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University Journal Subject Area: The *DDNJ* publishes high-quality research and evaluation about the multiple systems that serve individuals with disabilities and their families. Central to these systems is the “Developmental Disabilities Network,” a group of federally designated programs in each U.S. state and territory, that provide advocacy, training, research, and service focused on the unique needs of people with disabilities and their families. This journal specifically highlights programs, practices, and policies

that encourage the full inclusion of people with disabilities in communities and all aspects of public life.

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Acknowledgments

All of our lives have been redefined by the COVID-19 pandemic. The healthcare and social service system across our country has been strained to its breaking point. Everyone, from advocates to administrators, quickly pivoted at the beginning of the pandemic and adapted their operations. Many researchers recognized that the pandemic provided a unique opportunity to gather data and document how systems evolved to meet the needs of their constituents during the public health crisis. We are excited to share their work in this latest issue of *DDNJ*.

Just a couple of months into the pandemic we were contacted by Ronda Jenson from the AUCD Council on Research and Evaluation (CORE) about pulling together a

special issue of DDNJ focusing on the impact of the pandemic on the disability service system. We were excited to bring Ronda on as the Guest Editor for this issue and it has been a privilege to work with her over the last few months. We are also grateful to John Tschida, the AUCD Executive Director, for helping to co-author the introduction to this issue with Ronda Jensen. Please take some time to check out their introduction to this special issue.

The CORE membership was also vital to the success of this latest issue. CORE members responded with abstracts, articles, and served as peer reviewers for this special issue. The quality of the content in this issue is a direct reflection of the commitment of the AUCD Council on Research and Evaluation to high standards of scholarship and a commitment to research and evaluation that makes a difference.

This issue would not have been possible without the quick response to our call for abstracts and papers. We are grateful to all of the contributors and we have enjoyed working with all of you to bring your scholarship to press.

We are also deeply indebted to the hard work of many people who have served as peer reviewers for this issue of the journal. We have had faculty, researchers, teachers, direct support staff, family members, and self-advocates who have contributed to the reviews this time and we would like to thank each of you who have taken the time to provide your feedback to the journal staff and the authors.

We would especially like to thank the team at the

Georgetown University Center for Child and Human Development (Tawara Goode, Rachel Brady, Caitlin Schille, and Joan Christopher), who have worked with us over the past few months to evaluate a model for facilitating self-advocate input into the publishing process. We have learned much from their experience and look forward to continuing this work until we can arrive at a process that is adaptable and accessible for a variety of contexts.

We would like to thank the following individuals for their dedication and commitment to this project.

- The team at the USU Merrill-Cazier Library including **Becky Thoms, Rebecca Nelson, and Shannon Smith**
- **Benedek Nyikos** at Digital Commons/bepress
- The Production Team at the USU Center for Persons with Disabilities: **Bryce Fifield, Ph.D., Mary Ellen Heiner, and Kelly Smith**

We hope that you find value in this new journal and we are interested in your thoughts and feedback. If there are ways that we can make this publication more accessible or inclusive we want to hear from you. Please send your comments and feedback to editor.ddnj@usu.edu

Thank you.

Matthew T. Wappett, Ph.D.

DDNJ Editor-in-Chief

1.

THE IMPACT OF COVID-19 ON DISABILITY SERVICES AND SYSTEMS: PERSPECTIVES FROM THE FIELD

Ronda Jenson and John Tschida

Jenson, R., & Tschida, J. (2021). The Impact of COVID-19 on Disability Services and Systems: Perspectives from the Field. *Developmental Disabilities Network Journal*, (2), 1–3. <https://doi.org/10.26077/BE92-EF5C>

[The Impact of COVID-19 on Disability Services and Systems: Perspectives from the Field PDF File](#)

March 2021 is the 1-year anniversary of the dramatic halt in “life as we knew it” because of COVID-19. This issue is devoted to sharing what we, a network of self-advocates, families and caregivers, service providers, policy makers, educators, and researchers, have learned during this year of

unprecedented challenges. Programs have been forced to adapt and change in ways that will shape disability services in the years to come. In some cases, we have witnessed innovation and creativity as people have adapted to a new reality. In other situations, we have seen service and support systems struggle to be responsive.

Despite being in the metaphorical situation of “building the plane as we’re flying it,” timely sharing of lessons learned from across the Developmental Disabilities Network (DD Network) is critical. Over this past year, Council on Research and Evaluation (CORE) members have been grappling with ways of capturing the multitude of changes occurring across nearly all aspects of daily life and associated results. The offer to co-sponsor this issue of the *DDNJ* emerged from CORE discussions about the urgency of sharing lessons learned. The result is a journal issue that includes a range of perspectives and insights into the first-year impact of COVID-19. This range includes descriptions of the strain and stressors of life during a pandemic, as well as innovative adaptations of services and supports and resulting positive outcomes posing promise for lasting improvements. The 16 articles in this issue cover three main themes: (1) the pandemic effects experienced by individuals with disabilities and families/caregivers, (2) shifts in practice and research, and (3) supportive systems.

Experiences of Individuals With Disabilities and Families/

Caregivers

This issue begins with a self-advocate's story describing experiences of social isolation, mental health, and social supports. Two other articles describe the experiences of individuals with disabilities. *Monahan et al.* asked college students with autism about their needs and concerns as colleges changed the ways instruction was provided as well as protocols for COVID safety. *Sinclair et al.* describes the ways the pandemic has affected the working lives of individuals with disabilities. Four articles focus on the family and caregiver needs during the pandemic. *Bruder et al.* report a reduction in the supports available for parents of children with disabilities as well as the stressors associated with changes in special education services and lost family income. With a focus on immigrant parents of children with disabilities, *Rodriguez and McGrath* describe multiple challenges with accessing disability-specific services, language interpreter services, family services, and financial supports. *Llano et al.* echo the economic and social toll the pandemic has had on families of individuals with disabilities. For individuals with disabilities being supported by older family caregivers, *Milberger et al.* describes challenges associated with acclimating to using technologies for social and service interactions, as well as the unexpected "silver lining" of the valuing the how life's pace had slowed down.

Shifts in Practice and Research

Business-as-usual has dramatically been affected over this last year. Seven articles describe a form of pivot from the norm and the resulting effects. *Russell et al.*, *Pujol et al.*, and *Aller et al.* describe models of telepractice/telehealth and the benefits for providing services using technologies. *Burks-Abbott et al.* further promote the benefits of using technology by describing a virtual advocacy approach. Other shifts in practice and research have occurred in response to reducing the risk of participation. *Plavnick et al.* describes a toolkit for assessing and mitigating risk when providing applied behavior analysis therapy. *Ablers et al.* explore the implications for conducting participatory action research while maintaining COVID safety and suggested modifications. The final article, *Moriarta et al.*, describes reactions to meeting virtually and how this changed services for both clients and staff (i.e., how clients rated telehealth-based services and how they compared to in-person services; what problems staff experienced switching to the new technology; and what changes the program leaders had to make).

Supportive Systems

Two articles examine systems-level factors. Using a socio-ecological approach, *Bailey et al.* summarize expert viewpoints on person-centered practices and the supportive system for

facing individual and community pandemic challenges. *Day et al.* examined the extent to which a statewide DD Network collaboratively responded to individual, community, and state needs and the resulting collective strength that DD Network partners gained from collaboration.

Implications for the Field

While we are 1 year into the pandemic, and there are emerging signs of possible widespread immunity from COVID-19, the former normal may never return. Mitigation efforts may be long lasting. Technologies may continue to be central to our daily interactions with friends, family members, and service professionals. Adaptations made to services may become integral to providing access to those services. The stressors of navigating needed supports as well as financial and economic strain may persist. In other words, at this 1-year mark, our work is incomplete. More data and analysis are needed to understand the impact of the pandemic on individuals, practices, and systems. Collaboration across the DD Network, involving individuals with disabilities, families/caregivers, communities, service providers, policy makers, and researchers to define and share lessons learned is of the utmost importance.

About the AUCD Council on

Research and Evaluation

With a broad reach across the DD Network, as well as the Intellectual and Developmental Disabilities Research Centers, the Association of University Centers on Disabilities (AUCD) Council on Research and Evaluation (CORE) has sponsored this issue of the *Developmental Disabilities Network Journal (DDNJ)*. As one of five AUCD Councils, the purpose of CORE is to serve as a forum for researchers and evaluators to learn from each other, pose discussions on research/evaluation issues, and conduct activities that build capacity across the network regarding research and evaluation.

About the Guest Editor

Dr. Ronda Jenson is the current Chair of the AUCD Council on Research and Evaluation (CORE). Dr. Jenson is an Associate Professor at Northern Arizona University (NAU) and the Research Director at the NAU Institute for Human Development, a University Center on Disabilities. She has spent 17 years as a researcher and evaluator in the network of University Centers on Disabilities.

About the Editorial Co-Author

John Tschida is the Executive Director of Association of

University Centers on Disabilities (AUCD). He has spent more than 20 years using data and research to drive policy change and service development for individuals with disabilities.

2.

A SELF-ADVOCATE'S PERSPECTIVE ON THE COVID-19 PANDEMIC

D.R. Reff

Reff, D. R. (2020). A Self-Advocate's Perspective on the COVID-19 Pandemic. *The Developmental Disabilities Network Journal*, (2), 4–7. <https://doi.org/10.26077/5AAF-02B1>

[A Self-Advocate's Perspective on the COVID-19 Pandemic PDF File](#)

Plain Language Summary

This article is about the impact of the COVID-19 pandemic on a self-advocate from Idaho. It talks about important issues like loneliness, mental health, and social support. This article describes how the author worked with the DD Council in Idaho

to create her own support network during the pandemic.

I go by the name D.R. I am a 30-year-old with a bachelor's degree in criminal justice and history. I am an active community volunteer, completing at least 100 hours of community service yearly. One of the organizations I am a part of is the Idaho Council on Developmental Disabilities (ICDD). It is here that I am an active Vice-Chair and state leader on policy issues that impact people with disabilities.

Having both a schizoaffective disorder alongside a small aftertaste of autism always seems to add flavor to my life, but the COVID-19 pandemic added a new level of stress and anxiety. COVID-19 may have started in China, but it soon affected everyone in the U.S. and around the world. March 21st marked the first day the Idaho Governor told everyone to remain at home and only leave for important purposes such as shopping for food or emergency situations. I started this segment of my life a week or more prior to the Governor's order.

It is a common reaction to fear death. The only place or time I have read about people not fearing death has been in the book "*Brave New World*" where they are conditioned not to. I always thought fearing death made us human...or an animal at least. Nonetheless, my experience during the COVID pandemic has changed me forever.

During the initial seclusion order, I stayed in my room. I

only went downstairs or out of my room for bathroom and food breaks. I had snacks in my room along with every possible activity I would ever want to do, besides, of course, going outside or into a moving vehicle. For most people life was difficult, but for me it was a blast. I had a nook, desktop, laptop with at least 200 iTunes movies on it, phone, and other technological amazements. In addition to these, I had books galore and a chess board.

Every morning I had a similar routine. I would do exercise, eat breakfast, look at my Star Wars McQuarrie art book, write in my memoirs, write in my journal, and study Japanese or another language. During the day I would treat myself to either watching movies, study 23 vocab terms, or...well, buy stuff.

Though I was cut off from friends and certain locations, I still had ample opportunities to speak to them via audio or video, and I could “visit” places online. There were so many ways to communicate without being in person—the most common was Zoom. I used Zoom for DD Council meetings, story circles, and Autism Society Treasure Valley (ASTV) meetings. Unfortunately, these were not everyday events. I just met with them maybe once or twice a month, but I still looked forward to them with great anticipation.

Although I liked some parts of the pandemic, my anxiety increased, primarily because I was forced to communicate via phone and not in person. Ever since I was a child, I have had difficulties talking on the phone—although once I was on, I

was superb. At times I could not stop talking. But when I was told that I could not go to Social Security Administration to discuss in person my confusion over money sent to me in the form of SSI, I grew more and more anxious. Having financial miscommunications and not being able to address it increased my anxiety to such high levels that I knew it would only lead to disaster.

As I mentioned before, I have a schizoaffective disorder and with that I would sometimes slip into an inescapable negativity. This so-called negativity occurred on Saturday May 2, 2020; it was a blissfully surreal and painful reaction to what I was going through. I still cannot believe what happened on this date. I was feeling small amounts of anxiety and occasional “life flashing before my eyes” moments. At 4pm I took a shower, thinking that would relax me further. I got out of the shower and took my Abilify and Artane medications to help further manage my anxiety, but they did nothing.

Anxiety! Anxiety! I said to myself. But from where? What can I put in my worry basket like Dr. Desai said? A week earlier I had been on a DD Council webinar where a doctor named Desai had provided a technique for us to use to manage anxiety. He said that we should “Put all your worry in a basket and put it aside until a prearranged time.” This worked well for a while, but it was not working now! Nothing seemed to help! This is not normal. This is not real. “Please let it be COVID!” I prayed to myself.

I eventually took myself to the hospital, where I tried to

explain what was happening to me to four people. All they said was, "You seem to be having an acute anxiety attack." I clutched my stomach, which was hurting, in frustration. "Why can't I get COVID like a normal person?" I asked? Eventually, a female social worker entered my room. She spoke to me in a kind positive voice and said, "I'm going to talk to the doctor, but I don't think you'll be getting a prescription." After talking to the doctor, she told me "The doctor wants you to work out your prescription with your regular doctor." I said, "But it's Saturday and the clinic won't be open until Monday. What do I do until then? Can't you give me just enough to last before then?"

She looked at me intensely but seemed to ignore me too. She said, "We need to plan what you'll do if you don't get a prescription. You will need to practice coping techniques."

"What if I do every anxiety remedy known to mankind and still need medicine?"

Then she spoke the words that I most dreaded, "If you feel this again, you can come back."

I had already told her, "I don't want to bother you guys again."

She responded by saying, "We won't mind if you return."

I lowered my eyes with such intensity they could have broken. "But I will mind," I said to myself, "I will mind."

The doctor at the hospital only gave me an injection of half a milliliter of Ativan and sent me packing. After departing from the hospital, I learned that the earliest I could meet with

my med manager, even on the phone, was the following Friday—6 days away!

I left a voice message at my med appointment location in hopes that they would respond to my message soon. I got no reply until Monday. They said I could not see my doctor until till Friday.

“But this is an emergency!” I proclaimed in anger.

“I understand that you are in crisis, but we can’t deal with crises here. If you need immediate help you’ll have to go back to the hospital,” the woman on the phone said.

“Would you want to?” I almost said aloud, but I kept it to myself.

Instead, I nodded my head and said those dreaded, pointless words, “Thank you.”

The truly sad thing is that no one seems to believe people with mental illness, and when they do, they like to assume that you are overreacting. Who ever heard of a person with an anxiety attack go to the emergency room? Yet I did.

Anxiety attacks have the tendency to make me lose focus and forget things. So, in addition to being in quiet pain, I had to open my mouth and explain what was happening to me four times. And even then, I did not feel like they believed me.

My appointment with my med manager resulted in his agreement to all my wishes—one being to try a new medicine. All my medications are set now. Anxiety is decreasing. Most importantly, I can relax for a change.

After feeling such pain and degradation, I felt I needed to

find a way to help others. On most Fridays, the Idaho DD Council hosts webinars where individuals can learn coping strategies from various professionals. My favorite session was with a Dr. Desai, who taught me about the “worry basket.” He told me to “Put all your worry into your worry basket and only look back at it a few hours later.”

During each webinar, there are opportunities to ask questions. I decided to speak up during a webinar about coping strategies. In the chat section of the zoom webinar, I wrote, “Why can’t we create a way for people with mental health and social disorders to correspond with each other through mail or email?” To my surprise, many people responded positively to my suggestion. A few days later, I received my first letter from a DD Council member.

I am now leading the Pen Pal Club for the Idaho DD Council. It is intended to be an opportunity to provide a chance for people to connect with others, to alleviate isolation, and open up to a person who may otherwise sleep the day away or cry because of lack of friendship. People who participate in this club provide social connection and hope through these troubled times, and this helps me too.

Although I have experienced a lot of mental anguish during the pandemic, I have found connection and support through the Pen Pal Club and I have created many new friendships. This is what I want for everyone who participates in our Pen Pal Club—to have someone they can share their joys and sorrows with. I have gained two pen pals of my own. Both are

equally kind and accepting. One loves to discuss the disgusting world of politics while the other likes to discuss “Avatar the Airbender,” a kid’s television show. Both have helped me manage my mental health and have helped me feel connected and supported through this difficult time.

Through my personal experience, I have learned that everyone needs an outlet to share their personal stories and release pent-up frustration and pain and to realize they are not alone. Everyone is struggling during this time of crisis and everyone needs to be heard.

3.

VIRTUAL ADVOCACY: LIVED EXPERIENCE TAKES CENTER STAGE DURING AND AFTER PANDEMIC

Gyasi Burks-Abbott; Amanda V. Gannaway;
Amy Szarkowski; Jason M. Fogler; and
David T. Helm

Burks-Abbott, G., Gannaway, A. V., Szarkowski, A., Fogler, J. M., & Helm, D. T. (2020). Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic. *Developmental Disabilities Network Journal*, 1(2), 6–21. <https://digitalcommons.usu.edu/ddnj/vol1/iss2/4/>

[Virtual Advocacy: Lived Experience Takes Center Stage During and After Pandemic PDF File](#)

Plain Language Summary

An autistic self-advocate, a mother of a child with a disability, and three graduate and medical schoolteachers wrote this paper. They described meeting with government leaders to discuss disability issues. This paper includes ideas for advocating for disability policy and working together.

Self-advocate Jim Charlton (2000) famously titled his book, *Nothing About Us Without Us*, and disability advocates have long embraced the slogan. While advocacy has, at least in theory, been embraced, civic engagement for individuals with disabilities continues to face substantial barriers across intrapersonal, interpersonal, and organizational levels (Foster-Fishman et al., 2007). Insufficient opportunities have been afforded to self-advocates to develop skills and competencies needed for effective advocacy work. Interpersonal factors such as team dynamics can also make advocacy challenging. Organizationally, decision-making processes too often do not include the perspectives of individuals with disabilities and their families, and limited resources may be allocated elsewhere, leaving important potential improvements for those impacted by disability unfunded.

An Emancipatory Perspective

Involvement of persons with disabilities in advocacy is not novel but is also not widespread. Activist leaders like Judith Heumann, author of *Being Heumann* (2019), have had enormous impacts on the disability rights movement, yet too often processes intended to reduce barriers to fully inclusive participation are ad hoc and lack intentionality. In order to increase meaningful involvement of individuals with disabilities, systemic processes need to enable and support participation rather than place that onus on individuals. For example, the processes should not be alienating—either by requiring independent mobility to access legislators or being structured in a way that does not accommodate for variability in communication modes (Radermacher et al., 2010). Further, the advocacy itself should emphasize topics that individuals with disabilities determine to be important and about which they desire change (Moriña, 2020).

In the fields of research design and implementation, it has been recognized that involvement in the research process by those “being studied” can have a transformative effect, not only in addressing the necessary complexities of understanding others’ experiences, but also as a mechanism for promoting social change (Mertens, 2007). In health sciences research, stakeholder participation is increasingly becoming the norm, wherein funding for health-related research is generally contingent upon including the viewpoints and honoring the

wishes of patients with relevant conditions and their families (Denegri et al., 2015). Meta-analyses of community-based research and involvement of participants shows a positive impact on the participants and better-informed science (Ortiz et al., 2020). Shifting toward “researching with” and away from “researching on” (Moriña, 2020) has shown to be valuable in terms of understanding the research—and the types of outcomes—that self-advocates perceive to be useful. There is growing recognition that involvement of individuals with disabilities, even those who are young (Liddiard et al., 2019), can contribute valuable information to the understanding of a particular experience. Community-based participatory research methods/approaches are increasingly used in research that involves individuals with disabilities and have had a powerful impact in shaping this field (Wallerstein, 2020).

There have been a number of frameworks posited for meaningfully including people with disabilities and family members of individuals with disabilities in research—not only as “subjects” but as co-investigators. These include the participatory and emancipatory frameworks, subtly distinguished by: (a) the degree to which co-investigators with disabilities are included in the crafting of methodologies and hypotheses (with the emancipatory framework assuming full egalitarian partnership); and (b) how “agenda-forward” the research is, with emancipatory research implying a more explicit and *a priori* leaning toward advancing the public good

for people with disabilities through research (Kramer-Roy, 2015).

Questions have been raised about the true benefit of emancipatory research to self-advocates, in particular those with intellectual disabilities. Scholars have explored the limitations of emancipatory research, in practical as well as ethical terms (e.g., Barnes, 2008). It is true that the nature of one's disability can influence how an individual with a disability might engage in advocacy efforts. Naturally, the classification of "individuals with disabilities" encompasses a wide variety of individuals with divergent life experiences. For example, the experiences of a person with an acquired physical disability can be substantially different from those of a person with a congenital developmental disability. An important consideration is that "self-advocacy" can take different forms. For some individuals with intellectual disabilities, speaking to their peers about issues of concern to them and developing the ability to protect themselves are among the ways that they have self-identified their activism (Petri et al., 2020). Yet amongst individuals with intellectual disability, there has also been a demonstrated positive impact of inclusion as participants in studies (Schwartz et al., 2020). Individuals with intellectual disability have been found to value the direct and indirect benefits of research and see value in participating (McDonald et al., 2016).

From Research to Activism

Shifting from research to advocacy, on the individual level, policy-related activism promotes self-advocates' social integration, enhances feelings of self-efficacy, and contributes to the development of personal interest in policy (Petri et al., 2020). As groups of marginalized individuals engage in disability advocacy, they increase their awareness of their rights and responsibilities as citizens, experience "being a part of something," and feel empowered to use their collective experiences to inform the public discourse.

Through our collective advocacy efforts, we aimed not only to educate policy makers about specific topics of concern relevant to individuals with disabilities and their families, but also to highlight the importance of understanding the lived experiences of self-advocates and parents of children with developmental disabilities. It is in alignment with this notion that the authors of the present paper embrace the emancipatory perspective, believing that advocacy efforts are important not only to effect positive social change, but also to empower the change-makers as well.

Emancipatory Nature of Co-Authorship

Co-authorship is a natural extension of a collaboration undertaken from an emancipatory perspective. Creating space

in academic publishing and incorporating multiple perspectives, including self-advocates and family members, and centering the writing on their experiences, should be prioritized. However, a review of published literature on co-authorship found projects that adopted the label of “inclusive research” held no set standards for transparency regarding the extent and form in which self-advocates’ voices were reflected in the presentation of published results (Strnadová & Wamsley, 2018). To address this issue, guidelines have been proposed for increasing transparency in the publications produced by “inclusive projects,” which may help discourage tokenism and provide clear examples of how meaningful co-authorship can occur. The guidelines written by Strnadová and Wamsley suggest including an explicit description of how co-authored articles are written.

Prior to writing this article, the co-authors worked together as members of a Leadership Education in Neurodevelopmental and related Disabilities (LEND) cohort for a year during which time they came to know each other’s specific skill sets. The co-primary authors of this article, a self-advocate and a mother of a child with a developmental disability, both hold graduate degrees and have previous experience with academic writing. Over the course of the year, after having been moved and impressed by the other co-primary author’s life story, one co-primary author (Amanda) suggested that the voice of the other (Gyasi) be highlighted through publication. After collaborating together through the

COVID-19 pandemic on an unprecedented advocacy effort, a third co-author (Amy) suggested writing together about this shared experience, and interest emerged within the group. Building substantial relationships over time, understanding each co-author's strengths and interests, and being afforded a certain level of institutional flexibility throughout the early stages of the pandemic allowed for an organically inclusive collaboration from inception to completion that both responded to and was facilitated by the larger context of a global health crisis. For the present paper, the structure and content were decided by group consensus. Each co-author contributed to the conceptualization of the work and wrote about his/her/their own reflections. All authors were involved in editing the complete text. The co-authors actively participated in the virtual advocacy that is one focus of the present paper and engaged in the co-creation of this reflective piece.

Disability Policy Seminar

The annual Disability Policy Seminar (DPS)¹ has historically been a valuable opportunity to meet face-to-face with policy makers and to foster understanding among LEND fellows about educating their legislators regarding specific legislation. The DPS had traditionally consisted of two days of talking and learning about disability policy, followed by a day “on the Hill” speaking with legislators and their aides—which invariably

helped to demystify Washington, D.C., and the policy-making process. In the past, the journey to Washington, D.C., has united the cohort of LEND fellows and faculty, as they collectively learned to work with and support legislators to advance policies favorable to the disability community. Visiting one's legislative representatives allowed LEND fellows, alongside faculty, to formulate and practice how best to educate their legislators regarding specific policy. This has been an invaluable way to enhance these future leaders' confidence that they can channel their educational, clinical, or life experiences in new ways to impact policy effectively.

¹ The Disability Policy Seminar (DPS) is a three-day annual federal legislative conference co-sponsored by The Arc, Autism Society, American Association on Intellectual and Developmental Disabilities, Association of University Centers on Disabilities, National Association of Councils on Developmental Disabilities, National Down Syndrome Congress, United Cerebral Palsy, and Self Advocates Becoming Empowered (the partners).

Former LEND fellows' comments on the end-of-year survey regarding their Hill visits suggest this has been a positive learning experience: (1) *"The DPS in DC reassured me that we can influence policy on issues related to disability and disparity in health care issues"* (licensed clinical social worker); (2) *"I have a newfound appreciation for the unique and positive role*

we in the field can play in the care of and advocacy for the children that we see” (developmental-behavioral pediatrician); (3) “...the DPS and Hill visits...increased my confidence to voice my thoughts and concerns to legislators in order to advocate for disability rights and make a difference on a systemic level for all citizens with disabilities” (clinical psychologist); (4) “I learned more about Supplemental Security Income (SSI) and how important it is for people with disabilities to live more independent and meaningful lives in the community, I also learned about how to reach out to people using personal stories” (self-advocate); (5) “This has allowed me to become a better advocate. I want to bring our voice to the community and teach the parents a new way to advocate and a new way to engage” (parent of child with a developmental disability).

Impact of Shifting to a Virtual Disability Policy Seminar

When the pandemic arrived, the opportunity to participate in-person at DPS disappeared; LEND faculty were faced with the dilemma of how to provide a meaningful disability policy advocacy experience for fellows, without anyone needing to leave their homes. The logistics of this decision turned out to be easier in some ways than shifting our mindsets. Although uncertain of the outcome—and the new technology that would soon become a staple of our daily lives—we contacted the legislators’ aides and schedulers and proposed virtual Hill

visits. The meetings were set, yet faculty and fellows alike grappled with our own doubts about how effectively we could communicate in a virtual space undergirded by a video conference call that we feared could “drop” at any moment.

The change in preparing for an in-person Hill visit compared to the virtual visit with legislators presented us with the need for a quick turn-around. For in-person sessions, we had the advantage of close proximity to each other for support and the ability to quickly clarify any misperception that might arise. The nonverbal cues of the meeting, coupled with the feel of the office space and nearness to the source of policy making, is difficult to replicate in a virtual meeting. Traditionally, one prepares for the possibility of both an unexpectedly “hurried” in-person appointment as well as a more drawn-out meeting lasting up to 30 minutes or more. In the virtual setting, we had a firm time commitment in which to present and discuss our issues and priorities. Still, preparation for both modes persisted as each participant had practiced their “elevator speech” as well as rehearsed a more leisurely but focused discussion of the various topics. The attention originally directed toward our preparations for travel logistics including air, hotel, and ground transportation aligned with everyone’s needs (e.g., wheel-chair accessibility), turned to worries of secure and dependable internet connectivity and timing of a coordinated approach to our policy concerns. We lost the comradery and team-building experiences of traveling together and managing the logistics of the 3-day excursion. This was replaced with

opportunities to visit with more legislators, observe more meetings and, thus, learn from a broader array of experiences.

One of the LEND fellows who participated in the virtual advocacy visits is deaf. Short notice of the shift to a virtual format left the group unable to secure an American Sign Language (ASL)/English interpreter in time for the visit. One of the faculty members who can communicate in ASL agreed to serve in the “interpreter role” to support this fellow’s involvement. Importantly, the faculty and fellow had worked together over the year and knew each other’s communication styles. The faculty member is fluent in ASL, yet is not a certified interpreter; however, the fellow agreed to this arrangement and expressed a desire to be a part of the “virtual visit to the Hill.” Wearing the dual hats of LEND faculty and “interpreter” provided interesting insights: (1) legislative aids needed to be reminded of attending to constituents’ communication needs (e.g., allowing each person to finish talking – and the interpreter an opportunity to “catch up” at times – before the next person spoke); (2) there is benefit to having the person in the interpreter role be savvy about the topics in order to convey a full understanding of the content being discussed (e.g., numerous acronyms were used by the legislative aids; while some of the fellows in the group took notes about those acronyms in order to look them up later, a Deaf advocate relying on ASL would generally find note-taking and watching the interpreter quite difficult. Being able to “add in” information, such as providing an explanation of

the acronym in real-time proved useful); and (3) the legislative aides, initially seemingly surprised or perhaps uncomfortable adjusting the communication to allow for access to information through interpretation, did appear to relax and become more natural over the course of the visits. Had these meetings been held at “the Hill” without an ASL interpreter present, the perspective of that fellow/self-advocate/emerging professional would have been lost. At the conclusion of the session, one legislative assistant reported that the experience of adjusting the communication taught her as much about the need for communication access for individuals with disabilities as did the advocacy conversations that were held. This drove home the importance of representation (for advocates, by advocates—but also by a variety of advocates with different lived experiences) and provided greater insight into the “other burdens” that can be placed on self-advocates who desire to engage in advocacy efforts.

The congressional aides with whom we met during the virtual DPS meetings acknowledged that they truly had not considered the information or perspectives that were being shared with them by self-advocates and family members of individuals with developmental disabilities. Given the timing of these visits, the congressional aides were highly focused on the impact of COVID-19 on their constituents, yet they acknowledged that they had not realized what the impacts might be for their constituents with physical or developmental disabilities. As a group, the LEND fellows and faculty were

assured that the legislative aides would be bringing these concerns directly to the legislators. The facts about developmental disability conveyed to the legislators had a minor impact compared to the personal stories shared during the advocacy conversations. Allowing the lived experience of self-advocates and family members to determine the agenda for our virtual meetings proved to be the most effective strategy for educating legislators.

Virtual Disability Advocacy: Honoring Agency through Personal Narratives

Centering the voices of people with disabilities and their families in policy advocacy is an important tool in the effective education of legislators. Personal stories humanize and add dimension to issues that risk being reduced to legalese for those not personally impacted. Allowing lived experiences to direct discussions about policy also underscores for lawmakers two aspects of the disability community that are important to acknowledge: (1) the needs and priorities of people with disabilities and their families are diverse and intersectional (Kattari et al., 2017); and (2) these needs and priorities, like life with a disability, are dynamic, changing over time (Roebroek et al., 2009). The complexity and urgency of the challenges posed by the COVID-19 pandemic that were revealed by the personal stories shared during the virtual Hill visits served to underscore these points in a concrete way.

Individual stories, snapshot “portraits” of life with a disability at the onset of a global health emergency told firsthand by self-advocates and family members, were the centerpiece of our Hill visits and also serve as the backbone of this article, subverting long-entrenched academic power structures and aligning our collaboration with the emancipatory perspective (Oliver, 1992). As a group, we embraced the “hyper-specific” and “hyper-localized” situations that were of great importance to the self-advocates and family members of individuals with developmental disabilities, believing that as policy makers listened to and began to better comprehend the nuances of the challenges that COVID-19 was posing for individuals with developmental disabilities, they would better comprehend the big picture as well. Inclusion of these various perspectives were neither superficially perceived by the group as a “nice thing to include” nor as a tokenistic opportunity to “promote inclusion”; rather, there was a recognition that centering the messages of the collective group (LEND fellows and faculty) around the lived experiences of self-advocates and family members had the potential to deepen legislators’ understanding about the support needs of individuals with developmental disabilities, particularly in the context of the COVID-19 pandemic. What follows are reflections written by a self-advocate and a parent of a child with a developmental disability about the experience of sharing their stories during the virtual Hill visits in the early days of the COVID-19 pandemic.

Reflections from an Autistic Self-Advocate

COVID-19 completely upended my life. Conferences I had been looking forward to (one of which was in Ghana and I was to be a speaker) were cancelled or postponed. The conferences that did go forward, like the DPS, were conducted in a completely virtual format. In many ways, the actual disruption to my schedule was minimal. I was creating a website of autism and adulthood resources² as part of my fellowship at the Institute for Community Inclusion at the University of Massachusetts Boston. Most of my business could be completed from home, and I was only required to be in the office 20 hours a week. The Hill visits going virtual also did not fundamentally change my work. My task was still to talk about legislation that I felt was important. The major challenge I faced was the fact that the Hill visits were taking place in the context of a national emergency.

² <https://autismadulthood.net/>

One of my takeaways from the LEND Program was the importance of telling my story. Legislators no doubt go to Congress with their own priorities, but they are supposed to represent their constituents, and they want to be re-elected. Caught in a storm of competing obligations, demands, and requests coming from all sides, it is not easy for Congresspeople to know the right way to go. My story could

be their compass. In preparation for the Hill visits, I put together a packet of materials to distribute concerning pending legislation. But I knew the most important information I had to convey was my personal experience. A piece of legislation I was particularly excited about was the SSI Restoration Act, which would raise the asset limit on SSI beneficiaries from \$2,000 to \$10,000. I saw this bill as a game changer and was looking forward to telling the story about the dilemma I had been caught in for most of my adult life; not making enough money to be self-supporting but making just enough to jeopardize my benefits.

Then COVID-19 happened, and Congress' focus was understandably on dealing with this public health emergency. In the scheme of things, the SSI Restoration Act now seemed rather insignificant. How could I justify talking about it in the midst of a global pandemic? Then, the plan was set in motion to send every American a \$1,200 stimulus check—immediately raising the specter of the negative impact those checks would have on public benefits. As it would turn out, the situation with the stimulus checks would be resolved by not counting them as income for a year. However, the underlying issue remained of asset limits that placed an undue financial burden on people with disabilities. Indeed, as I pointed out during the Hill visits, the overly restrictive asset limits were among a number of problems that already existed but were magnified by the current crisis. Instead of waiting for things to get back to normal, I thought now was the perfect

opportunity to address some of the systemic flaws being highlighted by coming up with long-term solutions.

There is something transformative about having your story take center stage—a phenomenon I experienced when my mother wrote an article about my life with autism long before I had ever heard of participatory or emancipatory perspectives. My mother was an English professor who specialized in African American Literature and Film. Towards the end of her life, she shifted some of her focus towards the field of Disability Studies. While a student at the Harvard Graduate School of Education, my mother took a class in a qualitative research method called Portraiture. As Sara Lawrence-Lightfoot, a noted Portraitist and my mother's professor, explains in *The Art and Science of Portraiture*:

Portraiture is a method of qualitative research that blurs the boundaries of aesthetics and empiricism in an effort to capture the complexity, dynamics, and subtlety of human experience and organizational life. Portraitists seek to record and interpret the perspectives and experience of the people they are studying, documenting their voices and their visions — their authority, knowledge, and wisdom.
(p. XV)

In that spirit, my mother chose me as the subject of her Portrait, and what she wanted to capture was what being autistic meant to me. We sat down for a series of interviews in which my mother asked me questions covering a range of topics from my earliest memories of being different, to my

experiences in special education, to my current struggles in the world of work. My mother also recorded her own observations of me.

The final product was a biographical sketch called “*A Brief Portrait of an Autistic as a Young Man*,” a version of which was published in an anthology called, *Illness in the Academy: A Collection of Pathographies by Academics* (Myers, 2007). My mother and I also started co-presenting at conferences both domestically and abroad. One of the things our audiences said they appreciated the most was hearing the perspectives of both a parent and a self-advocate. For me, having my story put front and center was validating and empowering. It gave me the sense that I was part of a larger conversation. I was being listened to. What I had to say mattered.

My mother hoped that her Portrait of me would do more than just give me an avenue for self-expression, she also wanted to draw attention to the needs of “high-functioning” autistics, needs that are all too often overlooked. Like my mother’s Portrait, the Hill visits gave me a platform from which to speak, and, in a way, carry forth her message—my ability to understand the issues and articulate my thoughts did not translate into me needing no help. In fact, the assistance I required was what I was bringing to the legislators’ attention. And, by having me choose what legislation to discuss, the structure of the Hill visits made me an equal partner in determining the course of the conversation, which is very much in keeping with an emancipatory framework.

Reflections from a Parent of a Child with a Rare Genetic Disorder

Because of the last-minute changes instituted in response to the COVID-19 pandemic, my experience of the Hill visit significantly diverged from my expectations for the event in two ways: (1) I shifted the content of my conversations in anticipation of newly developing issues, and (2) the format in which those conversations took place was dramatically altered.

For me personally, the burgeoning pandemic made the issue of policy advocacy more urgent and less abstract. It also shifted my focus from preexisting policy proposals to potential future pitfalls. In the weeks leading up to the Hill visits, I had not yet identified the policies that I felt resonated most strongly with my family's story. As the parent of a toddler with a rare genetic condition, I lived very much in the moment, addressing new challenges as they arose with little ability to anticipate what the needs of my child might be in either the near or distant future. While I understood policy advocacy to be an important tool for advancing and protecting the rights of the disability community, how my family's immediate concerns might translate into broad, long-term solutions still felt vague to me in the weeks before our visits. This changed, however, with the onset of the pandemic.

Our virtual Hill visits took place one and a half weeks after my state of residence, Massachusetts, instituted a "stay-at-home advisory." At this time, general emergency preparedness advice was to have a 3-month supply of prescription

medications on hand in the event that supply chains were disrupted or visits to the pharmacy were deemed unsafe. My child held five prescriptions for a combination of maintenance and rescue medications, though even with the privilege of comprehensive private health insurance I could not acquire a 3-month supply of these medications without paying several hundred dollars for them out of pocket because of where they were in their various refill cycles. For me, insurance coverage for 90-day supplies of medication and more flexibility for refilling recurring prescriptions suddenly became an urgent topic for legislative discussion.

My child turned 3 the day before our virtual Hill visits, making the date of our meetings his official entrance into the public-school system. Until that point, his therapeutic services were delivered by an Early Intervention program. Remote instruction and the perceived threat of school districts potentially seeking waivers for providing special education services put protections for the Individuals with Disability Education Act, which until that point I had largely taken for granted, on my agenda for the Hill visit. Before the start of the pandemic, my family felt well prepared as we had spent nearly a year planning for my child's entrance into public school. Having a child who was now moving between systems during a moment of crisis, however, highlighted for me the particular vulnerabilities associated with major transitions throughout the lifespan. The new challenges and uncertainties that my child suddenly faced allowed me to raise awareness of these

weak points in our systems of care, which if not properly addressed can lead to the needs of those with disabilities being lost in the administrative fray of moving from one major life stage to the next.

Before the DPS shifted to an online format, my family had planned to travel together to the event. Among the logistical details attended to during planning were time off from work and therapies, funding the trip, finding accommodations that allowed us to prepare meals that met dietary restrictions, and the transportation of medications and equipment. Were the format established in advance, virtual meetings would have alleviated scheduling complications associated with care taking and negated the stress and expense of traveling.

In the shift to a virtual DPS, our LEND cohort missed opportunities for teambuilding and insight into the physical spaces and governmental processes that we would have been exposed to by moving through professional offices on Capitol Hill. The shift to a virtual format also, however, allowed my colleagues and I to listen in on and learn from more conversations than would have been possible if the meetings had been held in person as originally planned. There were up to as many as 32 of us on calls to senators' offices and 15 on calls to representatives' offices, affording us more experience and collegial support as we shared our stories. I attended our virtual Hill visits from my child's room, which in hindsight seems an appropriate venue. It was a comfortable space for me

and as a reflection of my child's identity, marked his presence in our discussion with legislators.

Implications of Virtual Advocacy for Centering the Experiences of Self-Advocates and Family Members

The experience of being in Washington, walking the halls of Congress, and meeting Representatives and Senators (and/or their aides) in their offices has had a significant impact on DPS attendees—yet involves a great deal of effort, organization, and planning, which invariably limits some participation. Not everyone can attend (e.g., family responsibilities may limit travel options) and attendees who have ambulation challenges (such as wheelchair users or those who use walkers) recognize that the accessibility is difficult and requires considerable planning and time-consuming execution. The cost of travel to and accommodation in Washington is substantial, thus limiting many. Benefits of virtual advocacy for self-advocates and families include reducing the burdens associated with travel including the direct costs involved, as well as the opportunity costs, such as having to miss work and/or having to leave children at home and the many necessary arrangements that being away demands. Thus, a greater number of people from a variety of backgrounds can participate in virtual advocacy efforts.

Virtual engagement can offer legislators greater insight into the lives of people with disabilities by welcoming them into

the homes of advocates. This may simultaneously “level the playing field” by shifting focus away from the power differences between advocates and those holding elected office, which are inherently emphasized by being on the Hill during in-person visits. The virtual experience reduces the angst that some self-advocates or family members, particularly those who are new to disability advocacy, may feel when face-to-face in engaging with policy makers. Being in the comfort of one’s home may make it easier to tell the emotional aspects of one’s own story, or that of one’s family. Advocates can convey their stories as they wish through either telling or showing, using their surroundings as a complementary mode of communication (e.g., by keeping their camera off if they feel more comfortable doing so, or by joining in from their child’s bedroom, to emphasize the durable medical equipment that is a part of their daily lives).

The flexibility that virtual advocacy permits can also facilitate engagement of individuals with disabilities who have a variety of learning styles or communication needs. It is possible, for example, to “screen share” a pre-prepared message crafted by an individual with a disability (perhaps with support, if necessary or useful to the self-advocate) with a legislative representative. Such a strategy can allow emphasis on points that may otherwise not be shared by self-advocates who have difficulty conveying messages in real-time, as might be the case for self-advocates who experience cognitive challenges or who rely on communication devices that require

time and effort to “program” specific statements. There is also a need to ensure that self-advocates can receive information from the legislative representatives, which can also require specific technology (e.g., speech-to-text) or the support of a sign language interpreter. While some of the necessary supports can be arranged for in-person Hill visits, the burden of ensuring accessibility often falls to the individuals with disabilities and their family members. Virtual participation in an advocacy meeting that is pre-planned can help to mitigate some of those structural barriers, improve accessibility for disability self-advocates in both giving and receiving messages with their representatives, and foster broader participation in advocacy efforts along with more authentic inclusion in the process.

Aligning with notable lessons from inclusion models for disability advocacy (Ife, 1995; Radermacher et al., 2010), our engagement in the virtual Hill visits were broad in scope, making space for self-advocates and family members to emphasize topics of importance to them, while also fostering a sense that their involvement mattered. Different forms and degrees of participation were acknowledged, valued, and supported, with efforts made to reduce the potentially alienating processes inherent in the advocacy structure.

