014). Many individuals in this group are susceptible to infections which affect breathing and experience respiratory distress more often and for longer periods than the general population (Axmon et al., 2017; Chang et al., 2017). Adults with IDD who live in group home settings were found to be in greater jeopardy of exposure to, and mortality from, COVID-19 (Landes et al., 2020). Thus, for medical reasons and because these individuals were positioned for increased risk of exposure to COVID-19, it was important to provide guidance on health and safety procedures to this vulnerable segment of the population.

METHODS

Rapid Needs Assessment
The GATFL research team conducted remote (online) interviews with participants with IDD. The sessions made use of Georgia Tech's approved WebEx platform for these sessions. A semi-structured interview protocol was developed that focused on CDC's existing COVID-19 content and users' experiences and

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needs. The interview questions are included in the appendix. Each participant with IDD joined the session with a parent who was their primary care provider. The sessions lasted around 50 minutes and were video recorded for later analysis.

The research team also conducted two group interview sessions with caregivers of adults with IDD including a total of four participants. A semi-structured protocol was also developed for the caregiver group interviews that focused on CDC's existing COVID-19 content and explored the participants' observations of the individuals for whom they provided care and their insights regarding what was effective and what was not. The questions are included in the appendix. The sessions lasted around 60 minutes and used the Georgia Tech WebEx online meeting platform. Sessions were video recorded for later analysis.

Development of Data Collection Protocols

Interview Protocol

An interview protocol was developed for the people with IDD, aiming to gather information about their experiences with CDC's COVID-19 information that is available through CDC's website, social media platforms, and printed media (such as flyers and posters).

The interview protocol consisted of three sections: (1) general information about the user, (2) questions for participants who previously used CDC's website for COVID-19 related information, and (3) questions for participants who have never used CDC's website for COVID-19 related information or participants who do not remember if they used CDC's website for COVID-19 related information.

General information about the user section includes five questions to understand participants' daily internet usage, AT that participants use to access the internet and computer, participants' experiences with CDC's website, social media platforms, and printed media.

Questions for participants who previously used CDC's website for COVID-19 related information section includes 17 questions to investigate participants' experiences with CDC's website, social media platforms, and printed media. Frequency of usage, information-seeking behavior, accessibility challenges faced, and alternative modalities preferred were asked in this section. These questions were planned to be asked to participants with previous experiences with the CDC's platforms and media.

Questions for participants who have never used CDC's website for COVID-19 related information or participants who do not remember if they used CDC's website for COVID-19 related information section includes 16 questions to investigate COVID-19 information resources used by participants and their evaluation of the CDC's website. These questions were planned to be asked to participants without previous experiences with the CDC's platforms and media.

The interview protocol was developed collaboratively by the research team at the Center for Inclusive Design and Innovation at Georgia Tech which included the authors of this article. The research team aimed to understand experiences of people with IDD with COVID-19 information resources and

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preferences they have for the alternative media modalities. CDC conducted the final evaluation of the interview protocol to make sure it serves the project's mission.

The project team decided to individually interview people with IDD to understand their unique experience in sufficient detail and prevent peer influence that could potentially occur in a focus group setting.

Focus Group Protocol

A focus group protocol was developed for the primary care providers of people with IDD, aiming to gather information about their observations of the individuals for whom they provided care. The focus group protocol consisted of the same three sections and questions as the Interview Protocol. The questions were slightly revised to target the primary care providers' observations. CDC conducted the final evaluation of the focus group protocol to make sure it served the project's mission.

The project team decided to include the primary care providers of the individuals with IDD in order to supplement the data collected from the interviews. The same questions were asked to confirm insights obtained through individual interviews. We chose to conduct a focus group with the care providers as we expected the discussion among them to reveal valuable insight.

Recruitment

The research team recruited participants for individual interviews within the state of Georgia using invitation emails. To expedite this process, the research team reached out to agencies and organizations that served adults with IDD and specifically to leaders who would be familiar with individuals' reading levels. These leaders passed word of our study to individuals who met the study criteria. Individuals signed up through an online portal where consent was secured.

Participants for the caregiver group interviews were also recruited from within the state of Georgia using invitation emails. All four of the group interview participants were family members or primary care providers of adults with IDD who took part in the survey. The participating caregivers signed up through an online portal where consent to participate was secured.

Demographics

The team interviewed six adults with IDD. All of the interview participants met the following criteria: 1) they were 18 years and older, (2) they had an intellectual, developmental, or cognitive disability or a linguistic impairment, (3) they could read in English, and (4) they were currently living in, and present in, the United States. Among those who responded to our invitations there were two male participants and four female participants. Two participants were between the ages of 18–24. Four participants were between the ages of 25 and 34.