Discussion: Lived Experience Takes Center Stage Through

Authentic Collaboration

The present paper examines the impact—for a self-advocate, a parent of a child with a developmental disability, and professionals working in the disability space—of centering lived narratives in advocacy during the early stages of the COVID-19 pandemic. What is described is a collaborative advocacy project undertaken from an emancipatory perspective, which was informed by recent advances in research. The emancipatory nature of this collaboration, from virtual Hill visits to co-authorship, was facilitated in part by the flexibility demanded by the context of a global health emergency, which may be crucial for generalizing our experience of working within an emancipatory perspective to similar collaborative efforts. In particular, the ways in which the shift to a virtual format for advocacy events and expanded opportunities in publishing created more accessible spaces for self-advocates and family members to share their personal stories may offer valuable insight into how authentic collaborations can be supported in the future.

As previously outlined, the shift to a virtual format has the potential for making several aspects of advocacy events more inclusive, thereby increasing direct communication between self-advocates, family members and legislators. This is of particular importance in times of crisis when people with developmental disabilities are disproportionately affected—as has been the case during the COVID-19 pandemic.

Preliminary data suggests that people with intellectual disabilities and developmental disorders may be three times more likely than the general population to die as a result of COVID-19 infection (Rabin, 2020). In addition, the challenges for individuals with disabilities and their families regarding accessing healthcare (Hall et al., 2019), reduced economic opportunities (Andresen & Nord, 2020), and social isolation (Singleton & Darcy, 2013), particularly as they age (Bradley et al., 2020), have been exacerbated by the COVID-19 pandemic. In times of such urgent concern, hierarchical settings and processes risk slowing the exchange of information between individuals with disabilities and their families—whose needs during an emergency are immediate and dynamic—and those in power who are responsible for addressing their concerns. Positioning self-advocates and family members as leaders of our group, which also included faculty, professionals, and trainees, benefitted our virtual advocacy efforts by providing legislators insight into these complex problems as they unfolded in real time.

Conclusion

An emancipatory perspective to collaboration requires that the involvement of all contributors be meaningful and authentic throughout the process, including in co-authorship. The rigidity of the academic publishing process, however, can present challenges to co-authorship for individuals with

developmental disabilities who comprise an enormously heterogeneous demographic that may, in contrast to the typical hierarchical structure, thrive in flexible inclusive research settings that respond to diversity (Stevenson, 2010). For our group, the context of COVID-19 may have eased some of the difficulty associated with highlighting the voices of self-advocates and family members in academic publishing. Recognition of the need to collect and share anecdotal experiences during this unprecedented time created a unique opportunity to widen the impact of our collaborative advocacy effort through co-authorship. Extrapolating upon lessons learned from this collaborative endeavor, the authorial team posits that academic writing could be made a more accessible platform for people with developmental disabilities by broadening the types of submissions and article formats accepted. This would allow collaborators to share the work generated by projects that, while related to common research interests, fall outside of the purview of formally designed research studies. More importantly, expanding the ways in which disability self-advocates and family members of individuals with disabilities can be meaningfully engaged in research and writing projects can advance the understanding and appreciation of the expertise contributed by those with lived experience.

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4.

ADAPTING PARTICIPATORY ACTION RESEARCH TO INCLUDE INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES DURING THE COVID-19 GLOBAL PANDEMIC

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[Adapting Participatory Action Research to Include
Individuals with Intellectual and Developmental Disabilities
During the COVID-19 Global Pandemic PDF File](#)

Plain Language Summary

Participatory action research, or PAR, includes people with disabilities on the research team. All team members are researchers. Researchers have changed the way they do work to keep people safe from COVID-19. This is important for people with disabilities because COVID-19 is dangerous. There are still many ways for research team members to work together and learn to trust each other. This article shares some ideas for including researchers with disabilities. We can find more ways for researchers to be a part of the team. We can ask people how they like to share their ideas. We can practice sharing ideas in different ways. And we can use small groups to get things done. “Nothing about us without us” is also a goal of research. There are many ways to include people with disabilities in

research. We are learning new ways to stay safe and get work done during the COVID-19 pandemic.

Despite acknowledging that individuals with I/DD are the experts on their own experiences, researches have traditionally viewed the roles of individuals with I/DD, including autistic people,¹ as research participants rather than co-researchers or collaborators in scientific inquiry (Chown et al., 2017; Coons & Watson, 2013). In response to the recognition that the inclusion of those living the experiences being studied contributes to more relevant and meaningful research, interest in participatory research with individuals with I/DD has blossomed in recent years (Jivraj et al., 2014; Nicolaidis et al., 2019). There is still a need for continued progress in meaningful inclusion of people with I/DD in research, and the impact of the COVID-19 pandemic on research processes and its disproportionate effects on people with disabilities (Constantino et al., 2020) threatens this progress. Therefore, this paper's aim is to provide recommendations for adapting participatory approaches to research with individuals with I/DD to the COVID-19 context.

Participatory Action Research with People with I/DD

Benefits and Challenges

Participatory action research (PAR) is a pluralistic research orientation that resists traditional roles and methodologies (Chambers, 2008). PAR positions research populations in dual roles of co-researcher with shared responsibilities and opportunities for the production and consumption of knowledge throughout the research process (Borda, 1996). Participatory research has many names (e.g., inclusive research, PAR, community-based participatory research [CBPR], emancipatory research); therefore, its “umbrella definition” leaves space for individual interpretation and variations in the ways in which individuals with I/DD are included (Bigby et al., 2014; Frankena et al., 2019). Engagement in PAR shifts the balance of knowledge and power, an imbalance, which has historically oppressed and exploited vulnerable populations, including people with I/DD.

Principles of PAR maintain that all stakeholders have valuable experience, and that research must be conducted with people instead of on or even for people (Chambers, 2008), a suitable complement for the well-known mantra of the disability community, “Nothing about us without us.” Inclusion of co-researchers also benefits the research team (Bigby et al., 2014; Tanabe et al., 2018). Co-researchers with

disabilities can integrate their lived experiences, have developed richer methods of data collection, and add unique interpretation to the data (Bigby et al., 2014). When people with I/DD are co-researchers, they are no longer inert objects of observation; rather, the power and control of knowledge is shared.

Despite the multiple benefits of inclusive PAR, there are barriers to its facilitation that predate COVID-19. The pluralistic nature of PAR means that while participants are expected to be engaged in active participation throughout the knowledge acquisition process, the manner in which participants are involved can vary widely. Meaningful involvement of co-researchers with I/DD can be challenged by the range of accommodations necessary to ensure equitable engagement. In true PAR (Seekins & White, 2013), co-researchers with disabilities are included in research question formation, study implementation, data analysis, and dissemination of results.

Although PAR actively aims to decrease biases and move towards social justice, the micropolitics of research institutions still present in PAR spaces (Smith et al., 2010). Decision-making about research processes and management of resources are often shared between researchers who do and do not align with the core principles of PAR. Systems that have more financial resources to provide accommodations may still be burdened by outdated procedures that limit involvement of co-researchers without certain credentials. It is important to

counteract biases about what constitutes sound or rigorous research and even who qualifies as a researcher.

Considerations for PAR with People with I/DD

Despite the growing emphasis on using participatory methods, there has been a lack of guidance on the “how to” or practice-based guidelines for including individuals with I/DD in research (Nicolaidis et al., 2019; Vega-Cordova et al., 2020). PAR promotes equitable, cooperative research partnerships. In theory, PAR should hold the potential to fully include people with I/DD in all phases of research, ensuring social relevance, inclusion, and accessibility (Hughes et al., 2020; Nicolaidis et al., 2015; Stack & McDonald, 2014). That potential may not be realized due to a lack of accommodations made to processes, items, procedures, or systems even with the application of universal design in the process (Centers for Disease Control and Prevention [CDC], 2020; Rios et al., 2016). More recently, researchers (e.g., Nicolaidis et al., 2019; Schwartz et al., 2020) have focused on identifying lessons learned to ensure that participatory methodologies for individuals with I/DD reflect truly inclusive, rather than tokenistic, collaborations.

A commitment to an accessible research environment is essential for the authentic inclusion of individuals with I/DD (Schwartz et al., 2020). Accommodations, such as

opportunities to review materials in advance and use of plain language, facilitate the participation of individuals with I/DD in research partnerships (Nicolaidis et al., 2019; Stack & McDonald, 2018). Accommodations should be individualized; for example, people with ID may prefer brief summaries and phone or in-person contact whereas autistic co-researchers may prefer detailed explanations and communication by text or the Internet (Powers, 2017).

Prioritizing accommodations and the continued reassessment of accommodations to ensure that individuals' needs are met communicates that researchers are sincerely committed to creating a supportive research environment for all their partners (Stack & McDonald, 2018). Relatedly, building and maintaining trust and relationships between researchers and individuals with I/DD is crucial to effective collaboration (Nicolaidis et al., 2019; Schwartz et al., 2020). Dedicated time to getting to know one another can facilitate teamwork, and icebreakers or other activities to identify shared goals can build motivation. In addition, the responsiveness and openness of researchers to feedback and evaluating the research process not only fosters trust but also improves the effectiveness of the research collaboration (Schwartz et al., 2020).

Ideally, project goals are developed collaboratively, so that all stakeholders are engaged from the start. Clear roles, goals, and responsibilities should be defined and can help to build trust and avoid future frustration or unmet expectations.

Transparency about compensation and funding as well as potential funding constraints is critical, so that individuals can make informed decisions about their participation (Nicolaidis et al., 2019). Further, regardless of the type of partnership, from an advisory or consultative model to full inclusion, the thoughtful identification of co-researchers and identifying partners with particular types of lived experience for the research team is fruitful (Schwartz et al., 2020).

Several participatory projects focused on topics important to the I/DD community have used these strategies, which have contributed to more relevant and meaningful research. One group (Hughes et al., 2020) held quarterly videoconferences with a national advisory board of people with intellectual disability. Advisors chose mentors who assisted them in connecting to the conference, reviewed meeting materials in advance, and supported their communication needs and understanding during meetings. Another participatory team adapted standardized measures by including hotlinks to define difficult terms and to provide examples, adding graphics for response options with Likert-type scales, and changing wording for purposes of clarity (Nicolaidis et al., 2015). Including individuals with I/DD as research partners enabled the researchers to increase the validity of their data collection, as standardized measures are often not accessible to people with I/DD without modification (Meyers & Andresen, 2000).

To conduct fully inclusive research, dissemination activities should include community partners with I/DD as co-authors

of peer-reviewed articles and lay language briefs. They should also be involved as co-authors and/or co-presenters of presentations on local, national, or international levels (Nicolaidis et al., 2019; Powers, 2017).

Effects of COVID-19 on People with I/DD

COVID-19 has disrupted nearly every segment of peoples' lives, and it has the potential to disrupt PAR with individuals with I/DD. COVID-19 disproportionately affects people with I/DD, who are at increased risk for poor medical outcomes from COVID-19 and associated restrictions. In the U.S., individuals with I/DD experience more severe outcomes from COVID-19 (e.g., higher case-fatality rates; Landes et al., 2020). Beyond the health consequences of COVID-19, the pandemic highlights broad inequities experienced by individuals with I/DD, including the loss of in-person services on which many individuals with I/DD rely for daily living (Arc of the U.S., 2020; Constantino et al., 2020).

Moreover, the pandemic has also brought attention to the inequities embedded in society that have systematically oppressed racial/ethnic minorities for generations (e.g., lack of access to quality healthcare, discrimination). Racial/ethnic minorities with I/DD have experienced significant disruptions to their daily lives because of the lost educational, healthcare, and personal assistance services given social distancing or

quarantine orders (Jeste et al., 2020; Sabatello et al., 2020). Although the historical marginalization of people of color with I/DD is documented, this population continues to be minimally represented in research (Luckasson & Schalock, 2020). The perspectives of people of color with I/DD should help guide practice, policy and research decisions that impact their health and quality of life (Luckasson & Schalock, 2020; Mello et al. 2020). The potential stagnation of research efforts because of COVID-19 threaten to further these inequities in research participation of people of color with I/DD.

Now, more than ever, a thoughtful and intentional focus on PAR is needed. Unfortunately, COVID-19 has disrupted traditional systems of conducting PAR with people with I/DD. As such, we offer potential considerations and recommendations for conducting PAR within the context of the pandemic.

Opportunities and Recommendations to Adapt Research Due to COVID-19 Response

A New Context for Relationship-Building

Trust, described as “the fragile foundation of contemporary

research,” is an underlying component of every study (Kass et al., 1996, p. 25) and is particularly relevant and complex in the inclusion of co-researchers with I/DD. Trust is a heightened need for those who commit to collaborations during a pandemic, which can be difficult given COVID-19 social distancing guidelines. Moreover, specific attention to engaging ethnic/racial minorities with I/DD who may be disproportionately affected by COVID-19 is needed. Having culturally diverse staff members who can explain the purpose of research in a community-friendly way and in co-researchers’ native languages can facilitate partnership building with underrepresented communities. Building rapport with and between co-researchers at distance and using potentially new methods of communication, like live video conferencing and email exchanges, is an emerging challenge.

Although responses to COVID-19 intensified some barriers to PAR’s inclusion of co-researchers with I/DD, it decreased the impact of others. Access to transportation is a one of the biggest barriers in many aspects of life (e.g., employment, access to healthcare, community living) for people with disabilities. Shelter-in-place orders affected the supply and demand for transportation and made it harder for everyone to get around (Lyu & Wehby, 2020). As more professionals from a wide range of backgrounds conduct research and learn new ways to establish and build relationships at distance, there are more options for virtual connection. Gaining entry to a community can often take several months given logistical

challenges of scheduling and transportation. With innovative applications of technology, researchers may be able to abbreviate some of these processes, but the necessity to build trust and rapport remains.

With targeted and sustained effort, PAR can support people with I/DD to participate safely via remote methods, such as video or phone focus groups, individual interviews, group interventions, and advisory board meetings. Accommodations to ensure accessibility should be individualized to meet unique needs. Questionnaires can be mailed to participants with instructions to have the paper formats available while responding to the questions administered by phone. Researchers can build the provision of Wi-Fi and electronic devices into their budgets, as these resources are often not available for people with I/DD. However, as Constantino et al. (2020) emphasized, electronic substitutions for in-person contact may not be beneficial for some people with I/DD.

Advocacy may be necessary to acquire the funding and flexibility needed to integrate accommodations as seamlessly as possible into the research team's processes. Researchers may need to allocate funding to hire culturally diverse research staff and to dedicate time for developing accommodations and cultural adaptations (e.g., translation). Researchers are increasingly under pressure from funding agencies to expedite timelines under a limited scope of budget. The benefits and challenges of PAR must be weighed against feasibility to ensure success as perceived by all parties.

Strategies to Promote Inclusive Virtual Engagement

Inherent power differentials within research teams often naturally emerge—even under the best circumstances. Virtual modalities pose challenges to aspects of team culture, including verbal and nonverbal communication, authentic relationship-building, and equal contribution from all members. PAR teams must, therefore, intentionally integrate strategies to promote opportunities for all members to contribute and ensure equitable voice. Suggested strategies are based on both the literature and the experience of the authors conducting virtual partnerships during the pandemic.

- *Provide multiple methods for team members to contribute to the conversation.* Members of the research team may have varying preferences for and level of comfort with different communication modalities. Soliciting input and feedback through verbal sharing, use of chat boxes, email, and other written options may help cultivate a group culture that honors individual preferences (Nicolaidis et al., 2011). Given that engagement in long virtual meetings can be difficult, teams may benefit from soliciting group ideas and feedback via follow-up listservs and surveys that are analyzed between meetings (Jessell et al., 2016; Tamí-Maury et al, 2017).
- *Ask about communication preferences upfront.* Relatedly,

it is easy to make assumptions that we understand others' communication preferences, either based upon our own biases or based upon experience with them from in-person engagement. However, these preferences may change in concert with adaptations to our virtual work context, and technological experience within a group can be diverse (Jessell et al., 2016). Assessment of communication preferences is important when engaging individuals with I/DD under usual circumstances, and it becomes more critical in virtual contexts. For new and existing teams, we suggest explicitly exploring communication preferences with all team members and regularly revisiting this topic throughout the research process. Instructional researchers have developed simple questionnaires (Bailie, 2017), and teams can develop their own surveys that are customized to their respective contexts. Helpful topics to explore may include style (e.g., verbal versus written communication), modality (e.g., preferred apps/platforms such as Zoom chat, Slack, Teams, text, Whatsapp, etc.), and engagement strategies (e.g., Does the person want to jump in independently? Do they prefer to be called on directly for an opportunity to contribute?).

- *Provide multiple opportunities for input.* Because researchers often have tight agendas and timelines, there is a tendency for meetings to move quickly. Given the complexities of sharing in a virtual format, opportunities

for feedback can be limited, which may not benefit all team members. Some may require time to process questions and ideas before being ready to offer feedback. Others may require additional time in the moment to formulate a response. Teams that continually revisit agenda items, solicit feedback both in the moment and via follow up (e.g., email, surveys), and cultivate openness to ongoing input will support meaningful engagement for all participants, which may result in more creative and responsive research strategies (Jessell et al., 2016).

- *Create space for small group discussion.* Large, virtual groups are a difficult environment to promote equitable voice. In large settings, the onus is on individuals to be willing to break into conversation without the ability to rely on the subtle and nonverbal cues that are available in person. Many people can feel shut out of large discussions, and people with I/DD may be especially prone to this type of exclusion. Small groups provide a more conducive environment for team members to contribute to their desired level. This can be accomplished through intentionally planning small group meetings, such as identifying subcommittees that branch off of larger projects. Many teams also utilize virtual breakout rooms for more intimate conversations within the context of large group meetings. Ideally, groups of about eight promote ample opportunities for

equitable contributions; however, information gathered about group communication preferences may influence ideal group size. For example, teams that include many members who prefer to use chat versus spoken communication may consider smaller breakouts.

Conclusion

Although COVID-19 exerts a major impact on research endeavors, academics and community partners can preserve the integrity of PAR by adapting processes to accommodate safe and meaningful participation of people with I/DD. Research with this population must move forward. Overlooking or postponing the inclusion of people with I/DD because of COVID-19 will only further inequities experienced by this population. Individuals with I/DD can provide positive contributions to research. Engagement in meaningful research can better the lives of participants. In addition to challenges rendered, the COVID-19 pandemic has increased the frequency of virtual methods of connection, thus potentially breaking down barriers of future participation for people with I/DD. As researchers examine ways to ensure their work is socially just and relevant, PAR is a challenging but worthwhile approach to the inclusion of people with I/DD in the research process.

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5.

CHANGING NEEDS OF INDIVIDUALS WITH DISABILITIES IN THE TIME OF COVID-19 AS OBSERVED BY A FAMILY NAVIGATION PROGRAM IN MIAMI, FL

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[Changing Needs of Individuals with Disabilities in the](https://digitalcommons.usu.edu/ddnj/vol1/iss2/6/)

[Time of COVID-19 as Observed by a Family Navigation
Program in Miami, FL PDF File](#)

Plain Language Summary

The Family Navigator Program (FNP) helps families of people with disabilities. The FNP is free for all people in South Florida. Families who work with the FNP are usually sent by their doctors, therapists, or friends. In this project, we looked at changes during COVID-19. Quarantine began in the middle of March in 2020. We looked at race, language, age, and disability for each family. We also looked at needs. Needs were topics that families wanted to learn more about or resources that the FNP told families about. We found no difference in age, race, or language before and after March 2020. During COVID, more families wanted help with money. More families also asked about government programs. Families asked less about school and therapy. These results help us know the problems of our clients during COVID. Families needed to focus more on money than school or therapy. This study shows how needs changed during COVID in one diverse city.

Background

Patient navigation programs—first established in the 1990s for breast cancer patients in Harlem, NY—aim to eliminate health disparities by addressing systemic barriers disproportionately affecting underserved populations (Freeman et al., 1995). Family navigation programs expanded this model to deliver services to families, including those of children and adults with intellectual and developmental disabilities (I/DD), chronic health conditions, mental health issues, and other special needs. This population of families faces unique challenges in navigating both the complex medical and disabilities services systems (King et al., 2002; Lightfoot, 2014). Barriers encountered by these families include lack of education on diagnoses and disabilities, as well as incongruities with providers' spoken languages and cultural beliefs (Freedman & Boyer, 2000; Stahmer et al., 2019). The Family Navigator Program (FNP) at the Mailman Center for Child Development in Miami, FL., has been providing free navigation services to families in the Southeast Florida region since 2016. Funded by grants from the Taft Foundation, the FNP navigators are able to provide social support, refer families to community resources, and assist in applying for federal, state, and local programs.

The city of Miami is located in Miami-Dade County, which has a population made up of primarily Spanish-speakers, with almost 70% of families speaking Spanish in the home (Florida

Legislature, Office of Economic and Demographic Research, 2020). Though these residents share a language, they represent over a dozen Spanish-speaking countries, each with their own culture. Additionally, nearly 20% of Miami-Dade County identifies as Black or African American, with a large population of Creole-speaking Haitian residents (Florida Legislature, Office of Economic and Demographic Research, 2020; Pierre, 2020). To best serve these populations necessitates cultural understanding and language proficiency. Additionally, 17% of all people and 23% of children live in poverty in Miami-Dade County (“ALICE County Profiles: Florida,” 2018; Florida Legislature, Office of Economic and Demographic Research, 2020). Families served by the FNP have varying financial, insurance, immigration documentation, and transportation needs that serve as barriers to accessing therapy and medical care. Many families rely on low-wage jobs and public assistance to care for their children. The FNP navigators are equipped to serve families in their native language to help them address social issues and improve their quality of life.

Families who are referred to the FNP go through an intake process, during which demographic information is collected. Navigators inquire about the families’ needs and concerns, which guides the next steps and individualizes this process for each family. At times, families have questions about various services that can be answered through an educational session with the navigator—these are referred to as the families’

educational components. Other times, families require direct referral to outside services and programs. The demographics, referrals, and topics on which families require education are documented in a client database, as well as dates of referral, intake, and follow-up communication. Finally, navigators record whether or not families have been connected to new resources as a result of their participation in the program. This database provides insight into the client population of the FNP; therefore, facilitating research and analysis for the sake of quality improvement. FNP client demographics and referral patterns can be monitored over time for changes, whether due to changes within the program or community circumstances.

In March 2020, the COVID-19 pandemic caused widespread unemployment, school closures, and financial strain on families in the U.S. A State of Emergency was declared in Miami-Dade County on March 12th, 2020, and by March 18th, stay-at-home orders and school closures were in effect throughout the region (Miami-Dade County Public Schools: Office of Communications and Community Engagement, 2020; Miami-Dade County Mayor's Office, 2020). The unemployment rate in Florida rose to 13.8% in April from 4.4% in March (U.S. Bureau of Labor Statistics, 2020). Moreover, telemedicine visits rose in the U.S. by 154% by the end of March (Koonin et al., 2020). Consequently, FNP navigators began anecdotally noting changes in where families were being referred from, in addition to shifting resource requests and educational needs. In this study, we

analyzed data from two independent cohorts of families served by the FNP before and during the COVID-19 crisis, specifically examining evolving demographics and family needs.

Methods

Sample and Inclusion Criteria

The study was conducted using data collected by the navigators of the FNP. Data from the 2019 and 2020 client logs were de-identified. The data were split into pre-COVID and COVID cohorts, with the pre-COVID subjects enrolled in the program from November 2019 to March 15, 2020, and the COVID subjects enrolled from March 15, 2020, until the end of September 2020. Data were utilized from families who completed all intake forms and were formally delivered services. Families found to have incomplete records were excluded from the study.

Variables for Analysis

Data were coded and uploaded to SPSS® software. The data analyzed included demographics, region of residence, referral methods, resources, and whether or not a family was successfully connected to resources.

Demographics

Demographic data collected included race/ethnicity, language of client preference, age group, and condition. All demographic values were self-reported by families, including the conditions of their children. Any value appearing only once was considered an outlier and not included in the analysis. Race was dummy-coded, and the categories included were White, Black/African American, and Hispanic/Latinx. Asymptotic significance (2-sided) was used to compare pre-COVID and COVID frequencies for each race individually, as participants may have self-identified as members of more than one racial/ethnic group. Language preferences included for comparison were English, Spanish, bilingual English/Spanish, and bilingual English/Creole. The Pearson chi-square test was used to compare pre-COVID and COVID rates for all groups. Age was identified in groups including birth to 2 years of age, 3 to 5 years, 6 to 12 years, 13 to 21 years, and greater than 21 years of age. The Pearson chi-square test was used to compare pre-COVID and COVID rates. A similar methodology was used to compare rates of conditions or diagnoses, which were reported by the family at intake. Asymptotic significance (2-sided) was used to compare pre-COVID and COVID rates. Zip codes detailing location of residence in South Florida were grouped by county name. A map was created using GIS mapping software (SAS JMP®) to visualize the neighborhoods in which clients reside.

Referral Method

Families are referred to the FNP via a variety of sources. These sources were grouped into the following categories: external agencies, family or friend, the Jackson Health System (Miami-Dade County's largest public hospital), self-referral, or referral through any University of Miami clinic. Fisher's exact test was used to compare pre-COVID and COVID groups. This test was implemented whenever greater than 20% of cells contained counts less than 5, as was seen when collecting referral method data.

Needs

Client needs are inferred by analyzing both the topics on which families requested education and the resources to which families were referred, as these are direct reflections of the families' concerns at intake. The topics on which families were educated were broad; therefore, for this study, they were grouped into the following categories: Medical, School Systems, Therapy, Federal and State Programs, and Other. Education on insurance coverage, dental coverage, medical needs, and information on the pandemic itself were all grouped into the Medical category. Education on afterschool programs and exceptional student education (ESE) were included in the School Systems category. Education on certain therapy providers or types of therapies available to families was included in the Therapy category. Any sort of education

on navigation of available government assistance programs for families was grouped into the Federal and State Programs category. The Other category included education on topics such as seeking legal counsel, custody agreements, assistive technologies, financial aid, and transition to adulthood.

Binary logistic regression was used to compare pre-COVID and COVID groups. Similarly, binary logistic regression was used to compare groups in terms of resources that families were referred to, which were grouped into the categories of Medical, Financial Crisis, Disability Services, Mental Health, and Federal and State Programs. Some medical resources that families were connected to include pediatric care, local hospital network care, psychiatry care, dental care, or Medicaid. A few of the resources that families were referred to in the Financial Crisis category included housing options, re-employment benefits, food stamps or similar resources, legal aid, and utility payment support. In the Disability Services resource category, families were referred to multiple therapy providers, various advocacy groups, vocational rehabilitation programs, Applied Behavioral Analysis, Parent-to-Parent of Miami, Parent-Child Interaction Therapy, and Florida's Assistive Technology Program. The Mental Health resource category refers to any mental health options with which the FNP was able to connect families. In the Federal and State Programs resource category, families were referred to certain social programs or the Department of Children and Families. Resources were

only coded into SPSS if they were used three or more times by study participants.

Connectivity to Resources

Rates of connectivity to resources were assessed based on individual demographic factors to evaluate predictors of families being connected to services. Connectivity rates between pre-COVID and COVID cohorts were compared first. Subsequently, cohorts were stratified by additional characteristics—language, age group, race, educational components, and resources— and were analyzed individually comparing connection rates pre- and during COVID. This was done using binomial logistic regression models with calculation of odds ratios and 95% confidence intervals. Models were created for each of the two cohorts in an identical fashion, and the aforementioned characteristics were analyzed as covariates.

Results

The “pre-COVID cohort” consisted of 145 families served by the FNP from November 1, 2019, to March 14, 2020. The “COVID cohort” consisted of 197 families served from March 15, 2020, to September 30, 2020.

Demographics

No statistically significant differences were found when comparing all demographic factors between the two groups. In terms of race/ethnicity, most families identified as Hispanic/Latinx both before and during the pandemic (57% vs 60%, $p = 0.556$; see Table 1 and Figure 1). Preferred language in which families received services also did not change significantly from before COVID to the time during the pandemic ($p = 0.156$). In both groups, Spanish alone was the most common language (47% before and 43% during COVID) when compared to English alone or bilingual English/Spanish or English/Creole (Table 1).

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Table 1
Demographic Language and Race/Ethnicity Data for
Pre-COVID (*n* = 145) and During COVID (*n* = 197) Cohorts

Demographic variable	Pre-COVID (%)	During COVID (%)	Chi square p value
Language			
English	38	34	0.156
Spanish	47	43	
English/Spanish	10	19	
English/Creole	5	4	
Race/Ethnicity			
White	18	19	0.750
Black / African American	26	21	0.305
Hispanic/ Spanish/Latinx	57	60	0.556

Note. Race/Ethnicity variables were analyzed separately due to many families identifying with more than one category.

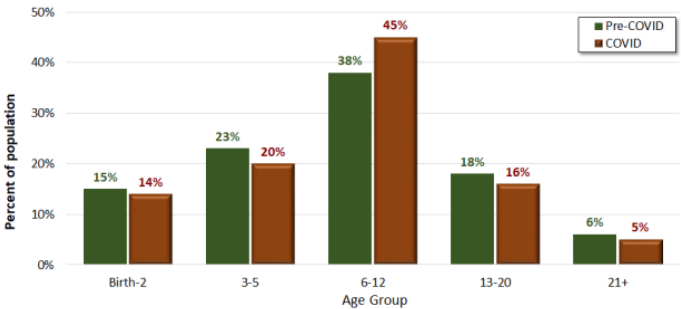


Figure 1

Demographic Age Data for Pre-COVID (n = 145) and During COVID (n = 197) Cohorts

The five age intervals showed no difference before or during COVID-19 ($p = 0.741$). In each group, the FNP mostly worked with parents of school-aged children in the age range of 6 to 12 years old (38% before and 45% during COVID). Regarding the condition or diagnosis of the family member with I/DD, it is important to note that this information was self-reported by family members and that a single individual could report multiple conditions. The most commonly reported conditions were autism spectrum disorder (ASD; 39% before COVID vs 32% during COVID), attention deficit/hyperactivity disorder (ADHD; 13% vs. 16%), global developmental delay (13% vs. 9%), and a mental health or behavioral condition (19% vs. 11%). There were no significant differences found between groups in comparing before COVID to during COVID ($p = 0.211$; see Figure 2).

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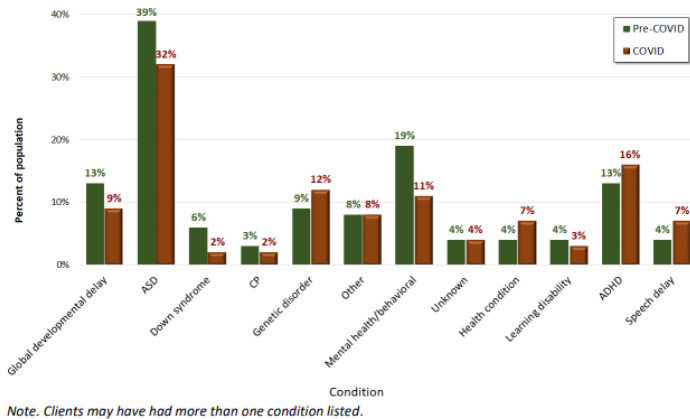


Figure 2

Family-Reported Conditions of Clients for Pre-COVID (n = 145) and During COVID (n = 197) Cohorts

Note. Clients may have had more than one condition listed.

GIS mapping software was utilized to visualize where families seeking services from the FNP resided both before and during the pandemic. Figure 3 demonstrates that the pre-COVID cohort resided in areas of South Florida that were further away from the Mailman Center in both north and south directions. During the pandemic, the program saw an increase in participants residing in neighborhoods that were geographically closer to the Mailman Center and were more centralized to downtown Miami, FL. This is especially true of zip codes representing Little Havana and Overtown.

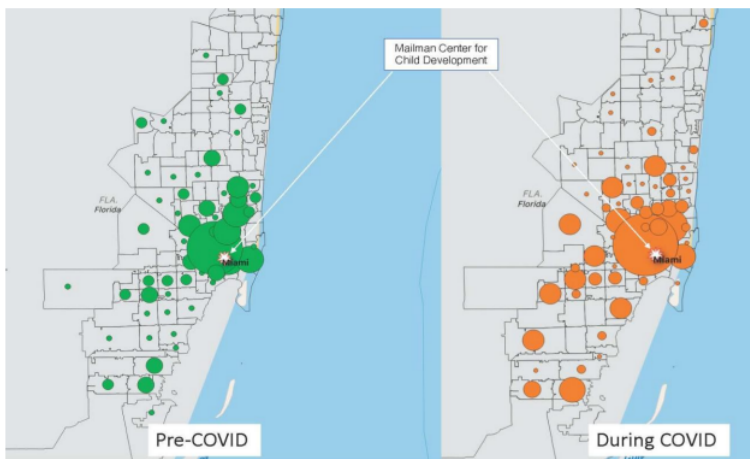


Figure 3

Demographic Location Data for Pre-COVID (n = 145) and during COVID (n = 197) Cohorts, Based on Family Zip Code

Note. Stars denote the location of the Mailman Center for Child Development, where the FNP is based. The regions depicted cover Miami-Dade and Broward counties in Southeast Florida, USA.

Referral Method

Five categories of referral methods were used in comparison between pre-COVID and COVID cohorts (Self-Referral, University of Miami clinics, Jackson Health system, Family or Friend, and External Agencies). The most common referral method used in both the pre-COVID and COVID cohorts was referral through the University of Miami clinics (73%

before and 71% during COVID). There was no significant difference between groups ($p = 0.564$).

Needs of Families

Table 2 shows the results of the differences between the two cohorts regarding educational components, which consists of education provided on Medical, School, Therapy, Federal and State Programs, and Other topics. Education provided by the navigators concerning school or therapy both decreased in frequency during COVID (OR = 0.531, 95% CI [0.328-0.858] and OR = 0.534, 95% CI [0.345-0.825], respectively). Conversely, education on federal and state programs or other topics increased during the pandemic (OR = 2.156, 95% CI [1.306-3.560] and OR = 1.902, 95% CI [1.081-3.348], respectively).

Table 2
Education Needs of Families During COVID ($n = 197$) vs.
Pre-COVID ($n = 145$)

Category	OR	95% CI	p value
Medical	1.225	.797-1.882	.355
School	.531	.328-.858	.010*
Therapy	.534	.345-.825	.005*
Federal/State Programs	2.156	1.306-3.560	.003*
Other	1.902	1.081-3.348	.026*

Note. Statistically significant values greater than 1.0 indicate increased needs in these categories during COVID; values less than 1.0 indicate decreased needs in these categories during COVID.**Denotes significance* ($p < 0.05$).

Families were then referred by the navigators to resources that best fit their unique case, taking into account the families’ transportation and socioeconomic restrictions. These results are displayed in Table 3. Of the types of resources reported, including the Medical, Financial Crisis, Disability Services, Mental Health, and Federal and State Programs categories, only the Financial Crisis category changed significantly from before COVID to during COVID (OR = 3.019, 95% CI [1.445-6.308]).

Table 3
Referral Needs of Families During COVID ($n = 197$) vs. Pre-COVID ($n = 145$)

Category	OR	95% CI	p value
Medical	1.221	.764-1.950	.404
Financial crisis	3.019	1.445-6.308	.003*
Disability services	.633	.366-1.094	.101
Mental Health	.717	.322-1.598	.416
Federal/state Program	.986	.587-1.655	.957

Note. Statistically significant values greater than 1.0 indicate increased needs in these categories during COVID.

**Denotes significance ($p < 0.05$)*

Connectivity to Resources

In the context of this study, connectivity rates indicate whether or not families were successfully connected to any new resources as a result of working with the FNP. Overall, connectivity rates were consistent across the two cohorts ($p = 0.676$). Upon further stratification, data indicated that before COVID, Spanish ($OR = 2.107$, 95% CI [1.001-4.435]) or bilingual English/Spanish ($OR = 5.828$, 95% CI [1.2-28.293]) speakers were more likely to be successfully connected to services than families that spoke English alone ($OR = 2.107$, 95% CI [1.001-4.435] and $OR = 5.828$ CI [1.200-28.293], respectively). There were no differences between English-speaking families and bilingual English/Creole families ($OR = 0.672$, 95% CI [0.137-3.290]). This effect was no longer observed during COVID. Examining educational components and connectivity prior to the pandemic, families who requested education on the school system were more likely to be successfully connected than those who did not request education on this topic ($OR = 2.331$, 95% CI [1.049-5.178]). Conversely, families who requested education on state and federal programs during the pandemic were more likely to be connected to services compared to families who did not request education on these programs ($OR = 2.546$, 95% CI [1.307-4.961]). Other demographics including age group,

race/ethnicity, and method of referral were never significant predictors of connection rates either before or during the pandemic.

Discussion

The aim of this study was to investigate connectivity trends among demographics and evaluate the needs of families enrolled in this FNP at the Mailman Center for Child Development before and during the COVID-19 pandemic. As the results illustrate, there were no statistically significant differences in the demographics of families who worked with the FNP before and during the pandemic. These demographic results indicate a consistency in population that were referred or self-referred for services from this program. In accordance with this observation, the methods by which families were referred did not significantly change. The largest source of referrals in both cohorts was through the University-affiliated clinics. With clinical care transferring to telemedicine platforms, both the volume and sources of referrals to our family navigation services were largely unaffected. This supports the strength of the program's relationship with these clinics—namely the genetics and neurology clinics—after 4 years of operating together in the Mailman Center. Navigators anecdotally noted a shift in referrals, as families networked less in school or community settings; however, these effects were not captured by the broad categories used in this analysis.

In general, the FNP mostly serves those who identify as Hispanic or Latino/Latinx. This is likely attributable to the ethnic composition of South Florida, the majority of which are Latinx individuals (Florida Legislature, Office of Economic and Demographic Research, 2020). Speaking Spanish alone was more common than English alone or speaking bilingual English/Spanish or English/Creole. Of note, this demographic is representative of the language preferred by families for receiving services from the program, not based on an inquiry of languages spoken in the home. Further describing the population, we found that the FNP works mostly with families of school-aged children from 6 to 12 years of age. This is likely because of the complex needs of children with I/DD in this age group. As children age, families potentially have an improved grasp on the systems in place to support their children. Consequently, navigators hypothesized that an increase in school-aged children during COVID-19 due to school closures could occur. Data analysis demonstrated a small increase, though it was not found to be statistically significant.

Families most commonly reported the following conditions to the navigators: ASD, followed by ADD or ADHD, global developmental delay, and mental health or behavioral conditions. Regarding the area of residence of families, a more centralized radius of zip codes was observed during the pandemic compared to before the pandemic. Navigators hypothesize this is because families rely on community

resources closer to their homes. Further, if families living far away were no longer seeking other services from the University of Miami network, then they were also less likely to be referred to the FNP. Perhaps families from Overtown and Little Havana, two neighborhoods with many residents of lower socioeconomic status, had few resources to turn to within their communities. Early in the pandemic, the FNP saw a drop in referrals, but they returned to previous rates after a few weeks. This is presumably due to the increased utilization of telemedicine appointments, during which providers referred families to the program.

As hypothesized, the needs of participants in the FNP did change significantly between groups. With respect to topics on which navigators educated families, significant differences were found between school systems, therapy, federal and state programs, and the category listed as “Other.” School systems and therapy were less likely to be inquired about during COVID, likely because of the closure of most schools and the decrease in likelihood that a family was encouraged to seek new therapy services. During the pandemic, federal and state programs were more likely to be inquired about—this observation is in accordance with trends in the U.S. of increased utilization of government resources (Center on Budget and Policy Priorities, 2020; Rudowitz & Hinton, 2020). Because of the pandemic, navigators began referring families to new resources. These were not previously coded in the client database; therefore, many were classified as “Other,”

explaining the statistically significant increase in this category during COVID. There was no difference before and during the pandemic in terms of seeking education on medical resources, most likely because the needs before the pandemic were widely replaced by COVID-related medical education needs. It can be hypothesized that during the pandemic, families were forced to prioritize the needs of the whole family while making additional sacrifices for the child with I/DD.

Of the broad variety of resources to which families were referred directly by the navigators, only resources regarding the financial crisis changed significantly during COVID-19. This is an indication that families during this time came to the FNP to seek resources to aid with newer financial burdens. These resources included re-employment benefits, housing and utility payment support, and food stamps. Interestingly, education on federal and state programs increased during the pandemic, but referrals to such resources did not. When examining these effects, it appears that prior to COVID, families were educated on and referred to federal and state programs at similar rates (20% and 22%, respectively); however, during the pandemic, there was only an increase in education (35%) and not referral to federal and state programs (22%, unchanged). Navigator testimony leads us to believe that this trend is because of an increase in educational conversations with families surrounding their rights as outlined by the Americans with Disabilities Act (ADA; U.S. Department of Education, 2020). Navigators noted many parents were not

aware of the ADA or its implications on their children's schooling until concerns arose during the pandemic. Families were educated by the FNP on the logistics of state and federal enforcement of the ADA, as well as updates on the obligations of public-school systems during the crisis.

When assessing the changes in needs of the families, topics on which clients were educated and categories of resources to which families were referred differed significantly between pre-COVID and during COVID cohorts. Rates of connecting families to proper resources alone did not change significantly from pre-COVID participants to those families served during COVID, indicating a successful transition to virtual platforms and adequate adaptation to the families' changing needs. However, upon further stratification some demographic factors and family needs did correlate with significant changes in connectivity. Specifically, language spoken was a significant predictor before the pandemic for connectivity rates, and this may be explained at least in part by the family navigators themselves being native Spanish speakers. This effect was not observed during the pandemic, possibly because connection to appropriate resources during a time of crisis likely naturally favors English-speaking individuals, making it more difficult for families to be adequately connected to the resources they may need. Families who sought education about their school systems were more likely to be connected compared to families who did not. This is likely indicative of already well-established school procedures with easy-to-navigate systems in place.

Additionally, during COVID-19, families seeking education about federal and state programs were found to be connected significantly more often. This effect may be twofold—families were likely to follow up on referrals out of urgent necessity, and federal and state programs became more accessible because of an increase of emergency funds on local and national levels.

Conclusions and Future Directions

In consideration of the future of the FNP at the Mailman Center for Child Development in Miami, Florida, this study highlights the strength of the program despite the drastic environmental and political changes brought about by the COVID-19 pandemic. The depth of information collected in the client database provides a unique opportunity to reflect on this population and provide insight to navigators and the community. Though the demographics of the client population served by the FNP did not change significantly during the pandemic, their needs for education and referrals did. Families needed less information about school systems and therapy providers; they needed more education on state and federal systems, as well as a variety of other topics not usually addressed by the navigators. The resources to which families were referred did not change as much—families were more likely to be given referrals only to state and federal agencies. Clients were successfully connected to resources at

the same frequencies during COVID as before, which is an indicator of a successful adaptation to the crisis.

Moving forward, this program intends to continue using virtual platforms and other methods elicited by the pandemic to continue to connect with families that the program serves. This makes the program more available to families with transportation limits, time constraints, or other barriers to accessing the program. In fact, the virtual protocol that exists now is more interactive and informative for families, as family navigators often utilize screen-sharing to involve family members as much as possible with their services. This increases the family's technological capabilities and allows for greater independence when needing services in the future. Unfortunately, because of pandemic constraints, the family navigators are no longer accompanying their clients to medical visits. At present, this extends to the patients' telehealth appointments. Therefore, navigators are entirely dependent on families to vocalize their needs and the recommendations of their clinicians. In the future, we hope to implement initiatives that allow for our program's involvement in the telehealth sphere to further serve families in need.

The FNP at the Mailman Center is concerned about the long-term effects of the pandemic on their client population. This upheaval of families' lives will likely lead to setbacks in the future, such as children going long periods of time without various therapies. As families are forced to budget limited funds for the needs of the entire family, lessening the priority

of the individual with special needs, there is ample opportunity for hardships or hindrances to arise. Mental health and behavioral concerns, for example, may go unaddressed for months. Additionally, resources in the community may have limited capacity to serve families or be forced to shut down altogether, as many establishments are going out of business. A future study examining the long-term effects of COVID-19 on the FNP client population will allow us to elucidate these quandaries and work to neutralize any negative consequences of the pandemic on our families.

Limitations

This project is not without its limitations. The data on connectivity only include whether or not families successfully connected with any resource but does not include exactly what or how many resources each family was able to access. All conditions and diagnoses are based on family reporting; and though there is a standardized client database, navigators may record varying degrees of data. Additionally, this analysis includes families from the FNP client database, reflecting a sample of specifically referred clients from a single diverse, urban community, rather than a randomized sample.

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6.

James Sinclair; Carly B. Gilson; Mary Whirley; and Yi-Fan Li

Sinclair, J., Gilson, C. B., Whirley, M., & Li, Y-F. (2020). “It’s an opportunity to get opportunities”: A brief report on the working lives of individuals with intellectual and developmental disabilities during the Covid-19 pandemic. *Developmental Disabilities Network Journal*, 1(2), 45-52. <https://digitalcommons.usu.edu/ddnj/vol1/iss2/7>

[“It’s an opportunity to get opportunities”: A brief report on the working lives of individuals with intellectual and developmental disabilities during the Covid-19 pandemic PDF File](#)

Plain Language Summary

The global pandemic has changed the lives of many people. It has also changed the lives of people with IDD. For many people, working is an important part of their life. Working provides the chance to achieve a desired quality of life. Currently, there is little known about the working lives of people with IDD. There is less known about how a pandemic impacts

work. We used the psychology of working theory to frame our brief report. We conducted six interviews with adults with IDD across the United States. We used the theory to understand how participants make meaning of work. We used content analysis to examine our data. We looked for themes across participant responses. Results show the pandemic changed people's work lives. Changes in work included reduced hours and loss of jobs. The pandemic also changed people's personal lives. People had less access to social contact with family and friends. Results also showed participants wanted to work. At the end of the brief, we talk about what it means to make decisions based on risk. We also talk about ways to support people with IDD as they continue to work.

Individuals with intellectual and developmental disabilities (IDD) strive for similar life outcomes as those that do not experience a disability, such as active community participation, postsecondary education, and integrated employment (Shogren & Plotner, 2012). While in school, transition-age students with IDD often work with teachers to make person-centered, self-determined goals for the future (Claes et al., 2010; Park & Bouck, 2018). For many students with disabilities, including students with IDD, these goals often are focused on gaining employment (Sinclair & Poteat, 2020).

Having opportunities to work provide a number of social benefits as well, including personal connection, economic benefits, self-pride and satisfaction, and an opportunity to learn (Lysaght et al., 2009). Ultimately, planning for adulthood helps an individual start preparing for the quality of life they desire (Cobb & Alwell, 2009; Morningstar & Clavenna-Deane, 2018).

Although young adults with IDD share the same employment aspirations as their peers without disabilities, the opportunities available to them are not equitable. Young adults with IDD continue to experience poorer post-school outcomes compared to peers with other disabilities or without disabilities (Lipscomb et al., 2017; Liu et al., 2018). There are multiple systemic factors (e.g., ableism, prejudice, ignorance) causing inequitable outcomes (Kocman et al., 2018). For example, current estimates report approximately 19% of all people with a disability were employed in 2019 in contrast to 66% of individuals without a disability (Bureau of Labor Statistics [BLS], 2020). These discrepant outcomes persist as new initiatives such as Employment First (i.e., laws and policies supporting competitive and integrated employment for individuals with IDD) are starting to make an impact on state and federal levels (Klayman & Coughlin, 2017). In addition, individuals with IDD continue to experience chronic rates of underemployment or unemployment (Kraus, 2017).

Furthermore, amid times of economic hardship and a global pandemic, individuals with IDD are likely to experience even

more challenges attaining and retaining integrated employment. Within the emergent research about the employment experiences of individuals with IDD (e.g., McMahon & Cuskelly, 2020), there is no research available specifically about the working lives of individuals with IDD during times of a global pandemic. The present study sought to explore this novel situation by capturing the working experiences and perspectives of people with IDD during the COVID-19 pandemic in 2020.

Theoretical Framework

This qualitative study was guided by the Psychology of Working Theory (PWT; Blustein, 2006; Duffy et al., 2016), which considers the importance of work through an equity-based social justice lens, contextualizing work within systems of power for certain populations. The theory also centralizes human behavior and the life experience to an individual's relationship with work. The PWT proposes three major functions of working: (a) social connection, (b) self-determination, and (c) power and survival (Blustein, 2006). Social connection encapsulates how individuals build community through networks and interpersonal relationships at work. Self-determination captures the motivating functions of work through extrinsic or intrinsic means. Last, power and survival convey the idea that work is a function of obtaining money in exchange for goods or services and provides

individual status and power. While the PWT has a strong foundation in understanding the employment lives of individuals, it has limited research in its application to individuals with disabilities.

Method

This research brief includes data from a larger qualitative study using the PWT lens to describe how individuals with IDD make meaning of work (see Gilson et al., under review) and explores the extent to which the global pandemic has impacted their working experiences. The current paper provides follow-up data gathered approximately 1 year after initial data collection through the member-checking process (Lincoln & Guba, 1985; Creswell & Poth, 2018), which has not been included in any previous analysis or publication. Approval for this study was granted by the Institutional Review Board of Texas A&M University (protocol number IRB2019-0018D).

Setting and Participants

A total of 18 participants were recruited to participate in semistructured interviews for the original study. Participants were recruited through national disability organizations (e.g., University Centers of Excellence of Developmental Disabilities, Autism Society, National Down Syndrome Society) and convenience sampling. Inclusion criteria for the

study consisted of (a) participants must have self-identified as someone with an intellectual or developmental disability, (b) had current or previous working experiences (i.e., within the last 6 months), and (c) were between the ages of 18-40.

Follow-up interviews related to the global pandemic were not part of the original study. After an IRB amendment was approved, the authors reached out to the original study participants for follow-up interviews. Six of the 18 participants agreed to participate in follow-up interviews; 4 identified as male and 2 identified as female. They ranged in age from 22 to 32 years ($M = 25$ years). Participants were from a diverse subset of the U.S. (Wisconsin, North Carolina, Wyoming, Nebraska, and Texas). Participants reported having intellectual disability ($n = 3$) or autism spectrum disorder ($n = 3$). One participant identified as Native American, and five participants identified as White. Four participants were working at the time of follow-up; two participants lost their jobs due to the COVID-19 pandemic. These interviews were conducted in June 2020, about 3 months after the start of the pandemic in the U.S.

Research Team and Positionality

The first author identifies as a White male with over 10 years of experience working with youth and young adults with disabilities in clinical and applied settings and holds a doctoral degree in special education. The second author identifies as a White female with prior experience as a secondary special

education teacher and job coach for individuals with IDD and holds a doctoral degree in special education. The third author is a doctoral candidate in special education who identifies as a White female. The final author identifies as an Asian woman, a doctoral candidate in special education, and former special education teacher.

Procedures

A semi-structured interview protocol was developed to address two research foci (contact corresponding author for interview protocol). First, participants were asked to share how the COVID-19 pandemic impacted their work and life. Specifically, participants were asked (a) how the pandemic impacted what they do at work, (b) if they are still employed, and (c) if they view work differently because of the pandemic. Second, as part of the member checking process, participants were asked to confirm or expand upon how the authors defined the three major functions of working based on their initial interviews 1 year prior. Confirming the findings with participants allowed the researchers to validate the PWT for individuals with IDD. Follow-up interviews lasted between 11 and 39 minutes ($M = 20.2$ minutes).

Data Analysis

All interviews were conducted via phone, recorded, and

transcribed through automated transcription software (Rev, 2020; Trint, 2020) with manual refinement. We analyzed the deidentified data using Dedoose (2020), a web-based qualitative data analysis software. All participants were given pseudonyms, which are presented in the current paper. Utilizing a qualitative content analysis framework, data were analyzed for deductive and inductive codes. Deductive coding allowed for the authors to review the data that aligned with the three major functions of work within PWT. Inductive coding allowed for the lived experience of individuals with IDD to emerge through the data as the participants navigated work through the COVID-19 pandemic. Coding procedures followed Saldaña (2016), including individual coding of participant interviews, in-depth consensus meetings and reconciliation of differences, and reflexive memoing. The first two authors coded all the transcripts and met to establish consensus and develop themes.

Results

Impact of the Pandemic

The pandemic altered participants' experiences in numerous ways some more drastically than others. Regarding the act of working, there was no one common experience held by all participants. The COVID-19 pandemic impacted each participant's work experience uniquely with participants

reflecting on a loss of job, loss of hours, and even loss of community at work. Two participants, Nicholas and John, lost their jobs indefinitely. Two other participants were able to keep their jobs, but only after losing their jobs for a couple months at the beginning of the pandemic. Another participant, Shelley, had her work reduced from 5 days a week to 3. Last, for Michael, circumstances beyond his control, including a move across country, resulted in his loss of job.

Nicholas discussed the hardships and challenges of unemployment. He stated "something I've been suffering from recently is a lack of opportunities. And that's because I don't really have a job. I'm not coming into contact with people. I'm not going to training. I'm not at a workplace." Michael discussed what his state of mind was being a job seeker during the pandemic. In his follow-up interview, Michael reported looking for jobs was difficult and that he was unsure if he wanted to obtain a job or wait until after COVID-19 was under control, stating "I'm still looking. I'm not dropping my-my stuff down. I'm looking and it's going to work out. It's just going to be... I may wait until after the whole corona thing is over to look for more jobs."

Last, those who were currently working discussed other changes at work including having to use safety precautions (e.g., wearing a mask) while at work, which they all disliked. Beth responded to the question, "do you like wearing the mask," by saying "I have to. But do I like it? No." In addition, Shelley remarked how she lost connections with co-workers

because they quit, "They actually quit the job. I lost three of my coworkers that worked hard...It's just too much for them, and because of the virus."

The pandemic altered the participants' lives in other ways as well. Participants discussed how their personal lives were impacted by not having access to important social activities, including seeing friends, going shopping, participating in Special Olympics, and attending church. John was reflecting on his lack of access to friends, and how that has impacted him, mentioning "I mean, it's been hard just because I'm usually a very social guy and like to hang out with people in person." John also reflected on the work life dichotomy. "It's just honestly been kind of crazy with the whole pandemic. Just not able to hang out with people...still being able to actually work, but not able to just hang out with people." Furthermore, participants were impacted close to home, with some participants, including Beth and John, reporting being unable to see their family members.

Psychology of Working Theory

Participants reflected on the meaning of work when prompted to discuss the three major functions of PWT (a) social connection, (b) self-determination, and (c) power and survival. Within the construct of social connection, participants reflected on a shift in their abilities to develop strong relationships while working during the pandemic. Reflecting

on his experiences of having a disability and the impact the pandemic had on his social connection, Nicholas shared, "...especially for us, if we have more limited opportunities elsewhere, our best friends that we have, might be at work since that's where we go every day." Nicholas, articulated how working provided a critical space for relationship building, Shelley suggested that work provided an opportunity to connect and engage with others—creating strong relationships, stating "Probably, like, get to know people better." Seamus' remarks also encapsulated the meaning of social connection because through his work he could create relational networks. Seamus enjoyed work because he got to "help other workers" and because of "teamwork."

Within the self-determination construct, participants found that working provides strong intrinsic rewards and is a motivating driver for their life. Sam was passionate about how he envisioned his future and was motivated to take advantage of upcoming opportunities if his job ended for some reason. "You're almost enabled or empowered to do something else, to go somewhere else or try something new. I think that work is an amazing opportunity. It's an opportunity to get opportunities." Shelley mentioned why she was so motivated to work: "[It is] real helpful in my life. And it makes me happy." Beth mentioned her drive for work was due to the people she worked with. "I have the best job coach. And that drives me to go to work.... Best people at work, too." Michael, who had moved and lost his job was motivated to find a job

and expressed not wanting to “look lazy” because he was not working.

Last, within the power and survival construct, participants discussed how jobs were critical to their independence and continued way of life. John talked about how getting two jobs after being let go of his previous job allowed him to keep making car payments. Michael also reflected on the importance of having a job even though he currently did not have one, stating bluntly, “Honestly. Because you’re going to have to have money” [referring to the need of a paycheck]. Seamus aligned with Michael, mentioning how his paycheck from work allowed him to send birthday cards to people.

Discussion

The pandemic’s impact on participants’ employment experiences consisted of hour reductions, loss of jobs, and other minor changes to working life. In addition, a theme found across discussing the pandemic and PWT with participants was a desire for social connection. Participants’ social interactions were negatively impacted not only by their own personal employment changes but the loss of social connection because of coworker changes as well. Another important finding was, even during a pandemic, participants affirmed that employment was a motivating factor in their lives. Participants were self-determined to engage in work and look for work.

Supporting Individuals' Rights to Work During a Pandemic

Employment provides opportunities for social connection, self-determination, and power and survival. Therefore, if an individual strives to work, even amid a pandemic, it is suggested to provide them the dignity to take the risk of working if they are determined to do so. Dignity of risk refers to the need to provide opportunities for individuals to take risk that may provide subsequent enhancement of quality of life (Marsh & Kelly, 2018; Perske, 1972). For example, although individuals with IDD are at an increased risk of dying from COVID-19 compared to individuals without disabilities (FAIR Health, West Health Institute, & Makary, 2020), yet higher risk individuals, including those with IDD, may be among the first to receive the vaccine (Rabin, 2020). When supporting the right to work, individuals with IDD should be presented with risks and given agency to make informed decisions.

Implications for Developmental Disability Organizations

Evolution of job preparation will be critical to meet the changes in expectations set by employers to function within a new era during and post-pandemic. First, educators and service providers will have to find ways to support individuals with

IDD during the pandemic through tailored supports and services. This may include social stories for mask wearing, video modeling for handwashing, and practicing job preparation skills through alternative means (e.g., video interviews). Future research can investigate the feasibility and application of research-based employment skill strategies using virtual modalities. In addition, the pandemic presents issues and barriers to traditional information sharing, building strong interdisciplinary partnerships with other community agencies can expand access to information and support the dissemination of employment and COVID-19 related information. Last, it is strongly recommended that developmental disability organizations disseminate information to their communities in a culturally responsive and timely manner because of the ever-changing nature of the pandemic.

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7.

PARENTS OF CHILDREN WITH DISABILITIES IN THE EARLY MONTHS OF COVID-19: KNOWLEDGE, BELIEFS AND NEEDS

Mary Beth Bruder PhD; Tara M. Lutz PhD;
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Bruder, M. B., Lutz, T. M., & Ferreira, K. E. (2020). Parents of Children with Disabilities in the Early Months of COVID-19: Knowledge, Beliefs and Needs. *Developmental Disabilities Network Journal*, 1(2), 21. <https://doi.org/10.26077/E7D4-7C9B>

[Parents of Children with Disabilities in the Early Months of COVID-19: Knowledge, Beliefs and Needs PDF File](#)

Plain Language Summary

Families have many needs as a result of COVID-19.

We wanted to find out about the needs of families with children with disabilities. We did a national survey and 457 families completed it. The families reported a decrease in the amount of services and supports they were receiving because of COVID-19. They reported being most concerned about their child's education and health. Most families reported high anxiety.

COVID-19 pandemic is unprecedented, and the effects will be long lasting. Many have speculated as to the impact the illness, social isolation, and absence of community will have on all of society (Coyne et al., 2020; Galea et al., 2020), including those with disabilities (Aishworiya & Kang, 2020; Alexander et al., 2020; Boyle et al., 2020; Leocani et al., 2020; Sabatello et al., 2020). Compared to the general population, children, youth, and adults with disabilities have historically experienced disparities in access and participation in health care, inclusive schools and classrooms, postsecondary education and work training, community living options and autonomy, decision, making and self-determination (Wehmeyer et al., 2017). The pandemic has exacerbated these disparities (Ervin & Hobson-Garcia, 2020; Lund et al., 2020; Thompson & Nygren, 2020), creating the need to examine and reform the systems, practices and policies that were in place prior to the pandemic (Bradley, 2020).

COVID-19 has also negatively affected families as

documented by studies conducted during the first few months of the pandemic (Coller & Webber, 2020). Parents have reported increased caregiver burden and subsequent stress as they tried to balance working from home while caring for children and supporting their learning needs when schools closed (Cluver et al., 2020; Weaver & Swank, 2020). These conditions resulted in increases in mental health needs, such as depression and anxiety as reported by families across a number of studies (Gassman-Pines et al., 2020; Patrick et al., 2020; Russell et al., 2020). These needs were exacerbated by worry about health, job loss, health insurance loss and food insecurity (Coller & Webber, 2020).

These stressors are increased for families of children with disabilities, many of whom have special health care needs. These conditions contribute to an increased stress burden for families, which has been recognized long before this current pandemic (Aldersey et al., 2017; Barroso et al., 2018; Hayes & Watson, 2013; Vanegas & Abdelrahim, 2016). This burden has been shown to increase a family's anxiety and decrease their quality of life over the lifespan of the child (Williamson & Perkins, 2014; Woodman et al., 2015).

The severity and contagiousness of the COVID-19 virus has created more anxiety for these families, as youth with intellectual and developmental disabilities (IDD) experience fatalities from COVID-19 at a higher rate than those without IDD—1.6% compared to less than 0.1% for those without IDD ages 0-17 (Turk et al., 2020). Adding to this anxiety are

the losses that many families are experiencing because of the pandemic. These include loss of work, income, food security, and access to community resources, each of which can threaten their sense of well-being (Brown et al., 2020; Prime et al., 2020). These threats add to the already high stress burden experienced by families with children with disabilities (Fontanesi et al., 2020).

Two studies have assessed the well-being of families of children with disabilities during the COVID-19 pandemic. Willner et al. (2020) focused on primary caregivers (mostly families) of children and adults with intellectual disabilities (ID) and families with children without ID living in Great Britain. The caregivers were recruited through email requests to disability organizations. Once the caregiver was determined to meet the inclusion criteria for the study, they were asked to complete several measures through the internet. These included a demographic questionnaire about their child and themselves and formal measures of coping strategies, social supports, anxiety, depression, and defeat and entrapment.

The group of participants included in the study consisted of caregivers of 107 adults over the age of 18 with ID, 100 caregivers of children under the age of 18 with ID, and 37 caregivers of children under 18 who did not have ID. Findings suggested that the caregivers of children and adults with ID had significantly higher levels of defeat and entrapment. Almost half (43%) reported moderate to severe levels of anxiety compared to 8% of caregivers of children without ID.

Similarly, 45% of the caregivers of children with ID reported moderate to severe levels of depression compared to 11% of caregivers of children without ID. The caregivers of children with ID also received significantly less social support than caregivers of children without ID. Further, these caregivers received significantly more support from professionals and significantly less support from family members and friends than caregivers of children without ID.

Another study on the effects of COVID-19 on families of children with disabilities was conducted by Neece et al. (2020). Seventy-seven parents of young children with disabilities ages 2-5, including autism, were recruited from an ongoing intervention study and asked to participate in a telephone interview. The parents were ethnically, linguistically, and socioeconomically diverse and resided in California and Oregon. The interview consisted of five questions that assessed the challenges of COVID-19, the impact of COVID-19 on their child's services, benefits because of COVID-19, their coping strategies, and the anticipated long-term impact of COVID-19 on their family.

The interviews were recorded and transcribed, and the responses to the questions were themed across the families. The biggest challenge from the pandemic reported by the families was being at home and unable to leave the house, followed by balancing work and caring for young children, and the lack of childcare. Most parents said that their child's services had decreased, though a majority reported benefits of

the pandemic such as spending more time as family. Parents identified economic concerns as the long-term impact of COVID-19. The concerns included employment, finances, and the emotional toll the pandemic was taking on themselves and their children.

The purpose of the present study was to document the effects of the COVID-19 pandemic on families of children with disabilities across the U.S. As the sample was national, the population base from which information was gathered was more relevant to the U.S. than the Willner et al. (2020) study, and broader in geographic scope than the Neece et al. (2020) study. This study was also part of a larger effort by the Department of Public Health Sciences at a School of Medicine in the Northeast to document the knowledge, beliefs, and behaviors of specific audiences at the inception of the pandemic.

Method

Participants

A modified snowball sampling (Morgan, 2008) method was used to recruit the participants for this survey. Electronic invitations to participate in an online survey about the effects of COVID-19 on their family's life was sent to parents of children with disabilities using state and national list serves, national disability organizations, and social media. The

invitation provided a brief description of the nature of the study and details including the fact that participation was voluntary. The invitation also contained a link to the survey instrument. The email invitation gave permission to those who received it to share with others who may be interested and eligible to participate. The survey was open from April 2, 2020, until June 1, 2020.

Inclusion criteria for the survey analysis was being a parent of a child with a disability who qualified for and was receiving early intervention or special education as stated in the demographic section of the survey. The final sample consisted of 457 parents who self-identified as having at least one child with a disability from 47 U.S. states and territories.

Most of the sample ($n = 335$, 73%) indicated that they had a child receiving special education services through an IEP, with 38 (8%) reporting that they had a child who was receiving early intervention services, and 84 (18%) reporting that they had children in both early intervention and special education (with an IEP). The average age of the parent who completed the survey was 42.5 years old ($SD = 8.7$), with the average age of the child with a disability just under 11 years of age ($M = 10.9$, $SD = 5.3$). The sample was primarily White (69%), female (79%), and married or living with partner (68%). More than half the sample (56%) reported being employed either part-time or full-time, and 58% indicated they had completed a 4-year college degree. These data are presented in Table 1.

Table 1 *Demographic Characteristics of Respondents*

Variable	<i>n</i>	%
Gender (<i>n</i> = 382)		
Male	15	3.3
Female	362	79.2
Gender non-conforming	1	0.2
Prefer not to respond	4	0.9
Race/Ethnicity (<i>n</i> = 382)		
African American	17	3.7
Black	9	2.0
LatinX/Hispanic	31	6.8
White	313	68.5
Indian	1	0.2
Asian/Pacific Islander	14	3.1
Native American/Indigenous	9	2.0
Other	5	1.1
Prefer not to answer	9	2.0
Marital status (<i>n</i> = 381)		
Single	32	7.0
Married or living with partner	309	67.6
Divorced/separated	32	7.0
Widowed	8	1.8

Variable	<i>n</i>	%
Highest educational level (<i>n</i> = 380)		
Less than high school	1	0.2
High school diploma/GED	29	6.3
Some college	57	12.5
2-year college degree	27	5.9
4-year college degree	128	28.0
Master's degree	102	22.3
Professional degree (e.g., JD, MD, PhD)	36	7.9
Employment (<i>n</i> = 380)		
Unemployed	14	3.1
>Employed part-time	70	15.3
Employed full-time	187	40.9
Laid off because of coronavirus (COVID-19)	31	6.8
Retired	5	1.1
Student	4	0.9
Stay-at-home parent	69	15.1
Number of children receiving early intervention services (<i>n</i> = 122)		
1	109	23.9
2	12	2.6
3	0	0.0

Variable	<i>n</i>	%
4	1	0.2
Number of children receiving special education services through an IEP (<i>n</i> = 419)		
1	340	74.4
2	63	13.8
3	15	3.3
4	1	0.2

Survey

The survey instrument was an adaptation of a survey designed and distributed to multiple target audiences by during the first months of the pandemic. The original survey was designed to measure knowledge, attitudes, and resulting behavior changes in target populations in response to COVID-19. The adaptation was designed by the University Center for Excellence in Developmental Disabilities (UCEDD) that is affiliated with the same School of Medicine where the original survey originated. The adapted survey instrument differed from the original survey in two ways: (1) the addition of questions specific to for families with children with disabilities, and (2) the recruitment of a national audience as the sample.

The survey instrument consisted of 36 closed-ended and 1 open-ended question. The adapted instrument used in this study collected additional data specific to families with

children with disabilities. In addition to demographic information, the survey included questions about (a) formal and informal supports before and during COVID-19, (b) sources of information about COVID-19, (c) knowledge about COVID-19, (d) behavioral changes due to COVID-19, (e) issues faced because of COVID-19, (f) current family needs, (g) beliefs about COVID-19, and (h) anxiety related to COVID-19. The instrument utilized skip logic to display questions based on a participant's previous responses. The instrument was estimated to take up to 15 minutes to complete.

Procedure

The web-based survey was administered through Qualtrics, a third-party online survey company. After receiving IRB approval, recruitment of families of children with disabilities occurred from the beginning of April 2020 through the beginning of June 2020 (2-month period). An online invitation was distributed that contained a link to the Qualtrics survey.

The first page of the survey was an information sheet that provided information about the purpose of the study, study procedures, potential risks, benefits, protection and rights of the participant if they chose to complete the survey, contact information regarding study content, and how to contact the PI of the survey. Respondents were given the option to

“accept” or “decline” participation before completing the survey, and this served as the consent to participate.

Once the survey was complete, the family member clicked “submit” and the survey was submitted through Qualtrics to the study team.

Analysis

All data that were collected through Qualtrics were downloaded into both Excel and SPSS version 25 (IBM Corp, 2017) to be cleaned for analysis. Data cleaning for the analysis reported herein involved the removal of surveys from parents who (a) did not report having a child in the home, and (b) did not report having a child who was receiving either early intervention services or special education through an IEP. Families who reported their child as having a special health care need and/or a diagnosed disability but did not report the child receiving services through early intervention or an IEP, were also removed from this analysis. Descriptive statistics, including frequencies, means, and standard deviations, were used to analyze the data from this survey. Qualitative responses from the open-ended item were thematically coded and reported in the results as quantitative data.

Results

Information Sources about COVID-19

The most frequently reported sources of information about COVID-19 were news media (82%), which included television and newspapers, followed by social media (47%), such as Facebook, Twitter, and Instagram. The least frequently reported sources included schools (28%) and faith-based leaders (7%) (see Figure 1). The average number of sources of information used was 4.3 ($SD = 2.2$). Respondents were also asked how much they trusted their sources of information (see Figure 2). Respondents reported high levels of trust in both scientific informants and their governments, with most families trusting the Centers for Disease Control and Prevention (CDC; 77%), Dr. Anthony Fauci (74%), and their state department of public health (73%).

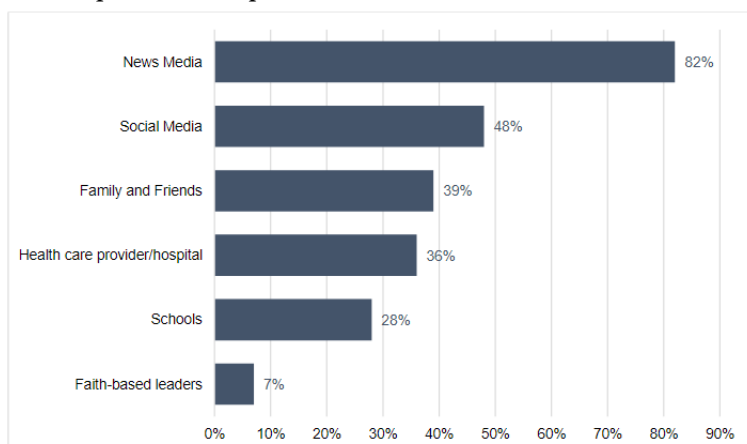


Figure 1 *Sources of Information about COVID-19*

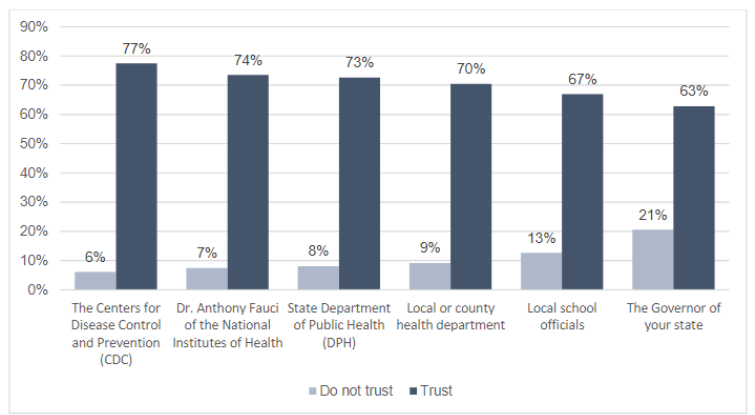


Figure 2 *Trust in Scientific Informants and Government*

Knowledge about COVID-19

Respondents were asked about their knowledge of COVID-19, including where the virus began, how the virus is transmitted, and how it could be prevented. Most of the sample answered correctly for each knowledge item (see Figure 3 for percent of respondents who said the statement was true/correct on each item). Respondents were also asked about their knowledge of COVID-19 symptoms. Most families (86%) reported that fever was one of the earliest symptoms, followed by a dry cough (80%), shortness of breath (71%), fatigue (63%), and body aches (52%).

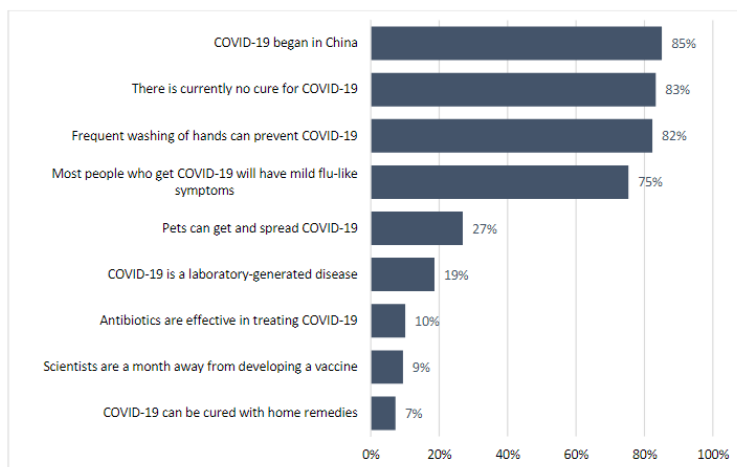


Figure 3 *Knowledge about COVID-19*

Behaviors as a Result of COVID-19

When asked to report changes made to reduce the chances that they (respondent) and their child would get COVID-19, the most frequently reported changes were: (a) stay home as much as possible (87%), (b) wash hands frequently (86%), and (c) avoid physical contact (85%). Among the least frequently reported changes were to wear a mask when going out (63%) and wear sanitary gloves when outside the home (30%) (Table 2). The average number of changes made by respondents was 10.3.

Table 2 *Changes Made by Families to Reduce the Chances of Getting COVID-19*

Changes made by families	<i>n</i>	%
Stay home as much as possible	397	86.9
Wash hands frequently	394	86.2
Avoid physical contact with people (e.g., no hugs and handshaking)	388	84.9
Avoid sick people	371	81.2
Keep physical distance between people	369	86.7
Do not gather with more than 5 people	369	80.7
Cough and sneeze into the crook of my elbow	353	77.2
Avoid public transportation	338	74.0
Clean frequently touched surfaces with products such as sanitizers that have at least 60% alcohol by volume (120 proof)	337	73.7
Avoid touching my face (eyes, nose, mouth, ears)	330	72.2
Wear a mask when going out	288	63.0
Wear sanitary gloves when out of the home	139	30.4

Respondents were also asked what they would do if they thought that they or their child had symptoms of COVID-19. Most of the sample (87%) reported that they would monitor their symptoms and seek care if necessary (e.g., call their health care provider, stay at home to rest, monitor symptoms, stay in touch with their primary care provider, and seek a COVID-19 test). Most respondents (86%) also reported that they would

engage in quarantining/social distancing measures and quarantine from other family members and visitors, minimize contact from the rest of the family, and receive no visitors. Additional measures respondents reported were cleaning or increased hygienic practices (82%), such as washing their hands frequently, cleaning all high-touch surfaces, and not sharing dishes, utensils, towels.

Access to Formal and Informal Support as a Result of COVID-19

Results indicated that most respondents (78%) received formal supports such as a service coordinator, case manager or care coordinator, health services, early intervention, or special education prior to COVID-19 pandemic. When asked if they were receiving these services after the pandemic began, almost two thirds of the sample (60%) reported they were receiving less than before the pandemic or not receiving them at all. Respondents were also asked if prior to the pandemic they used informal supports such as disability support groups, family support groups, faith-based groups, social media groups, friends, and neighbors. Most (75%) indicated accessing informal supports before the pandemic, and almost half (48%) indicated they accessed less or no informal supports after the pandemic began (Figure 4).

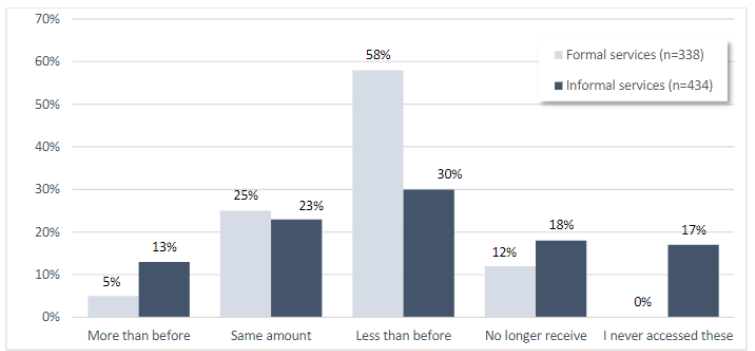


Figure 4 *Formal and Informal Supports Before and After as a Result of COVID-19*

Concerns as a Result of COVID-19

Participants were asked to respond to a list of concerns and identify which, if any, they were experiencing because of COVID-19 (see Table 3). They reported concerns about the physical health (74%), mental health (75%), well-being (80%), and safety (68%) of family members. Participants also reported concerns about their own physical health (59%), mental health (61%), well-being (63%), and safety (37%). A quarter (26%) reported concerns about the loss of a job while 39% reported concerns about the loss of income. Delays in education for their children were reported by 71% of respondents, and 77% reported concerns with changes in special education services. A quarter (23%) had concerns about meals (lack of) because of the move to online/remote learning. This move also concerned 25% of respondents because of a lack of access to technology

(i.e., devices and internet/Wi-Fi). Another 38% reported concerns about using technology for virtual meetings, school, and work. Almost half of families reported boredom (46%) and loneliness (43%). Only 5% reported issues accessing transportation (as most reported staying at home).

Table 3 *Concerns as a Result of COVID-19*

Concerns of families	<i>n</i>	%
Concern about the well-being of family members	364	79.6
Changes in education going online affecting services (special education)	352	77.0
Concern about the mental health of family members	344	75.3
Concern about the physical health of family members	338	74.0
Delays in educational services	326	71.3
Not able to visit or support older relatives and friends	325	71.1
Concern about the safety of family members	310	67.8
Concern about my own well-being	289	63.2
Concern about my own mental health	278	60.8
Concern about my own physical health	269	58.9
Concern about accessing the health care system	257	56.2
Boredom	208	45.5
Loneliness	197	43.1
No one to take care of children	184	40.3
Loss of income	180	39.4
Concern related to using technology (virtual meetings, school, work, etc.)	173	37.9
Concern about my own safety	168	36.8

Concerns of families	<i>n</i>	%
Unable to get enough food, medications, and supplies in the home	145	31.7
Loss of job	117	25.6
Concern related to accessing technology (devices, internet)	116	25.4
Changes in education going online affecting services (meals)	105	23.0
Access to transportation	24	5.3

Needs as a Result of COVID-19

Respondents were asked to report two current needs of their family. A total of 388 respondents (85%) entered needs, with 355 listing two separate needs, resulting in 743 separate needs being reported. Using thematic analysis (Gavin, 2008), needs were coded into eight main categories. The most reported needs were educational (38%), followed by family support (16%) and financial (15%) needs. Additional needs were health and safety (7%), respite (5%), stability (4%), medical (3%), and access to information and resources (2%). The other category (10%) included responses such as “N/A,” “I don’t know,” and various other responses such as sleep and patience (see Figure 5).

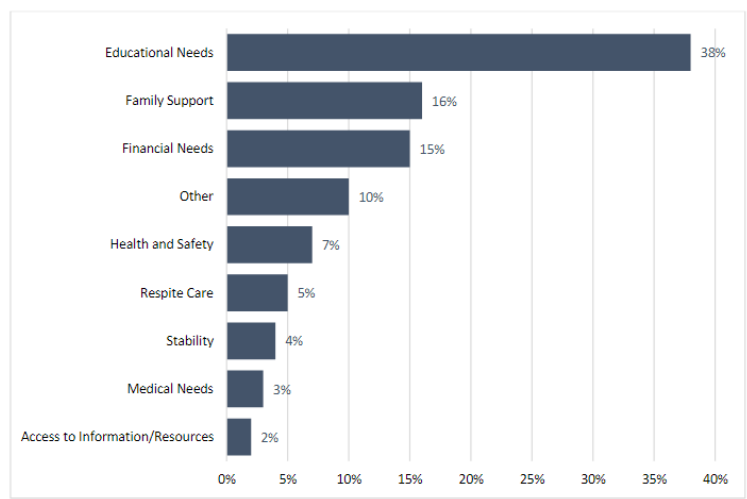


Figure 5 *Needs as a Result of COVID-19*

The category of educational need for their child included three sub themes: (1) therapeutic services and support, (2) educational services and support, and (3) special education services and support. Therapeutic services and support, which comprised 40% of this category, included needs such “mental health services;” “physical therapy, occupational therapy, and speech-language services;” and “crisis support.” Educational services and support (37% of the category) included items such as “academic assistance/support,” “access to learning tools,” “educational instruction,” “assistance with online/home schooling.” Last, 23% of respondents reported needs for special education services and supports, such as “IEP supports at home,” “developing an IFSP,” “get special education services,” “in-home support to implement special education

services through virtual resources,” and “access to special education services.”

The category of family support was comprised of four subcategories. The most reported need was social support (41%), followed by childcare (22%), general support (20%), and child activities (17%). Examples of social support needs included “social interaction opportunities,” “lunch with friends,” “getting back into the community,” and “daily social interaction with non-family members.” Examples of childcare included “childcare supervision,” “support for kids so I can work,” “daycare,” and “childcare for children with complex health needs.” Reported needs surrounding general support included “support,” “consistency in support,” and “continued support.” Last, examples of child engagement include “activities for my special needs child,” “engaging activities for child to understand the current situation,” and “ways to fight boredom.”

Beliefs about the Effects of COVID-19

Respondents were asked how serious COVID-19 was for different population groups. The majority (98%) indicated the virus was somewhat or very serious for the U.S. and for their state or territory (97%). Eighty-seven percent indicated the virus was somewhat or very serious for their family.

Respondents were also asked how long they thought the COVID-19 crisis would continue, and whether they thought

that life would go back to the way it was before COVID-19. Approximately 22% reported that they thought the crisis would last until the end of the school year, 31% reported that they thought it would continue through the beginning of the next school year (fall 2020), and 33% reported that they believed the crisis would last longer. The majority (74%) of families reported that they did not think that life would go back to the way it was before the pandemic. More specifically, when asked what they thought would change, 59% of the families reported that they expected closer connections within families, 53% reported increased community or neighborhood support, and 44% reported an increased sense of social connectedness. Regarding schools and special services, 40% of the families reported expecting permanent changes in schools for children ages 5-21, 38% reported expecting changes in special services, 23% reported expecting changes in early intervention services and preschool special education, and 36% reported expecting changes in higher education.

Anxiety as a Result of COVID-19

Respondents were asked to indicate their current anxiety level from very low to very high. Of those who responded to this question, most families (76%) reported their current anxiety as somewhat or very high, as presented in Figure 6.

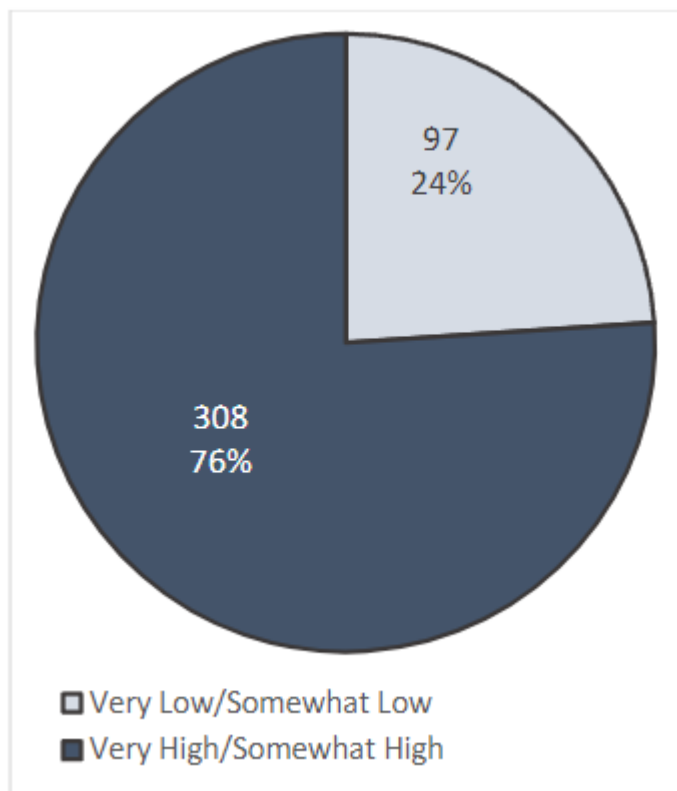


Figure 6 *Family Anxiety as a Result of COVID-19* ($n = 405$)

Discussion

The purpose of this study was to describe the knowledge, beliefs, and needs of parents of children with disabilities during the beginning months of COVID-19. The participants in the study responded to online invitations from multiple solicitations and invitations to parents of children with disabilities, thus prohibiting the calculation of a response rate.

The respondents were also skewed to those who have access to the internet and had the skills to complete the online questionnaire. As a result, the sample who completed the survey were homogeneous: highly educated, employed, the majority reported their race/ethnicity as White, their sex as female, and their role as a parent with a child with disabilities.