The caregiver group interview consisted of four adult care providers. Each care provider was the parent of an individual with IDD. All of the caregiver group interview participants were female. All met the following criteria: (1) they were 18 years and older, (2) they were caregivers of individuals with intellectual, developmental, or cognitive disability or linguistic impairments, (3) they could read in English, and (4)

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they were currently living in and present in the United States.

As the need for this study was time-sensitive, the research team decided to move forward with the study once the number of participating adults with IDD passed five. Neilsen (2000) suggests that a five-member panel is sufficient for user experience focus groups.

Data Analysis

The recorded interviews were transcribed using Webex's automated captioning capabilities. Captioning files for the sessions were then manually reviewed and revised by the authors to ensure accuracy.

Transcripts from the interview sessions were combined and analyzed together to identify patterns and connections. Transcripts from the focus group sessions were analyzed to identify themes. Results were discussed for each question asked.

INDIVIDUAL INTERVIEW RESULTS

The individual interviews followed a semi-structured interview protocol that addressed several topics including: internet activity and assistive technology (AT) usage, experiences with CDC websites and social media platforms, and experiences with CDC printed materials (flyers and posters; see Figure 1). Then participants were instructed to read and examine a webpage from a CDC COVID-19 guidance site. Information was gathered regarding general impressions, readability and accessibility.

Figure 1: Examples of CDC Flyers and Poster

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Internet Activity and Assistive Technology Usage

Each of the participants reported having an iPad that they used as their primary tool to connect to the Internet. Three participants reported having computers (a Chromebook, a tablet computer, and a PC) and used them less frequently than their iPads. Only one participant reported having a smart phone.

Four of the participants used YouTube for listening to music videos. Only one participant reported having a Facebook account. None of the participants reported having an Instagram account. Two of the participants mentioned using the BrainPOP app (an educational website with short, animated movies targeted for students in grades K–12) on their iPad.

Five of the participants reported that they spend less than an hour on the internet daily, while one participant reported spending two hours daily. All of the participants reported having used the Zoom video meeting platform in other online meetings, and had some experience navigating virtual platforms.

Experience with CDC's Website and Social Media Platforms

None of the participants reported having used CDC's website or social media platforms to find information about COVID-19. Only one participant reported that she had heard about the CDC web site, but had never visited it. One participant stated that sometimes COVID-19 information comes up on Facebook or YouTube, but he was not interested and had never clicked on it.

Experience with CDC's Flyers and Posters

None of the participants reported having seen CDC's flyers on COVID-19. Two participants stated that they have seen CDC's COVID-19 posters; these were observed at an individual's workplace. Other posters were reportedly seen at grocery stores and at medical clinics—although the individuals were not sure if these were the CDC's posters. An example of CDC flyers and posters is presented in Figure 1.

Use of CDC's Digital Platforms

None of the participants reported using CDC's digital platforms. The section below presents the results for questions targeting participants who have not used CDC's digital platforms for seeking COVID-19 information.

Frequency

Only one participant reported having searched for COVID-19 information. She had a weather app on her iPad and it has a link for COVID-19 statistics (new cases, deaths, etc.). The individual checked it every day as her coach told her that her Special Olympics Softball team might resume practices if the numbers came down. The other 5 participants responded that they do not search for news about COVID-19. One participant expressed that he watches COVID-19 information on TV if it comes up, but does not seek it out.

Resources and Platforms Utilized

Four of the participants reported having learned about COVID-19 from their family members. Of these

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four, two participants mentioned that their therapists talked with them about COVID-19. Two reported having experienced family members becoming sick and going through quarantine with COVID-19.

Four of the participants expressed that they have seen COVID-19 news on TV. Two participants mentioned that they have seen COVID-19 videos on the BrainPOP app. One participant said, as stated earlier, that she looked at her weather app on her iPad for COVID-19 statistics. The same participant reported having seen posters and having conversations at their workplace about COVID-19.

Distribution of the resources used for COVID-19 information by number of participants can be seen in Figure 2.

Figure 2: Resources for COVID-19
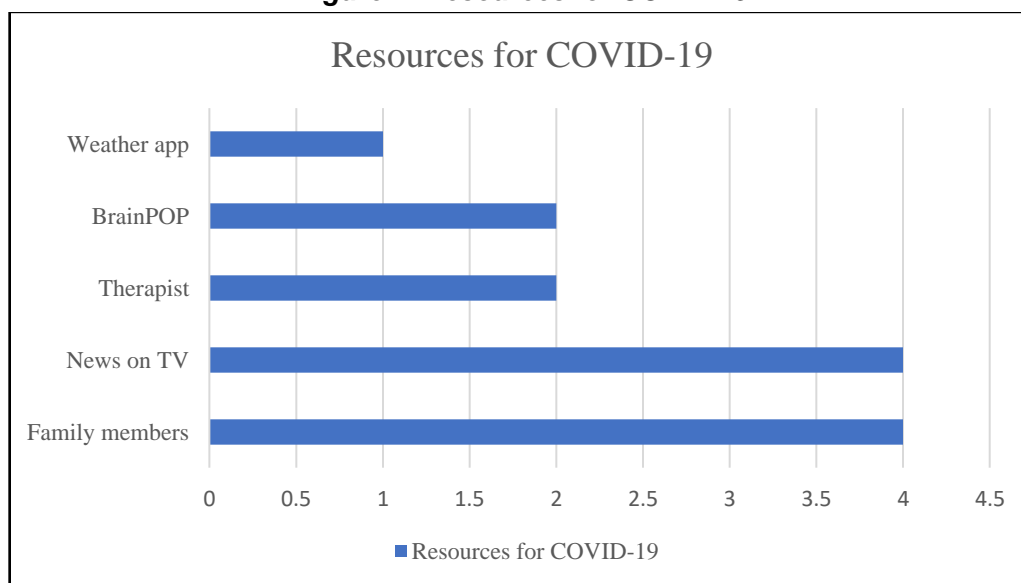
Types of Information