It is no surprise that the parent respondents to this survey reported getting their information from credible sources such as news media and having a high trust in government sources of information. Of those who reported their education level (83% of the sample), 18% reported having at least some college or a 2-year degree, 28% had a bachelor's degree, and 30% reported having graduate degrees. The parents also demonstrated correct knowledge of COVID-19 and its symptoms and were accurate in changes they should make in response to the virus. Using a mask was one of the lowest ranked behaviors at 63%, but it should be noted that this survey was conducted before the recommendations for wearing a mask was widespread. The parents also responded accurately about what they would do if they or their child contracted the virus. Last, the parents described accurate beliefs about COVID-19, as almost 100% described it as being serious for the U.S. Only 33% projected that the pandemic would last beyond September 2020, which was not accurate, but reflects the thinking at the time of the survey.

Parent respondents reported a marked decrease in the amount of formal support and informal services they were

receiving because of the pandemic. This is reflected in the many concerns they identified in the survey. Their primary concern was the well-being of their family members (80%), including their mental and physical well-being (75% and 74%, respectively). Concern for their own well-being, both physical and mental, and safety of their family followed as concerns for most parent respondents. Also of concern was education, with 77% of parents identifying it as a concern, followed by delays in education (71%).

The current needs identified by parents also followed this pattern. Over 85% of parents identified two separate current needs. Qualitative theming of all needs resulted in the most reported need of parents being educational services and supports for their children followed by family support. Educational needs included special education, therapeutic education (e.g., therapies), and general educational needs.

Children with disabilities receive education through early intervention (usually delivered in the home) or special education (usually delivered in public schools). These options changed when the U.S. shut down home visits and schools during the spring of 2020 to stop the spread of the virus. Families with children who could no longer attend school or have a home visitor were thrust into the role of special educator (Hughes & Anderson, 2020). Those who had access to technology were able to participate in some type of online/remote learning, though for fewer hours than their child had been in school. In addition to losing the individualized and

specialized supports and services provided by early intervention and special education, online/remote learning also eliminated access to peers without disabilities in an environment to learn and socialize together (Leocani et al., 2020). As a result, it has been suggested that students with disabilities have lost critical educational time (e.g., Masonbrink & Hurley, 2020; Neece et al., 2020), as documented by the Tulsa Seed Study (2020). The data collected in this study indicated that parents of children with special needs were more likely to report challenges with distance learning compared to parents of children without special needs. The findings were consistent with evidence about the impact of COVID-19 on families who have children with educational or social needs are great than the general population (Brown et al. 2020; Coyne et al., 2020, Fontanesi et al., 2020).

The educational challenges experienced under the pandemic have been exacerbated by parental concerns about managing their own daily work needs as well as their child's learning needs (e.g., Fontanesi et al., 2020; Neece et al., 2020). It comes as no surprise that the second highest need area reported by parents in this survey was family support. This area included social support, childcare, general support, and child activities. Parents reported a decrease in both formal supports as well and informal supports since the pandemic began. A conclusion being that this lack of family support contributed to the finding that over three-fourths of the parent respondents reported their current anxiety as somewhat or

very high because of the COVID-19 pandemic. This finding is consistent with Willner et al. (2020) who reported extremely high levels of unmet mental health needs among caregivers for children and adults with ID because of the pandemic.

Family support has been found to be significantly related to positive family outcomes in families with children with disabilities (Kyzar et al., 2012). These outcomes include increased family functioning, increased family quality of life, and decreased family stress (Boehm & Carter, 2019). Thus, the provision of family support has been recommended for many years as a mediator to the family burden and stress reported by families with children with disabilities, and a facilitator of positive adaptation and outcomes (Patton et al., 2018; Vanegas & Abdelrahim, 2016). The decrease in formal support services and informal support networks is of most concern as most families would be at an additional risk for an increased stress burden and decreased quality of life.

Limitations

There are several limitations to this study. The sample who completed the survey was highly educated, employed, and had access to technology. Families who live in poverty or are struggling to meet basic needs such as food, housing, and/or electricity, are not likely to be represented in our data. Nor are families of diverse backgrounds. The survey collected data in real time and only provides a brief snapshot of the knowledge,

beliefs, and needs of families during 2 months in 2020, at the beginning of the pandemic.

Conclusion

The present research contributes to a growing body of evidence of the challenges families of children with disabilities have faced during the COVID-19 pandemic. As stated by Willner et al. (2020), the

pandemic has demonstrated how families provide the safety net when the systems around them shut down, highlighting the need to ensure they are adequately informed, supported, valued, and prioritized. (p. 8)

Moving forward, families of children with disabilities must be at the center of all planning for emergencies that result in societal shutdowns and closures or changes in service systems. Inequity of resources must also be addressed to help all families adapt to short- and long-term changes in type, frequency, and location of critical services such as early intervention, special education, and therapeutic services. While this is an example of only one critical support for families and their children, the changes in practice and policy around schooling was reported to be a major concern and need of parents at the beginning of the pandemic. Other infrastructure supports, both formal and informal, were also identified as needed by families. Concerns included the well-being of their family members and

themselves, which is understandable in times of a public health crises. These findings support the continuance of formal and informal family support services and strategies during times of crisis, as a decrease or removal of them may result in increases in anxiety and decreases in quality of life. The infrastructure that families rely on to maintain equilibrium must be supported and strengthened. Their experiences during this pandemic, as reported in this survey and others, should provide ample direction on what should happen to avoid some of the stress they have endured during future emergencies. (Neece et al., 2020; Willner et al., 2020). Last, as the data reported in this study were collected at the beginning of the pandemic, it is imperative that there continues to be examination of the impact of the pandemic on family functioning and well-being over time.

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8.

PERSPECTIVES OF IMMIGRANT FAMILIES AND PERSONS WITH DISABILITIES DURING COVID-19

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[Perspectives of Immigrant Families and Persons with Disabilities During COVID-19 PDF File](#)

Plain Language Summary

COVID-19 is hard for immigrants and people with disabilities. We interviewed 12 immigrant families in

New York City who have a child with a disability. Parents were afraid they would have to leave the United States. Families needed support and technology from schools. Families also found that hospitals and medical centers did not have information in Spanish. Parents were also afraid to get money from the government.

Background

In early 2020, the coronavirus—also known as COVID-19—took the world by storm. As of November 20, 2020, a total of 57,365,029 cases were reported globally and 11,854,203 cases within the U.S. alone. The highest number of COVID-related cases and deaths have occurred in the U.S., followed by India and Brazil. Within New York City (NYC), there have been a total of 292,718 cases since the start of the pandemic, and 12,071 cases over the past 7 days (Centers for Disease Control and Prevention [CDC], 2020b; Johns Hopkins University of Medicine, 2020). With the arrival of colder weather throughout the country, the number of COVID-19 cases are expected to grow until vaccines are approved and implemented (Argulian, 2020). Aside from the devastating health effects of the virus—namely, widespread mortality, illness, and hospitalizations—the COVID-19 pandemic has also created a multitude of economic, social, political, and psychological consequences.

Adapting to the changes required by the pandemic has proven challenging to those even in the most ideal of circumstances. For persons at increased risk, including persons with disabilities, communities of color, immigrant communities, and persons with lower socioeconomic means, the negative effects of the pandemic have been even more destabilizing and consequential. Structural biases embedded in our social, political, medical, and economic systems contribute to health and other disparities experienced by disenfranchised groups. This has been particularly evident throughout the COVID-19 pandemic, as certain communities have experienced a disproportionate burden of COVID-related outcomes (NYC Department of Health and Mental Hygiene, 2020). In this study, we aim to explore the heightened challenges and compounded stressors experienced by immigrant parents who have a child with a developmental and/or intellectual disability.

COVID-19 Has Compounded Existing Health and Socioeconomic Disparities

COVID-19 has disproportionately impacted disenfranchised communities within the U.S., exposing weaknesses and vulnerabilities in our country's medical, economic, and political systems. Those hardest hit by the pandemic include Black, Hispanic/Latino, immigrant, and low-income communities, as well as persons with disabilities (Gold, 2020;

Millet et al., 2020; Price-Haywood et al., 2020). African Americans and Hispanic/Latinos remain overrepresented among both COVID-19 cases and COVID-related mortality throughout the U.S. (Bibbins-Domingo, 2020). For instance, although only 20% of U.S. counties are predominately comprised of African Americans, 52% of COVID cases and 58% of COVID-related deaths have occurred in disproportionately black counties (Millett, 2020). Cardiovascular disease, respiratory illness, diabetes, chronic kidney disease, and obesity, known risk factors for COVID-19 mortality and morbidity, tend to be more prevalent among diverse populations in the U.S. (Killerby et al., 2020; Stokes et al., 2020). This also includes immigrant groups of both African and Hispanic/Latino origin (Aguayo-Mazzucato et al., 2019; Carillo-Larco et al., 2019; Commodore-Mensah et al., 2018; Kindarara et al., 2017; Sewali et al., 2015). COVID-related hospitalizations were six times higher among persons with these aforementioned medical conditions, while death rates were 12 times higher (Killerby et al., 2020; Stokes et al., 2020).

A variety of barriers and systemic factors contribute to health and socioeconomic inequities in the U.S., particularly among racial, ethnic, and linguistic minority groups and persons with disabilities. The CDC (2020a) have identified five primary contributors to COVID-19-related health disparities. These contributors include: (1) systemic discrimination (i.e., housing, health care, education); (2)

limited healthcare access and utilization; (3) overrepresentation of racial and ethnic minorities in essential occupations such as grocery stores, healthcare facilities, factories, and public transit; (4) educational, income, and wealth gaps; (5) crowded housing conditions (i.e., multi-generational family members in one household). Social and physical determinants of health have significantly contributed to the disparities experienced by disenfranchised communities both prior to and during the COVID-19 pandemic.

Social determinants of health may include access to high-quality education, resources for basic human survival (i.e., affordable grocery stores and housing), medical services, opportunity for economic growth, vocational opportunities, vocational training, community-based facilities (i.e., recreation or community centers, religious institutions), transportation options, social supports, and technologies (i.e., computers, iPads, internet, etc.). Additionally, social norms and attitudes (i.e., discrimination, racism), culture, socioeconomic conditions, public safety, and residential segregation can also influence health outcomes. Physical determinants of health can include built environment (i.e., pedestrian-friendly walkways, roads), natural environment (i.e., green space, climate), housing design, school setting, work setting, physical barriers, exposure to toxic substances and physical hazards, and aesthetics (i.e., lighting, trees; Office of Disease Prevention and Health Promotion, 2020). Both physical and social contextual

drivers have played a major role in disparities observed in COVID-related outcomes.

Immigrant groups have been particularly hard hit by the COVID-19 pandemic. A county-level analysis across the U.S. revealed that counties with more immigrant (specifically, Central American) and Black residents had higher rates of COVID cases. In the Midwestern and Northeastern regions of the U.S., counties with higher concentrations of Puerto Rican residents also had higher rates of COVID cases (Greenaway et al., 2020). Specifically, immigrant populations experience health and socioeconomic disparities at a higher rate than the general population. This is attributed to several factors including poverty, lack of resources, barriers to accessing healthcare services, healthcare treatment biases, variations in culturally specific health practices, mistrust of government and medical systems, stress from acculturation and migration experiences, discrimination, and lack of health data specific to immigrants and refugees. However, it is very important to mention that immigrant communities possess many strengths and cultural practices that promote resiliency, overall health, and wellbeing (Edberg et al., 2011).

The economic consequences of the COVID-19 pandemic have been far greater for immigrants and other racial/ethnic minorities. In fact, the economic fallout from the pandemic has been deemed the most unequal recession in U.S. history. While the 2001 and 2008-2009, economic recessions more equivocally affected the country's population, COVID-19 has

been most financially detrimental to immigrants and other minorities, mothers of school-aged children, and low-wage workers (Long et al., 2020). Immigrants and other minorities, who were already at increased socioeconomic risk prior to COVID-19, tend to be employed in industries devastated by the pandemic and pandemic-related restrictions (Bovell-Ammon, 2019). These industries include tourism and hospitality, retail, transportation, and other service sectors (Sönmez et al., 2020). Occupational settings, for certain, have been a major driver of COVID-19 disparities and have created increased risk for potential acquisition of COVID-19 (McClure et al., 2020). Immigrants are also highly represented among low-wage and essential workforce positions in the U.S. Findings from the U.S Bureau of Labor Statistics (2020) indicate that Hispanic/Latinos are overrepresented in healthcare support occupations (i.e., nursing, psychiatric, and home health aides; OT, PT, and other support positions) that require home visits and frequent travel between sites and patient homes, as well as service sector positions.

While social distancing and quarantine requirements have been mandated throughout the pandemic, many immigrants were among those serving on the front lines, risking their own health and safety. A spatial analysis of subway ridership in NYC during the peak of the COVID-19 pandemic (March-April 2020) revealed that the greatest usage occurred among lower income residents, non-White residents, Hispanic/Latino residents, healthcare workers, and essential workers.

Interestingly, when the percent of essential workers was adjusted for, these associations were no longer present. This suggests that greater subway ridership in communities of color and lower income communities is likely driven by essential work. Additionally, this study revealed that essential workers in NYC experienced higher rates of COVID-19 infections (Sy et al., 2020). The opportunity to socially distance has also been hindered among some immigrants because of unstable housing conditions, variability in access to COVID-19 testing, food insecurity, and lack of health insurance (Dunn et al., 2020; Rader et al., 2020; Souch & Cossman, 2020; Tsai & Wilson, 2020; Van Lancker & Parolin, 2020; Wadhera et al., 2020; Wood et al., 2020).

NYC, home to 3.1 million immigrants (approximately 23% of the city's population), is still recovering from the economic blow of the COVID-19 pandemic (Migration Policy Institute, 2020). Even after the passing of the first COVID-19 wave, the city's unemployment rate remains about 7% higher than the rest of the nation. This is attributed to two primary factors. First, because of the high morbidity and mortality rates in NYC when COVID-19 first hit, city and state officials have been hesitant to fully reopen the economy. Second, NYC residents are overrepresented among the industries hardest hit by the pandemic—namely, retail, transportation, hotel and food services, and arts and entertainment (David, 2020). Between March and June of 2020, over 1.5 million New Yorkers filed for unemployment (Lew, 2020; New York

Department of Labor, 2020). Financial insecurity, layoffs, unemployment, food insecurity, and inability to pay rent have been higher among immigrant New Yorkers and New Yorkers of color (Lew, 2020; Parrott, 2020). Findings from the U.S. Census Household Pulse Survey revealed that between July and September 2020, approximately 16.1% of households in the New York metropolitan area reported either sometimes or often not having enough to eat within the past week, while 23.5% of renters have reported they have not yet caught up on last month's rent. Additionally, households receiving unemployment insurance and Supplemental Nutrition Assistance Program (SNAP) benefits are still experiencing housing and food insecurity, suggesting that current state benefits are inadequate in providing economic stability (Parrott, 2020).

Challenges for Persons with Disabilities During COVID-19

Persons with intellectual and developmental disabilities (IDD) have also faced heightened health risks and stressors throughout the COVID-19 pandemic. Children and adults with IDD generally have overall higher rates of co-occurring or underlying physical health conditions than the general population (Glover et al., 2017; Perera et al., 2020; Special Olympics, 2020). Adults with IDD are three times more likely to have heart disease, diabetes, stroke, and cancer—known risk

factors for COVID-related mortality. Additionally, adults with genetic developmental disabilities are more likely to have compromised immunity and health function, placing them at higher risk if infected with COVID-19 (Constantino, 2020). Certain medical conditions that tend to be more prevalent among children and adults with IDD (i.e., respiratory disease, obesity) also create increased risk for COVID-19 infection and poorer COVID-related health outcomes (Biswas et al., 2010; Perera et al., 2020).

Research from the past several decades has consistently demonstrated that persons with IDD experience shorter life expectancies and premature death at a higher rate than those without disabilities (Forsgren et al., 1996; Forssman & Ekesson, 2008; Glover et al., 2017; Heslop et al., 2014; Hollins et al., 1998). This increased mortality risk is because of several factors, including limited screenings for preventable physical health conditions (i.e., from a primary care physician) and challenges with nutrition and exercise (Perera et al., 2020). In their systematic review, O’Leary et al. (2018) found that persons with intellectual disabilities experienced death approximately 20 years earlier than average. Premature mortality was highest among women, those with more severe disabilities, and those with co-occurring medical conditions (mainly respiratory and circulatory conditions). Limited access and other barriers to receiving medical care is also believed to contribute to premature death and other health disparities experienced by the IDD community (Williamson et al., 2017).

Additionally, many persons with IDD do not have access to high-quality medical care and many physicians (approximately 80%) have not been trained to treat persons with IDD (Special Olympics, 2020). This has created exacerbated health risk during the COVID-19 pandemic. Further compounding disparities experienced by persons with IDD, Black and Hispanic/Latino individuals with IDD have been found to experience even greater health disparities than their White counterparts (Magaña et al., 2016).

In addition to the increased health risks that persons with IDD already face, additional unanticipated barriers and risks have also emerged during the COVID-19 pandemic. Persons living in group homes, supportive living environments, inpatient facilities, and other congregated settings are at greater risk of COVID-19 acquisition and do not possess the same opportunity to socially distance from other individuals (Perera & Courtenay, 2018). Prior to the COVID-19 pandemic, shifts from institutionalized living to community-based living was a celebratory success for the IDD community. However, with the emergence of COVID-19, persons living in the community or with family members have faced new, unanticipated challenges. A study from Navas et al. (2020) found that families are struggling with changes in routine. Health safety measures have taken priority over leisure and other activities. In a separate qualitative study of 77 ethnically, linguistically, and demographically diverse families of children with IDD, Neece et al. (2020) found that parents' greatest

challenge was caring for their children at home while losing many essential services. Additionally, parents expressed concerns about how loss of quality services, socialization opportunities, and remote schooling may impact their child's development.

Interruption to in-person medical care, socialization opportunities, job training, and schooling has been a devastating consequence of the COVID-19 pandemic. The majority of individuals with IDD require critical therapies and in-person care (Constantino et al., 2020). Changes in routine care and access to regular clinical and educational services can escalate stress and problematic behaviors. Additionally, social isolation and loss of community supports increases risk of abuse and exploitation (Courtenay & Perera, 2020). The cancellation of summer programs such as Extended School Year (ESY) and other social and educational programs has been a huge loss for both persons with IDD and their families (Constantino et al., 2020; Embregts et al., 2020; Navas et al., 2020). Telehealth services and remote learning thought advantageous in many regards, also present major limitations. For families with limited financial resources, or those without access to internet and technological devices, remote learning and telehealth may not be a feasible option. Some clinical services (i.e., physical examination, medication management) are best conducted in person (Constantino et al., 2020; Galea et al., 2020). Additionally, because of technological (i.e., digital divide) and communication barriers, some persons with IDD

have experienced barriers in receiving pertinent COVID-related health information from local, state, and federal health agencies (Courtenay & Perera, 2020; Embregts et al., 2020).

Children and adults with IDD also face increased risk for mental health stressors. Co-occurring psychiatric conditions and symptoms are typically more prevalent among persons with IDD. However, existing research suggests there is some variability in the prevalence and magnitude of mental health co-morbidities experienced by persons with IDD. This can depend on both the type of disability and the measures and definitions used to operationalize psychiatric symptoms and conditions (Buckles et al., 2013; Cooper et al., 2007; Einfeld et al., 2011; Hughes-McCormack et al., 2017). For example, in their systematic review of epidemiological dual-diagnosis studies on adults with intellectual disability, Cooper and Van der Speck (2009) found that persons with intellectual impairment were more likely to experience mental health problems than the general population. However, persons with Down syndrome were less likely to have mental health concerns when compared to the general population. Nevertheless, mental health comorbidities and inequities among persons with IDD are of concern and should remain a top priority for clinicians and researchers (Krahn & Havercamp, 2019).

Although research on the psychological impact of large-scale disease outbreaks (i.e., influenza pandemics, Zika virus, SARS, Ebola) is sparse, the impact of previous national and

global disasters on mental health has been well studied. After disasters such as Hurricane Katrina and the September 11th attacks, sociodemographic factors, vulnerabilities prior to the event, loss of personal items or family members, exposure to multiple stressors, and financial loss were all associated with negative mental health outcomes such as post-traumatic stress disorder (PTSD) and depression (Galea et al., 2020; Neria et al., 2008; Tracy et al., 2011; Vlahov et al., 2004; World Health Organization, 2020). Similar mental health concerns, including PTSD and depression, have been on the rise throughout the COVID-19 pandemic. In their systematic review of 24 studies on COVID-19 related mental health outcomes, Brooks et al. (2020) found that prolonged quarantine has been associated with depression, post-traumatic stress, anger, and confusion. The severity and magnitude of these mental health symptoms are influenced by quarantine duration, financial loss, stigma, boredom, frustration, lack of necessary supplies or information, and fear of infection. Taking these factors into consideration, we hope to better understand the mental health and other stressors that immigrant families and persons with disabilities may be dealing with during this unprecedented time. In this paper, we hope to create a platform for immigrant families who have a child with a disability to voice their concerns and struggles.

Research Question and Study Aim

Because of the complex and compounded stressors that both immigrants and persons with disabilities are facing during the COVID-19 pandemic, we hope to gain a more nuanced understanding of the experiences and perspectives of these families. More specifically, we aim to address the following research question: *What are the experiences and stressors of immigrant families of children with disabilities during the COVID-19 pandemic?*

Methodology

Setting

This study was conducted at the Rose F. Kennedy Children's Evaluation and Rehabilitation Center (RFK CERC) at Albert Einstein College of Medicine, the University Hospital for Montefiore Medical System, in the Bronx, New York. RFK CERC is an interdisciplinary, tertiary care center that provides diagnostic and clinical services to both children and adults with developmental and intellectual disabilities. Services include, but are not limited to, speech and language therapy, occupational therapy, physical therapy, developmental behavioral pediatric care, primary care, case management, psychoeducation, ophthalmological evaluations, mental

health services, health education, nutritional counseling, dental care, and audiology.

Bronx County, New York, is a racially, ethnically, and demographically diverse county. Fifty-six percent of its residents identify as Hispanic or Latino (vs. 19% in NY state and 18% nationally) and 29% identify as African American (vs. 14% in NY and 12% nationally). The Bronx is also one of the poorest counties in the U.S., with 29% of its residents living below the federal poverty line (vs. 15% in NY and 14% nationally; Emory University, 2020). Out of all New York counties, New York ranks 62/62 for overall health outcomes, quality of life, poor physical health days, and poor mental health days. In addition, Bronx residents have higher rates of diabetes and asthma than the national and state averages. These physical and mental health vulnerabilities are likely due to the high level of poverty most residents experience. Approximately 38% of children from the Bronx live in poverty, 39% of residents experience severe housing problems, and 32% experience severe housing cost burden (University of Wisconsin Population Health Institute, 2020). As of November 30, 2020, Bronx County has the 5th highest COVID-related death count in the nation, with a cumulative total of 5,026 deaths (Johns Hopkins University, 2020). NYC was hardest hit during March and April of 2020. During this time, RFK CERC patients who had either contracted COVID-19 or who had a family member with COVID-19 were flocking to local hospitals in large numbers.

Population

The majority of Hispanic/Latino immigrant families who receive services at RFK CERC have emigrated from Mexico, the Dominican Republic, or Ecuador and currently reside in the Bronx. Most immigrant families seen at RFK CERC are comprised of a two-parent household and are with lower socioeconomic means. The mothers often stay home to care for their children. The fathers generally work in Manhattan, usually as a cook or construction worker. Most, if not all, are undocumented and work off the books. They work long hours, 7 days a week—leaving early in the morning and not returning until 11:00pm or later. Most parents have less than a 2nd grade education and have come to the U.S. in search of a better life. While some parents are bilingual (Spanish and English speaking), most speak only Spanish. All families who receive clinical services at RFK CERC have a child with special needs. The most common conditions treated include autism spectrum disorder, intellectual disability, speech and language delays, Down syndrome, learning disability, Attention Deficit Hyperactivity Disorder (ADHD), cerebral palsy, or global developmental delay.

Recruitment

Convenience sampling was used to recruit study participants. Families who participated in this study receive treatment

services with a bilingual social worker at RFK CERC. Parents attend a weekly Spanish-speaking parent-support group and receive family psychotherapy. Their children also receive disability treatment services up to 3 times per week. Child treatment services include individual psychotherapy; weekly speech, occupational, and physical therapy; social skills training; and medical care with developmental pediatricians. Children can receive services at RFK CERC from birth through adulthood.

Data Collection and Analysis

Semistructured interviews were completed with 12 parents from Spanish-speaking countries, including Ecuador, Mexico, and the Dominican Republic. Interview questions (Table 1) were administered in Spanish by a bilingual pediatric social worker. Parent responses were transcribed and then coded. Using a conventional thematic analysis approach and inductive inquiry, codes were then grouped into four primary themes. These main themes are discussed further in the results section.

Table 1
Semistructured Parent Interview Questions

Spanish	English
Como estas?	How are you?
Tienen comida?	Do you have food?
Tienen dinero para pagar la renta?	Do you have money to pay the rent?
Como estas emocionalmente?	How are you emotionally?
Como estan con las clases en remote para usted y sus hijos?	How is remote learning coming along for you and your child?
¿Las escuelas han traducido información sobre aprendizaje remoto?	Have the schools translated information about remote learning?
Porque no quieres ir al hospital?	Why don't you want to go to the hospital?

Results

The 12 parents interviewed in this study are first-generation Mexican immigrants and currently reside in the Bronx, New York. Their children receive clinical care at RFK CERC, primarily for global developmental delay, autism, ADHD, learning disability, and mental health diagnoses. As evidenced via parent interviews, these families have experienced an extraordinary amount of stress, both prior to and during the pandemic. All families who participated in this study live

either in a one- or two-bedroom apartment, with typically 5-10 people in a household (sometimes more, including extended family members). Those families living in a two-bedroom apartment typically rent out their second room as an additional source of income. The majority of families interviewed are undocumented, uninsured, and work very long hours, trying to survive on a minimum-wage income. Overall, most of the concerns that parents expressed centered on surviving the COVID-19 pandemic, barriers to accessing essential services, and fear of deportation. We have further classified findings from parent interviews into four themes: (1) fear of deportation, (2) fear of accessing services, financial and economic concerns and (4) disability-related and schooling challenges.

Fear of Deportation

Because of their immigration status, fear of deportation was the greatest concern that parents voiced and seemed to be an underlying theme in all parent interviews. All families reported that they migrated to the U.S. in hope of providing better opportunities for their children. Because these parents have a child with special needs, these opportunities are even more critical. Returning to their home country would result in loss of educational opportunities and loss of clinical services for their children. For this reason, parents' civil rights are often

restricted, and their voices are silenced due to fear of deportation. One parent stated,

“I cannot go back home because there are no resources for my disabled child. Plus, I would definitely be arrested for entering the USA illegally.”

Another parent reported that he tolerates maltreatment at work because of the risk of potential repercussions, including job loss. Several parents even acquired COVID-19 on the job, while others were required to attend work knowing that others were infected with the virus. Several parents who acquired COVID-19 on the job in such circumstances were later hospitalized and ended up in the Intensive Care Unit. In one such case, the father’s employer, fearing a lawsuit, contacted his employee’s wife, offering to pay their rent, food, and utilities until her husband was discharged from the hospital. The family was unable to press charges because of immigration status and lack of financial resources.

Fear of Accessing Services

Parents and other family members who contracted COVID-19 reported that they experienced discrimination when seeking medical care. Translation services were not offered at the hospital and families were not informed of their loved one’s prognosis. Some families were denied services altogether. Others were afraid to seek medical care at all for fear that they

may be deported. Overall, families expressed that they felt marginalized and ignored during their interactions with the healthcare system. Additionally, because of language barriers, parents did not receive adequate information on COVID-19 and their family members' health status. Parents reported that often information was not available in their native language. In addition to challenges experienced within the medical system, parents also expressed fear of accessing unemployment or welfare benefits, such as Supplemental Nutrition Assistance Program (SNAP) benefits.

Economic Fallout and Financial Problems

Unfortunately, a number of parents and family members have lost their jobs because of the COVID-19 pandemic. These families primarily depend on food pantries for nourishment. These food pantries have long lines and quickly run empty. Immigrant families have struggled, and continue to struggle, during the pandemic because of the lack of resources. One parent reported,

“This pandemic is taking a huge emotional toll on our family. I cannot afford to get sick. We do not have the resources or the finances [to not work].”

In addition to the economic consequences experienced from job loss, parents were either ineligible or afraid to apply for

stimulus checks, unemployment insurance, SNAP, and emergency rent assistance. This has required families to rely solely on charitable donations, which, aside from food pantries, have been sparse.

Disability- and School-Related Challenges

Both parents and children have been required to adapt to an entirely new way of living while losing many of their previous support systems. Remote learning has proven extremely challenging among families interviewed in this study. Most children do not have access to a working computer or internet. While some children received tablets from the Department of Education (DOE), most of these devices do not work. However, many parents fear that, although their child is a U.S. citizen, contacting the DOE to advocate for services and technologies would put their family at risk. These families expressed worry that if they complained to the DOE, they could possibly be detained by U.S. Immigration and Customs Enforcement. As an alternative, parents have been in search of computer and tablet donations for their child's education. One family who has a child with a more severe learning disability has not yet been able to find a school for their child. Because this child has been home since September, the family has needed legal intervention to advocate for their daughter. Overall, parents expressed that home schooling and remote

learning has been “a nightmare.” Distractibility, particularly among children with autism, learning disability, and ADHD, has been a significant barrier to at-home learning. Additionally, most educational information has been provided to parents in English, without Spanish translation. Parents also reported challenges in getting their child to wear a mask when outside of the home.

Discussion

Consistent with findings from recent COVID-related literature, the families who participated in this study expressed many of the same concerns and challenges that other immigrants and persons with disabilities are currently experiencing in the U.S. during the COVID-19 pandemic. As evidenced through parent interviews, COVID-19 has most certainly exacerbated the weaknesses of the U.S. political, socioeconomic, and medical systems. For Hispanic/Latino immigrant families who have a child with a disability, these systemic barriers have been catastrophic. The financial and socioeconomic consequences of the pandemic, in conjunction with the challenges of simultaneously trying to manage their child’s schooling without necessary resources and support, has placed an extraordinary burden on immigrant families. Continuous fear of deportation (either for themselves or a family member) and fear of interaction with healthcare and social service agencies govern many of the decisions that

immigrant families make. Discrimination against Mexican and other Hispanic/Latino immigrants, particularly those who are undocumented, is still very rampant in the U.S. Immigration enforcement, anti-immigrant policies, forced acculturation, and discrimination take a heavy toll on the health and well-being of immigrant families (Almeida et al., 2016; Mann-Jackson, 2018; Molina et al., 2016). Children are also very vulnerable to anti-Hispanic/Latino immigrant discrimination and rhetoric, which has increased since the 2016 election (Callaghan et al., 2019).

Discriminatory policies and practices, particularly during times of crisis, create a culture of fear and animosity toward those deemed as “other.” The families interviewed in this study described many instances of explicit discrimination because of immigration status, health insurance status, and language status. Furthermore, some families were denied medical care altogether. Others were forced to tolerate discriminatory and potentially unlawful circumstances in the workplace. Unfortunately, healthcare access and quality for immigrants (particularly those who are non-White or from non-English speaking countries) has declined over the past several decades. Limited access to affordable public health insurance programs, decreased protections against deportation, caps on the number of refugees allowed in the country, intimidation in healthcare settings, and discriminatory narratives that discourage use of social services, all contribute to health disparities experienced by Hispanic/Latino immigrants (Khullar & Chokshi, 2019).

Immigrant families are at higher risk of food insecurity and financial insecurity. However, immigrants often avoid using any type of public assistance—including SNAP and public health insurance—even when eligible, because of the fear of risking future citizenship (i.e., green card) status (Bernstein et al., 2019; Bovell-Ammon, 2019; Callaghan et al., 2019; Singer et al., 2018).

Immigrant families, including those who have a child with special needs, are experiencing firsthand COVID-related health disparities and have been among the hardest hit by COVID cases, complications, and mortality. Prior to the pandemic, these families already had many cards stacked against them—no health insurance, immigration status, limited financial resources, language barriers, and crowded living conditions. Despite the complex and compounded stressors they face, these families have persevered through life’s challenges and worked tirelessly to create a better life for their children. Toxic rhetoric around immigration, in conjunction with discriminatory government policies, should be challenged. Immigrants, both documented and undocumented, and persons of color have been among those serving on the front lines in public service capacities throughout the COVID pandemic. Immigrant workers also play a vital role in sustaining the economy of NYC and the U.S. Most importantly, immigrants enrich and sustain the diverse fiber of our nation and should be celebrated, rather than feared or hated. Similarly, children and adults with IDD

also bring richness and diversity of experience and perspective. Changing our narrative on immigration and disability, in conjunction with challenging our own implicit and explicit biases, can help to strengthen our nation, rather than jeopardize it. In addition, because immigration is such a politically charged topic, securing benefits and other pro-immigration policy changes may best be approached at the state or local, rather than federal, level (Khullar & Chokshi, 2019).

The COVID-19 pandemic has also both created and exacerbated service gaps for immigrant families and persons with disabilities. In addition to healthcare barriers, parents are also struggling to obtain proper educational services and technologies for their children. Because of their immigration status, the families interviewed in this study expressed repeated concern over accessing available emergency government services. Additionally, educational barriers (i.e., lack of internet or working devices) and clinical service gaps (i.e., disruption of care) for persons with disabilities has also been a significant problem that has emerged during COVID-19. Regardless of a parent's immigration status, all children born in the U.S. are legally entitled to a free, public school education. Additional protections are in place for children with special needs. On September 28, 2020, the Office of Special Education Programs (OSEP), a subdivision of the U.S. Department of Special Education and Rehabilitative Services, released a document outlining parents' rights under the Individuals with

Disabilities Education Act (IDEA) Part B provision. This document highlights legal provisions indicating that all children with disabilities are entitled to a free, appropriate public education, regardless of type of instructional delivery type. Additionally, school districts are still required to conduct all special education evaluations and team meetings (i.e., Individualized Education Program [IEP]) in a timely manner. Should issues arise, special education legal advocates from the American Bar Association suggest the following: (1) contact the school districts' legal counsel or director of special education; (2) assist families in documenting a student's regressions and setbacks (i.e., maintaining a log); (3) seek support from community-based providers; (4) prepare for potential gaps in treatment; (5) advocate for students to receive schooling in person; (6) if ESY services were missed over the summer, advocate for their continuation during the normal school year (Garcia & Morrow, 2020).

Last, the COVID-19 pandemic has also revealed certain medical and social needs of the IDD community that can create increased risk. Disruption to critical services (i.e., physical therapy, speech-language therapy, etc.), schooling, vocational training, and other programming, as well as increased risk for physical and mental health concerns, has created numerous challenges for individuals with IDD. To reduce the negative impact of these COVID-related challenges, further steps should be taken to protect the IDD community. To address heightened physiological risk, particularly for

persons living in group homes, Grier et al. (2020) suggest that families and caregivers create an emergency plan in case COVID-19 is contracted. This includes preparing for a hospital visit and making sure an advocate is present (if necessary) for shared medical decision making. Additionally, if any language barriers are present, families and caregivers should work to develop clear communication pathways so that symptoms can be monitored and treated. Frequent health checks are also advised (Perera et al., 2020). Measures should also be taken to ensure that persons with IDD have access to the proper technologies (i.e., tablets) to continue their treatments and other programs, which can help mitigate some social stressors. Enhancing online support systems has also proven beneficial to persons with IDD (Zaagsma et al., 2020). On a broader scale, ensuring health coverage and accessibility, training healthcare professionals to provide IDD-inclusive care, prohibiting discriminatory practices, reducing physical barriers to care (i.e., providing ramps), and empowering persons with IDD to make health-related decisions can help to reduce COVID-related disparities and outcomes (United Nations, 2020).

Conclusion

As evidenced in both our study findings and other recent research studies, COVID-19 has created a new set of unanticipated challenges and health risks for both immigrants

and persons with IDD. The families interviewed in this study have, unfortunately, experienced extreme stress and discrimination throughout the COVID-19 pandemic. Parents voiced multiple concerns that generally centered on fear of deportation, fear of accessing services, financial and economic stress, and challenges specific to managing their child's disability and education with little to no support. Additional research should be conducted to further explore the unique needs that immigrant families and persons with disabilities encounter during this time of global crisis. Qualitative research can be used to identify general themes and specific needs, while quantitative data collection can help provide a bird's eye perspective on health outcomes and health monitoring. Reducing COVID-19 disparities is absolutely possible but requires collective commitment and flexibility.

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9.

FAMILY CAREGIVING DURING THE COVID-19 PANDEMIC

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Milberger, S., Marsack-Topelewski, C., Janks, E., & Samuel, P. S. (2020). Family Caregiving During the COVID-19 Pandemic. *Developmental Disabilities Network Journal*, 1(2), 91–101. https://digitalcommons.usu.edu/ddnj/vol1/iss2/10/Family_Caregiving_During_the_COVID-19_Pandemic_PDF_File

Plain Language Summary

The COVID-19 pandemic made life difficult for families of adults with disabilities. We had a group discussion of 30 family members on the pros and cons of staying at home. Family members said that

it was hard to get medicine and see their doctor. Many struggled to use the internet to talk to people. They did not like to stay home all the time. They felt alone because they could not see their family and friends. There were also some good changes. They liked staying connected with family and friends online. They also liked that the slow pace of life was more relaxed. Many of these problems are not new but have gotten worse because of the pandemic. Understanding the pros and cons of staying at home can help us decrease the burden on families.

Background

The Coronavirus Disease-2019 (COVID-19) pandemic has taken a disproportionate toll on people with intellectual and developmental disabilities (I/DD) as well as their family caregivers. In the United States, approximately 5.1 million children and 2.1 million adults are living with I/DD (Braddock et al., 2015). The majority (72%) of individuals with I/DD live with their family, with 24% of these individuals living with family caregivers above the age of 60 (Tanis et al., 2021). Similarly, in Michigan, 66% of the 225,925 adults with I/DD live with their families (Tanis et al., 2021).

Family caregivers may experience emotional and physical burdens that can lead to negative health consequences, such as increased depression, anxiety, and lower quality of life (Javalkar

et al., 2017). These consequences are especially true for older family caregivers, many of whom assume dual or compound caregiving roles, while they face their own age-related challenges (Marsack-Topolewski, 2020; Perkins, 2010).

In the wake of the COVID-19 pandemic, caregivers are now supporting their family member(s) with I/DD around the clock because of school closures and diminished in-person support opportunities (Manning et al., 2020). Many families require in-person care or therapeutic support within their homes and are likely to face challenges in hiring staff to provide in-home support because of fears of contracting the virus. Caregiver stress is likely to increase with little backup or systemic coverage for prolonged interruption of services.

While millions of people are using screen-based technologies to mediate personal connection, this technology can be challenging for many people with I/DD. Virtual interaction can be an inadequate substitute for human connection (Annaswamy et al., 2020). Limited access to trained caregivers and community service providers, who can assist people with I/DD to use web-based technology adds to the underutilization of web-based services (Constantino et al., 2020).

The Centers for Disease Control and Prevention (CDC, 2021) have indicated that people with I/DD are at increased risk of infection and complications from COVID-19. Adults with disabilities are three times more likely to have heart disease, stroke, diabetes, or cancer than their peers without

disabilities (Constantino et al., 2020; Friedman & Spassiani, 2018). Additionally, a number of genetically based developmental disabilities are associated with health liabilities that may adversely affect individuals with I/DD who contract the virus. This disproportionate impact must be offset by clarifying the extent to which pre-existing health conditions are exacerbated by COVID-19. Limited in-person medical appointments and/or rationing of care may negatively impact individuals with I/DD who have pre-existing conditions (Constantino et al., 2020).

The World Health Organization (WHO, 2020) reported that people with disabilities may also be at greater risk of contracting COVID-19 because of their inability to participate in basic hygiene measures. Poor hygiene can be attributed to physical limitations (i.e., not being able to rub hands together when washing) and cognitive/behavioral challenges (e.g., inability to comprehend the need for effective handwashing routines). Some people with I/DD may not be able to tolerate masks because of underlying sensory processing challenges resulting from atypical neurological systems (Dorfman & Raz, 2020). Social distancing may be difficult for them because of their need for one-on-one support and their inability to understand social distancing requirements (WHO, 2020). These health conditions may be linked to an increased risk of more serious health outcomes if people with I/DD contract the virus.

Understandably, many family caregivers are concerned

about increased health risks when a loved one is exposed to COVID-19, especially for their family members with disabilities. These concerns and fears place an added layer of stress in their lives as they navigate a new world, where previously safe and enjoyable activities are now possible health risks for their family member with a disability and others in the family. This research brief presents findings from a virtual discussion group with family caregivers of adults with I/DD to understand how the COVID-19 pandemic has affected their lives. The following research questions were addressed.

1. What challenges are family caregivers of adults with I/DD facing because of COVID-19?
2. What is working well for them (i.e., “silver linings”)?

Method

This study is a subset of a larger project using participants from the Michigan Older Caregivers of Emerging Adults with Autism and Neurodevelopmental Disabilities (MI-OCEAN) program, a statewide service navigation program for aging caregivers of adults with I/DD. The project is grounded in a family quality of life framework and uses a peer-support model of support to identify and address various issues that may negatively impact caregivers’ health and well-being. Family Support Navigators (FSNs) reported that they were hearing from the caregivers they were serving about challenges

they were experiencing because of COVID-19. Prior to holding the meeting, Wayne State University's Institutional Partial Review Board determined that this study conformed to recognized human subjects research standards.

Recruitment

Family caregivers who were providing care for their adult family members with I/DD were recruited through the aging caregiving project email listserv and the University Center for Excellence in Developmental Disabilities (UCEDD) Education, Research, and Service's social media platforms, such as Twitter, Instagram, and Facebook.

Participants

The inclusion criteria for participation in the support group meeting included being a family caregiver supporting an adult (at least 18 years old) with I/DD. Participants had the option to remain anonymous and did not have to register for the Zoom discussion group. As expected, since the impetus for having the discussion group came through our project on aging caregivers, the majority (56.7%) of family caregivers in this study were 50 years of age or older. Most were parents (53.3%) while others were siblings or other family members. All participants were supporting family members with I/DD

ranging in age from 20 to 57 years old. Participants came from 10 counties across Michigan (see Table 1).

Table 1
Participant Demographics (*N* = 30)

Characteristics	n	%
Age of participant		
Under 50	7	23.3
50 and over	17	56.7
Missing	6	20.0
Gender of participant		
Male	3	10.0
Female	25	83.3
Missing	2	6.7
Race of participant		
African American/Black	2	6.7
Caucasian/White	20	66.7
Hispanic	1	3.3
Arab American	1	3.3
Missing	6	20.0
Relationship to care-recipient		
Parent	16	53.3
Sibling	4	13.3
Spouse	1	3.3
Other Relative (aunt, cousin)	4	13.3

Missing	5	16.7
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Procedures

A 1-hour caregiver discussion group meeting was held in April 2020. The session used Zoom as a meeting platform. The meeting was recorded and then transcribed by a research assistant. All participant identifiers were redacted from the transcript, which was analyzed by two independent researchers to identify common themes using content analysis. A qualitative phenomenological research methodology was used to examine challenges and “silver linings” faced by family caregivers of adults with I/DD during COVID-19. Phenomenology is an approach to qualitative research that focuses on the commonality of a lived experience within a particular group. The fundamental goal of the approach is to arrive at a description of the nature of the phenomenon (Creswell, 2013). Typically, an interview is conducted with a group of individuals who have first-hand knowledge of an event, situation, or experience. The data are then read and reread and culled for like phrases and themes that are then grouped to form clusters of meaning (Creswell, 2013). Through this process, the researcher may construct the universal meaning of the event, situation, or experience and arrive at a more profound understanding of the phenomenon.

Results

Two overarching themes (challenges and silver linings) were illustrated by caregivers of individuals with I/DD. A summary of themes with corresponding subthemes is presented in Table 2.

Table 2
Themes and Subthemes from Discussion Group

Themes/ subthemes	Examples
Challenges	
Obtaining medical services	
Transitioning to technology	Use of telehealth without appropriate training for users/clinicians
Covid-19 Prevention Efforts	Difficulties with wearing masks and social distancing
Social Isolation	Lack of socialization with family and friends
Silver linings	
Social Connectedness	More time with immediate family
Coping strategies	Use of creative physical and social activities to break isolation routines during the pandemic

Challenges

Described below are some of the challenges that were faced by caregivers of individuals with I/DD.

Obtaining Medical Services

The most common challenge identified by participants was difficulties associated with obtaining medical services, such as cancellation of appointments and getting medications. One caregiver stated,

Medical treatment is huge for my sister, she had breast cancer and is now having some issues that make us suspect recurrence, but we can't see the doctor.

Evidence of anticipatory anxiety was present because of rumors regarding possible medication shortages, as illustrated in the following comment.

I've heard a lot of horror stories about medication that people got very quickly before and now they can't get them.

Transition to Technology

The quick transition to telehealth without adequate training for users or clinicians was also seen as a challenge. Practitioners had to rely on information that was being reported in lieu of

actually observing the person. The difficulty of the shift to telehealth is best reflected by this participant comment.

His telemedicine appointments have been difficult because we really don't have some of the technology that's required for him right now and his iPad is not working so, you know, you go through all of these challenges.

Telehealth was especially challenging for non-English speakers who found it difficult to communicate with their doctors, therapists, and pharmacists in this manner. The increased use of technology also presented difficulties in other areas of life, such as education and employment. These difficulties were related to inadequate equipment, internet service, having to share the limited equipment, insufficient experience using technology, and taking more time to support the technology user. One participant stated,

Working from home is creating challenges since it's our whole family and it is hard carving out office space and having boundaries in our house.

COVID-19 Prevention Efforts

Efforts to prevent infection from COVID-19 were an area of concern for caregivers. They worried about their family member's ability to communicate symptoms, should they arise. For example, one participant shared,

My brother is the kind of person that unless you physically

saw him sick, he wouldn't say anything. He wouldn't say I have a headache, or I have a stomachache. You would have to see him not getting up or some of those things.

Caregivers expressed frustration in training their care-recipients to use masks properly. Proper and regular use of the mask was also raised, and they found it difficult to enforce social distancing because of the nature of their family member's support needs, such as the need to provide physical cueing to complete activities of daily living.

Social Isolation

Caregivers reported feeling isolated because they could not leave their homes and were not able to see family or friends. This social isolation was reflected in caregiver comments. One caregiver stated,

Everything's changed, like literally, everything, we've now been isolated for two months and my husband's a first responder so he has to be isolated in a different part of the house.

While another caregiver shared, "Not being able to kiss your loved ones has been really hard."

While caregivers discussed social isolation, they also described frustration of being together all the time and not being able to get out, especially in inclement weather. One caregiver shared,

It feels very restricted, my son has decided to move his life onto the couch rather than in his room, which is frustrating as a parent and he's okay until evening when he starts to get a little cranky.

Caregivers also described the negative impact the pandemic is having on their family member (e.g., lack of routine, not able to meet with people, loss of skills, increased anxiety, hard to fill the day with activities, bored). One parent expressed,

Our son thrives on routine because he has autism so one of the things that has been challenging is everything has changed, like literally everything...so he is losing a lot of the skills that he's been able to acquire.

Online school was identified as a challenge, yielding frustration for both students and caregivers. Caregivers had the extra job of encouraging students to stay on task during online classes. Screen overload and inequitable school-related resources were also mentioned in the discussion.

Silver Linings

Caregivers also reported several unexpected positive consequences, referred to as “silver linings.”

Social Connectedness

A common theme was that the pandemic allowed for greater family social connectedness. Caregivers indicated that because

of the pandemic, the pace of life slowed, allowing for more flexibility and time with their families, as well as gratitude for everyday things. While technology was discussed as a challenge, it was also mentioned as a positive because it allowed for social connectedness. Several creative uses of the Zoom meeting platform to connect with family and friends were discussed, including virtual game nights, dance parties, cocktail parties, and happy hours. Some shared that their family members were able to make friends more easily online where they had difficulties doing so in person. Although too much togetherness was discussed as a challenge, it was also identified as a positive. Some participants highlighted the benefits of staying at home and being together more.

Coping Strategies

Helpful strategies to cope with the pandemic included physical activity (e.g., walking, dancing, yoga, etc.), hobbies (e.g., sidewalk chalk art, puzzles, scavenger hunts, beading, adopting a pet), and games (virtual and outdoors). One caregiver stated,

We've been having game nights—even my grandma was on the game night via Zoom. My brother really likes music, so we'll play music and dance around and he'll come and join us occasionally.

Another described,

It was my son's birthday and we usually have people over

and it's a big deal because cognitively he's still a little kid and we couldn't do that this year; however, my friend arranged for us to have his birthday outside and the police and the fire department came by and did the sirens. My son volunteers at the police department so it was pretty special for him.

Discussion

The purpose of this study was to better understand how the COVID-19 pandemic has affected the lives of family caregivers of adults with I/DD. The impact of COVID-19 has placed considerable challenges on society as a whole. However, family caregivers of adults with I/DD face considerable challenges as they navigate the many responsibilities to balance the demands of caregiving and daily life. Simple things like wearing a mask and maintaining social distance can be exceptionally difficult for individuals with I/DD. Caregivers often prefer social isolation with their care recipients than trying to make their loved ones wear masks and enforce social distancing.

The duration of COVID-19 and its ramifications are unknown. Many challenges experienced by family caregivers are not new, rather they are intensified because of the pandemic (Constantino et al., 2020). Family caregivers indicated challenges and needs related to accessing medical services and use of telehealth. Evidence is available that supports the many challenges that family caregivers of adults with I/DD experience with regard to accessing appropriate

services in normal times (Marsack-Topolewski & Weisz, 2020). Consistent with past research, accessing medical services using telehealth has been a challenge for family caregivers of individuals with I/DD (Zhou & Parmanto, 2019). This challenge is exacerbated because of the pandemic. Addressing realistic strategies to provide accessible, quality medical care using telehealth is needed. Service delivery systems should consider the needs of individuals with I/DD and their families.

Another challenge that appears to affect family caregivers of individuals with I/DD is increased use of technology. Schools are using virtual instruction, which requires students to use computer platforms such as Zoom. These programs may be unfamiliar to caregivers who have limited computer skills or experience. In addition, students with I/DD are required to sit for long periods in front of a computer screen, making it more difficult for caregivers who are responsible for helping to teach them. Working family caregivers may need extra help in supporting their family member's online experience while at the same time managing their own work schedules (Garbe et al., 2020).

Family caregivers also shared "silver linings" or unanticipated positive outcomes, such as staying connected to family and friends as well as making new friends. Although socially isolated because of the inherent challenges posed by the COVID-19 pandemic, family caregivers found innovative ways to connect with others in their social networks. The pandemic was instrumental in making life proceed at a slower

pace, lending itself to greater flexibility, and providing time for things that are most important.

Strategies that build on family caregivers' concerns and strengths are needed to offset the burden posed by COVID-19. In the present study, family caregivers recounted positives surrounding coping strategies, such as the use of physical activity. These types of diversions can involve playing games, walking, bike riding, and other outdoor activities that can help ease feelings of boredom and isolation. The pandemic also puts both individuals with I/DD and their family caregivers at risk for mental health challenges, such as loneliness, anxiety, and depression; with physical activity having the potential to serve as a powerful outlet (Ameis et al., 2020; Bazzano et al., 2015).

Study Limitations

Several limitations regarding these findings should be acknowledged. Given the sudden circumstances associated with the pandemic, this support group was convened to address an emerging need. As family caregivers volunteered to participate in the group, they may not be representative of family caregivers across the state or nation. The sample was homogeneous and consisted mainly of older Caucasian women. In addition, to have known about this support group opportunity, caregivers were likely to be more connected with community supports and agencies. Future studies should seek to recruit a more diverse group of family caregivers and extend

recruitment efforts to reach subsets of caregivers who are less connected to increase the generalizability of findings. In addition, while there were 30 caregivers in the discussion group, we are unable to quantify if involvement was equally shared across participants or whether the information shared is primarily from a few individuals. The facilitator of the discussion group was a social worker with decades of experience leading group discussions and redirecting the conversation if it was being dominated by a few individuals.

Conclusion

The pandemic has placed many challenges on society as a whole, particularly for groups such as family caregivers of individuals with I/DD. During the pandemic, family caregivers were more likely to be stressed as they navigated changes in lifestyle and to their support networks. FSNs and other supportive individuals can play integral roles in helping family caregivers during these unprecedented times. These supportive individuals need to be aware of the pre-existing challenges (e.g., the challenges prior to the COVID-19 pandemic) that family caregivers of individuals with I/DD experienced and new challenges resulting from the COVID-19 pandemic.

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10.

AUTISTIC COLLEGE STUDENTS AND COVID-19: ANXIETY, SUPPORT NEEDS AND RESPONSES BY SPECIALIZED PROGRAMS

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Plain Language Summary

Many college students with autism have had to learn online because of COVID-19. We sent a survey to autistic college students in the summer of 2020. The questions were about COVID-19 and going back to school. The students talked about getting sick with the virus or getting other people sick. They were not scared to wear masks or social distance. Students wanted help with classes and making friends. They also wanted help with mental health. We end the paper with things autism programs can do to help students.

Individuals with autism are enrolling in institutions of higher education (IHE) at increasing rates (Baio et al., 2018; McDermott & Nachman, 2020). One third of individuals with autism who do not have a co-occurring intellectual disability attend some form of postsecondary education within 8 years of exiting high school (Shattuck et al., 2012; Wei et al., 2013). Because trend lines indicate increasing enrollment

in college for this population and considering the later-in-life diagnoses and self-diagnoses (Lewis, 2017), it is believed more autistic individuals attend college than captured in recent data.

Many students with autism benefit from support beyond what is typically offered through disability support services and the Americans with Disabilities Act Amendment Act of 2008 (ADAAA, 2008). Given the increasing number of autistic students enrolling in postsecondary education, several universities have created or expanded programs supporting the unique strengths and needs of autistic college students (Cox et al., 2020). The services provided by autism support programs are far reaching and cover various components of college life. While program support differs, a recent report of 60 autism-specific programs indicates 93% of programs provide life skills support, 88% provide social skills training, and 85% offer peer mentoring (Cox et al., 2020). In addition, 48% of programs also offer tutoring and 47% offer mental health support (Cox et al., 2020). Many programs focus on working collaboratively with support staff available to all students (like tutoring and mental health services) to ensure they are accessible to autistic students instead of replicating these services within their programs.

Novel Coronavirus: COVID-19 Global Pandemic

In the spring of 2020, the novel coronavirus (COVID-19)

pandemic shut down many IHEs and forced all learning, services, and supports, including autism support services, to transition into an online environment. Both professionals and students, not only in this field, but across all IHEs, needed to adjust to a new way of providing and receiving support and instruction with little to no notice or preparation. The pandemic increased feelings of anxiety and decreased psychological well-being among the general population (Vindegard & Benros, 2020) and was especially difficult for autistic individuals (Ameis et al., 2020). Chronic uncertainty, along with disruptions to routine and loss of structure, heavily impacts those with autism who often depend on consistent, reliable schedules and predictable environments (Colizzi et al., 2020).

Autistic individuals are disproportionately impacted by co-occurring mental health and chronic health conditions, magnifying the impact of COVID-19 (Lai et al., 2019; Tyler et al., 2011). According to research, 40% of people with autism struggle with anxiety, and the worries associated with a global pandemic can play a significant role in deteriorating mental health (den Houting, 2020; van Steensel et al., 2011). Loss of self-care routines used as coping mechanisms, and difficulty accessing remote support networks, can also escalate anxiety and leave autistic individuals feeling increasingly stressed and isolated (den Houting, 2020; Pellicano et al., 2020). College students who are required to self-quarantine or shelter-in-place have become more socially isolated, which, in turn,

further impacts their mental health (Son et al., 2020). Students who live on campus and become ill or have been exposed to COVID-19 may be required to relocate to special quarantine housing (Centers for Disease Control and Prevention [CDC], 2020a; Lederman, 2020). Transitioning to and navigating a new environment while adjusting to new rules and protocols can further increase stress and anxiety for autistic college students, ultimately impacting their academic success in college and general quality of life (Colizzi et al., 2020).

Individuals with many chronic health conditions are at increased risk of fatal complications from COVID-19 (CDC, 2020b). Given the higher risk of co-occurring chronic health conditions among people with autism, this might also explain why people with developmental disorders, including autism spectrum disorder, are three times more likely to die from COVID-19 (FAIR Health, West Health Institute, 2020). It is possible that the increased risk some college students with autism face may impact their overall anxieties related to COVID-19.

Problem Statement

While we are beginning to understand the multiplicative impact of the pandemic on the autistic community, there has yet to be a study in which college students with autism are the sole focus. Given the distinctiveness of the setting and the unique challenges faced by autistic college students, this

particular focus is warranted. The current research seeks to explore the unique challenges experienced by autistic college students in the face of COVID-19. Additionally, the research considers the targeted supports that can be offered as students begin to transition back to campus. In this exploratory study, we sought to answer the following research questions.

1. How has the COVID-19 global pandemic impacted the anxiety levels of autistic college students in the United States?
2. What are common concerns that autistic college students experience related to online learning and in-person learning amidst the global pandemic?
3. What can institutions of higher education (IHEs) and autism support programs do to increase the likelihood that autistic college students are successful?

Methods

A group of collegiate autism support program leaders developed a survey to better understand students' anxieties and support needs related to returning to campus in the fall of 2020 amidst the COVID-19 global pandemic. Quantitative survey data were analyzed with descriptive statistics. Qualitative responses were analyzed using thematic analysis. The Institutional Review Board at the University of Delaware approved this study.

Instrument Development and Dissemination

Following the challenges observed during the initial campus shutdowns in spring 2020, program leaders sought to understand how students with autism were processing the return to college in the fall to ensure that provided support addressed the concerns felt by this community. Over the course of several meetings, the team identified potential areas that students with autism may feel anxious about regarding school resumption. Ideas were based on interactions that team members had with students in their support programs in the spring when the global pandemic initially shut down most IHEs and over the summer as students prepared to return.

The survey included 15 demographic questions, two questions about student housing before and after the pandemic, and an option for students to indicate if they planned to continue enrollment in the fall. The survey included eight Likert scale questions referencing student anxiety levels related to various topics, detailed in Table 1. The Likert scale ranged from “Not anxious at all” to “Very anxious.” Finally, the survey included three open-ended questions, allowing students to describe (a) ways that support programs and universities can support them emotionally, socially, and academically; (b) concerns about online classes; and (c) concerns about in-person classes.

Table 1
Instrument Items: Anxiety

Rating	Please identify your levels of anxiety about the following:
	Going to in person classes
	Taking online classes
	Wearing masks
	Social distancing
	Getting sick from COVID-19
	Getting someone else sick from COVID-19
	Transportation to classes if they are offered in person
	Needing to quarantine

The survey was created using an anonymous university Qualtrics account. Before mass distribution, each team member sent the survey to select students in their respective programs, requesting feedback about the length of time it took to complete, clarity of the items, and general feedback on the content. Overall, students had favorable feedback, and the survey was distributed widely. One team member sent the survey and a request for dissemination to approximately 50 autism support program staff across the country, as well as to autism specific and higher education focused listservs.

Analysis

Survey results were downloaded and shared with the lead author. Descriptive statistics for participant demographics and anxiety levels were calculated using SPSS Statistics (Version 26). The qualitative data were analyzed using a thematic analysis, as our goal was to systematically organize and make sense of the data to answer our research questions (Braun & Clarke, 2012). It was important that the survey results be disseminated as quickly as possible to guide other programs in developing and revising their support services amidst the pandemic. Therefore, a thematic analysis was conducted for the three open-ended questions using Rapid Analysis (Gale et al., 2019). First, the data were compiled and reviewed by two coders to determine initial themes. Next, each coder independently coded all of the data and met to discuss discrepancies or variations in the coding data. Coders then collectively decided on subthemes and calculated the frequency that each subtheme was mentioned. Finally, definitions of subthemes were created based on the responses coded for each.

Results

When the survey closed, 100 individuals had opened or begun the survey. Of those, 10 participants did not plan to re-enroll in the fall of 2020. The nonreturning students were asked

why they did not plan to re-enroll, after which the survey terminated. The reasons for not returning included concerns about getting sick with COVID-19, getting someone else sick with COVID-19, not feeling comfortable with in-person learning, and various reasons not related to COVID-19 (e.g., graduation, transferring, leave of absence, not ready to live on their own, and general anxiety). One participant identified themselves as nonautistic and was removed from the sample. Overall, 76 participants answered all or most of the questions.

Participant Demographics

The full report of participant demographics is presented in Table 2. Participants reported residence across 14 states: Pennsylvania ($n = 38$), Michigan ($n = 9$), Delaware ($n = 6$), New Jersey ($n = 5$), Illinois ($n = 4$), New York ($n = 4$), Virginia ($n = 3$), and California, Connecticut, Indiana, Maryland, Ohio, West Virginia, and Wisconsin ($n = 1$ each). The majority of participants reported being supported by their university autism support program (69.7%). Participants were also asked about their living situation before the COVID-19 related shutdowns (spring 2020) and their residential plans for fall of 2020 (Table 3).

Table 2
Participant Demographics

Variable	<i>n</i>	%
Age (<i>n</i> = 76)		
Under 18	18	23.7
19-24	57	75.0
25-29	1	1.3
Over 30	0	0
Ethnicity^a (<i>n</i> = 69)		
Asian	4	5.3
Black/ African American	4	5.3
White	56	73.7
Multi-ethnic	5	6.6
Gender (<i>n</i> = 75)		
Female	21	27.6
Male	51	67.1
Non-binary	3	3.9
Transgender	0	0
Other	0	0
Year (<i>n</i> = 76)		
First	23	30.3
Second	18	23.7

Variable	<i>n</i>	%
Third	18	23.7
Fourth	10	13.2
Fifth	3	3.9
Other	2	2.6
Graduate	2	2.6
Fall 2020 Credits (<i>n</i> = 75)		
1-6	6	7.9
6-9	4	5.3
10-12	13	17.1
13-15	29	38.2
16-18	17	22.4
Above 18	3	3.9
On co-op/Internship	3	3.9
Transfer Student (<i>n</i> = 76)		
Yes	9	11.8
No	67	88.2
GPA (<i>n</i> = 72)		
Below 1.8	0	0
1.9 – 2.5	6	7.9
2.6 – 3.0	18	23.7
3.1 – 3.5	15	19.7

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Variable	<i>n</i>	%
3.6 or above	33	43.4
Autism Support Program (<i>n</i> = 75)		
Yes	53	69.7
No	5	6.6
I don't know	16	21.1
Prefer not to answer	1	1.3

Note. Percentages calculated on total sample ($N = 76$).

^aParticipants could choose all that applied, other ethnicities reported 0% and are not listed.

Table 3
Residential Status

	Pre-COVID (n = 75)		Fall 2020 plans (n = 75)	
Residential status	<i>n</i>	%	<i>n</i>	%
On campus- single	12	15.8	13	17.1
On campus- roommate	21	27.6	14	18.4
Off campus- alone	2	2.6	2	2.6
Off campus- roommate	3	3.9	3	3.9
At home- family	37	48.7	36	47.4
I don't know	0	0	7	9.2

Survey Results

Overall, students were most concerned about getting sick with COVID-19, getting someone else sick with COVID-19, and managing academics in an online learning environment. Students were least worried about mask-wearing and following social distancing guidelines. The following section describes the quantitative and qualitative results of this study in detail.

Quantitative Results

Quantitative data were collected regarding preference for

receiving autism support and anxiety levels related to a variety of topics. Fifty-three respondents provided feedback about their preferences related to the delivery of autism support services. Almost 21% of students preferred online delivery of services, 15.1% preferred in-person services, 50.9% indicated they would prefer a mix of online and in-person support services, and 13.2% of participants indicated they had no service delivery preference. Table 4 details the means and standard deviations of anxiety scores across the following areas: in-person classes, online classes, wearing a mask, getting COVID-19, getting someone else sick with COVID-19, transportation to in-person classes, and needing to quarantine. Only 66 participants responded to questions regarding anxiety levels for in-person classes, and 64 participants responded to questions about transportation to in-person classes. The remaining categories had between 74 and 76 respondents. Participants rated their anxiety level for each category on a scale from 0 to 3, with a 0 equaling not anxious at all and a 3 corresponding to very anxious. Students reported the highest levels of anxiety for getting sick with COVID-19 ($M = 1.63$) and getting someone else sick with COVID-19 ($M = 1.79$), while the lowest levels of anxiety were for wearing a mask ($M = 0.39$) and needing to socially distance ($M = 0.63$).

Table 4
Means and Standard Deviations for Anxiety-Related Items

Topic	<i>n</i>	<i>M</i>	<i>SD</i>
Going to in person classes	66	1.23	1.093
Taking online classes	74	1.26	1.073
Wearing masks	75	0.39	0.695
Social distancing	73	0.63	0.936
Getting sick from COVID-19	76	1.63	1.164
Getting someone else sick from COVID-19	75	1.79	1.142
Transportation to classes if they are offered in person	63	0.83	1.009
Needing to quarantine	74	1.19	1.119

Qualitative Results

The responses to the open-ended questions were analyzed separately for each question. The main findings for the qualitative portion of the survey indicate that students who seek academic and generalized support from IHEs and autism support programs were most concerned about keeping up with academics, managing online learning logistics, and contracting COVID-19 if required to attend in-person classes. The themes, frequency counts, and definitions for each question are detailed in Tables 5, 6, and 7.

Table 5
***Qualitative Results for Requested Support from Universities
and Support Programs***

Theme	Frequency	Definition
Academic support and considerations	28	Concern with keeping up academically and requested support with things like tutoring, accessing online learning, and support with time management.
General support	17	Need for general check-ins and support on an as-needed basis.
Social support	14	Create opportunities for students to engage socially in a remote environment. Students also reported wanting instructions and support in navigating social life (i.e., making friends, learning social skills, etc.).
Mental health support	9	Need for mental health support specific to anxiety, depression, and loneliness.
Miscellaneous	6	Variety of responses: counseling related to academic advising, concerns over tuition and financial aid, and asking for specific support like “wake up calls.”
Don’t know	6	Not knowing how the university or autism programs could support them.

Theme	Frequency	Definition
Accommodations	4	Ensure that accommodations will be available and accessible.
Adjusting to college	3	Need for support adjusting to college or navigating the campus.
Campus experience	2	Want the university to help them feel like they were still in college, despite the circumstances.

Table 6
***Qualitative Results for Requested Support from Universities
and Support Programs***

Theme	Frequency	Definition
Attendance and work completion	26	Ability to attend, participate in, and complete work for online classes. Common concerns included difficulty with time management, concentration, and motivation.
Logistics	24	Logistics of learning online. Specifically, students were worried about technology, the format of delivery for online courses, and understanding how to actually access classes and supports online.
Quality of learning	21	Quality of learning in an online class versus an in-person class. These concerns were about the student's ability to learn new information meaningfully.
Lack of support or connection to others	10	Receiving support from professors as well as feeling connections with other students in class.
No concerns	6	No concerns about online learning.
Mental health	3	Mental health being negatively impacted by taking online classes.

Theme	Frequency	Definition
Accommodations	2	Availability of accommodations in an online learning environment.
Tuition	2	Paying full tuition for an online learning experience.

Table 7
Qualitative Results for Concerns Related to In-Person Learning

Theme	Frequency	Definition
Catching COVID-19	19	Concerns about the possibility of contracting the COVID-19 virus.
Miscellaneous/ don't know	15	Responses were not common enough to create a theme. Concerns included holding in-person classes, tuition costs, unexpected changes in delivery format, and lack of planning from government and IHEs
Others following safety procedures	11	Concerns about other students on campus following safety procedures like wearing a mask and social distancing.
No concerns	9	No concerns about in-person courses. Some responses may be due to no in-person classes scheduled.
General anxiety or concerns	8	Anxiety about in-person classes not specific to COVID-19, e.g., worries about social situations or focusing in large classes.
Spreading COVID-19	6	Concerns about the possibility of infecting others with COVID-19.
Hold in person classes	4	General statements about strong preferences for classes to be held in person.

Theme	Frequency	Definition
Following safety procedures (self)	2	Concerns with being able to follow safety procedures.

Institutions of Higher Education and Autism Program Support

Overall, 62 participants (81.5%) responded to the question: *“What are some ways your support program or university can help you be successful (academically, socially, and emotionally) during the semester?”* Students reported a need for academic support from their IHEs and programs (cited 28 times; this number is not the number of participants who cited the subtheme, but the number of times the theme was cited). More specifically, students expressed concerns about keeping up academically and felt they needed support in tutoring, time management, and accessing online learning. Also, students reported varying preferences for the delivery of academic content, ranging from a desire for in-person learning to a preference for online learning. Some students did not want any synchronous (or live) classes, while others preferred only synchronous classes. The second most common type of support students reported was a need for general support (cited 17 times). Within this theme, students discussed the need for general check-ins and support on an “as-needed basis.” Many students reported that they would like their

autism support services to continue remotely, but also expressed the need for clear communication and explicit messages from support staff.

The third most commonly cited theme was the desire for social support (cited 14 times). Students requested that IHEs and autism support programs create opportunities for students to engage socially in a remote environment. For example, students requested online meetups or other group social activities. Additionally, students reported wanting instruction and support in navigating social relationships (i.e., making friends, learning social skills).

The fourth most cited theme was support for mental health (cited nine times). Students expressed a need for mental health support specific to anxiety, depression, and loneliness. Many students referenced a need for long-term support related to the pandemic and the negative psychological effects that might be brought on by subsequent shutdowns. While not as commonly cited, students also reported the following: a lack of awareness about what they needed the IHEs and support programs (cited six times); a need for assistance with understanding and obtaining accommodations (cited four times); not knowing how to adjust to college life (cited three times); and a need for assurance that they would still have a genuine college experience (cited two times).

Concerns with Online Learning

Forty-five students (59%) reported online learning concerns,

with the primary concerns being attendance and work completion, the logistics of how learning online works, and the quality of their learning. The most commonly cited theme related to online learning was concerns about attendance and work completion (cited 26 times). Students expressed concerns regarding their ability to attend, participate in, and complete work for online classes. Common apprehensions included difficulty with time management, concentration, and motivation. The second most commonly cited concern with online learning was logistics (cited 24 times). Specifically, many students were worried about technology, the delivery format for online courses, and anticipated difficulty understanding how to access classes and support online. Almost as frequently cited as logistics (21 times) was the students' concerns with the quality of online instruction. Students were worried that they would not learn as much online as they would in-person. While not as commonly cited, other themes related to online learning were the lack of support or connections to others (10 times), concerns related to mental health (three times), and worries about accommodation usage (two times) and tuition (two times). Finally, some students expressed no concerns related to online learning (cited six times).

Concerns with In-person Learning

There were 41 respondents for the question related to concerns with in-person learning. The top worry about in-person learning was the risk of becoming sick with COVID-19

(cited 19 times). Students also expressed concern with getting other people sick; however, this theme was only cited six times. Some students identified no concerns about going to in-person classes (cited nine times), while others reported more generalized anxieties that were not specific to COVID-19 (cited eight times [i.e., social situations, ability to focus in large classes]). A number of students expressed a preference for in-person classes (cited four times). The open-ended formatting of concerns for in-person learning led to a sizeable miscellaneous theme (cited 15 times), composed of answers that could not be grouped in a meaningful way. Some of the responses in this category related to not wanting in-person classes to resume, not knowing what they were worried about related to in-person classes, concerns with tuition or the sudden need to move to a fully online model after in-person has begun, and the lack of planning or response from IHEs or the federal government.

Discussion

In this exploratory study, 76 autistic college students provided quantitative and qualitative data related to COVID-19 and the return to college. Overall, students rated their anxiety levels highest for becoming sick with COVID-19 and spreading COVID-19 to others. Their lowest rated anxieties were related to mask-wearing and following social distancing guidelines. When asked about the types of support universities and autism

support programs could provide, students reported needing assistance in academic support, general support, and social functioning. Concerning online learning, respondents were most concerned with attendance and work completion, logistics of learning online, and the quality of learning they might receive. Finally, when asked about concerns with in-person learning, students were most concerned with the risks of becoming ill from COVID-19. This discussion will outline specific recommendations for autism support programs based on the survey results and examine the shift in model delivery and the implications related to those shifts.

Of note in our study is that some students reported having no concerns about in-person learning, and some reported no concerns about online learning. While the sample size was modest, there is a lack of consensus among autistic students when discussing the mode of learning they are most comfortable with during the pandemic. Similarly, when asked about their preference for receiving autism support services during the pandemic, students had mixed preferences. About one half of those who responded indicated they would prefer a combination of in-person and online supports. Not only does this highlight the need for individualization, but it also addresses an essential consideration for providing services once it is safe to resume in-person activities (discussed in Shift to Model Delivery). It is possible that allowing only the traditional in-person method of providing support may create

barriers for some students that are easily removed by offering the option of virtual support.

The need to collect data about the autistic students supported by specialized autism support programs was highlighted by the fact that some of our study results were contradictory to what we expected, or what others had experienced anecdotally. For example, we anticipated that many students might be highly anxious about wearing a mask mainly due to sensory concerns; however, the data showed that mask wearing was rated as the lowest anxiety for students in this sample. Additionally, some students reported concerns about in-person learning that were not related to COVID-19 (e.g., sensory concerns in large classes, meeting new people), highlighting that students are still working through worries and anxieties unrelated to the pandemic.

Program Recommendations

Based on findings of this study, existing literature on effective supports for young adults with autism, and experience of the authors—who oversee college-based support programs—this section describes recommendations for practice in the following domains: academics and executive functioning, mental health support, and socialization and connections with others. The most recent review of interventions for individuals with autism spanned the ages of birth to 22 (Steinbrenner et al., 2020), the purpose being to provide an update to identified

evidence-based practices (EBP) for autistic individuals. While there was no mention of college or postsecondary education, the authors did identify EBPs by age group. There are very few interventions that have enough empirical evidence to be considered EBPs for autistic individuals aged 19-22 (Steinbrenner et al., 2020) and it is important to note that there are no EBPs that have been identified for supporting autistic individuals specifically in the college setting (Anderson et al., 2019).

While researchers are working to build this literature base, program staff who are actively working with students with autism are left to refer to EBPs in other settings. Specifically, many programs use components of EBPs for autistic children and youth or transition services for students with disabilities. Summaries of recommendations for programs are shown and discussed later in this section. Tables 8, 9, and 10. Overall, we recommend that programs offer individualized online supports and in-person options for students when it is deemed safe to do so.

Academic Recommendations

Many autistic students have difficulty with executive functioning tasks (e.g., time management, working memory, self-control), which can hinder academic success. In this study, students expressed concern about academic performance in online learning, specifically attendance, work completion, and

online learning logistics, all of which require strong executive functioning skills. We recommend that program staff consider executive functioning support for students who are learning online. For example, students may benefit from learning to self-monitor the creation and evaluation of short, specific, measurable, and attainable goals (Shogren et al., 2019). Another recommendation is to employ the use of scaffolding, especially in the online environment. Scaffolding is a process in which a task that would otherwise be outside of the student's current ability is supported, and supports are gradually removed until they can complete the task without assistance (Wood et al., 1976). A recent study by Doo et al. (2020) showed that scaffolding in an online higher education environment had a significant positive effect on student outcomes. A specific example of scaffolding provided to college students is a digital calendar with task lists. A staff member could create a digital calendar with specific tasks based on one course's syllabus and due dates that would be created with the student present online, while the staff member models. The student would then create the calendar for another class, and the staff member would observe and correct it as needed. This will help the student through COVID-19 and after the pandemic.

Students were concerned with the quality of learning in the online environment. To this end, we recommend that staff support students in navigating the process of advocating with professors to discuss their learning needs (including

accommodations) and accessing academic supports offered by the IHE. Creating and providing students with visual supports and resources about how to access institution-offered academic supports, like a graphic organizer or flow chart (Dexter & Hughes, 2011; Steinbrenner et al., 2020), may help students struggling to get connected. Additionally, students may benefit from having sample scripts (Steinbrenner et al., 2020) for emailing or discussing concerns about the quality of learning with professors. Table 8 highlights other areas to consider when supporting students academically in the online environment.

Table 8
Academic Recommendations

Provide	Purpose	Tip, tool or resource
Executive functioning support	Providing an easy way for the student to plan the term, set academic and other goals, break down each course and integrate into a total plan for the term that includes all courses; reviewing progress as the term continues	Planning apps or processes (e.g., Google Docs, Sheets, Calendar; My Study Life, LMS Assignment Trackers, Goal setting, Backwards Planning)

Provide	Purpose	Tip, tool or resource
Access to staff	Keeping lines of communication open; reaching a support person in case of urgent need; getting answers to questions that feel urgent; supporting access to campus and other (e.g., community mental health) resources	• Schedule appointments online • Text Message app • Virtual Office Hours • Support person available via chat during work hours • Create a Google voice number and forward your office telephone number to google voice number on your cell phone

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Provide	Purpose	Tip, tool or resource
Tutoring opportunities	Facilitating access to tutoring services; encouraging use of existing academic supports; determining barriers that may exist; supporting student in scheduling and attending tutoring	• Academic Support Services • Online Tutoring • Faculty Office Hours • Teaching Assistants/ GA
Check-ins	Creating scheduled weekly or bi-weekly individual or group virtual check-ins to ensure the student is on the right track and understands their weekly plan, has the opportunity to connect with others, and the opportunity to build responsibility and interdependence	• Virtual meeting platforms • Breakout rooms for personal information sharing or teamwork • Visual supports such as checklists, calendars, agendas, whiteboards, and applicable handouts

Wellness and Mental Health

Recommendations

In our study, students requested that IHEs and support programs offer more extensive mental health support. Mental health concerns were also cited a few times when students were asked about online learning. As seen in the Pellicano et al. (2020) study, autistic individuals had mental health concerns related to COVID-19 shutdown. Cox et al. (2020) highlighted that specialized mental health supports are not routinely offered in higher education, even by colleges that have specialized programs for autistic students. Given the high rates that individuals with autism experience co-occurring mental health disorders (Ung et al., 2015) and limited availability, even pre-pandemic, of long-term support offered through college counseling centers (Center for Collegiate Mental Health, 2020), autism support programs must find ways to encourage positive mental health practices for students.

While there is a paucity of research related to mental health interventions and supports for autistic college students, programs should consider implementing practices from relevant literature regarding mental health and interventions for autistic young adults that show initial evidence of efficacy. For example, programs may offer students weekly mindfulness activities remotely (Hofmann & Gómez, 2017; Spek et al., 2013). Twenty minutes a week a staff member or peer mentor may lead a virtual call doing mindful breathing, yoga, or guided meditation. Additionally, program staff may review

self-care routines that encourage positive habits with students and encourage the development (or adjustment) of routines that encourage positive habits related to sleep, nutrition, and exercise (Wong et al., 2013). Table 9 outlines a number of recommendations for programs to consider when supporting their students' mental health needs.

Table 9
Wellness and Mental Health Recommendations

Provide	Purpose	Tip, tool or resource
Anxiety management	Teaching strategies for helping the student to manage anxiety that might otherwise hinder their success	• Professional counseling • Mindfulness (e.g., meditation, breathing, yoga, apps) • Identify triggers and calming strategies • Self-Care Routine (e.g., Sleep, nutrition, movement)
Mental breaks	Encouraging study breaks and relaxing activities on a regular schedule to help prevent feelings of drained or overwhelmed	• Activity (e.g., exercise, change of scenery, journaling, drawing) • Schedules for breaks (e.g., focus keeper, Pomodoro focus timer) • Social connection (e.g., call, talk, text, video chat)

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Provide	Purpose	Tip, tool or resource
COVID-19 preparedness	Providing reassurance, information, and resources about COVID and related university safety plans	• University's on-line training re COVID-19 precautions and trusted sources (e.g., CDC) • Discussion, workshops, information-sharing about staying healthy during the pandemic

Socialization Recommendations

Pellicano et al. (2020) found that it is a common misconception that autistic people do not crave social interaction. Respondents who reported positive experiences during lockdown valued the added time they could spend with their family members and pets. Those who described challenges with lockdown also expressed the need for personal interaction with friends, classmates, support providers, and, for some, periodic interaction with ambient groups as they traveled through everyday life. Participants were looking forward to social interaction again (Pellicano et al., 2020). In our study, many students expressed that they wanted the IHE and autism support programs to provide social engagement opportunities in a remote environment. Specifically, students

who responded were interested in engaging in online meetings, group activities, and receiving support in navigating social relationships to develop friendships.

We recommend that autism support staff think critically and creatively about engaging their students in meaningful social interactions. As with any support and interventions involving autistic young adults, it is crucial to engage students in this process to ensure that the planned activities are engaging, accessible, and of interest to students. Programs may ask students individually what types of social support they seek or send a short survey to students requesting input on social activities that they may be interested in. Table 10 outlines several resources and ideas for social engagement.

Table 10
Social Recommendations

Provide	Purpose	Tip, Tool or Reference
Virtual engagement events	Staying connected and socially engaged	• Gaming platforms (e.g., Kahoot, Jackbox, Scribio, xbox-live) • Group Chats (e.g., Group Me, Discord) • Watch parties (e.g., Netflix, Disney+)
Social networks	Staying active and connecting with peers who have similar interests	• Campus Clubs/ Organization (e.g., interest, service, Greek life) • Campus events and activities (e.g., Campus Life, Residence Life) • Connections with academic groups and peers with similar majors (e.g., study groups, academic clubs)

Shift in Model Delivery

In the spring of 2020, when many IHEs and subsequent autism support programs had their in-person services and support moved remotely, the authors of this paper needed to think strategically about how to ensure that their programs

still met the needs of the students they serviced. The pandemic exacerbated existing mental health concerns for college students because of the lack of social connectivity and financial hardship to their lives (Lederer et al., 2021). In addition, it is well documented that transitions of any kind can be especially challenging for autistic people (Pinder-Amaker, 2014). This section begins with a discussion of the ways that the authors adapted their service models in response to the need for virtual support. All four programs immediately sought to understand their students' needs given the sudden shifts and changes to their routines and daily life using online surveys or individual conversations with students. They also began regular one-on-one sessions with students virtually through teleconferencing platforms like Zoom, and like many IHEs across the country, this frequency of support was increased compared with what had been offered before the pandemic (Brown, 2020).

Armed with the knowledge that college students with autism already faced increased social difficulties and challenges (Elias & White, 2017), program staff explored creative ways to keep students socially connected (Davis, 2020). For example, some social relationship groups held in-person shifted to an online environment and focused on relationship building while socially distancing or quarantining. Others created new social engagement groups, and students were empowered to host game nights using various technologies. While all programs had already been considering their students' mental health needs, there was a greater focus during individual

sessions and in the creation of group activities (e.g., weekly virtual mindfulness activities). Finally, programs worked to ensure that students' career development was not sacrificed, as the COVID-19 pandemic has hurt much of the workforce and those pursuing employment (Capelle-Blancard & Desrozier, 2020).

For most, the shift to remote learning and support has multiple impacts on students and those who support them. The pandemic has required flexibility in how to ensure access to these services. Most students indicated that they would prefer an online or a combination of in-person and online support from their autism support programs in our sample. While this model is helpful during the COVID-19 pandemic for safety purposes, students may benefit from this model long-term, after it is safe to resume in-person activities. First, the option of remote or in-person support will increase access for students moving forward, allowing students to choose the method of support that best suits their preferences or needs. As Pellicano et al. (2020) reported, many people with autism and their families cited that people with disabilities have been advocating for the ability to access education and services remotely for years and that the pandemic has shown that this is, in fact, possible.

While the shift to remote support has potential impacts on students, one must also consider the impact this shift may have on staff within these programs. While our study did not explore the effect on staff, many authors are direct support

providers and have experienced these ramifications firsthand. Following the switch to online, many staff had to learn new technologies and needed to pivot to different methods of supporting students to address the individualized needs of those who struggle with online learning and experienced barriers to accessing services and supports (Gillis & Krull, 2020). Similarly, staff needed to be creative about ways to intervene with students who became disengaged or entered a mental health crisis (Hoyt et al., 2021; Wang et al., 2020) while re-thinking engagement with families, as many students moved back to their primary homes (Ackles et al., personal communication, December 7, 2020). This is a heavy task without the added complexity of confidentiality practices in higher education, which prohibit discussion of student progress with families (unless allowed by the student; Family Educational Rights and Privacy Act [FERPA], 1974).

While the increase in support and services for students is necessary, it is crucial to highlight the fact that for many, this meant an increase in workload with no increase in resources or support staff. Many programs are already understaffed and under-funded, creating anxieties around job security for those working in them. Support staff are also living in the pandemic and face personal fears and anxieties around the COVID-19 pandemic, much like the world's population (Torales et al., 2020). When considering how to best support students with autism, we cannot ignore the fact that these recommendations impact those who implement them.

Limitations and Future Research

As with any study, it is important to discuss the limitations of the research, the implications these limitations have on interpreting findings, and areas of future research. Conducting research with autistic college students has a number of challenges, one of which is recruitment. Because of the time-sensitive nature of our study, we decided to move forward with a sample of 76 to quickly analyze and disseminate the results to share them with programs and allow the results to inform their programming. We must use caution when interpreting the results of this study because of the low sample size. Additionally, our sample was heavily skewed toward White males, which has a number of implications related to generalizability. While it is true that many students who participate in autism support programs are White males (which reflects diversity challenges within these programs themselves), there are a variety of gender identities and races represented throughout the country who are not reflected in this sample. Finally, there is the possibility of self-selection bias; that is, the idea that participants could choose to participate (Lavrakas, 2008). The individuals who chose not to participate may have answered questions differently.