Only one participant reported having happened upon any COVID-19 information while using a digital platform. She reported using the weather app to learn about COVID-19 statistics and returned to this site later for updates. The other five participants reported that they had not searched for any COVID-19 information on any digital platform including that of the CDC. Only one participant expressed that they knew CDC had a website. None of the participants had ever visited it.

Experience with "How to Wear Masks" Page

During the interview, participants were asked to visit a CDC webpage about face masks (https://www.cdc.gov/coronavirus/2in this 019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html). All of the participants visited the website and read the page aloud. Their responses to the questions are presented in the section that follows.

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Initial Impressions

Participants reported having found the page difficult to read. Participants commented, "This is boring" and "There is [*sic*] a lot of words here." Another participant said she already knew about masks, and there was no information in the page that was new. Four of the participants specifically mentioned having difficulties understanding the sentence which read: *"CDC does not recommend use of masks or cloth masks for source control if they have an exhalation valve or vent."* They said they did not understand the words exhalation, valve, and vent. Two participants reported that they did not understand the word "incapacitated." One participant stated that they did not understand the word "symptoms."

All of the participants liked the pictures on the page (see images in Figure 3). When probed further on the pictures, participants said, "They were nice," or "They were funny." When asked about what they saw, the participants appeared to miss the meaning of arrows, and the check marks and Xs within the images. One individual commented about the image that illustrated social distancing, saying, "I don't think they like each other." This suggested to the research team that these images did not contribute to understanding of the intended message.

Figure 3: Images from CDC "How to Wear Masks" Page

Three of the participants explored other areas of the CDC's site after completing the reading. They said they clicked on the links at the bottom of the web page (under More Information). Two participants clicked on the *"ASL Video Series: Easy DIY Mask"* link. Another participant watched the ASL video for the *"Use of Cloth Face Coverings to Help Slow the Spread of COVID-19"*. Each of these participants said they enjoyed watching the video and suggested that they would watch something similar to this video to learn about COVID-19.

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All of the participants reported having liked the pictures. Three of the participants reported having greatly liked the ASL video. One participant reported having disliked the difficult words. One participant commented that there are too many things on the page, and this made them "dizzy." None of the participants reported any difficulty navigating the page. Two participants observed that it was easy to get to the page and click on the items and links.

Other Ways to Present This Information More Clearly

When asked if there might be other ways to present this information that would help them better understand, two participants commented that it would be helpful if the page used simpler words. Another suggested using fewer words. Three of the participants stated that they would like to see pictures that helped them understand.

One participant reported that "videos would be good." He said that he did not understand the words *exhalation*, *valve*, or *vent* and he did not understand the differences between the mask types (surgical vs. others). He suggested that it would be helpful if someone explained this to them in a video. Another participant commented that she would learn more if the site had interactive activities like those on BrainPOP.

Preferences Around Text Simplification

In order to investigate the participants' preferences and to help identify the level of text complexity that would be appropriate for individuals with IDD, the following questions were asked: 1) Did you understand the words in this webpage? 2) Did you understand what the webpage was saying? 3) Would you like it if the webpage used words that are easier to understand?

Two participants said that they would like it if the webpage used words that are easier to understand. Four of the participants reported understanding what the webpage was saying. However, after follow-up questions, they all said that there were words that they did not understand. They mentioned the words: *exhalation*, *valve*, *vent*, *incapacitated*, and *infected*.

Future Usage of CDC's Website

After visiting the site, three participants said that they would come back to CDC's website for more information about COVID-19 in the future. Two participants said that they would not come back to CDC's website for information about COVID-19 in the future. Of these, one participant commented that they prefer BrainPOP (interactive activities vs. reading).

Preferences Around CDC Flyers

Two of the participants expressed that they would not read a COVID-19 flyer. Two of the participants stated that they would try to read a COVID-19 flyer and one of them suggested that they doubted that they would understand it fully. One of the participants expressed that they would like to see information on prevention in the workplace, specifically about social distancing at the workplace.