To address the limitations in this study and to explore new questions that were developed based on findings, we propose a number of areas of future research. Future studies related to COVID-19 should make a concerted effort to engage with

students of color and female, transgender, or non-binary students. Additionally, future studies should engage autistic college students to understand the long-term impacts that the pandemic, subsequent shutdown, and model delivery shift have had on their academic success, social experiences, and mental health. In these studies, researchers should understand the support and services that were most impactful and helpful to students. We also suggest that studies examine the impact that the shutdown and model delivery shift has had on the staff within IHEs who support students with autism.

Conclusion

The COVID-19 pandemic and subsequent shutdowns have impacted how autistic students access support in the postsecondary setting. Before returning to campus in the fall of 2020, students were anxious about getting and spreading COVID-19, least anxious about wearing masks and social distancing, and were hoping to find support from their universities and autism programs across academic, social, and mental health domains. We recommend that programs work individually with students to assess their needs and provide academic, mental health, and socialization support.

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11.

USING TELEHEALTH TO ADAPT SERVICE DELIVERY FOR CHILDREN DURING THE COVID-19 PANDEMIC

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Russell, M., Donaldson, C., Pleasant, J., & Roberts, K. (2020). Using Telehealth to Adapt Service Delivery for Children during the COVID-19 Pandemic. *Developmental Disabilities Network Journal*, 1(2), 123–136.

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[Using Telehealth to Adapt Service Delivery for Children during the COVID-19 Pandemic PDF File](#)

Plain Language Summary

The Institute for Human Development (IHD) at

Northern Arizona University evaluates children who have problems with their development. These problems are called developmental disabilities (DD). Evaluations give families information about how the child talks, walks, thinks, and does things for themselves like eat or dress. Families can use this information to get services to help their child.

The COVID-19 virus stopped people from seeing each other. Therapists at IHD stopped doing evaluations and therapy visits. Children were not getting the therapy they needed. However, IHD therapists decided to provide some of these services using technology and computers instead of seeing the children in person. This is called teletherapy. During teletherapy, the parents, child, and therapists can see and talk to each other. For this to work, the family needed to have a computer or a tablet device and internet service. The therapists also had technology plus a special computer program called Zoom.

By trying something new, therapists learned that they could use technology for some evaluations and therapy. They did not always need to see the child in person. Teletherapy did not work for all families, but it did help many families. It was something good that came out of the COVID-19 virus. IHD is helping other therapists learn about teletherapy.

The COVID-19 pandemic brought and continues to bring extraordinary financial, physical, and mental health challenges to families throughout the world. Families who have children with intellectual and developmental disabilities (I/DD) have heightened parenting stress even in pre-pandemic times compared to parents of typically developing children (Hayes & Watson, 2013; Woodman et al., 2015). During COVID-19, families who have children with I/DD may confront additional short- and long-term consequences. The loss of essential services due to the need for social distancing places more responsibilities on families to meet all the educational, behavioral, and daily living needs of their child with special needs (Fontanesi et al., 2020). Families may worry about the long-term impact on their child's development due to the suspension of educational programs and lack of social opportunities (Neece et al., 2020). This concern is valid because better outcomes in children with I/DD are obtained through early diagnosis and treatment. Early intervention uses the brain plasticity present in early childhood and contributes to rapid and positive changes in learning and development (National Institute of Child Health and Human Development [NICHD], 2017). Children from ethnically and linguistically diverse backgrounds may have more difficulty obtaining an accurate diagnosis for a developmental disability. Under- and over-representation of ethnic and racial minorities in terms of disability may be promoted by issues such as decreased access to health care, inadequate health

insurance, and lack of culturally sensitive approaches for evaluation (Flores & Tomany-Korman, et al., 2008; Zuckerman et al., 2014). Although in many areas of the U.S., diagnostic and intervention services for children with I/DD were discontinued at the onset of the COVID-19 pandemic, many programs including those at the Institute for Human Development (IHD) at Northern Arizona University (NAU), continued to serve children with I/DD by modifying or adapting their service delivery to a telehealth model (U.S. Office of Special Education Programs, 2020).

Adaptation in the context of an implementation of an intervention is “defined as a process of thoughtful and deliberate alteration to the design or delivery of an intervention, with the goal of improving its fit or effectiveness in a given context” (Stirman et al., 2019, p. 1). Three child evaluation and intervention programs provided through NAU are examples of programs that were adapted to meet the needs of families when in-person services were restricted. In reporting adaptations to our assessment and intervention processes in response to the COVID-19 pandemic, the adaptations will be discussed in the context of the expanded Framework for Modification and Adaptations (FRAME) developed by Stirman et al. The FRAME process of modifying evidence-based interventions has the following eight components:

1. When and how in the implementation process the

- modification was made;
2. Whether the modification was planned or unplanned;
 3. Who determined that the modification should be made.
 4. What is modified;
 5. At what level of delivery the modification is made;
 6. The type or nature of context or content-level modification;
 7. The extent to which the modification is fidelity-consistent; and
 8. The reasons for the modification: (a) the intent or goal and (b) the contextual factors that influenced the decision.

Description of Three UCEDD-Provided Direct Services

The Northern Arizona University-Institute for Human Development (NAU-IHD) is a University Center for Excellence in Developmental Disabilities (UCEDD), one of two in the state of Arizona. IHD is an interdisciplinary unit working on projects across a range of university departments, research institutes, community organizations, consumer advocacy groups, and state agencies that impact the delivery of services and supports to persons with disabilities. As part of its vision to promote inclusion of individuals with disabilities, IHD provides training, technical assistance, and direct services in Arizona communities.

This article describes the adaptations that were made in three community service programs at the IHD at NAU in response to the COVID-19 pandemic. We will report on the modifications made to the provision of evaluations and therapeutic interventions to children with developmental disabilities. The three programs include: The *Augmentative and Alternative Communication (AAC) program*, the *Growing in Beauty Partnership Program (GIBPP)*, and the *Interdisciplinary Training Clinic (ITC)*. These modifications are examined in the context of the eight components of the updated FRAME, a framework for reporting adaptations and modifications to evidence-based interventions (Stirman et al., 2019).

IHD has provided Augmentative and Alternative Communication (AAC) evaluations for almost 20 years. These comprehensive, team-based assessments conducted by a speech-language pathologist (SLP) and an occupational therapist (OT) have traditionally been performed face-to-face. The evidence-based process includes a thorough review of the client's referral information and the onsite assessment incorporates the funder's requirement for hands-on device trials with at least three different types of AAC devices (including, when appropriate, use of access equipment such as switches and mounting options). Furthermore, the evaluations are typically performed in natural setting such as the client's home or school and involve engaging the client in age-appropriate activities designed to elicit contextual

communication. The SLP and OT assume responsibility for managing the use of the devices aligned with the activities throughout the evaluation. After the client receives the recommended AAC device, follow-up training by an SLP is provided to the client and family in their home, school, or day program setting.

The *Growing in Beauty Partnership Program* (GIBPP) is comprised of OTs, SLPs, and physical therapists (PT) as a subcontracted program to the Part C Early Intervention program on the Navajo Nation. Services are provided to children birth through 3 years old with significant delays and disabilities and supports their families. Therapists evaluate the child to determine eligibility and scope of services, and then provide interventions to address needs and work towards identified child and family outcomes. Services are typically provided in natural environments, which for children in this age group is most often the home.

The Interdisciplinary Training Clinic (ITC) provides assessment services for young children and their families who have concerns or questions about their children's developmental progress. ITC services are free of charge to families and take place at an IHD clinic on the campus of NAU. The assessment team works collaboratively to determine a diagnosis and follow-up plan. The team typically includes a developmental pediatrician, PT, OT, SLP, and a school psychologist. The ITC also provides university students who are working on advanced degrees in health, education,

or other related human service professions with opportunities to observe and participate in the interdisciplinary assessment process.

Impact of COVID on Service Delivery

In March 2020, with new COVID-19 restrictions in place, the three direct service programs were challenged to serve children with I/DD or at-risk for I/DD. Delaying or eliminating services would place this vulnerable population at further risk as they would not receive necessary and timely diagnostic or intervention services to improve their skills and advance their development. The components of the FRAME model are used to describe the modifications made by the three service programs in response to COVID-19.

Component 1: When and How in the Implementation Process the Modification Was Made

This component in the FRAME addresses the timing of the modification and the challenges that may emerge during the planning and implementation phases (Stirman et al., 2019).

Modifications to all three service programs were made at the end of March 2020 because of the COVID-19 outbreak

and its rapid spread in the state of Arizona and on the Navajo Nation. Following the recommendations of the Centers for Disease Control (CDC, 2020), the Governor issued a stay-at-home order that included the following: closure of schools and business, banning of large gatherings, and restricted travel. State and tribally funded (Navajo Nation) programs for individuals with disabilities suspended home-based services. This stay-at-home order affected both the AAC and the GIBPP programs. All buildings on the NAU campus were closed, requiring the closure of the ITC clinic where the interdisciplinary evaluations were conducted.

A logical modification to home-based and in-person assessments was the use of telemedicine, or the evaluation and treatment by health professionals using telecommunications technology. Telemedicine or telehealth has long been a consideration in efficiently serving individuals with developmental disabilities, particularly those living in rural areas (Dimian & Symons, 2017.) A barrier to telehealth throughout the U.S. has been reimbursement restrictions through insurance and government programs.

In Arizona, the Governor authorized an expansion of and payment for telehealth services shortly after the pandemic-imposed shutdowns (Exec. Order No. 2020-15, 2020). Because this was now a sanctioned option, the AAC program pivoted to telehealth service delivery as a choice for AAC device training for families who desired this option and had the technology infrastructure to support its use. However,

transitioning to a completely remote “virtual” AAC evaluation was initially deemed problematic primarily for reasons associated with the use and management of the AAC equipment—an essential element of the evaluations.

Component 2: Whether the Modification was Planned or Unplanned

Modifications to interventions that are planned or proactive to enhance intervention goals may differ in outcomes from those that are unplanned or reactive. Planned changes are generally made to enhance implementation success and minimize disruption of the intervention. In contrast, a reactive modification may strive to maintain the elements of the intervention that make it effective (Moore et al., 2013; Stirman et al., 2019).

The COVID-19 pandemic presented a sudden and unanticipated challenge to IHD’s community service programs. The AAC program already had a sizable evaluation waiting list due to non-pandemic factors beyond the program’s control. The AAC staff members struggled to address new referrals as well as the existing backlog. The discontinuation of services affected both the clients and the staff. For the clients, the evaluation is a critical step in the process to obtain a communication device. For the therapists, a long-term hold on service provision and the resulting inability

to generate revenue could jeopardize job security. For the GIBPP and ITC programs, evaluations are important when connecting families with needed services and supports. For young children, early identification and subsequent intervention provide better developmental outcomes (NICHD, 2017). Although modifications were reactive rather than proactive because of the pandemic, alternatives needed to be identified to overcome these challenges and continue to serve these children at risk.

Component 3: Who Determined the Modification

This component addresses the participatory nature of the modification and the decision making. The drivers of the change may influence the impact of the modification and its widespread use (Stirman et al., 2019).

In the AAC program, team members and leadership had several meetings to discuss how services could be resumed in a manner that (a) protected the health of all participants, (b) would maintain the fidelity of the in-person assessment process, and (c) result in valid device recommendations. As a stopgap measure to restart service delivery, the initial strategy was to begin the evaluation through a remote intake session. This allowed the therapists to gather critical assessment planning information and informally observe the client within the home setting. If the family did not have internet and a

computer or mobile device for Zoom access, the intake was carried out telephonically. These meetings were successful, and because of this first “virtual” step, the team re-evaluated their initial assumption that a virtual evaluation was not a feasible alternative, coming to believe instead that some AAC evaluations could be undertaken in a completely virtual format for clients meeting certain criteria.

In the GIBPP program, all major stakeholders in early intervention services were involved in the decision for change in service delivery method, including the Navajo Office of Special Education director and assistant director, the Navajo GIB supervisor, and the GIBPP director. Therapists and families were also consulted to provide information on possibilities of service- delivery methods. Additionally, caretakers at the local foster home on the Navajo Nation were also involved, as multiple children who reside there are serviced by GIBPP. Families with children who were already on caseload for GIBPP, and who indicated a preference to continue services in some format, were surveyed as to their ability to participate in telehealth services. The survey included questions on the availability of a device (phone, tablet, or computer) for telehealth sessions, as well as the family’s current access to cellular data and/or WiFi for internet access for live stream video sessions. Additionally, families who identified that they did have access to internet services were further queried as to whether they had limitations in the amount of data that they had available each month, because

video streaming for services requires a large amount of data and may not be possible on a limited data plan.

Additional practice guidelines for telehealth were provided by professional organizations such as the American Physical Therapy Association and the American Occupational Therapy Association. These national organizations support legislation and policies that recognize telehealth as a valid service-delivery modality and support reimbursement of services through telehealth. In addition, these organizations, as well as state and local groups, provided online resources and materials to assist health professionals in delivering telehealth services.

Component 4: What is Modified

This component of the framework focuses on the types of changes that were made and the relationship of these changes to implementation success and recipient-level outcomes. This component also examines if differences in outcomes are attributable to differences in how the intervention was implemented (Stirman et al., 2019, 2013).

A move to telehealth by the AAC and GIBPP programs necessitated adaptation to service-delivery methods and consideration of the population that could be served; criteria was necessary to ensure virtual connectivity and responsible use of equipment by the family. For the AAC program, a

virtual format was adopted for device training and the recipients of the evaluation were screened to meet certain criteria. In the AAC program, based on team consensus, the criteria for virtual evaluations included the following.

1. Clients whose communication needs did not involve significant motor access issues (in other words, clients who could make message selections directly through the device display and did not require alternative access methods such as switch use, head control, or eye gaze). The rationale being that for clients with more complex bodies, the OT would need to be physically present to set up and adjust the access equipment tailored to the client's needs—something that a parent or caregiver would be challenged to do during the evaluation.
2. Parent/guardian's signed agreement to proceed with a remote evaluation, acknowledging the process had been explained to them.
3. Sufficient internet access and a device (computer or tablet) to connect to Zoom.
4. Family agreement to accept delivery of the loaned AAC equipment and return the equipment on time using the prepaid label and instructions.

Serving the GIBPP population presented some unique challenges to telehealth delivery due to the remoteness of the Navajo Nation. The Navajo are historically nomadic, with

clusters of homes scattered in primarily rural regions other than a few small towns with populations less than 10,000 (Navajo Division of Health, 2013). The infrastructure for internet broadband coverage is often spotty or very limited (Graves et al., 2020). Additionally, many families live in poverty (Combrink, 2019) and are not able to purchase unlimited cellular data or WIFI coverage plans for access to a strong internet signal necessary for live-streaming video. Families typically own a cellular phone but often do not have a larger screen device (tablet or computer) as would be preferable for tele-intervention sessions.

A loaner program of iPad tablets and/or hotspots with prepaid SIM cards for cellular data was piloted in various areas with existing GIBPP families. An initial survey was completed by families on the caseload inquiring about their access to internet capability. Those who were not able to participate in video services due to inadequate device and/or limited internet access were offered a loaner iPad and/or cellular data hotspot. Importantly, only families who had a strong and consistent relationship with GIBPP providers were offered loaner equipment, as a relationship was key to trust for safekeeping and eventual return of equipment.

Families who reported they did not have internet access via WIFI or cellular data, or who reported having monthly data caps, were surveyed as to which cellular plans provide coverage in their area and their current subscription plan. Regions on the Navajo Nation vary widely as to which cellular provider

offers the most reliable and strongest coverage for internet capability, and word of mouth from families who live in the region appeared to offer the greatest validity in determining which company offers coverage within each family's home area.

The technology equipment delivery method was individualized to each family, as many families live in remote areas of the Navajo Nation. Some families who traveled to Flagstaff (home of GIBPP) for other reasons, were met by their provider and given equipment. When a delivery on the Navajo Nation was required, the therapist making the delivery followed all precautions including wearing a mask and gloves. Typically, the delivering therapist contacted the family on arrival to the home and deposited the equipment on the family's doorstep, then returned to their vehicle but remained in the driveway during a trial video session with the family.

An additional challenge to serving Navajo families through telehealth is the importance of delivering culturally competent care. In a systematic review of telehealth for indigenous peoples, Fraser et al. (2017) reported that although telehealth overcomes some barriers related to access, it must be delivered in culturally appropriate and acceptable methods. Relationship-based care is an important component of Part C services, as parents in everyday caretaking practices are recognized as having the most impact on children in this age group (Adams & Tapia, 2013). As a result, telehealth services need to be culturally sensitive to engage families and be

effective (Dawson et al., 2020; Fraser et al., 2017). Part C services on the Navajo Nation are delivered in a team-based model, where GIBPP therapists typically work with Navajo early childhood providers. As part of the modification to telehealth services, GIBPP therapists have continued to consult with Navajo providers to incorporate culturally sensitive practices into video-based services.

Component 5: At What Level of Delivery the Modification is Made

This component reports the effectiveness of modifications at both the individual and group level (Stirman et al., 2019, 2013). To date, 45 virtual AAC evaluations have been successfully completed with device recommendations. The teams reported being able to make sound AAC device recommendations equivalent to those completed during in-person sessions. The funder has not challenged recommendations based on the virtual evaluation format. Only one family expressed concerns about the recommendations from the remote format and the team agreed to do an in-person reassessment.

GIBPP providers and families completed follow-up surveys as to the success and satisfaction with the video services using the loaner equipment. Although limited data has been obtained to date, preliminary results indicate high satisfaction with the use of loaner iPads for video sessions when the family

has access to an internet signal within their home. Results are mixed for those families who were also provided a cellular hotspot. Data collected for hotspot sessions included the number of screen freezes and/or dropped calls during the session; 100% of sessions completed with this equipment resulted in some degree of difficulty with the quality of the call based on these measurements. Diagnostics are continuing as to whether other cellular providers may give better results for various families, or if a monthly cellular data plan instead of prepaid data would result in better quality of cellular services for improved video streaming. For families who were not able to achieve adequate video for sessions, services continued through phone calls based on the families' interest.

Component 6: Type or Nature of Content-Level Modifications

This component examines the drift from the original content of the intervention and return or the departure from the original protocol (Stirman et al., 2019, 2013).

At this time, the AAC Program and ITC have returned to limited in-person evaluations while still offering virtual evaluations. AAC has also implemented a hybrid model combining virtual and in-person participation as another option for conducting evaluations. This model has one team member onsite and the other participating remotely. As a COVID-19 precaution, this limits the number of people in the

same physical environment, but a therapist remains physically present to manage the device interactions.

The ITC has continued to administer interview measures such as the Vineland, Sensory Profile, and the Functional Communication Assessment in a virtual format. Ideally, this decreases the amount of face-to-face time needed with the child and family and provides essential background information prior to the in-person evaluation. For the ITC in-person portion of the evaluation, and for onsite AAC evaluations, a COVID-19 protocol was instituted that includes temperature checks for staff and family members, use of personal protective equipment (PPE), plexiglass barriers, sanitizing of all surfaces and materials in the evaluation room, limiting the number of family members present, and limiting the number of examiners in contact with the family.

GIBPP continues to provide only virtual services. Therapists can offer families more flexibility in the frequency and duration of sessions. Some families report difficulty engaging in an hour-long session over Zoom or the phone and prefer shorter, more frequent sessions.

Component 7: The Relationship to Fidelity

This component in the FRAME discusses fidelity-consistent modifications that preserve the core elements of the practice. In contrast, the fidelity-inconsistent modifications fail to

preserve core elements of the modification (Shelton et al., 2018; Stirman et al., 2019, 2013).

Following attempts at virtual evaluations, the ITC evaluation team determined that a fully virtual evaluation was providing an incomplete picture of the child and was, therefore, a fidelity-inconsistent modification. The modifications in ITC that were fidelity consistent included a reliance on parent report through interview. This was effectively completed through Zoom meetings with primary caregivers. The interview measures are flexible in allowing the examiner to ask follow-up questions and request examples of the child's skills or behaviors. Measures that required specific materials, such as the Battelle Developmental Inventory 2nd edition (BDI-2; Newborg, 2005), or required the skills of a trained examiner were deemed fidelity-inconsistent modifications. By coaching a parent to administer an item, or by substituting available materials, the core elements of the assessment may be compromised.

Use of alternative measures for assessing development, such as the Developmental Assessment of Young Children, 2nd ed. (DAYC-2; Voress & Maddox, 2013) were initially attempted through virtual administration. However, the interview or child observations resulted in incomplete information or unwillingness of the child to perform in their home environment. In addition, child observation was compromised by setup of the technology, poor lighting or sound, or camera angles that were not conducive to observation of the child

while they were engaged in a task. Furthermore, medical examination by the developmental pediatrician was not feasible and subtle motor signs such as muscle tone were difficult to detect on camera. Children who were initially seen through Zoom and then later assessed in person in the clinic setting presented differently in the clinic setting. Some appeared to have more severe developmental delays in-person due to the difficulty in detecting subtle motor signs on camera. Other children engaged more with the examiners in the clinic setting, showing higher social and language abilities.

Coaching families virtually is a practice that in many instances has been successful and fidelity consistent. In the GIBPP program, early intervention services are typically provided through a coaching model for caregivers with instruction and mentorship by therapists and developmental specialists. Through this coaching model, caregivers are intended to be supported and instructed in how to provide therapeutic care for their infants and children so that they can continue interventions between sessions. However, prior to the COVID-19 shutdown, some caregivers displayed reluctance in attempting activities as directed by the GIBPP therapist during sessions, and many preferred to have the therapist provide the interventions. During video and/ or phone sessions, therapists are not able to provide direct treatment to the child and so video sessions more closely adhere to coaching of caregivers. Thus, caregivers have improved opportunities to practice interventions for their

child with the support and direction of therapists during virtual sessions, and presumably are more adept at continuing treatment between sessions for greater duration and frequency of therapeutic interventions. Because of the limited abilities to observe the child directly, therapists have developed their interview techniques to better determine the child's status.

Component 8: The Reasons for the Modification (a) the Intent or Goal, (b) Contextual Factors that Influence the Decision

This component addresses the goal for the modification that may include improvement in feasibility, increased fit or reach, improved engagement, reduction in cost, improvement in clinical outcomes, or alignment with cultural values (Stirman et al., 2019). In the context of COVID-19, the overall goal of the modification was to maintain engagement within the disability community to identify needs and supports. In addition, it was critical to maintain relationships with GIBPP families that would continue to support the development of children with disabilities.

The shift to remote service delivery yielded unanticipated value-added benefits. Conducting virtual intake sessions for both AAC and ITC evaluations provided the therapists with valuable information beyond what could be gleaned from just reading the referral information and allowed them to be more

prepared for the evaluation and what to expect from the client. The practice of virtual intakes will continue even when full in-person services resume.

Family engagement and participation is always a goal and of utmost importance in promoting the child's development (Zwaigenbaum et al., 2015). Therapists in all three programs observed a greater degree of family engagement and participation during virtual evaluations. For example, having the parent be physically responsible for using the devices with their child during the AAC evaluation resulted in a shift away from the expert model where the therapists control the situation, to one in which the therapists coach the parent, thus giving them a more active role. The team noted increased confidence and capability expressed by the parents. It is hoped that this confidence will continue when clients receive their own devices and begin the implementation training.

Telehealth has reduced travel costs for staff—although there have been added costs and more staff time for shipping or delivering the devices to the clients. For the AAC evaluations, occasionally follow-up is needed when the family delays returning the borrowed devices. A small percentage of the clients referred for AAC assessments do not have the technology available to support virtual services. In these situations, the alternatives offered were either an in-person, office evaluation with strict adherence to CDC COVID-19 precautions or the referral was given back to the funder for service by another provider.

Disparities have a greater impact on the delivery of telehealth evaluations and services to GIBPP families living on the Navajo Nation. The barriers to service delivery due to inadequate internet connectivity continue to be an issue in rural Arizona, the Navajo Nation, as well as many other parts of the country (Cole et al., 2019; Farmer et al., 2020), limiting health and educational opportunities. Rural communities are at a high risk during COVID-19 with poorer access to healthcare in general and less access to telehealth services (Summers-Gabr, 2020). As well as access, unfamiliarity with technology in homes may influence the quality of the information that is obtained through remote administration of assessments. Young children may not engage as easily as they may during an in-person assessment if they are unfamiliar with video platforms (Farmer et al., 2020).

Some families initially requested to pause services due to a preference for in-person service delivery or because of pandemic-related stress. As the duration of the pandemic persisted, these families were periodically recontacted to see if they wanted to resume services as the timeline for return to in-person services continues to seem unlikely in the foreseeable future. Telehealth may place additional demands on caregivers that can affect the quality and validity of an assessment. There may be many home demands on caregivers, particularly during COVID-19, with other children needing supervision for online education (Prime et al., 2020). Caregivers may be unfamiliar with evaluation and intervention processes and

how they might facilitate the child's performance (Farmer et al., 2020).

When technology and broadband issues can be overcome, telehealth for IDEA Part C evaluation and intervention services can be an important avenue for service delivery in rural areas such as the Navajo Nation. Although indigenous people have identified a preference for in-person services when feasible, a service-delivery method of an initial visit in-person followed by telehealth visits has been deemed effective and can increase access to services (Fraser et al., 2017). The opportunity to initiate use of telehealth with Navajo families for early intervention highlights an opportunity to continue to use this method post COVID-19 for supplemental services between in-person visits, thereby increasing services for improved relationships and outcomes for children.

Summary

The emergence of COVID-19 as a public health threat required unexpected and rapid modifications for three programs at IHD. A change to a telehealth format provided critical services to a vulnerable population while protecting the health of clients, family, and staff. This modification required teamwork, attention to maintaining fidelity-consistent practices, and a thoughtful assessment of criteria for recipients and infrastructure considerations. Evaluations of program delivery as COVID-19 continues, and in its aftermath, should

guide assessment procedures and interventions provided through telehealth and hybrid formats. Program evaluations would include family and provider perspectives, fidelity to practices, and financial considerations.

Our experiences with telepractice for evaluation and intervention delivery highlight the need for administrative support and for providers who demonstrate flexibility and high levels of clinical skills that can translate to telepractice. Clinicians must be able to assess family and child strengths and needs via interview and limited observation through telehealth. Importantly, next steps following an evaluation need to be feasible and based upon the family's identified priorities and resources. Clinician skills are also critical in effective coaching of caregivers to ensure the caregiver's understanding of their child's needs and caregiver confidence in implementing activities that will facilitate their child's development. Additionally, clinicians must be skilled in delivering culturally competent care—both through telehealth and in-person services (Farmer et al., 2020). As the COVID-19 pandemic continues, programs will continue to modify their practices in supporting children and families with developmental disabilities. Clinician competency and clinician engagement with families will be critical post-COVID-19 as programs begin to reopen and as families confront new concerns and challenges (Neece et al., 2020).

Many families from ethnically and linguistically diverse background throughout the U.S. have experienced

disproportionate health and socioeconomic disparities during the COVID-19 pandemic (Webb Hooper et al., 2020). Our families with children with developmental disabilities on the Navajo Nation have suffered greatly throughout the pandemic. Further investigation of the utility of telehealth during and following the pandemic for individuals with I/DD from tribal communities is needed. The response to the COVID-19 pandemic, and the health and education disparities that were revealed, highlight the need for social change that achieves true equity and support for individuals with disabilities and particularly for those who are most impacted due to health risks and poverty.

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12.

COMING TOGETHER DURING COVID-19: A MIXED METHODS EXPLORATORY STUDY ON COLLECTIVE EFFICACY IN A STATE DEVELOPMENTAL DISABILITIES NETWORK

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[Coming Together During COVID-19: A Mixed Methods
Exploratory Study on Collective Efficacy in a State
Developmental Disabilities Network PDF File](#)

Plain Language Summary

A group that believes they can reach a common goal by working together is more likely to achieve that goal. This is called collective efficacy (CE). CE is connected to many positive outcomes. For example, teachers with CE can help student grades. Communities with high CE have people who are less stressed. The pandemic has made new problems for people with disabilities. Many groups that serve those with disabilities need to work together in new ways. Groups with high CE might respond better to these crises.

Disability-serving agencies in Arizona worked together in new ways. This study looked at what made this group a success. This study also looked at what helped the group have high CE. We talked one-on-one with people from this group. We also sent a survey to this group. We asked questions on their CE before and during the pandemic. We also asked what they thought would happen in the future.

We found that trust, group ability, and leadership are all important pieces of CE. We also found that the CE did change in this group because of the pandemic. The group thought they were more successful now than before when they had low CE.

Every person, organization, and agency has been impacted by the COVID-19 pandemic, and disability-serving agencies and organizations are no different. This pandemic has challenged the status quo of how agency and organizational systems partner and provide services, requiring them to adapt to continuously evolving circumstances. The purpose of this study was to explore how a statewide disability network of organizations has evolved in response to COVID-19. Literature examining community responses to traumatic events, such as natural disasters, describes the role of collective efficacy (CE) in empowering the community to form a coordinated response (Benight, 2004; Boon et al., 2012; Norris et al., 2008). CE is defined as a group's shared belief and resulting coordinated actions that can result in a stronger system for collective voice and action (Bandura, 1993, 1995, 2000). Furthermore, researchers have identified that common exposure to an external event of magnitude can prompt CE (Watson et al., 2001). Therefore, the hypothesis of this study was that COVID-19 had an impact on the CE of the statewide disability network. Specifically, this study was designed to address the research question, "How did COVID-19 impact

the shared group perception of collective efficacy among the Arizona Developmental Disabilities Network (ADDN)?”

Urgency of Disability Organizations to Adapt in Response to COVID-19

The COVID-19 pandemic has exacerbated pre-existing inequities that minority groups, like those with disabilities, face in their daily lives (Horner-Johnson, 2020). Individuals with intellectual and developmental disabilities (IDD) are at greater risk for COVID-19 for many reasons including their physical health, mental health conditions, and social circumstances (Grier et al., 2020). For example, once lockdown orders were made from state officials, many day habilitation and other support service programs were unable to provide services, causing a temporary disruption in physical and mental health supports for individuals with IDD (Villani et al., 2020). The COVID-19 pandemic has also negatively impacted families and caregivers financially, mentally, and emotionally (Arc, 2020; Willner et al., 2020). Nonmedical supports and services have also been impacted by COVID-19. Many students with disabilities are participating in remote schooling without the necessary accommodations, support personnel, and supportive environmental conditions they need in order to learn (Arc, 2020; Hughes & Anderson, 2020;

Sutton, 2020). In addition to the state's developmental disability network, there are many state and local organizations that provide supports to help individuals with disabilities and their families. This paper aims to examine how the Arizona disability network adapted and organized itself to identify the needs and advocate on behalf of individuals with IDD as a collaborative network in the wake of COVID-19.

Impact of COVID-19 on Organizational Factors

COVID-19 has forced organizations to quickly adapt to changes brought forth by the pandemic including assessing and adjusting their communication and service delivery systems, as well as their processes for monitoring the services they provide. Resources and recommendations that were identified by the Centers for Disease Control and Prevention for the general population to convey information about the pandemic were not initially designed to consider individuals with IDD (e.g., access to information and plain-language materials and explanations). Therefore, communications about the pandemic were frequently left to personnel from organizations that serve individuals with disabilities (Sabatello et al., 2020). Since COVID-19, researchers have cited that collaborations such as expanding community partnerships are of the utmost importance (Campbell, 2020; Dooley, 2020). Resiliency at multiple organizational levels (individual, team,

and organizations) is also needed to respond to turbulence caused by natural disasters and public health crises (McCann et al., 2009). Collaboration and organizational resilience are key components that contribute to our understanding of how organizations respond or adapt to change.

Collaboration, or the process of working with others to produce or create something (e.g., networks and associations), is often cited as being beneficial especially during crises (Kapucu et al., 2010; Waugh & Streib, 2006). Collaboration among organizational systems includes sharing financial resources, transferring knowledge, sharing responsibilities, and producing synergistic solutions (Guo & Acar, 2005; Hardy et al., 2003; Shaw, 2003; Snavely & Tracy, 2000). Collaborations often take a considerable amount of effort and time to facilitate; however, when a crisis situation occurs, it can impact the speed at which these collaborations are formed, as well as how often the organizations collaborate. Additionally, research has outlined some characteristics of successful collaboration partnerships, which include trust, flexibility, balance of power, shared mission, communication, and commitment (Bergquist et al., 1995; Shaw, 2003). These traits can be considered when leadership discusses what a collaboration among organizations looks like.

Like collaboration, organizational resilience is an important factor for predicting how well organizations handle crises such as pandemics. Organizational resilience is the dynamic process that mediates a close relationship within a system and between

the system and its environment (Witmer & Mellinger, 2016). Resilience is the psychological capacity and capability of adapting to stressful, potentially long-term conditions (Maher et al., 2020; Masten, 2001). Key aspects to increasing organizational resilience in response to crises include the use of multidisciplinary teams and the expansion of job descriptions to allow more flexibility (Peterson & Mannix, 2003; Witmer & Mellinger, 2016). In times of crises, when teams must work quickly to respond to immediate needs, multidisciplinary teams are often beneficial as they are associated with greater team collaboration and achievement of goals (Jankouskas et al., 2007; Quinlan et al., 2016). Solutions developed through multidisciplinary teams are often more comprehensive, addressing a variety of aspects of problems based on the individual disciplines of the team members (Uitdewilligen & Waller, 2018). Broadening job descriptions may also help organizations have employees take on a variety of tasks when needed. This is particularly helpful during crises when job descriptions may expand due to shifts in organizational priorities.

Because of the overlap between collaboration and resiliency, attempts at creating theoretical frameworks that include these constructs have been developed in workplace contexts (Rees et al., 2017), though this has not been applied to intra-organizational research. Given the many factors in organizational settings, collaboration and resilience within a network are subject to change given the complex systems

guiding these interactions (e.g., personal relations, economics, politics; Bertalanffy, 1969). Social and organizational psychologists have long investigated environmental change in organizations (Lengnick-Hall & Beck, 2005), yet less is known on how collaborations are formed, triggers for collaboration, and adaptation of collaboration during crises situations (Parker et al., 2020). Little is also known about how organizational resilience might alleviate the negative impacts of COVID-19 in organizations. This study contributes to research on how state organizations can collaborate as multidisciplinary teams and work together during times of crises to better serve the disability community. We developed a questionnaire to assess CE attributes experienced by the ADDN by respectively examining CE prior to COVID-19, currently, and predicted likelihood of CE attributes continuing in the future.

Collective Efficacy

This study aimed to understand the ADDN partners shared perception of CE and the change in CE over time. CE is a group's shared belief that through their united efforts they can overcome challenges to achieve common goals (Bandura, 1993, 1995). This construct is grounded in the social cognitive theory (SCT) of behavior change that asserts a person's behavior is connected to their own efficacy or belief that they can act. Elements of SCT and efficacy have been supported by

research demonstrating individual efficacy beliefs to be strong predictors of individual behavior (Anderson et al., 2007; Multon et al., 1991; Osborn et al., 2010; Sundborg, 2019).

While self-efficacy has been well-defined and the components well-researched, CE is less distinct, and the identified components tend to vary based on the discipline. For example, within the educational literature, CE in teachers has been defined and measured through the use of group competence and task analysis (Adams & Forsyth, 2006; Goddard, 2002). However, within the sociological and social psychology literature, CE tends to be measured using social cohesion (trust) and social control (Arad et al., 2020; Heid et al., 2017). Some educational literature has expanded to include social competence and various enabling structures (e.g., leadership), in addition to group competence (Gray & Summers, 2016; Hoy, 2002).

Despite these differences in definitional components, researchers generally argue the need to retire the idea that self-efficacy and CE can be measured and defined using the same components because focusing just on the elements of self-efficacy can ignore important contexts that contribute to CE (Adams & Forsyth, 2006). Additionally, an examination of literature across disciplines points to some consistency in measuring components of CE. In measuring CE, many studies have included the following components: perception of group competence (Adams & Forsyth, 2006; Goddard, 2002), social cohesion (trust; Gray & Summers, 2016; Heid et al., 2017;

Hoy, 2002), and other enabling structures, such as supportive leadership (Gray & Summers, 2016; Hoy, 2002). For the purposes of the current study, the authors took a multidisciplinary approach in defining CE, choosing to specifically examine the most impactful components and created a questionnaire reflecting CE elements. In the following section, we define the CE elements and explain how these elements align with responding to emergency crises.

Group competence has been used as a measure for CE (Goddard, 2002) because it has been found to predict successful outcomes in groups with high CE under conditions of stress (Goddard et al., 2000). Social cohesion that reflects the trust and connections among members of groups has also been found to moderate relationships between adversity or stress and negative outcomes and promote actions from members for the benefit of the group (Heid et al., 2017; Wang & Fowler, 2019). Trust between group members may facilitate a willingness to participate in actions that mutually benefit the group and its goals (Sampson et al., 1997). Enabling structures help to create organizational environments that allow personnel and staff to be professionally autonomous, collaborate with others, and engage in problem solving (Adams & Forsyth, 2006; Gray & Summers, 2016; Hoy, 2002). These activities establish working relationships and trust with peers that has the potential to foster greater levels of efficacy (Adams & Forsyth, 2006; Hoy, 2002).

Research has shown that high levels of group CE are

connected to a variety of organizational benefits, including improvements in professional growth and decreases in stress. In addition, and in alignment with the current study, some research has demonstrated high levels of CE is associated with improvements in the overall collaborative impact of groups responding to ongoing challenges as well as unforeseen circumstances (i.e., teachers, first responders, and community responses to natural disasters; Benight, 2004; Carroll et al., 2005; Donohoo, 2016; Prati et al., 2011). Of particular interest to this study has been the recent work showing CE and overall collective responses to be useful in sustaining changes made in response to a disaster (Smith & Gibson, 2020). However, to date, no current literature examines how a pandemic or natural disaster has specifically brought together a group of organizations to better serve the disability community.

Arizona Developmental Disability Network

Developmental Disability Networks exist in all states and territories, comprised of three major partners as authorized under the Developmental Disabilities Assistance and Bill of Rights Act of 2000. These partners include University Centers for Excellence in Developmental Disabilities (UCEDD), State Developmental Disability Councils, and State Protection and Advocacy Systems. Given the many systems involved, it is unsurprising that there is individual yet complementary roles

to these sets of agencies in addressing state-level challenges to the disability community (Rudolph, 2009). Arizona is home to two UCEDDs: The Northern Arizona University Institute for Human Development and the University of Arizona Sonoran Center for Excellence in Disabilities.

The Arizona Developmental Disability Network (ADDN) is a group of organizations that work in partnership to serve the Arizona disability community (Sonoran Center for Excellence in Disabilities, n.d.). The core members of the ADDN consist of the Arizona Developmental Disabilities Planning Council (ADDPC), the Arizona Center for Disability Law (ACDL), the Institute for Human Development (IHD), and the Sonoran Center (UCEDD). The ADDN began to organize as a collective network around 2007 (ADDN, 2007). The purpose of the network, as outlined in their Memorandum of Understanding, is to work collaboratively and strategically to identify and address common goals through the identification of best practices and mutually shared goals (ADDN, 2017).

In mid-March 2020, as a national emergency was declared in the U.S. in response to the COVID-19 pandemic, the ADDN leadership team identified a need to respond to the disability community believing they would be more severely impacted by COVID-19 than other populations (White House, 2020). In responding to this perceived need, the ADDN partners met to determine how they could better identify and respond to gaps occurring as a result of the pandemic, while developing a

coordinated effort to help the Arizona disability community. As the ADDN partners worked to respond to the ever-growing need in the community, they expanded to capitalize on the expertise of other partnering agencies including the Arc of Arizona, the Native American Disability Law Center, and Raising Special Kids. For example, the ADDN and its partnering agencies worked together to coordinate virtual town hall meetings to understand community needs, develop weekly state-wide informational webinars open to the public, and advocate for the community at state-level agencies. For more details on the activities of the ADDN and partnering agencies, please see the Appendix.

Agencies within state DD Networks are nested within two systems—the individual state DD Network (e.g., IHD within the ADDN) and their national-level organization (e.g., IHD within the Association of University Centers on Disability [AUCD]). This multilevel system presents unique challenges and opportunities in how DD Networks communicate and share information among states. This exploratory study on the collective response of one state's DD Network, the ADDN, provides a chance to examine the critical components of that successful response, providing opportunities for other DD Networks to learn from these experiences. While in some instances DD Networks are already sharing information in pursuit of learning from each other, such as through the AUCD national conference and national weekly conference calls with the DD Planning Councils, this study provides

another such opportunity to examine best practices of DD Networks. This exploratory study was conducted to answer the following question: *How did COVID-19 impact the ADDN's shared group perception of collective efficacy?*

Methods

Methodological Design

The methodological framework of this study follows a concurrent design with quantitative study results embedded within qualitative themes. This mixed-method approach helps researchers identify similar themes in quantitative and qualitative results in order to draw conclusions (Creswell & Creswell, 2017). A mixed method approach was utilized to help researchers triangulate data using multiple methods, which is particularly useful during exploratory phases of research. Questionnaire and interview items were developed with consideration to CE subdomains and early conversations with ADDN members about their work. ADDN members then pretested the questionnaire and interview items to ensure validity (Bowden et al., 2002). The Institutional Review Board at Northern Arizona University approved all research components prior to recruitment and data collection.

Quantitative Questionnaire

Development and Design

The following section covers the development of the questionnaire items, as well as information on the reliability and validity of the questionnaire and the recruitment of participants.

Development of CE Questionnaire

The quantitative questionnaire was developed using established guidelines pertaining to questionnaire development (Krosnick & Presser, 2009). The questionnaire focused on measurement of CE as a group-level assessment rather than aggregated assessments of individual efficacy within a group (Bandura, 2000). This measurement decision allowed for the examination of group functioning and group members' reliance on each other to achieve outcomes, rather than the examination of how individuals functioned within the group.

Questionnaire items were developed and adapted from previous literature (Bandura, 1995; Goddard, 2002; Wang & Fowler, 2019) regarding CE in education-based contexts. Questionnaire concepts and items were first piloted with three ADDN members to provide the opportunity for feedback and to ensure questions were appropriate and aligned with their perspectives of activities and outcomes associated with the ADDN. Questionnaire response options included descriptive, frequency, and Likert-scale (strongly disagree to strongly agree)

items. These questions focused on subdomains of CE including: (1) social cohesion and trust, (2) group competence, and (3) enabling structures. The subdomain of “social cohesion and trust” included the following three items referencing components shown to contribute to trust within groups.

- Members of the ADDN and partnering agencies have shown they can be trusted to complete tasks that contribute to the group’s goals in a timely fashion.
- As an organization in the ADDN or partnering agencies, we have reached out to other members of the ADDN and partnering agencies to help with challenges experienced by Arizona citizens with disabilities.
- As an organization in the ADDN or partnering agencies, we have sought input from other organizations in this network of agencies.

The group competence subdomain included the following four items addressing different aspects of expertise within the group.

- I am confident that the leaders of the ADDN and partnering agencies could effectively coordinate collective action.
- I am convinced the ADDN and partnering agencies have the organizational and agency capacity to improve

quality of life in the community, even if resources are limited.

- I am familiar with the strengths of partners across this network of agencies.
- The ADDN and partnering agencies have shown they are effective at leveraging the resources of outside organizations as part of a network coordinated response or activity.

Finally, the enabling structures subdomain included the following two items referencing components shown to provide support to CE, such as sharing resources and supportive leadership structures.

- My supervisor has supported me in learning new skills so I could help support the ADDN and partnering agencies.
- Members of the ADDN and partnering agencies have shared resources across agencies to serve the disability community.

The questionnaire was estimated to take approximately 20 minutes. All questionnaire items were asked considering three time points (past, present, and a prediction of future collaboration): (1) prior to COVID-19, (2) at time of survey completion (late September/early October 2020), and (3) after the pandemic has ended. These dates were determined

considering our original research question that considered how COVID-19 impacted the ADDN's group perception of CE. Because COVID-19 was unplanned, data collection could not be collected before the pandemic providing us with limited measurement options. However, there is evidence that retrospective questionnaire designs can provide valuable information, especially when no other options for study are available (Euser et al., 2009).

Reliability and Validity

As mentioned above, there were no validated questionnaires on CE that were appropriate for the purposes of this study. Therefore, the research team designed a CE questionnaire to assess the ADDN's response to COVID-19. Reliability estimates were calculated using Cronbach's alpha for two time points. Prior to COVID-19 estimates were .81 and currently (late September/ early October 2020) were at .539. The unstable and low alphas were expected as small sample sizes, such as the one used in this study, tend to result in unstable estimates of reliability (Tavakol & Dennick, 2011). Throughout the qualitative results section of the paper, we do provide evidence of the alignment between the two types of data, contributing to measures of construct validity. Face validity was assessed through feedback provided by ADDN members (considered experts in the field) on the appropriateness of the CE constructs and questionnaire items.

Recruitment and Sample

ADDN members and their partnering agencies were sent a Qualtrics questionnaire link via email from an ADDN member known by the research team. The questionnaire was sent to 19 individuals and completed by 13 participants. This reflected an overall participation rate of 68%. All ADDN member and partner agencies were represented in the 13 participants who completed the questionnaire. Participants represented a variety of organizational roles, including executive directors of agencies/organizations, project coordinators, and other staff positions. Length of time in these roles also varied from less than a year to 19 years. On average, participants were at their current positions for about 5 years. After data were screened and no outliers found, all items on the CE scale were scored by taking the average, following recommended Likert-type scale practices (Sullivan & Artino, 2013).

Qualitative Interview Development

The following sections cover the development of the qualitative interview questions, as well as information on the recruitment of participants and details on the qualitative analysis methods used.

Question Development

Semistructured interviews were chosen as the interview approach. This allowed researchers to start with a list of structured questions but allowed interviewers to ask additional questions when a response introduced novel concepts that might be important to CE. Participants were asked about ADDN activities, roles, and perceptions, thus, adding a valuable dimension to our understanding of CE in the network. Interview questions were developed to align with questionnaire items that were aligned with the subdomains of CE including: (1) social cohesion and trust, (2) group competence, and (3) enabling structures. Questions in the social cohesion and trust subdomain probed how group composition and the quality of relationships in the group had changed over time, and the impact on group outcomes.

- How has the makeup of the group changed since COVID? Why did it change? What has been the impact? How do you know?
- How has the quality or strength of relationships between partners within the group changed as group activities increased in response to the COVID-19 pandemic?
- What did those relationships look like before? What do they look like now?

Questions in the enabling structures subdomain examine the

impact of external factors that helped or hindered the group's progress, and focused specifically on leadership and roles within the ADDN.

- What is your role in this group? How long have you known about the group? How has your role as a member of the group changed from before the COVID-19 pandemic to now?
- Are there particular group leaders or members who were the main drivers in facilitating the group's activities?
- What was the role within the group of the individuals who were most likely to follow through on the work of the ADDN group? How were these leaders identified?
- Were there factors or anything else that hindered the group's ability to respond to the COVID-19 pandemic?

Finally, questions in the group competence subdomain allowed researchers to probe for more in-depth information on the accomplishments of the group and how the competencies of its members impacted those accomplishments.

- What were some of the actions taken by the group during the COVID-19 pandemic that you believe were effective? Why were they effective?
- In what ways has the group's role in identifying and responding to the Arizona disability community needs changed since COVID-19?

- How has your perspective on the importance and relevance of the group changed since before the COVID-19 pandemic to now?
- What do you think the impact of this group has been on the communities the group aims to serve? What do you think are next steps for this group?

Recruitment and Sample

After participating in the questionnaire, a subset of eight participants who completed the questionnaire were emailed by the research team and asked to participate in a virtual individual interview. Out of the eight participants who were contacted, five participated in an interview. Interviews occurred within 4 to 8 weeks of completing the questionnaire. In order to incorporate a breadth of participant experiences, interview participants were selected based on their representation of a diverse sample of organizational affiliations and roles. Interview participants represented most organizations involved in the ADDN as well as partnering agencies, including the Arizona Developmental Disabilities Planning Council, the Institute for Human Development, the Arc of Arizona, and the Native American Disability Law Center, and a variety of roles from organizational directors to dissemination experts. Interview participants also ranged in terms of length of time in their current role from 15 years to less than a year. More specific information about interview

participants cannot be provided because of the small sample size.

Qualitative Interview Analysis

The 31- to 70-minute interviews were conducted in a one-on-one virtual Zoom meeting with one researcher conducting all the interviews. All interviews were recorded using Zoom and transcribed using the built-in automatic transcription service. Transcripts were then reviewed and edited by the research team to clean up mistakes in automatic transcription. Finally, the research team analyzed transcripts by hand using the commenting feature in Word. The research team used a deductive method of analyzing the interview data, taking the overarching theoretical framework previously identified and developing a coding tree based on those concepts (Kyngäs & Kaakinen, 2020; Teufel-Shone et al., 2006). A primary researcher coded all transcripts, with an additional researcher confirming all codes and identifying gaps or additional codes. If new codes were identified, researchers would come together to reconfirm those codes. While approaching the qualitative interview data with predetermined codes, the researchers still allowed new concepts to emerge from the data if important ideas were not fully encompassed within the structured and preidentified codes. For example, while a portion of the predetermined codes included enabling structures, the interviews added further depth to those codes through the identification of the importance of shared leadership.

Results

From March 2020 (the start of the pandemic) to November 2020, increases in time collaborating, partnering on activities, and sharing resources to better serve the disability community were noted. A paired t test was conducted to examine the response to the questionnaire data. On average, ADDN and their partnering agencies perceived lower CE of the group before the COVID-19 pandemic ($M = 3.93$, $SD = 0.52$) compared to currently ($M = 4.51$, $SD = .45$). This difference was statistically significant $t(11)-3.56$, $p = .002$. When asked to make future predictions related to CE and the COVID-19 pandemic ending, most participants (92%) believed that after the pandemic the group would be trusted to complete tasks that contribute to the group's goals in a timely fashion. All participants (100%) were confident in the ADDN and partnering agencies in coordinated effective collective action.

The quantitative results alone are not sufficient in this study to draw robust conclusions but can be used to add strength and support to the main qualitative study. Thus, where applicable, additional descriptive statistics comparing retrospective questionnaire responses from prior to COVID-19 to current questionnaire responses are embedded in the qualitative themes that were confirmed through or emerged from the data and are described below. Three of the themes described align with the CE subdomains: social cohesion and trust, group competence, and enabling

structures. The two additional themes described emerged from the data and include group functioning prior to COVID-19 and network outcomes. The themes below are ordered in a timeline that seemed to reflect the most natural flow of the themes. These themes begin with group functioning prior to COVID-19 and end with the outcomes of the group.

Group Functioning Prior to COVID-19

Through the process of the interviews, participants often spoke of the way the group functioned prior to creating a system for responding to the COVID-19 pandemic. Prior to the pandemic, agencies and organizations in the ADDN worked as independent organizations rather than as a collective whole. While they might work across organizations on a single grant-funded project, much of their work was conducted independently.

One participant spoke of how their perception of coordinated actions changed as a result of their recent work with the ADDN,

At the very beginning when [another ADDN group member] came [to Arizona], she was saying we need to do things more coordinated. We need to do more coordinated activities and I was confused because I was like why, we already do things that are coordinated, you know, we work together on grants.

Other participants also spoke of the lack of collective action prior to the activities in response to the pandemic.

In a great many discussions and a great many projects that sort of touched on these issues in the past, but it was always kind of a one off. It was always working individually with one agency, one DD network partner or member or another. It was never kind of a collective effort.

The changes to the perception of the group's capacity to act as a collective network was reflected in the questionnaire results with most questionnaire participants reporting that they were more confident at the time of the questionnaire that the ADDN could effectively leverage resources as part of a coordinated action than prior to COVID-19, increasing from 67% to 100%.

Social Cohesion and Trust

Social cohesion was confirmed as a theme for the individuals interviewed. Participants talked about how the increase in the amount of time spent working together and resulting relationships and trust between members of the ADDN created a positive effect and aided the success of their work. This discussion about the importance of social cohesion reflects previous literature on CE in groups (Wang & Fowler, 2019). Trust and confidence in fellow group members aids the effectiveness and efficiency of completing the work. Participants described how social cohesion and trust

contributed to their understanding of the group's capacity to effectively accomplish goals and how the pandemic has contributed to setting the tone of this group's response.

It has taught me a lot more about what the organizations are capable of and it's taught me much more about what they do routinely, things that I didn't know before. What I've learned is that they really are capable of responding very rapidly and responding in ways that make a difference for people in ways that make an immediate difference. So I guess I feel like they're even more important now and will continue to be because it seems like a different tone has been set, and it doesn't seem like.... It doesn't seem to me that that tone is going to disappear, that your organizations will revert back to some former look.

Participants also described how the cohesiveness of the group and their common goals lead to greater outcomes.

I think it dawned on me a little bit how you can get a lot more done with a collective group like that. You know, coming together with a similar mission and purpose or at least you can reach more people whether or not you get anything more accomplished remains to be seen. But there's just power in that. Common goals and objectives with a larger group, I think better inform people and get the point across, and get things accomplished maybe.

Questionnaire results reflected increases in social cohesion from prior to COVID-19 to the time of questionnaire. ADDN members and their partnering agencies shared that

they were more likely to seek input a few times per month or more frequently from other ADDN members after COVID-19 began, increasing from 33% to 67%. They were also more likely to request assistance from their fellow partner agencies when encountering challenges, with participants reporting an increase from 25% to 75% in requests that occurred at least a few times.

Group Competence

Another theme that was confirmed from the interviews that also aligned with literature in this area was group competence—or the perception that the group has the capacity to serve the disability community. Participants who were interviewed by ADDN pointed to the capacity of the group to recognize and fill gaps, creating a space for the disability community to come together and voice their concerns.

Participants discussed the idea that different organizations came together to fill different gaps, leading to a more comprehensive and responsive system, which contributed to the overall sense of group competence.

There's a lot of diversity of expertise within the group, having a [Protection and Advocacy agency] with its legal expertise. You know there's just an amazing amount of knowledge held by the individuals who've been involved in this process.

While only one participant described how their organization fulfilled a role that many other organizations could not, this idea reflects the unique and complementary roles of the DD network agencies.

Unlike those agencies which are prohibited from lobbying because of their funding for the most part anyway prohibited to lobbying we do quite a lot of lobbying. We do a lot of work at the legislature that sometimes would cross a line for those organizations.

Perceptions of group competence were also displayed through confidence that group members could advocate successfully on behalf of disability community members.

I think that we're creating more of a permanent space for people to be able to have their issues heard. So, I think that's changed... I believe that the community knows now who to go to if they have issues. They can go to any of our organizations and let us know when there's issues or email us or something. So, it's almost building trust with the community to come to us if there's issues that we can help advocate the state.

Enabling Structures

Enabling structures or resources, supportive leadership, and prior knowledge, was confirmed as the final theme aligned with the framework used to approach this study. These structures created an environment in which the ADDN could

successfully complete their work, providing opportunities for staff members and agency leaders to collaboratively execute plans to alternatively gather and distribute information to the disability community. These structures contributing to the success of the group included intentional diversity in the roles of the ADDN members, a shared leadership model, and leadership skills.

Participants discussed how the diversity in agency leaders, as well as their combined supportive leadership styles contributed to the success of this group.

Every one of the directors for each one of the Network have a way of looking at this in an overarching universal way. And they're all paying attention. They all have different personalities about how to communicate and I could probably talk about how each one of them contributed very well to the situation. And when you have that blend. And when you have that diversity. I think, not many things don't get left on the table at that point to think about and to approach.

Participants also mentioned the necessity of the shared leadership model in response to the COVID-19 pandemic.

There was some natural roles that just came about, especially on the leadership side. With something this, for a lack of a better word, monumental there had to be many leaders. And then the leaders that were identified or the directors had to be able to give sort of a little bit, give a little bit up on the control side of things. And what happened was, we had a very active team.

Another component of enabling structures included supporting other organizations outside the ADDN. In one specific example, a leader was conversing with a newer member of the group who worked on the Navajo Nation. This new member brought up how their specific organization fit into the webinar conversations given that the Navajo Nation operates different than the state agencies. The ADDN leader responded,

I told [the new member] like that you don't understand, we also serve the entire state. So we care about the Navajo Nation and [the new member] was like, Well, what I have learned is that, you know, the things that you guys are looking at I have taken those same questions to our Navajo Nation DDD.

An increase in supporting partner agencies from prior to COVID-19 to currently through resource sharing was also demonstrated through the questionnaire results, with questionnaire participants reporting that they were more likely to share resources with fellow network members at least a few times per month, seeing an increase from 42% to 83%.

Network Outcomes

The final theme that emerged from the interviews was an understanding of the network's success or outcomes because of their collective action. Network outcomes identified by interview participants included the more responsive nature of

their activities, through which ADDN group members felt they were more able to meet the needs of the disability community.

The silver lining from this pandemic is [it] clearly increased our responsiveness to collective discussion and action. We believe that there has been a renewed reunification among the DD Network stakeholders to the work of serving the IDD population and their families.

The responsive nature of the ADDN was only improved by the creation of forums (webinars) in which the disability community could make their needs understood and known. While the COVID-19 activities were initially created out of a desire to understand and respond to the communities the ADDN supports, these activities might serve a longer-lasting purpose.

I think that we're creating more of a permanent space for people to be able to have their issues heard.

There's been a lot more interaction with community members and a lot more idea generation from those community members. They've made their needs known, they've made their concerns known, they've made it clear what is affecting them and how they would like the DD network members to address those issues.

While the collective action of the group was viewed as its own outcome, that action brought an entirely new set of outcomes

including an increase in trust and prestige from the perspective of state agencies.

So now we've actually re-positioned ourselves as a group, as being more prestigious, I guess, and having more, you know, power.... And so they have listened now, there's some things that we're still fighting them on, but they have responded to many of our requests for changes to be made.

However, participants still acknowledged that they had more work to do in advocating for their community, but they were confident that they were exactly the right mix of group members to achieve their goal.

There are just a lot of lessons to be learned from this and we as partners should be pointing out what those lessons are and recommending ways to be better prepared in the future. I honestly believe that is—That is one of the most important things this group can do and there probably is not a better composed, better comprised group in the state to do just that.

Discussion

Results from this study suggest that CE within the ADDN has increased due to the collaborative actions consciously taken in response to the COVID-19 pandemic. While ADDN agencies have historically worked together, COVID-19 required the ADDN to act in more cohesive and synergistic ways across all agencies to advocate for the Arizona disability population

more effectively. Interview data and questionnaire responses support this conclusion. Participants reported CE components were present to a lesser extent prior to the start of the pandemic and increased after the initial shutdowns in March 2020. In examining how COVID-19 impacted the shared group perception of CE among the ADDN, interview and questionnaire data from this study provide support for the importance of the stated CE components (i.e., social cohesion/trust, group competence, and enabling structures) and how changes in these CE components impacted the group perception of CE among ADDN members. This study fills a gap in research by addressing how strengthening CE components within a group might improve the collective response to crises, such as the pandemic. By examining the results of this study and how the components of CE were employed within the ADDN, we might build upon the results to cultivate CE in other DD networks.

In many ways, the results of this study were not unexpected, and our study results align with previous literature on CE. Evidence of collaboration and organizational resiliency was found as many organizations tend to rely on other organizations during crises (Kapucu et al., 2010; McCann et al., 2009; Waugh & Streib, 2006). Also aligned with previous literature, characteristics of successful collaborative partnerships were found within the ADDN, with interviews and questionnaire data noting elements of trust, flexibility, balance of power, shared mission, communication, and

commitment (Bergquist et al., 1995; Shaw, 2003). Group competence through the varied skill sets of a multidisciplinary team (Jankouskas et al., 2007; Quinlan et al., 2016) was also found within this study. Overall, the benefits of CE in the ADDN were expected, as they are often noted during crises situations (Gray & Summers, 2016; Heid et al., 2017). The benefits of this study are not only in its support of previous literature on CE, but in how other DD networks may use and apply this information in other contexts.

DD networks interested in facilitating CE to generate significant change in their communities should focus on strong leadership and diversity in experience and skill set, two crucial components found in this study. Strong leadership acts as an enabling structure providing clear direction and setting a work agenda for the group. It also provides needed permission for other members of the group to act on ideas and flex time spent on projects to provide support when needed to other group members in other agencies. While an initial strong leadership component is often needed to have a cohesive start to the conversation among network members, this study also found that flexibility within leadership models over time was necessary. As the responsive work of the ADDN grew, leadership responsibilities often shifted to trusted staff members. This evolving shared leadership model can help facilitate more effective and efficient activities. In this instance, when called to action over a clear goal, many staff members

rose to the occasion and took on the leadership roles with the support of agency directors.

Diversity in knowledge, experience, and skills were crucial to the ADDN's ability to collaborate and achieve outcomes. With more diverse leaders and perspectives contributing to a network, they are better able to address the diverse needs of the state's disability community. Diversity of community connections within a single network can help the network connect to different communities across a state and identify and address common concerns the larger disability population is facing. Additionally, diversity of roles and skill sets within a DD network allow for better diffusion of skills across the network, with network members teaching and learning from each other. In helping other DD network members learn new skills, the capacity and cohesion and trust of the DD network is continually expanding. This need for diversity can also be reflected in diversity of expertise within the disability community (e.g., disability and legal policy, advocacy, etc.), contributing to overall group competence, which was found to be critical in the effectiveness of ADDN activities. DD networks should find creative ways to leverage the skill sets and expertise of their members, as they work together to strengthen their DD network.

Finally, the cohesive and responsive actions of a DD network might be aided by regular and consistent communication with the disability community. The ADDN achieved this by creating a virtual space through webinars and

virtual town halls to discuss topics that were impacting them. This allowed the group to leverage the diversity of their network by bringing in additional partners and guests to discuss perspectives, experiences, and resources for the community. These opportunities were especially important as they created spaces for the Arizona disability community to voice their opinions and concerns during a time when they were otherwise isolated. Potentially, the most important piece of this is the way the network responded to the voices of this community by specifically planning their activities around these concerns. It is not enough to listen if the DD network is not also reacting and responding.

By leveraging the resources of all the agencies and organizations within their DD network and listening to the needs of the community, the ADDN has been able to provide recommendations and successfully advocate for the needs of their disability community. They have provided various recommendations to state agencies and have seen policy change occur as a result of their work. Their work as a collective network has shown that power is in numbers. By working together on a cohesive message and goal, they had more influence to advocate for and serve the disability community compared to working as separate independent organizations, illustrating the power of CE.

Limitations

Limitations for this study included a small sample size in the quantitative analysis; therefore, careful interpretation of these results is recommended. It should also be acknowledged that our questionnaire was made for this specific study, although the questions were drawn from an extensive review of CE and it was piloted with some ADDN members. Additional consideration of CE components and a thorough psychometric assessment in a large sample are needed for this scale to be adapted for additional contexts. An additional limitation lies in the retrospective questionnaire design, which can introduce bias into questionnaire results (Nimon et al., 2011), though some research recognizes the value for retrospective design during unprecedented circumstances such as a crises situation (Euser et al., 2009). The unique and unexpected nature of events that this questionnaire sought to study warranted using a retrospective design.

Finally, both the COVID-19 pandemic and the actions taken by the ADDN provided the unique context in which this study took place. This is another potential limitation, as it is unknown whether similar organizations and agencies and the resulting collaboration would have happened in another context. This study, however, presents one step toward understanding what makes these DD network collaborations exceptional and effective.

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Appendix

To date (September 2020), the ADDN has facilitated a total of 16 webinars. Topics for these webinars were selected by the ADDN and partnering agencies based on virtual conversations and town hall meetings held with community members. Webinar topics included the impact of COVID-19 on the disability community, managing benefits and finances during COVID-19, maintaining mental health during a pandemic, and living as a person of color with IDD during COVID-19. Generally, guest speakers were invited by the ADDN and their partnering agencies. These guest speakers were invited based on their expertise or experiences on the topic. Members of the ADDN moderated the sessions—this included monitoring video and chat functions to make sure that the speakers could address comments and questions being asked. The ADDN worked together to send email invitations to individuals with IDD, family members, and providers to those with disabilities to the webinars. Participants could join the webinar by computer or phone. As October 2020, there were 1,218 individuals who attended one of the 16 events held with—many individuals participating in multiple webinars. There were additional network activities that occurred within the ADDN such as collaborating on several letters advocating for the rights of those with disabilities. However, these activities are not as well documented.

13.

MENTAL HEALTH SUPPORTIVE SERVICES DURING COVID-19: PROPOSING AN ONLINE, SELF-GUIDED ACCEPTANCE AND COMMITMENT THERAPY PROGRAM FOR PARENTS IN THE DISABILITY COMMUNITY

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[Mental Health Supportive Services During COVID-19:
Proposing an Online, Self-Guided Acceptance and
Commitment Therapy Program for Parents in the Disability
Community PDF File](#)

Plain Language Summary

Parents of children with intellectual and developmental disabilities (I/DD) often experience stress. The COVID-19 pandemic has likely increased parents' stress. In this paper, we describe four things. First, we describe how mental telehealth treatments can decrease parent stress. Telehealth programs are often delivered by phone or computer. These programs include those that target behavior training and those that provide therapy. Second, we describe challenges of these programs. Then we explain how online, self-guided programs may help address these challenges. Third, we explain our online, self-guided Acceptance and Commitment Therapy (ACT) program. ACT is a type of therapy that helps people notice their moods and their thoughts to help manage stress. Finally, we ask for collaboration to improve and expand our ACT program.

Parents of children with intellectual and developmental disabilities (I/DD) experience significant stress from physical, cognitive, and behavioral characteristics of their child, balancing their child's needs with that of other family members, and support factors including navigating complicated service systems for their children (Marquis et al., 2019). These stressors are exacerbated in the context of COVID-19 where new financial and social challenges arise, coupled with an environment where many I/DD and mental health services have been canceled or adapted into telehealth modalities (Bradley, 2020; Pierce et al., 2020). Accordingly, this paper describes the effectiveness of mental telehealth options for parents of children with disabilities. Next, we discuss several challenges of service-delivery models, explaining how online, self-guided programs may provide a viable and effective option to meet the growing psychological needs of these parents, particularly during COVID-19. Last, we introduce our online program that targets stress and wellbeing in parents and propose a call for collaboration with clinicians, therapists, and advocates working with parents of children with I/DD.

Telehealth Services

Across the U.S., telehealth services provide a socially distanced and safer solution in the wake of COVID-19 (Adalja et al., 2020). Telehealth services use technology to communicate

with clients remotely, often provided synchronously, using videoconferencing or telephone calls (Hilty et al., 2018). Most commonly, appointments are scheduled *a priori*, take place during normal business hours, utilize similar amounts of service provision time, and are available to individuals, families, and groups (Pierce et al., 2020). Telehealth services can be asynchronous, allowing individuals and service providers to interface at different times, or for clients to access resources independently (i.e., self-guided). Examples include “patient portal” models where clients upload materials or information at their convenience and the provider reviews and responds later. Self-guided education and supportive services are also asynchronous options in which individuals review resources on their own delivered through text, audio, video, or interactive modules. Telehealth programs have addressed mental health needs of parents of children with autism spectrum disorder (ASD), parents of children with life-threatening illnesses, and parents of children with other health conditions (Bearss et al., 2018; Hinton et al., 2017; Muscara et al., 2020; Nieto et al., 2019; Vismara et al., 2013).

Effectiveness of Synchronous Telehealth Services

Even prior to COVID-19, synchronous telehealth services were available for parents of children with I/DD, targeting behavioral symptoms and parenting skills, and reporting

positive outcomes (Bearss et al., 2018; Muscara et al., 2020; Xie et al., 2013). In a program for parents of children with autism (Bearss et al., 2018), therapists trained parents via video conferencing. Participating parents reported increased confidence when managing behavioral symptoms and endorsed recommending the program to others (Bearss et al., 2018). In another program, parents of children with ADHD improved their disciplinary practices and other parenting skills after 10 small-group videoconference sessions with a therapist (Xie et al., 2013). This program evaluation included a face-to-face therapy comparison group; levels of improvement were positive and similar across both modalities, suggesting that telehealth services can be as effective as in-person services (Xie et al., 2013).

Telehealth has been studied in highly stressed parents, not limited to parents of children with I/DD. Muscara et al. (2020) studied the effects of an acceptance and commitment therapy (ACT) group intervention delivered via video conferencing. Parents had children who were recently diagnosed with a life-threatening illness or injury. Parent groups met with a mental health facilitator to build skills in reducing posttraumatic stress symptoms (PTSS). Over six sessions, parents significantly decreased PTSS and had greater improvements in their subjective experiences of their child's illness, as compared to a control group (Muscara et al., 2020). This is promising evidence that telehealth services, specifically ACT-based services, can reduce parental stress.

Effectiveness of Telehealth-Online Hybrid Programs

While some telehealth services are completed entirely in real time with a service provider, others implement combinations (a hybrid) of synchronous and asynchronous delivery (Bai et al., 2015; Hinton et al., 2017; Vismara et al., 2013). One example is the Triple P Online-Disability (TPOL-D) program, which helps parents of children with disabilities increase parenting skills and self-efficacy, while also decreasing behavior symptoms in their children (Hinton et al., 2017). The program included self-guided modules, an online parent-support group, and an optional weekly call with a facilitator. Parents who participated in TPOL-D significantly increased their self-efficacy and positive parenting practices (Hinton et al., 2017). Similarly, in a program for parents of children with ASD, synchronous and asynchronous hybrid delivery included live video conferencing combined with self-guided work online. Improvements were identified in building parents' confidence in addressing their child's needs and in teaching parents effective ways of relaying that information to other caretakers (Vismara et al., 2013). Another hybrid program for parents of children with ADHD used online lectures and group sessions led by a facilitator. Compared to a control group, participating parents reported increased knowledge of ADHD and intention to adhere to medication (Bai et al., 2015).

The emphasis for the above programs is primarily helping parents manage behavioral symptoms. While these programs effectively reduce exposure to stressors and improve parents' self-efficacy, other programs specifically target mental health and overall wellness of these parents. Pennefather et al. (2018) tested an online program for parents of children with ASD that not only covered topics about reducing certain behaviors in children through applied behavior analysis (ABA) but also used ACT principles to reduce parents' stress. Parents attended weekly synchronous sessions, accessed a webpage with additional resources and a group support feature, and completed homework. The program was associated with improved behavior symptoms in children and decreased parental stress.

Considerations of Delivering Synchronous and Hybrid Telehealth Programs

While telehealth-delivered supportive services for parents of children with I/DD offers clear advantages from face-to-face programs in terms of convenience, and minimizing travel and risk of viral exposure, four main limitations remain for synchronous telehealth: quality and consistent internet access, scheduling, scaling, and cost. Infrastructure to support internet access, while beyond the scope of this paper, is an issue that still exists throughout the rural U.S. and needs to be

addressed to support access to telehealth services (Greenberg et al., 2018). Scheduling appointments is also challenging for any parent but may be more so for parents of children with I/DD. Dowling and Dolan (2001) report numerous barriers including waitlists, scheduling conflicts when managing multiple providers, and appointments conflicting with work/school schedules.

The service ratio of synchronous services (one provider for one client) and the need to hire trained therapists creates issues with scaling and cost. Unmet needs are a known problem; long waitlists are documented in the Medicare system where the mental health needs of individuals with I/DD and their families are often unaddressed (Slayter, 2010).

Asynchronous Self-Guided Online Programs

Asynchronous self-guided (online-only) programs overcome burdens of scheduling, scaling, and cost (but not internet availability) by providing resources that parents can access at their convenience, without a provider, and at low cost. There are minimal provider cost-differences in offering self-guided resources to one parent versus 1,000 parents; thus, services are highly scalable. While these programs are costly to develop, once available they can often be offered at low-cost.

Effectiveness of Self-Guided Online Programs

The evidence for online, asynchronous interventions for mental health in the general population, albeit not specific to parents with I/DD, is compelling (Andersson, 2016). In a systematic review and meta-analysis, Cuijpers et al. (2010) included 21 studies of 810 participants with anxiety and depressive disorders and determined that online self-guided therapies are equally as effective as face-to-face therapy, even in studies with up to 1 year of follow-up (Cuijpers et al., 2010). Lorenzo-Luaces et al. (2018) reported that these kinds of findings are not an artifact of sample differences; participants across 21 studies completing internet-based Cognitive Behavioral Therapy (CBT) programs were comparable to participants included in studies of antidepressants and face-to-face therapy.

ACT and other therapeutic models have been used to teach parents of children with health issues or disabilities particular parenting skills (Lock et al., 2017; Nieto et al., 2019; Wainer & Ingersoll, 2012). These online programs have been implemented with parents of children who have anorexia nervosa (Locke et al., 2017), functional abdominal pain (Nieto et al., 2019), and ASD (Wainer & Ingersoll, 2012). A program using lectures, practice examples, videos, and quizzes to help parents and professionals address behavioral symptoms of children with ASD identified that users increased their

knowledge of behavior strategies (Hamad et al., 2010). In a study of an asynchronous gaming platform, vulnerable parents were incentivized by the game to learn positive parenting skills by offering virtual rewards for practicing a variety of parenting and stress-reduction skills. The program was effective, with parents reporting lower stress after completion (Love et al., 2016). The success of these studies supports that online, self-guided therapies targeting mental health symptoms and stress management must be considered a viable option for vulnerable persons, including parents of children with I/DD.

A Novel Online Self-Guided Program to Reduce Stress in Parents of Children with Intellectual and Developmental Disabilities

The stress faced by parents of children with I/DD is well-documented and already considered an important target for intervention (Marquis et al., 2019). The COVID-19 pandemic has forced clinicians, therapists, and researchers of parents with I/DD to adapt quickly to virtual formats to safely address the increased parental stress. Online asynchronous delivery is an effective option for therapeutic stress management, with this modality overcoming barriers of scheduling, scaling, and cost. Here we introduce our program, ACT for Parents: an

online self-guided program building ACT skills, specifically adapted for parents of children with I/DD. We first explain ACT principles, as these are core to the program and make it unique from online CBT. We then present evidence of the effectiveness of online ACT in similar populations. We briefly describe our program, and we end with a call for collaboration.

ACT is a modern form of CBT that focuses on increasing psychological flexibility (i.e., engaging in meaningful patterns of activity while accepting whatever internal experiences arise) through a combination of acceptance, mindfulness, and values-based skills (Hayes et al., 2006). Psychological inflexibility, the opposite of psychological flexibility, is when behavior is rigidly controlled by cognition, emotions, and internal experiences, or when attempts to avoid these experiences result in less meaningful or ineffective behaviors (Hayes et al., 2006). ACT uses six core components to facilitate psychological flexibility: (1) acceptance, (2) cognitive defusion, (3) present moment awareness, (4) values, (5) self as context, and (6) committed action (Hayes et al., 2006). Acceptance and cognitive defusion emphasize decreasing the maladaptive behavior regulatory effects of internal experiences. Acceptance focuses on experiencing aversive internal experiences for what they are, rather than attempting to avoid them. Cognitive defusion involves relating to thoughts as “just thoughts,” rather than true facts. Other skills aim to shift clients’ sensitivity to meaningful parts of their environment by more flexibly attending to the present moment and developing

a more flexible sense of self-as-context (i.e., a sense that self is not the rigid, evaluative self-narratives we create, nor a “container for experiences”). A third subset of skills focus on increasing meaningful, effective patterns of behavior through values (i.e., identifying what one wants their life to stand for) and committed action (i.e., developing patterns of activity linked to one’s personal values).

ACT is well-established and well-supported in robust empirical studies. A review of 20 meta-analyses, summarizing results from 133 Randomized Control Trials (RCTs) with 12,477 participants, found strong empirical support for ACT in treating a wide range of mental health concerns (Gloster et al., 2020). Specific to parents of children with I/DD, ACT has helped mothers of children with autism improve emotion regulation (Salimi et al., 2019). In a meta-analysis restricted to 24 studies of diverse caregiving roles, such as caregivers of individuals with dementia and children with disabilities (Han et al., 2020), ACT had small but significant effects on reducing anxiety, small-to-moderate effects on reducing stress, and moderate effects on reducing depression and improving quality of life.

Online Acceptance and Commitment Therapy

ACT has been adapted to online, self-guided delivery in a range of populations, demonstrating effectiveness in multiple

RCTs. Levin et al.'s (2017) RCT found online-ACT to reduce depression and anxiety in college students. An RCT of a mobile app-based ACT program identified improved wellbeing and valued action in people seeking self-help, compared to a general population (Krafft et al., 2019). One meta-analysis of 10 RCTs identified that online ACT was effective in managing depressive symptoms (Brown et al., 2016); another meta-analysis of 17 RCTs supported effectiveness of online ACT for reducing depressive symptoms and anxiety (French et al., 2017).

Our own team at Utah State University recently developed and tested ACT for Caregivers—an online, self-guided ACT program for caregivers of people with dementia. Pre/post follow-up analyses of 51 caregivers identified statistically significant improvements across all care-related outcomes: decreased depressive symptoms, care-related burden, and stress reactions to behavioral symptoms, and increased positive aspects of caregiving and quality of life. ACT-specific outcomes also improved, with decreased cognitive fusion and psychological inflexibility, and improvements in living according to personal values (Fauth et al., 2019, 2021). Population similarities are noted here. Like parents of children with I/DD, dementia caregivers face behavior symptoms and chronic stress from their family caregiving role and have limited ability to schedule and attend appointments.

Based on promising results from ACT for Caregivers and other ACT programs, we developed online ACT for Parents.

This program is specifically tailored to build psychological flexibility, stress-management skills, and well-being within the context of parenting a child with I/DD, via 10 self-guided sessions of 20-30 minutes each. Each session focuses on one or more ACT concepts, building skills through practicing techniques, and applying concepts learned.

In developing ACT for Parents, we were purposeful in addressing limitations we have identified in many online programs. We note that many online programs are “text-heavy,” requiring users to spend considerable time reading about concepts, potentially contributing to skimming instead of internalizing the material, and general disengagement. Our modules use short-text formats—phrases, bullets, and graphic layouts that minimize visual fatigue. We also employ interactive exercises to reduce passive text reading. For example, rather than providing large blocks of text explaining a concept, we ask users to write in how the concept presents itself in their life. This interactive format is unique, providing multiple opportunities for participants to learn the important processes that increase psychological flexibility.

We also noted that some online resources are “watch and learn” or “read and learn,” with interaction only in the form of quizzes. We purposefully vary the content delivery, engaging the user in a variety of media, but avoiding quizzes. Users interface with material at multiple occasions in the module—allowing them to select options that resonate with their own challenges, and/or type in examples from their own

life, which are carried through to examples later on. For example, in one activity participants actively engage with a metaphor titled, “passengers on the bus.” After reading the metaphor, participants select multiple options for how a bus driver could respond to unruly passengers and what the outcomes might be for each response, thus informing the concept of cognitive defusion. In another defusion activity, participants type a thought that “hooks” them. They then use the software interface to change the size, color, and shape of the text to practice noticing “the thought is just a thought.” These activities provide variety for participants while encouraging active practice of ACT processes.

A Call for Collaboration: Online Service Delivery and Program Evaluation

ACT for Parents was developed before and during the COVID-19 pandemic, and we seek collaborators to provide this program to their networks of parents with I/DD. We have developed the program with the Center for Persons with Disabilities at Utah State University, who have content experts in parents of children with I/DD, and mental health and therapy; however, we would like to “beta test” this program with parents or other focus groups with lived and professional experience. We feel strongly that creating and adapting

programs requires additional involvement of more individuals and professionals with the lived experience. In line with this, we have worked to create relationships with parent groups throughout the rural west and plan to collaborate with these groups to compete for future funding opportunities while also working with these respective groups to find more effective ways to disseminate information through their established networks.

We also foresee opportunities for collaborative funding development. If a network or provider wants to seek external funding for their program and thinks ACT for Parents might enhance their portfolio of service options/modalities, we could include this program, assisting with grant preparation, and building in program evaluation components that could empirically examine the translation of this program into this population. We also seek further development of the program, specifically for individuals living with I/DD, to address their own mental health needs; collaborations for further modifications in this regard would be impactful. Importantly, we emphasize that this program is not “for sale”; it was developed in a clinical academic setting for clinical and research applications, and not developed for private, for-profit purposes. Our goal is to present this program as a novel, empirically based option, with opportunities for collaboration with networks and providers serving this population who are likely seeking “already developed” programs suitable for the COVID-19 environment. This approach could lead through

future collaborations with the Association of University Centers on Disability through educational or awareness campaigns, as it is likely that the program is unknown and, in our experience, dissemination largely depends upon healthy and active relationships to spread information across silos.

Conclusion

In general, the mental health and disability fields often function “in silos,” creating and adapting services for clients independently—with overlap, but without collaboration. Parents of children with I/DD are at the intersection of these fields—under chronic stress from their role, and more recently facing additional context-specific stress from the pandemic. Now more than ever, this population needs empirically supported telehealth options that embed mental health supportive services within the I/DD context, and which overcome barriers of social distancing, scheduling, scalability, and cost. Our program offers an extension of existing I/DD parent stress programs and of traditional ACT programs from other populations, teaching ACT skills in a fully online asynchronous interactive platform. To our knowledge, ACT for Parents is the first program to offer this. Being newly developed, we seek collaborators for understanding the program through the lived experience of users and providers. We also seek for networks or providers for scalable service delivery to foster program evaluation and sustainable funding.

Through online, self-guided, and empirically validated programs, including but not limited to ACT for Parents, both the mental health and disabilities fields can offer support to parents of children with I/DD, in this unique COVID-19 pandemic, and in the future.

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14.

INCREASING ACCESS TO AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SERVICES FOR PEOPLE WITH COMPLEX COMMUNICATION NEEDS DURING COVID-19 AND BEYOND

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Plain Language Summary

COVID-19 has affected the disability network across the world. There are millions of people who cannot use their natural speech. Augmentative and alternative communication (AAC) tools help these people to communicate. Examples of AAC include printed pictures and speech-generating devices. Professionals work with the person and their family to choose the right AAC. Often, people who use AAC need ongoing support. During COVID-19, many AAC services stopped to keep people safe. This paper describes how one center adapted AAC services. First, we outline the use of tele-AAC services. Then, we discuss how we used state AAC resources. Last, we highlight how we used tele-coaching to support caregivers. We conclude with suggestions for providing tele-AAC during COVID-19 and beyond.

The COVID-19 global pandemic has affected the disability network across the world (World Health Organization [WHO], 2020). Approximately 4 million Americans with complex communication needs (CCNs) cannot use their natural speech to communicate (Beukelman & Mirenda, 2013). Augmentative and alternative communication (AAC), a form of assistive technology (AT), is an evidence-based approach to help people with CCNs communicate (Morin et al., 2018). AAC consists of AT tools such as printed pictures and symbols displayed on manual boards and speech-generating devices (American Speech-Language-Hearing Association [ASHA], n.d.a.). People with CCNs who may have a temporary or permanent need for AAC include individuals with developmental disabilities such as autism spectrum disorders (ASD), cerebral palsy (CP), intellectual disabilities (ID), and genetic disorders (ASHA, n.d.a.; Morin et al. 2018). Furthermore, people with acquired conditions such as traumatic brain injuries, cerebral vascular accidents, brainstem strokes, and amyotrophic lateral sclerosis (ALS) may also require AAC services (Rehabilitation Engineering Research Center on AAC, 2019).

To assess a person's need for AAC, a team of professionals work together with the person and their caregivers to determine the appropriate AAC system (Schladant et al., in press). Often, people with CCNs require face-to-face and ongoing AAC support to promote communicative competence (ASHA, n.d.a.). However, with school closures

and stay-at-home orders resulting from the COVID-19 pandemic, many services for people with disabilities abruptly stopped worldwide (Fong et al., 2020; Salas-Provance et al., 2020). Service providers needed to swiftly adapt speech and language services to ensure people's safety (Fong et al., 2020). This paper describes how one AT Program at a University Center for Excellence in Developmental Disabilities (UCEDD) adapted AAC services and increased access to support using (a) tele-AAC assessment practices, (b) services through a partnership with our state AT Act program, and (c) tele-coaching strategies to help providers and caregivers in their facilitation and implementation of AAC services. We will present a case example highlighting how we used these innovative approaches and discuss key considerations in tele-AAC practices to help people with CCNs and their caregivers during COVID-19 and beyond.

Findings from over three decades of research demonstrate that AAC improves outcomes for children and adults with CCNs. These outcomes include enhancing their ability to be understood, assisting with conversation maintenance, and increasing social interactions (Beukelman & Mirenda, 2013; McNaughton & Light, 2015). A meta-analysis conducted by Ganz et al. (2012) revealed AAC interventions effectively promoted academic performance and reduced challenging behaviors for children with CCNs. In a systematic review across 17 studies on AAC service delivery, Morin et al. (2018) found that high-tech AAC improved communication

outcomes for people with CCNs. Researchers in the study also found that people using high-tech AAC did not perform significantly better than those using other low-tech forms of AAC, such as manual communication boards. This finding suggests that a range of high- and low-tech AAC modalities are effective in improving communication skills for people with CCNs (Morin et al., 2018).

Furthermore, researchers have shown that AAC benefits not only people with CCNs but also benefits their caregivers. For example, Aydin and Diken (2020) surveyed families of children using high-tech AAC and found that caregivers reported that their children's independence and communicative competence improved at school and in the community. In a study conducted by Schladant and Dowling (2020), mothers of children with fragile X syndrome found various low- and high-tech AAC tools useful in addressing their children's communication needs at home. In a study conducted by Richardson et al. (2019), adults with ASD who used AAC in their employment reported success in using AAC with appropriate support from their employers. Although there are proven benefits to AAC use for people with CCNs, there are many challenges (Light et al., 2019; Schladant & Dowling, 2020).