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CAREGIVER GROUP INTERVIEW RESULTS

The research team also conducted online group interviews with caregivers of these participants as part of this study. Their responses and observations are recorded in the sections below.

Assistive Technology Usage
All panelists reported that the individuals with IDD they worked with do not use any assistive technology to access internet or to use a computer.

Experience with CDC's Website and Social Media Platforms
Participants reported that none of the individuals with IDD they represented have used CDC's website or social media platforms (YouTube, Facebook, Twitter, or Instagram) for COVID-19 related information. Two participants reported that individuals with IDD they care for do not use Facebook, while two reported infrequent use. One reported that her son uses Instagram. All of the participants stated that the individuals with IDD use YouTube mainly for watching movies and music videos. Two of the participants with IDD were reported to have email accounts, but they rarely send emails. One participant's daughter uses a weather app on her iPad that has a link for COVID-19 statistics (cases, death, etc.). She reportedly checks it every day.

Participants commented that the individuals with IDD they represented might be seeing CDC's COVID-19 information when they use YouTube (as an ad or link) but that they never clicked on these links.

Experience with CDC's Flyers and Posters
Participants reported that most of the individuals with IDD they represented had not seen any flyers from the CDC on COVID-19. One reported having seen CDC's posters on COVID-19 at grocery stores and at the gym. Those posters were about wearing masks. Another participant said her daughter had reported having seen CDC posters at her work in a restaurant.

Use of CDC's Digital Platforms
The panel said that none of the individuals with IDD had used any of CDC's digital platforms. The section below presents the results for questions targeting participants with IDD reported to have not used CDC's digital platforms for seeking COVID-19 information.

Frequency
Three participants stated that individuals with IDD they represented do not actively seek COVID-19 information utilizing any digital format. Instead, they are informed by their family members about COVID-19. One participant reported that her daughter checks COVID-19 statistics pretty much every day using a weather app installed on an iPad.

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Resources and Platforms Utilized

All of the panelists reported that the individuals with IDD they represented have been informed about COVID-19 by their families. Two of the participants specifically mentioned that their individuals had watched news on TV and learned supplementary information about COVID-19. One participant mentioned that her daughter has also been informed about COVID-19 through training at her workplace. Another participant expressed that her daughter's therapist talks with her about COVID-19 frequently.

Types of Information

One participant's daughter was interested in when COVID-19 will be over so she can go on vacation or can see her friends again in person. Another participant's daughter was interested in COVID-19 statistics, as she was looking forward to the resumption of Special Olympics softball. Several panelists reported the individuals with IDD they provided care to had questions about self-quarantine practices, as well as precautions they can take, such as washing hands and covering coughs and sneezes to keep the germs away.

One participant's son was focused on what he needs to do in different situations (e.g., when does he need to wear a mask, how can he tell what the requirements of the situation or environment might be, etc.). Another explained that her daughter (who had been one of the participants in the individual interviews) experienced confusion about the purpose of wearing masks. The individual had commented that she thought masks were for protecting herself and not others.

Reasons Why CDC Platforms Have Not Been Used

All of the participants agreed that the individuals with IDD they represented do not conduct internet searches, but rather click on familiar links. None of the individuals reported actively seeking COVID-19 information online. So, they are not singling out CDC's website to avoid. Panelists also volunteered that the individuals with IDD they represented have not seen their parents visiting CDC's website so there was not a model in the house for this either. Another participant mentioned their daughter probably did not think about going to CDC's website. They added that their daughter probably heard about CDC in the TV news.

Experience with "How to Wear Masks" Page

During the caregiver group interviews, participants were asked to visit CDC's webpage providing guidance for wearing face masks (Centers for Disease Control and Prevention, 2020). Their answers to our questions are provided in the sections that follow.

Initial Impressions

Panelists explained that it is laborious for individuals with IDD to read so much text. One stated that fonts used are not big enough for people who struggle with reading. One participant explained that their child would not understand the difference between masks mentioned in the following sentences: *"Do NOT use a mask meant for a healthcare worker. Currently, surgical masks and N95 respirators are critical supplies that should be reserved for healthcare workers and other first responders."* Another panelist commented

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that CDC should explain the meanings of exhalation valve and vent instead of just using these words in the sentence without any further explanation.

The care provider panel discussed their observations that the pictures used on this page were not very helpful. One suggestion for improvement was to use the pictures to show what was said in the text such as showing the pictures of N-95 masks saying: "this is what it looks like." One participant mentioned that images need to be more concrete, perhaps using real people instead of the illustrations. Another participant agreed on this comment.

Figure 4: Social Distancing Image
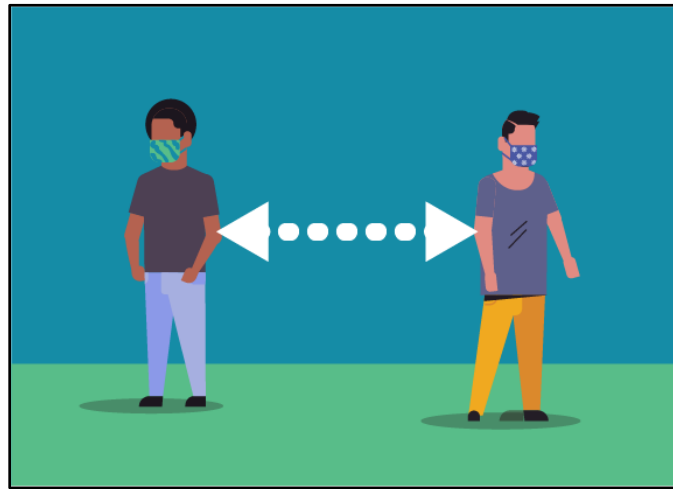
Another observation was made regarding the social distancing picture (see Figure 4 above) on this webpage. One participant posited that this picture may not convey what CDC is trying to say. Another panelist suggested to change the picture to show two people having their arms stretched out to both sides and still not touching each other (fingertips to fingertips). The other participants liked this suggestion. Three of the panelists agreed that the individuals with IDD would need more explanation or background information in order to understand how the pictures applied to the content on the page.

All of the participants agreed that the individuals with IDD they represented would enjoy and learn from a video. Two of the participants reported that their individuals had watched ASL videos for face masks (a link was provided at the bottom of the web page) during their interviews and liked them a lot. One participant suggested to have interactive features on the site such as a game, activities, or *"something that the individuals can click on."* They added that would help their adult child learn better.

Preferred Features

One of the panelists observed that her daughter (who was one of the study participants) did not have any problem with the page about masks during her interview. She added that her adult child was very knowledgeable about the content. However, she asserted that her daughter's experience with the site would be different if she did not already know so much about COVID-19. All of the participants discussed

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that some sentences were complex and that vocabulary could be simplified. The vocabulary words specifically mentioned were *sanitizer*, *disinfect*, *exhalation valve*, and *vent*.

Another participant expressed concern that text supported by a picture may not have the intended effect for individuals with IDD. She added that length of the text and the vocabulary used in the text is crucial. For example, if the text includes new vocabulary, such as exhalation vent, that will cause a problem. She also suggested that the picture should directly support what the text says. Another participant commented on the layout of the page (text is on one side of the page and the picture is on the other side) and stated that if their adult child sees the picture in close proximity to the text she reads, it is much easier for her to absorb and understand.

Other Ways to Present Information More Clearly

Two participants suggested to have a *"speaker"* button for people with IDD to press to read the text on the webpage out loud. Other participants also liked the suggestion. Another panelist suggested having a button that produces a simpler version of the page when clicked.

One participant suggested making the site more interactive utilizing videos, games, and quizzes. That way, they added, "younger people with disabilities would stay longer on the site and get more information without realizing they are getting more information." All of the participants agreed that the individuals with IDD they represented would enjoy and learn from a video.

Preferences Around Simplified Text

The panel agreed that the text used was difficult and would be daunting for individuals with IDD to comprehend. One participant observed that there are a lot of words on the page and that would discourage their adult child from trying to read it. They also expressed that sometimes their adult child reads text and can pronounce all the words, but when they finish reading, they are unable to remember anything or answer questions about the text. The participant's suggestion was to provide a video together with the text, which they believed would work a lot better.

The care providers also commented on the importance of the dissemination. They expressed that these resources should be distributed to the specific groups in the community that serve individuals with disabilities. They added that people who might go over these resources with individuals with IDD (such as doctors, therapists, program coordinators, coaches, etc.) should be made aware that these resources are available. They also commented that there are other groups who can benefit from simpler text such as younger readers, ESL students and families, etc. Another participant suggested having a button to print the simpler version of the document on the website.

Preferences Around CDC Flyers and Posters

All of the participants agreed that the individuals with IDD they provided care to might look at posters but would probably not read them unless prompted. They added that the location of posters is important, since they are not going outside frequently at this time.

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One participant explained that individuals with developmental disabilities tend to talk to a parent, caregiver, teacher, therapist, or someone who has some kind of authority for information, especially when it relates to COVID-19. The caregivers agreed that these people should be informed about CDC resources available with simplified text.

One participant stated that her daughter might try to read a simplified version of CDC's COVID-19 flyers. She added that her daughter needs to read any printed material several times before she understands it. Participants discussed whether or not the individuals with IDD would read CDC's COVID-19 articles when provided with a printed copy. They all agreed that they would probably not read them unless prompted by their parents.

One of the panelists commented that her son did not have any difficulty reading the page, but that was because he already knew about the content. She was curious to see what her son's reading performance would be with unfamiliar content.

Another parent commented that her daughter does not understand that pictures on the page are connected to the text on the page. As a result, she suggested pictures be located closer to the related content and added that maybe a little video would also be helpful.

SUMMARY AND DISCUSSIONS

Summary of Findings

When presented with CDC's web-based guidance on the "How to Wear Masks" page, the individual participants reported having difficulties reading and understanding the content. Unfamiliar vocabulary, lengthy and complex sentences, and dense text presented issues for the participants. More space between lines and larger fonts were also identified as ways to improve readability. The caregivers in the group interviews were unanimous in their assertion that the individual participants brought a great deal of background knowledge to their encounter with CDC's site. Without this prior learning, these participants would have had even greater difficulty comprehending the content.

Findings from the interviews also appear to suggest that images on the site did not clarify or inform. When asked about the images, the interview participants failed to identify the information the images were intended to convey. Researchers noted that the images were not contributing to comprehension. Caregiver group interview participants reported that the pictures were generally not instructive or helpful and lacked concrete detail that people with IDD require.

The caregivers agreed that less complex and less compact text would help individuals with IDD be able to read and comprehend the content. Panelists asserted that images needed to be more concrete, more closely aligned to the content, and placed in closer physical proximity to the content on the page in order to be of value for comprehension. The caregivers also suggested the inclusion of a button embedded on each page in the CDC site that would open a simpler version of CDC documents. The caregivers also encouraged dissemination of readable documents to the groups in the communities with which these

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individuals associate, as people with IDD will seek information and clarification from authority figures they trust.

Discussion of Findings

It is clear from the literature that adults with IDD are a particularly vulnerable population relative to the COVID-19 virus. These individuals often live and work in situations where they may be at risk for exposure to COVID-19. Based upon their disability and their living and working circumstances, they are often poorly situated to assess risks and to adjust behavioral patterns that may increase their vulnerability. Hence, clear concrete practical health guidance is essential to help this group stay safe during a pandemic.

The CDC is to be commended for its care and concern that their messaging was effectively connecting with people with IDD. It would be a mistake to ignore or underestimate this group of adults regarding their capacity to learn and adopt healthy practices. These findings suggest that the individuals can and do make significant adjustments in their lifestyles to adopt safety and health practices. The CDC was wise to investigate the sources of their guidance. While this group was familiar with technology, it should be remembered that not all individuals with IDD have such experience or access.

While the individuals in this study demonstrated a pattern of technology use that was largely limited to familiar and preferred activities (music, movies, interactive activities, and games), it is worth noting that none of them or their care providers saw themselves as using "assistive" technology. All of the participants had demonstrated some level of comfort using consumer platforms like tablets, computers, Chromebooks, and cellphones. Further, it is noteworthy that these individuals had some level of social media activity—even if they did not seek out COVID-19 related information from it—and that all of the participants had experience with remote conferencing systems like Zoom. This suggests that such media and platforms *could* play a role in disseminating critical information to this population in the future if the message was communicated appropriately and individuals were aware of it.

Nonetheless, it was observed that none of our participants engaged in searches that involve typing URLs. Rather, these adults with IDD appeared to rely on the familiar and look to established sources of authority for guidance. Families and care providers had been their primary source of health information. The strategy that emerged from our panel to emphasize dissemination of easy-to-read documents to the leaders and groups in the community, as well as to adults with IDD, may prove to be especially valuable.

The findings of this study also make clear the need to simplify the guidance provided by health officials. The individuals with IDD and the care provider panelists were in agreement that written materials for this population needed a simplified, uncomplicated approach. Familiar words, uncomplicated sentences, well-spaced lines using slightly enlarged fonts, and which address focused, relevant topics, have all been identified as elements of an appropriate approach to creating documentation that is accessible for this group.

It was confusing to hear that our participants like images and want images included, but are unable to derive the intended meaning from the images presented. The literature does suggest, however, that

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without proper instruction, images may actually distract from understanding of text. It seemed to the research team that our participants valued the aesthetic quality of having pictures.

CONCLUSIONS AND FUTURE STUDY

The results of the interviews with individuals with IDD suggest several considerations for language that is used to communicate information and guidance about COVID-19 to persons with IDD. First, such guidance needs to incorporate the following suggestions:

- Maintain a single, clear focus in each document
- Shorten sentences and avoid complex sentence structure
- Limit the amount of text on a page
- Increase the font size of the text that is presented
- Increase line spacing
- Reduce the complexity of vocabulary and use high-frequency words

Second, providing health and safety advice to individuals with IDD will require intentionality and care in the presentation of content, as well as thoughtful approaches to dissemination in order to have an impact on their lives. Thoughtful use of social media supported by consistent messaging from groups and leaders in local communities can help adults with IDD be aware of important health and safety information and be able to access and understand the content to be shared.

Third, images used in any such health and safety documentation need to be concrete and closely aligned to the content. Images should be placed in close physical proximity to the content on the page in order to be of value for comprehension. While the individuals appear to prefer images in documents they read, the research team does not believe that the images used have contributed to understanding. However, they may be providing aesthetic value, which the participants appreciated. Further examination of the use of images in such presentations is recommended.

Limitations

The findings regarding difficulty with complex text experience by adults with IDD are consistent with the lessons from the research literature. However, the user experience testing in this study was conducted as a rapid response to the CDC's immediate need for information. Only a single study was conducted, and that was done with a limited population. The findings may not be representative of all adults with IDD. As the pressure from the COVID-19 pandemic subsides, these interview protocols should be repeated with more geographically and culturally diverse populations to confirm the generalizability of the findings.

OUTCOMES AND BENEFITS

There are several outcomes and benefits from this study. This article describes the vulnerable nature of adults with IDD and their need for health and safety information that they can read and comprehend. This

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is important for agencies to keep in mind when sharing the guidance and suggestions derived from scientists' and researchers' findings. The participants in this study have presented valuable insight into the complexity of currently available resources and have identified specific ways to simplify the content and presentation of such materials for consumption by adults with IDD. These findings will be particularly useful to those who care for and provide guidance to these individuals. Care providers, employers, therapists, and disability service professionals will find these suggestions helpful when selecting materials to share with their charges. These findings further support the research being done on Minimized Text Complexity (MTC) which is described in another article in this journal volume.

One care provider commented on the importance of having a simplified format available for her son. Her comment speaks to the greater desired outcome which lies beneath our collective efforts:

> *"Our hope is that our [individuals] will be independent one day. I am not going to be here forever. At some point my child may have to seek information on his own and develop skills to do that. He needs to have something available that he can understand whether he goes there by himself or not, because at some point, I want him to develop that skill."*

DECLARATIONS

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APPENDIX

Individual Interview Questions

General Information About the User
1. Do you have any special tools to help you use your computer?
   Can you tell me about them?
   Do you use any special software to help find things on the internet?

2. Have you ever used the CDC's webpage to find information about COVID-19?
   Have you ever seen the CDC information about COVID-19 on Facebook? YouTube?
   Instagram? Twitter?
   (Yes/No question)

3. Have you ever read a paper from the CDC on COVID-19?
   (Yes/No question)

4. Have you ever seen or read a poster from the CDC on COVID-19?

*If the participant **has not previously used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 5 to 21.*

*If the participant **has not used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 22 to 37.*

5. Where do you go to get information from the CDC on COVID-19? CDC webpages? Facebook?
   Instagram? Twitter? Other?

6. Which of the places in [the] last question do you go to most often? Which do you go to second
   most often?

7. How many times a week do you look for information about COVID-19 from the CDC?

8. What do you search for when you go to the CDC for COVID-19 information? Can you give me
   some examples?

9. *(choose one example the participant mentioned)* Did you find what were you looking for in that
   webpage?
   (if the participants do not remember, let them visit the resources while answering the question)

10. How would you change that webpage to make it more helpful?

11. What did you like the best about that webpage?

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12. What did you not like about that webpage?

13. Did you have any trouble reading the CDC's webpage?
    (wait for the answer; if participant says yes, ask the following probe)
    Tell me about the trouble you had.

14. What ways could the CDC use to present this information more clearly?

15. Did you understand the words on this webpage?
    Did you understand what the webpage was saying?
    Would you like it if the webpage used words that are easier to understand?

16. What information about COVID-19 would [you] like to see the CDC talk about?

17. What else would you like to tell me about how you have learned about COVID-19?

(if time permits, ask the questions below; if not, skip them)

18. Would you read the CDC information about COVID-19 if you could get it printed on paper?
    (wait for the answer, then ask the following probe)
    Can you tell me why?

19. What COVID-19 information would you like to see on a paper?

20. Would you read the CDC information about COVID-19 if you could get it on a poster?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

21. What COVID-19 information would you like to see on a poster?

(thank the participant and conclude the sessions)

22. How often do you search for COVID-19 related information?

23. Where do you go to get information about COVID-19?
    Google search? Facebook? Instagram? Twitter? Friends and family?
    Papers?
    Posters?
    Organizations?

24. Which one of the sites/sources in the question above do you use most?
    Second most?
    Third?

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25. What kinds of information about COVID-19 do you search for?
    Can you give me a couple of examples?

26. Is there any information about COVID-19 that you searched for but could not find?

27. Can you talk to me about why you do not use the information from the CDC?

Now, I want you to visit the CDC's website and find the page on "how to wear masks."
(there are a variety of resources on the CDC website for face masks but this is what we would like participants to visit: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html. You may help or lead participants to find this page; you can put the link in the chat)

28. Please tell me what you think about the face mask information you saw on the CDC's webpage.
    What things did you like the best about it?
    What things did you not like about it?

29. Do you have any trouble:
    Getting to the page, getting around the page, or reading the webpage?
    Tell me about the trouble you had?

30. What other ways could the CDC used to present this information more clearly?

31. Did you understand the words on this webpage?
    Did you understand what the webpage was saying?
    Would you like it if the webpage used words that are easier to understand?

32. Would you come back to the CDC's webpage for more information about COVID-19?
    Please tell me why or why not.

33. What else would you like to tell me about how you have learned about COVID-19?

(if time permits, ask the questions below; if not, skip them)

34. Would you read the COVID-19 information if you could get it printed on paper?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

35. What COVID-19 information would you like to see on a paper?

36. Would you read COVID-19 information if you could get it on a poster?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

37. What COVID-19 information would you like to see on a poster?

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Caregiver Group Interview Questions

General Information About the User
1. Can you describe any assistive technology the person you provide care for uses for accessing the internet and computer?

2. Has the person you provide care for ever used the CDC's website or social media platforms, such as YouTube, Facebook, Twitter, or Instagram for COVID-19 related information? (Yes/No question)

3. Has the person you provide care for ever read the CDC's flyers on COVID-19? (Yes/No question)

4. Has the person you provide care for ever seen/read the CDC's posters on COVID-19? (Yes/No question)

*If the majority of the participants **have previously used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 5 to 16.*

*If the majority of the participants **have not used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 17 to 28.*

5. Which CDC platform(s) does the person you provide care for use for finding COVID-19 related information? Website; YouTube; Facebook; Twitter; Instagram; other?

6. How often does the person you provide care to use the CDC platforms for finding COVID-19 related information?

7. What types of COVID-19 related information the person you provide care to search on the CDC's platforms? Can you give me a couple of examples?

8. *(chose one example mentioned the most by the participants)* Did they find what they were looking for in that resource?

9. How would you change that resource to make it more helpful to the person you provide care to?

10. Are there any other COVID-19 related information you would like to see added to the CDC's platforms for the person you provide care to? Which ones?

11. Did the person you provide care to experience accessibility challenges with the CDC's COVID-19 resources?
(wait for the answers; if even one participant says yes, ask the following probe)
Can you tell me about those accessibility challenges?

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12. Are there alternative accessible formats you would like to see added to the CDC's platforms for the person you provide care to?
(wait for the answers; if even one participant says yes, ask the following probe)
Which ones?

13. Would the person you provide care to use Minimized Text Complexity version of the COVID-19 information on the CDC's website if it was made available to them?
(explain MTC to the group; wait for the answers; then ask the following probes)
Why?
Why not?

14. Do you have any other comments about the COVID-19 information on the CDC's platforms or the experiences of the person you provide care to?

(if time permits, ask the questions below; if not, skip them)

15. Would the person you provide care to read the CDC's COVID-19 flyers if they were made accessible to them?
(wait for the answer, then ask the following probe)
Why?
Why not?

16. Would the person you provide care to read the CDC's COVID-19 posters if they were made accessible to them?
(wait for the answers; then ask the following probes)
Why?
Why not?

(thank all the participants and conclude the session)

17. How often does the person you provide care to search for COVID-19 related information?
(if there is no report from the group for COVID-19 related information, skip to question 21)

18. Where does the person you provide care to get COVID-19 related information?
(if not getting clear answers, probe: Organization websites? Google search? Social media? Friends and family? Flyers? Posters?)

19. What types of COVID-19 related information does the person you provide care to search? Can you give me a couple of examples?

20. Are there any COVID-19 related information the person you provide care to has searched for but could not find?

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21. Can you tell me why the person you provide care to has ever used the CDC's COVID-19 resources?

Now, I want you to visit CDC's website and find the page on "how to wear masks."
(there are a variety of resources on the CDC website for face masks but this is what we would like participants to visit: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html. You may help or lead participants to find this page; you can put the link in the chat)

22. Please give me your initial impressions about this resource.
    (tell the group that we are asking them to consider the needs of the persons that are providing care to)

23. Which things did you like about it? Which things did you not like about it? What would you most want to change about it?

24. Would the person you provide care to use a Minimized Text Complexity version of the COVID-19 information on CDC's website, if it was made available to them?
    (wait for the answers; then ask the following probes)
    Why?
    Why not?

25. Are there alternative accessible formats you would like to see added to the CDC's platforms for the person you provide care to?
    (wait for the answers; if even one participant says yes, ask the following probe)
    Which ones?

26. Do you have any other comments about the COVID-19 resources the person you provide care to uses?

(if time permits, ask the questions below; if not, skip them)

27. Would the person you provide care to read the COVID-19 flyers if they were made accessible to them?
    (wait for the answer; then ask the following probes)
    Why?
    Why not?

28. Would the person you provide care to read the CDC's COVID-19 posters if they were made accessible to them?
    (wait for the answer; then ask the following probes)
    Why?
    Why not?

(thank all the participants and conclude the session)

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