One of the biggest challenges for AAC users and their caregivers is access to AAC support (Baxter et al., 2012). Smith and Connelly (as cited by Baxter et al., 2012) found that few people with CP had ongoing support for programming and

maintenance once provided with their AAC devices. In another study, parents described difficulties finding AAC specialists or professionals with sufficient AAC expertise (McNaughton et al., 2015). In a similar study, the lack of local AAC support was one of the major obstacles impacting successful AAC integration in the home (Schladant & Dowling, 2020). Last, when working with children from linguistically diverse backgrounds, Soto and Yu (2014) described difficulties finding professionals with in-depth knowledge about bilingualism related to AAC and language development.

To address these challenges in AAC implementation and reduce the risk of device abandonment, persons with CCNs and their caregivers often require face-to-face and ongoing support by a team of professionals working together (Jackson & Schladant, 2017). Effective AAC service delivery plays a critical role in determining whether people with CCNs will be successful AAC users in everyday life (Steel et al., 2012). Although federal laws mandate AAC service delivery in the community, educational, and vocational settings, service providers also face many challenges in effectively implementing AAC services (Schladant & Dowling 2020). First, AAC service delivery often requires multiple perspectives by an interdisciplinary team with AAC knowledge and expertise (Jackson & Schladant, 2017). Second, AAC service delivery is a collaborative, decision-making process that includes numerous steps and the involvement of key stakeholders

(Binger et al., 2012). Last, when considering AAC for people with CCNs, merely providing a person with access to the device is not enough (Schladant & Dowling, 2020). To optimize the integration of AAC in everyday life, the AAC users and their caregivers and providers may require ongoing services to learn the selected system (Schladant et al., in press).

AAC services are most effective when provided by an interdisciplinary team (Jackson & Schladant, 2017). These team members often include the person with CCNs, caregivers, speech-language pathologists (SLPs), assistive technology professionals (ATPs), educational/vocational specialists, occupational therapists (OTs), physical therapists (PTs), vendors, and other medical professionals as needed (ASHA, n.d.a., Binger et al., 2012). Central to the team is the person with CCNs and their caregivers (Schladant et al., in press). A person- and family-centered approach provides a process for identifying strengths and resources and ensures shared goals and decision-making for AAC use (Mandak et al., 2017). Each individual lends a unique perspective and area of expertise to make recommendations about the most appropriate AAC system to promote functional communication across partners and settings (Jackson & Schladant, 2017). The interdisciplinary team works together to gather and synthesize information and collaborate to develop coordinated AAC recommendations for the person with CCNs (Schladant et al., in press).

The AAC assessment process involves several necessary

steps, with key stakeholders being instrumental to this process. First, it is imperative to consider the various contexts in which the AAC system will be used, including the community and educational settings and communication partners (Beukelman & Mirenda, 2013). Second, collaborating with key stakeholders, such as the caregivers, school district, and other allied health professionals, is critical for successfully implementing the AAC system into the natural environment (Binger et al., 2012). Third, access to devices to trial during the assessment process, knowledge of various funding sources, and documentation required for AAC system acquisition are necessary (Baxter et al., 2012; Beukelman & Mirenda, 2013; Jackson & Schladant, 2017). Effective communication and ongoing support among the AAC user, their caregivers, and other key stakeholders are essential to ensure the appropriate AAC selection and reduce device abandonment risk (Schladant et al., in press). In the section that follows, we highlight how one AT program at a UCEDD swiftly modified services to increase access to AAC support to address past, present, and future challenges in AAC service delivery.

AAC Service Delivery: Past, Present, and Future Directions

Setting

The AT program described in this paper is in the southeastern U.S. and is one of the 67 designated UCEDD in the U.S. and territories. As a UCEDD, our center employs an interdisciplinary faculty representing over 15 disciplines to provide: preservice training to 80 pediatric interdisciplinary graduate and post-graduate students; direct services to more than 14,000 children and young adults; community outreach to over 3,000 consumers and professionals; and research activities, technical assistance, and information dissemination reaching thousands each year. Our AT program provides AT and AAC services to children and adults with disabilities and their caregivers. Our AAC interdisciplinary team consists of two bilingual SLPs, an OT, a PT, and two ATPs. AAC evaluations emphasize family involvement to determine an appropriate AAC plan specific to the person's needs. The center's AT program also offers information and referrals, device demonstrations, AT training and outreach, and a device-lending library through a 20-year partnership with our state AT Act program.

Previous AAC Service Delivery Model

Our AT program is one of the few facilities in the region that offers AAC assessment and intervention services. Before the COVID-19 pandemic, we provided all AAC services face-to-face at our center. As shown in Table 1, the essential steps in our interdisciplinary AAC process included: (a) gathering background information; (b) conducting the initial assessment; (c) implementing a device trial; (d) obtaining the device and assisting with device programming and maintenance.

Table 1
Interdisciplinary AAC Assessment Process

Key components	Steps	Primary team member(s) responsible
Gather background information about the person with CCNs from the primary caregiver(s)	1. Complete background questionnaire form: ◦ Relevant medical information, diagnosis; ◦ Current educational/work setting, therapies; and ◦ Current communication needs and methods and previous AAC experience. 2. Submit a video of the person’s communication in a natural setting: ◦ 3-5-minute video clip of person communicating with caregivers in home, community, work, or school setting. 3. Submit previous evaluations: ◦ Individual Education Plan (IEP), Individual Family Service Plan (IFSP), Individualized Plan for Employment (IPE); ◦ Previous reports from	Primary caregiver(s), the person with CCNs

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Key components	Steps	Primary team member(s) responsible
	relevant therapies (e.g., SLP, OT, PT); and ◦ Previous AAC evaluations	

Key components	Steps	Primary team member(s) responsible
The interdisciplinary team conducts an initial assessment	4. Interview caregivers and conduct clinical observations: ◦ Hearing, vision, motor, communication, cognition (follow directions, attention, problem-solving). 5. Conduct objective speech and language assessment (standardized, informal, or obtain information from a previous evaluation). 6. Trial a minimum of 3 AAC devices and/or systems ranging from no-tech to high tech: ◦ Determine access (best and alternate; scanning, head tracking, eye gaze, direct select). 7. Write AAC report: ◦ Sections of the report include background information, communication needs, vision, hearing, motor, receptive and expressive language, cognition, devices	The person with CCNs, primary caregiver(s), assistive technology specialist (ATP), speech language pathologist (SLP), the person with CCNs' SLP, OT, PT

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Key components	Steps	Primary team member(s) responsible
	trialed and outcomes, summary, and recommendations. 8. Conduct a family conference (1 week later) and complete written report (2 weeks later): ◦ In-person, telephone, videoconference.	

Key components	Steps	Primary team member(s) responsible
Conduct device trial with the person with CCNs and primary caregiver	9. Conduct 4 device trial sessions over a 4- to 6-week period to gather data to determine appropriate AAC system: ◦ SLP develops a Plan of Care (short- and long-term goals- specific for device usage); and ◦ May also include OT for access and/or ATP for caregiver device training. 10. Caregivers borrow a device to carry over implementation in the natural environment: ◦ Use of State AT Act program- https://www.at3center.net/stateprogram 11. Caregiver training: ◦ How to use, program, and maintain the device ◦ AAC strategies to support communication 12. Write addendum with final device recommendation to the	SLP, OT, ATP, the person with CCNs, and primary caregiver(s)

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Key components	Steps	Primary team member(s) responsible
	AAC written report.	

Key components	Steps	Primary team member(s) responsible
Apply for device funding	13. Contact AAC vendor for funding packet: ◦ Obtain prescription and/or a certificate of Medical Necessity depending on insurance requirements; ◦ Complete Release of Information Form to communicate with AAC vendor; ◦ Complete Device Selection Form; and ◦ Provide written AAC report with a summary from device trial	ATP, SLP, primary caregiver(s)
Device training after the device is obtained	14. Provide resources for device training and continued support: ◦ Vendors website, YouTube ◦ School AAC team ◦ State AT program ◦ Community providers ◦ AAC Clinic	ATP, primary caregiver(s), the person with CCNs

Gather Background Information

Before the face-to-face appointment at our center, the person's primary caregiver completed a comprehensive background form and provided the team with previous reports and short videos to determine their current communication abilities. Next, our team reviewed the background information, videos, and prior reports to develop an AAC assessment plan. Using a feature match approach based on the person's communication needs (Beukelman & Mirenda, 2013), our team selected a minimum of three AAC devices with a range of vocabulary displays, access methods, and activities to use during the assessment. When choosing the devices, vocabulary, and activities, our team also considered each person's linguistic and cultural diversity.

The Initial AAC Assessment

On the day of the face-to-face assessment, one of our SLPs led the interaction with the child or adult and was assisted by one of our ATPs and OT or PT if needed. During the appointment, the caregiver(s) observed the assessment through a one-way mirror. Our ATP accompanied the caregiver(s), who explained the strategies and the methods used by our SLP and collected more background information from the caregiver(s). After our SLP completed the AAC assessment, the caregiver(s) met with our team to discuss

preliminary recommendations and planned for the AAC device trial period.

The AAC Device Trial Period

Based on feedback from the caregiver(s) and our team's recommendations, the person and their caregiver(s) participated in three to four face-to-face device trial sessions over a 4- to 6-week period to collect data and determine the most appropriate AAC system. During this time, we leveraged our partnership with our state AT Act program to provide the person and their caregivers with a device loan to use at home during the device trial period. Our SLP trained the caregiver to use, program, and maintain the device, as well as provided caregivers with information on essential AAC strategies to support the person's communication. Our team also invited caregivers to bring the person's service providers (e.g., SLP, OT, PT) to participate in the device trial training and share their input.

Obtain AAC Device and Training

After the device trial period, our SLP finalized the AAC written report. Our ATP then worked with the caregiver and AAC vendor's funding department to complete the paperwork to obtain the device through insurance. In addition to the written AAC report, the funding packet included a *Certificate of Medical Necessity* completed by the person's primary care physician, an *Assignment of Benefits* to allow the AAC vendor's funding department to communicate with the

insurance on behalf of the person, and a Device Selection sheet specifying device features. After the person received their funded device, our team connected the family with our state AT Act program for further training and resources to support device programming and maintenance.

Partnership with Our State AT Act Program

As previously mentioned, one way we leveraged support to offer AAC services was through a partnership with our state AT Act program, funded through the Assistive Technology Act of 2004 (The AT Act, 2004). Every U.S. state and territory is supported by the AT Act, which provides funding to states to assist individuals with disabilities to obtain AT devices and services (The AT Act, 2004). The purpose of state AT Act programs is to increase access to and acquisition of AT devices and services to people with disabilities (AT Act, 2004). These state AT Act programs offer three core services relevant to AAC. These services include: (a) information and assistance on AAC devices and support, including finding local AAC service providers, vendors and securing AAC funding; (b) AAC device demonstrations; and (c) free short-term AAC device loans (Binger et al., 2012). State AT Act programs are required to serve all people with all types of disabilities and in all environments (e.g., early intervention, K-12 education, post-secondary, vocational rehabilitation, community living, aging services). These programs address all types of AT along

with mainstream accessible information and communication technologies.

Before the onset of COVID-19, our team supplemented the AAC assessment with services from our state AT regional office, housed at our center. Caregivers borrowed a range of AAC devices, including switches and mounts, during the device trial period. In-person AAC demonstrations during the trial and acquisition phase provided the opportunity for people with CCNs and their caregiver(s) to become familiar with different types of AAC by comparing and contrasting each device's functions and features through hands-on exploration. Last, after the caregiver acquired the device, our state AT Act program offered caregivers and providers additional training and resources in programming and maintaining the device.

Challenges

Although our team used a systematic process for face-to-face services and leveraged our partnership with our state AT Act program, some caregivers faced challenges in obtaining AAC services. As one of the only AAC programs in our region, one barrier to receiving services was our center's location in a large metropolitan city. Therefore, families residing in other cities or the counties' extreme ends found it difficult to attend face-to-face sessions because of traffic and distance. Some of our clients with significant motor or medical issues found leaving their homes a burden. Some caregivers of children with ASD

also reported problems with their child's adaptability to new environments. They were worried about their child's ability to feel comfortable in a clinical setting. When COVID-19 hit in March 2020, the pandemic provided our team with an opportunity to address past and current challenges in AAC service delivery.

AAC Service Delivery During COVID-19: A Shift to Tele-AAC Practice

While we typically conducted AAC service delivery face-to-face, this was not possible due to the COVID-19 pandemic and federal and state mandates to socially distance and stay-at-home orders (Centers for Disease Control and Prevention [CDC], 2020). It is unclear how long these guidelines will be in place. Many people with CCNs also have underlying medical conditions placing them at higher risk for contracting COVID-19. Therefore, we needed to adapt our AAC services to increase access and continue providing support to people with CCNs and their caregivers. While most service delivery systems have made some pivot to telehealth, the implications of these changes for AAC users have not been adequately explored. In the section that follows, we discuss key considerations in tele-AAC assessment practices and present a case example illustrating how we shifted our AAC services to a tele-AAC model.

Tele-AAC Assessment Practices

Telehealth, also known as telepractice, is defined by ASHA as

...the application of telecommunications technology to the delivery of speech-language pathology and audiology professional services at a distance by linking clinician to client/patient or clinician to clinician for assessment, intervention, and/or consultation. (ASHA, n.d.b.)

In a systematic review on telehealth in ASD, Knutsen et al. (2016) found that telepractice increased access to services and specialists, provided opportunities for caregiver coaching, and supported service providers and educators. The researchers also found consistent patterns of high acceptance by caregivers and efficacy across various settings, caregivers, and formats. Furthermore, Snodgrass et al. (2016) highlighted the benefits of implementing telepractice in speech and language therapy service delivery, such as reduced travel time and increased access to services for people in rural areas or neighborhoods. Researchers in other studies also found no difference in speech and language intervention outcomes between the use of telepractice services and traditional on-site services (Grogan-Johnson et al., 2013, Hall et al, 2014).

Tele-AAC is a unique type of telepractice in the field of speech and language pathology that requires technical expertise in both telepractice and AAC systems (Anderson et al., 2012). Tele-AAC services range from direct services (where an AAC user receives real-time feedback on their device from

an experienced clinician) to more indirect services (where novice practitioners and family members receive feedback to support the AAC user; Hall & Boisvert, 2014). The real-time feedback from an expert in AAC in both direct and indirect tele-AAC practice is crucial to successfully help the AAC user (Hall & Boisvert, 2014). In a series of case studies, Curtis (2014) found that tele-AAC provided access to skilled AAC clinicians not otherwise available in the community because of geographic constraints, travel issues, and time. Also, tele-AAC services made it easier for AAC users and families to obtain ongoing services in the home and fostered collaboration with home health therapists.

As a result of the global pandemic, our center shifted our AAC service delivery model from clinician-led face-to-face sessions to a caregiver-led tele-AAC approach. To conduct tele-AAC assessments, we followed the ASHA Code of Ethics (ASHA, 1970) and used our center's enterprise license, Zoom for Healthcare,TM a HIPAA-compliant video conferencing platform. The Health Insurance Portability and Accountability Act and supplemental legislation (collectively referred to as HIPAA) lays out privacy and security standards that protect the person's health information (CDC, 2018). As shown in Table 2, the key steps and technology considerations in our tele-AAC service delivery model included: (a) conducting a technology-based assessment to prepare the caregiver for the tele-AAC process, (b) conducting a tele-AAC assessment guided by the interdisciplinary team and facilitated

by the caregiver, (c) coaching the caregiver during tele-AAC device trial period, (d) providing ongoing support to the AAC user and caregivers to obtain, program and maintain the AAC device through our partnership with our state AT Act program.

Table 2
Interdisciplinary Tele-AAC Process and Communication
Methods

Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
Conduct a technology-based assessment to prepare the family for the tele-AAC assessment	- Caregiver emails completed questionnaire forms, previous evaluations, and video to ATP - ATP schedules call or Zoom™ with caregiver to discuss: - Tele-AAC assessment process; - HIPAA compliant technology to be used during the tele-sessions; and - Review consent forms (FERPA, video consent). - ATP and SLP conduct an initial video consultation to determine the caregiver's technology needs and computer equipment needed for the AAC assessment:	Phone, email, Computer/ tablet, video conferencing/ Zoom,™ U.S.P.S, FedEx, UPS

Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
	◦ Computer/ tablet, Zoom™ for video conferencing; ◦ smartphone/ tablet with mount for viewing AAC screen; ◦ Bluetooth™ headphones to communicate with caregiver; ◦ Pre-programmed AAC device(s) to use with person with CCNs. 4. ATP and SLP assess the home environment to determine: ◦ Where the assessment will take place; ◦ Where to position the camera; and ◦ What activities to prepare in	

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Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
	advance. 5. ATP and SLP discuss with caregiver the possibility of inviting person's service providers (SLP, OT, PT) to the tele-AAC assessment. 6. SLP borrows AAC and additional technology needed (tablet with mount, Bluetooth™ headphones, mount) from state AT Act program and pre-programs the AAC device and ships to caregiver. 7. Caregiver receives pre-programmed AAC devices and technology for the AAC assessment from state AT Act program.	

Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
Conduct tele-AAC assessment guided by the interdisciplinary team and facilitated by the caregiver.	8. SLP conducts tele-AAC assessment via Zoom™ by coaching the caregiver 9. Other members of AAC team (e.g., ATP, OT, PT) join via Zoom™ to assist SLP in determining the device access method 10. The person’s service providers join via Zoom™ or at person’s home 11. The SLP uses Screen Mirroring app and screen sharing via Zoom™ to program the device on-the-spot 12. AAC team, caregiver, and service providers determine AAC to trial	Computer/ tablet, Zoom,™ smartphone/ tablet, mount, Bluetooth headphones, pre-programmed AAC device(s), Screen Mirroring app, screen sharing

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Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
Coach caregiver during tele-AAC device trial.	13. ATP coordinates a device loan from local AAC vendor or state AT Act program to use during device trial 14. AAC vendor and SLP meet with caregiver and person to provide training and technical support on how to use the AAC device during the trial. Vendor or SLP use the following technology: ◦ Screen share ◦ Remote into AAC device ◦ Screen Mirroring app 15. SLP conducts trial sessions via Zoom™, coaches caregiver to facilitate the communication interactions, and gathers data to determine appropriate AAC system	Computer/ tablet, Zoom™, pre-programmed AAC device, Bluetooth headphones, Screen Mirroring app, screen sharing

Key Components	Tele-AAC Steps	Communication Methods/ Technology Needs
	◦ May include OT for access and/or ATP for caregiver device training ◦ May include the person’s service providers	
Provide ongoing support to the AAC user and caregiver(s) during acquisition, programming, and maintenance of the AAC device.	16. ATP works with family via phone or Zoom™ to apply for AAC funding 17. ATP and SLP provide AAC resources from state AT Act program for device training and continued support	Phone or computer/tablet, Zoom™

Conduct Technology-Based Assessment

Before meeting the caregivers for the tele-AAC appointment, one of our ATPs contacted the caregiver via telephone or Zoom™ to explain the tele-AAC assessment process and procedures. This call included (a) explaining how to set up their profiles on the electronic medical record system and

downloading the Zoom™ software to their device, (b) obtaining consent to record the sessions, (c) explaining the tele-AAC procedures, and (d) confirming the time and date of the tele-appointment. After this phone call, one of our SLPs and ATPs scheduled the initial consult with caregiver(s) to (a) review the person's current communication abilities, developmental and medical history, (b) discuss environmental considerations and technology set-up, and (c) determine preferred activities to motivate and engage the AAC user during the assessment.

To prepare the caregiver(s) for the tele-AAC services, we conducted a technology needs assessment to evaluate the home environment. Technology concerns included the caregiver's access to appropriate technology such as reliable Internet connection, smartphone, computer or tablet with webcam, mount, and Bluetooth™ headphones. Caregivers provided our SLP with preferred activities to have prepared for the day of the assessment. We also encouraged caregivers to invite any other service providers to attend the assessment either in the caregiver's home or to join the session remotely via Zoom.™ Before the tele-AAC assessment, our SLP borrowed device(s) from our state AT Act program's lending library and programmed the devices with target vocabulary before shipping the device to the caregiver. If the caregiver had questions regarding the device set-up, our ATP scheduled a videoconference or phone call to answer their questions.

Conduct Tele-AAC Assessment

On the tele-AAC assessment day, our SLP coached the caregivers throughout the session using Bluetooth™ headphones. Using parent-coaching techniques (Roberts & Kaiser, 2011), our SLP directed the caregiver on specific AAC strategies (e.g., modeling, least to most prompting) to facilitate the person's use of the device. Our SLP used an iPad™ with various communication apps and downloaded the screen mirroring app, Smart Mirror – TV & Device on her iPhone™ to project the AAC device screen on her laptop. She then used screen sharing via Zoom™ to show the caregiver how to program words on the device. After we gathered the necessary data and clinical observations during the assessment, we met with the caregiver(s) to discuss preliminary findings and recommendations for the subsequent device trial period.

Coach Caregiver During Tele-AAC Device Trial

If there was a need for a dedicated high-tech AAC, we collaborated with one of our local AAC vendor representatives to obtain the device loan directly from the company. The AAC device trial period focused on the implementation of one to two AAC systems. Caregivers were asked to invite the AAC client's service providers to participate in the device trials and provide additional feedback.

As our service delivery model shifted from face-to-face

sessions to telepractice, our team also shifted from a clinician-led approach to a caregiver-led process. A meta-analysis conducted by Roberts and Kaiser (2011) found that caregiver-implemented language interventions effectively promoted language development in young children with disabilities. Snodgrass et al. (2016) implemented a telepractice framework incorporating caregiver training and coaching to aid SLPs in providing remote early intervention services to children with communication disorders and found that parents were able to effectively learn strategies (e.g., modeling, mand-model, and time delay) to improve their child's communication skills.

Furthermore, in a technical report by Hall and Boisvert (2014), the authors discussed clinical aspects for supporting caregivers and providers to implement tele-AAC services. They highlighted indirect AAC services, such as Active Consultation and e-Supervision, to coach caregivers on using the AAC device with the client. The authors emphasized that when working with caregivers and professionals who are less familiar with AAC, the immediacy of the feedback offered via Active Consultation is essential to successfully support caregivers and AAC users (Hall & Boisvert, 2014).

Provide Ongoing Remote Support

The challenges faced with COVID-19 allowed our team to think more creatively about leveraging our partnership with our state's AT Act program to deliver synchronous and asynchronous AAC support. Synchronous support occurred

in real-time. One of our ATPs, who coordinates the regional office for our state AT Act program, provided device loans and training to the caregiver(s) and providers on how to program and maintain the device. Once caregivers obtained their device through funding, the ATP scheduled a remote meeting to discuss the device's features and provided technical support, as necessary.

In addition to synchronous support, we collaborated with our state AT Act program to provide asynchronous support by creating YouTube video demonstrations and curating a collection of online resources. This type of asynchronous support allowed caregivers the opportunity to view video demonstrations and resources at their own time and pace. Hence, we developed an online library of video tutorials and device demonstrations that could be accessed “anytime, anywhere.” We archived and posted these videos on our center’s YouTube channel, a platform familiar to the public. We also made these videos available on our state AT Act program website. In the next section, we present a case example to illustrate how we used these tele-AAC practices.

Case Example

Erica and David

Erica is the mother of David, a 4-year-old boy with ASD. He is an emerging communicator with limited verbal speech. Although David had been receiving speech therapy

interventions and applied behavior analysis (ABA) services for the past 2½ years, he did not have a reliable means to communicate with his family members, peers, and other communication partners. His previous AAC experience included some low-tech forms such as picture symbols and single message voice output devices that he used in school and therapies. Because of COVID-19, David no longer attended school in person and received all educational services at home through remote learning. He also received OT and ABA therapies at home. His SLP temporarily suspended services because she was not able to provide telepractice services at the time. Erica contacted our AAC team in the summer of 2020 to help David find a reliable way to express his immediate needs and make choices effectively and efficiently. His complex communication needs limited his interactions with others and increased his frustration when he could not meet his needs.

Preparing for the Tele-AAC Process

Before the tele-AAC assessment, we conducted a video consultation with Erica to explain the tele-AAC process and how to log in to the electronic medical record to access Zoom™. We also determined her technology needs and the computer equipment needed to complete the assessment. We decided that based on her previous experience with using technology for David's remote learning and videoconferencing, she would be comfortable using Zoom™ for the upcoming session. We also problem-solved what device

she would use to view the AAC device screen and where to set up the device's camera. We determined that Erica would use her smartphone camera to view the AAC screen via Zoom™. David's OT would be part of the assessment to hold the smartphone and help engage David during the session. To interact with our team via Zoom™, Erica decided to use her laptop. She used her Bluetooth™ headphones via her computer to communicate with our team discreetly. We planned a few of David's preferred activities, such as bubbles, a favorite pop-up toy, snack, and balloons. Last, we explored potential AAC systems based on David's communication needs and feature-matching.

After the video consultation, we coordinated a device loan through our state AT Act program to obtain an iPad™ with several communication apps. We pre-programmed each communication app with specific vocabulary related to David's preferred activities. As shown in Figure 1, we programmed LAMP Words for Life™, a core word-based system with the following words: "want," "go," "stop," "help," and "turn." We programmed the TouchChat™ app, a category word-based system with various words, including pronouns, verbs, and activity-specific words (see Figure 2). Finally, we programmed an activity-based communication app called the Go Talk Now™ with four symbols, which included "want," "more," "bubbles," and a picture of a preferred toy (see Figure 3). We planned to use these pre-selected words and vocabulary during David's favorite activities. After

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programming the communication apps, we shipped the iPad™ to Erica's home.

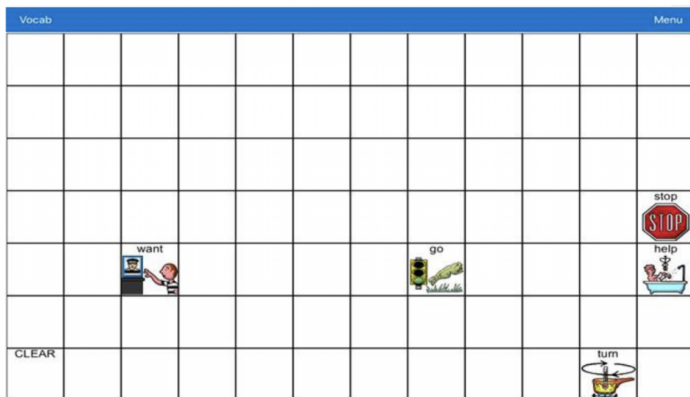


Figure 1

Pre-Programmed LAMP Words for Life™ Vocabulary

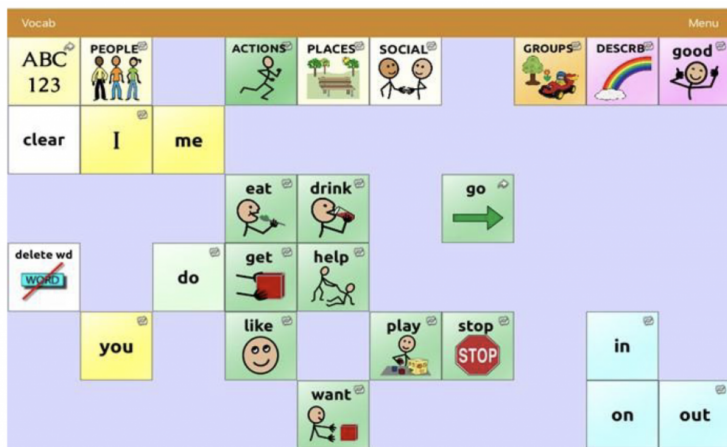


Figure 2

Pre-Programmed AAC Device TouchChat™ Software

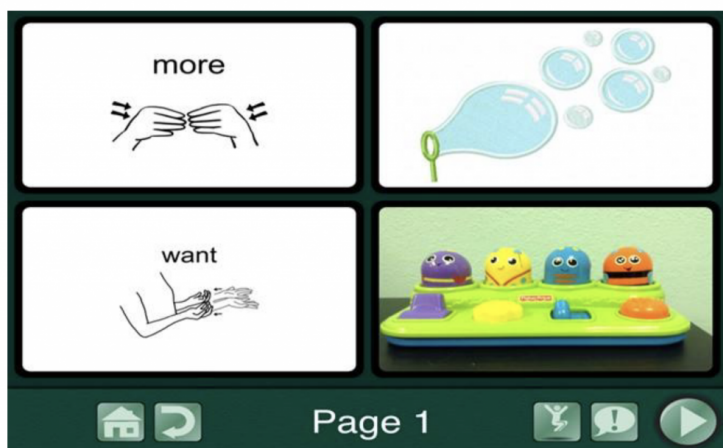


Figure 3
Pre-Programmed AAC Device Go Talk Now™

Conducting the Tele-AAC Assessment

On the day of the tele-AAC assessment, our team met with Erica, David, and his OT via Zoom™ (see Figure 4). As shown in Figure 5, Erica logged into Zoom™ on her smartphone, and David's OT held it so our team could view David's AAC screen. Erica also logged into Zoom™ on her laptop to see our SLP and ATP, who participated remotely. Using her Bluetooth™ headphones, Erica could hear our SLP, who guided her on eliciting David's use of the device to communicate, responding to his communication attempts, and navigating the pages on the AAC devices. David's OT held the smartphone's camera to ensure we could see the AAC screen. The OT also assisted Erica with behavior support to maintain David's engagement during the assessment. Our SLP

utilized a screen mirroring app on her smartphone and screen sharing on Zoom™ to guide Erica on programming more words on-the-spot. Once the team gathered sufficient information, we discussed each communication apps' features with Erica and David's OT to decide which AAC system to use during the trial period. Using the input provided by Erica and David's OT, our team discussed how to proceed for the trials. We found the Go Talk Now™ app was too limiting for David's communication needs, although there were some features of this app Erica found helpful. We also thought navigating the TouchChat™ app required longer periods of sustained attention, which was too difficult for David at the time. Therefore, we decided to trial LAMP Words for Life™ as this vocabulary system provided David with immediate feedback and an efficient way to communicate his needs and wants.

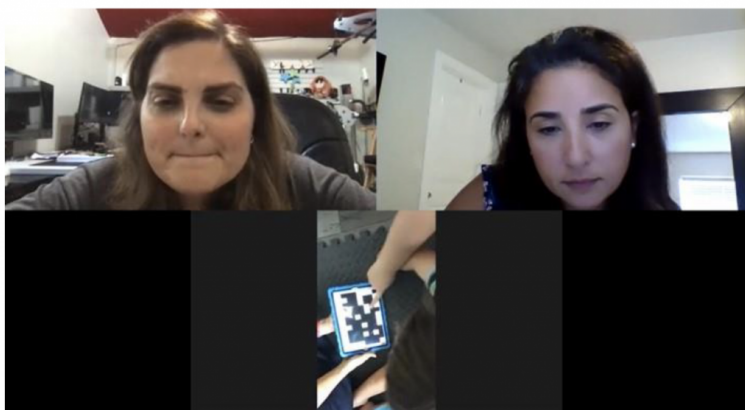


Figure 4

Tele-AAC Assessment.

Top Row: SLP and ATP. Bottom Row: View of pre-programmed AAC device, caregiver, and child

Coaching Erica During the AAC Device Trial

Following the tele-AAC assessment, our SLP conducted a 4-week trial with Erica and David. During this time, we helped Erica obtain the Via Pro™ device with LAMP Words for Life™ from our local AAC vendor representative, who also provided Erica with device training and technical support. This type of support offered Erica, David, and his therapists the opportunity to try out the AAC device for 4 weeks. During this trial period, Erica and David's therapists explored the software features before we made a final decision.

Additionally, during this time, we provided Erica with targeted AAC strategies using parent-implemented techniques (Roberts & Kaiser, 2011) to support effective AAC implementation in David's natural environment. Following the principles of aided language stimulation (Biggs et al, 2019), we guided Erica on how to model language by pointing to the symbol on David's device and repeating the word at the same time the device speaks. We focused on coaching Erica and his therapists to engage with David in various communication acts such as requesting, making comments, and directing actions throughout a particular activity. The coaching also included training in the prompt hierarchy using least-to-most prompts (e.g., when to offer a gesture, verbal, or physical cue to elicit a response) to maximize David's intentional use of the device

(Finke et al, 2017). Between trial sessions, Erica used natural routines to teach David how to communicate with his AAC device. At the beginning of each trial session, our SLP helped Erica reflect on successes and challenges she faced during the week and collaborated with her to solve any obstacles she encountered.

Providing Continued Support

Once we completed the trial and gathered enough information, we finalized the written AAC report. We then proceeded with helping Erica apply for funding to obtain David's device through private insurance. After receiving his device, we connected Erica and his team with our ATP, who coordinates services for our state AT Act Program to support Erica and David's team in programming and maintaining his device. We leveraged our partnership with our state AT program to support their ongoing AAC implementation and maintenance.

By shifting our AAC service delivery from a clinician-implemented to a caregiver-implemented approach, Erica and David's team played a more active role in the assessment process. As a result, they received more hands-on practice and direct guidance to support David's AAC use in the natural environment. Ultimately, the tele-AAC model offered our team the opportunity to serve in a supportive role, providing targeted feedback, and allowing the space for Erica and David's

team to reflect and determine the strategies that could support David's continued AAC use.

Tele-AAC Service Delivery: Future Directions

The COVID-19 pandemic has brought about dramatic changes to many aspects of our lives (WHO, 2020) and significantly impacted AAC service delivery. The COVID-19 global pandemic has accelerated the use of telepractice in SLP globally as an alternative service delivery during stay-at-home orders (Fong et al., 2020). There are many challenges in implementing AAC service delivery, such as geographic constraints, access to skilled AAC clinicians, and ongoing support to integrate AAC in the natural environment (Curtis, 2014; Light et al., 2019). There is emerging evidence to support the implementation of tele-AAC, a newer subset of telepractice in the field of SLP (Hall & Boisvert, 2014). The shift to tele-AAC practices as a result of the global pandemic offers a unique opportunity to address past, current, and future challenges in AAC service delivery. Competent tele-AAC implementation is contingent upon adequate technological infrastructure such as hardware/software, internet, telecommunications, and trained personnel in both AAC and telepractice (Anderson et al., 2012). The tele-AAC practices and technological infrastructure described in this paper resulted in innovative and feasible solutions to AAC

service delivery during the COVID-19 pandemic that has future implications for providing effective AAC intervention.

One of the biggest obstacles we faced in our tele-AAC assessment process was the additional technology needed to view the client's AAC device screen and for the caregivers to view our AAC screen for modeling how to program the device on-the-spot. During the tele-AAC assessment, the remote AAC clinician must be able to view vocabulary displayed on the device's screen, the message generated, and the caregiver and person interacting with the AAC device (Hall & Boisvert, 2014). The caregiver must also be able to view the remote AAC clinician's screen to allow for shared and concurrent interaction between the caregiver, clinician, and shared content on the screen (Hall & Boisvert, 2014). There are several ways to address the challenge of AAC screen sharing. With Erica and David (as shown in Figure 5), we used a no-tech method where Erica logged into Zoom™ on her smartphone, and David's OT held it so the team could view David's AAC screen. Although not ideal, a no-tech option for caregivers without a way to mount the webcam could be to have an additional person in the client's setting hold the smartphone or tablet to view the AAC screen. Another option that we have used with other AAC clients is to mount the smartphone or tablet with a flexible, gooseneck smartphone holder mounted to a table and position it above the AAC device screen. A more sophisticated option would be to use a specialized device called the Adjustable J-Mount. The

Adjustable J-Mount is a flexible mount with a webcam that runs from a second computer and is attached to the AAC device mounting plate (Hall & Boisvert, 2014).

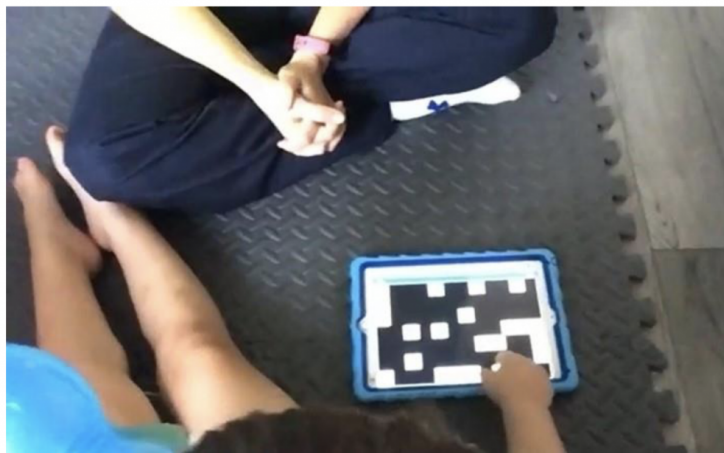


Figure 5

*Pre-Programmed AAC Device Used During Tele-AAC
Assessment*

The Adjustable J-Mount also allows the AAC clinician to share their AAC screen. In Erica's case, we used the Smart Mirror-TV & Device™ app on the iPhone™ (Zengapp Company, 2020) as a document camera (i.e., screen projector) using a desktop mount to view the SLP's AAC device. When used as a document camera, the Smart Mirror-TV & Device™ app allowed our SLP to project the screen on her laptop and then screen share the AAC device via Zoom™. The additional equipment to view the AAC screen via Zoom™ or other video

conferencing platform was critical to the tele-AAC assessment process for both AAC clinicians and caregivers.

The second consideration in tele-AAC service delivery was tele-coaching caregivers and service providers who may be inexperienced in AAC implementation. Our AAC service delivery model shifted from a clinician-led to a caregiver-led approach where our team provided real-time tele-coaching via bug-in-the-ear (BITE) technology to caregivers supporting their child's communication needs at home. During the tele-AAC assessment process, it was essential for caregivers and service providers to receive coaching and training to facilitate AAC use with the client and provide aided language input and modeling (Hall & Boisvert, 2014). Researchers have demonstrated that parents can learn new AAC strategies and implement them with fidelity (Mandak et al, 2017). Tele-coaching via BITE technology (Ottley, 2016; Snodgrass et al., 2016) is one way to guide caregivers and other service providers in AAC implementation. Through BITE, the caregiver wears BluetoothTM headphones connected to a smartphone or laptop's audio allowing our team to provide immediate feedback was necessary to support the caregivers during the assessment successfully (Hall & Boisvert, 2014). We found that implementing AAC in the natural environment (i.e., in the home) increased caregiver engagement and provided a more accessible way for providers to be involved in the AAC process (Biggs et al., 2019).

The third consideration in tele-AAC practices is capitalizing

on resources to provide ongoing training support for caregivers and providers. The use of asynchronous supports (e.g., video demonstrations) is a cost-effective way to give caregivers and service providers access to support “anytime, anywhere” (Hall & Boisvert, 2014; Snodgrass et al., 2016). Another option for ongoing training is to leverage support from state AT Act programs funded through the AT Act of 2004. Our partnership with our state AT Act program provided device loans and asynchronous supports for caregivers and providers. We leveraged this partnership to give caregivers access to devices from the state AT program’s lending library. The power of leveraging partnerships through state AT Act programs is an untapped resource available in every single state and territory in the U.S. To find your state or territory AT Act program, visit the National AT Act Technical Assistance and Training (AT3) Center’s website at <https://www.at3center.net/stateprogram>. Providers seeking to deliver AAC services are encouraged to seek out opportunities to collaborate with their state AT Act programs for device loans, outreach services, and demonstrations. These services are free and offer services to people with disabilities, caregivers, as well as providers.

Anecdotal accounts from caregivers who participated in our tele-AAC model reported having more confidence in device programming and implementing AAC strategies to teach their child how to use the selected AAC system. It is important to note that tele-AAC practices are not a “one size fits all,” and

this form of service delivery should be carefully considered if it is appropriate for each individual client (Hall & Boisvert, 2014). In some cases, persons with CCNs and their caregivers may prefer or require face-to-face support. AAC clinicians should consider a hybrid approach that incorporates both face-to-face and tele-AAC services based on the person and caregiver's preferences and needs (Anderson et al., 2012). Telepractice is already an established practice in many areas of speech and language pathology, and there is strong evidence to support its efficacy. However, more research is needed to evaluate the effectiveness of tele-AAC services.

Conclusion

This paper highlighted how one AT program at a UCEDD swiftly pivoted AAC services to a completely virtual format using HIPAA-compliant video conferencing software, screen sharing options, and tele-coaching via BITE technology. We also leveraged support from our state AT Act program to provide asynchronous supports and resources and ongoing training for caregivers and AAC users. These technology-based solutions and our strategic partnership with our state AT Act program were viable methods for conducting tele-AAC assessment practices in our clinic. These innovative approaches have the potential to revolutionize AAC service delivery and increase access for all. It is important to note, while tele-AAC can be an invaluable resource, some individuals with CCNs

and their families may need face-to-face services. Tele-AAC practices have the potential to overcome challenges in AAC service delivery and provide people with CCNs, their caregivers, and the providers that serve them access to expert AAC specialists, real-time feedback, and ongoing support in the natural environment during COVID-19 and beyond.

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15.

PERSON-CENTERED PRACTICE AS ANCHOR AND BEACON: PANDEMIC WISDOM FROM THE NCAPPS COMMUNITY

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[Person-Centered Practice as Anchor and Beacon: Pandemic Wisdom from the NCAPPS Community PDF File](#)

Plain Language Summary

COVID-19 is a new virus that has changed all of our lives. It has been especially challenging for people with disabilities. The National Center on Advancing Person-Centered Practices and Systems or NCAPPS is a group of people who help everyone to live their lives the way they want to. To be person-centered means that nothing is done to or for a person without their permission.

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) asked their community members to share how important it is for all of us to be person-centered during this time of COVID-19. Sixteen people shared their thoughts and experiences by recording their own short video. The 16 people were all different. Some were people using services, some were people who provide services, and some were researchers. Each person made a short video that is now on the NCAPPS website, YouTube channel and Facebook page. You can find these videos when you search for “NCAPPS Pandemic Wisdom.”

NCAPPS wanted to share what they have learned

from those sixteen videos with everyone. NCAPPS worked with some of the people who shared their thoughts in the video to summarize and organize main ideas. Here are the big four themes.

1. The challenges we face because of COVID-19.
2. How we can use person-centered practices to get through these hard times.
3. How we can help each other make good decisions and take care of each other.
4. What we can do as a community to work together to get through COVID-19 and make positive changes.

NCAPPS believes that being person-centered is more important now than in any other time. NCAPPS hopes that people with disabilities and those who support them will continue working together through COVID-19. Working together to make sure we all are being person-centered will guide us to get through this difficult time safely.

Introduction

Historically, pandemics have forced humans to break with the past and imagine their world anew. This one is no different. It is a portal, a gateway between one world and

the next. We can choose to walk through it, dragging...our prejudice...behind us. Or we can walk through lightly, with little luggage, ready to imagine another world. And ready to fight for it.

~Excerpt from “*The Pandemic Is a Portal*,” an essay by Arundhati Roy (2000)

As Roy suggests in the above-quoted passage, the COVID-19 pandemic represents a transformational moment for all aspects of society, and disability support systems are no exception. As disability advocates and leaders in the disability services sector find themselves at “a gateway between one world and the next,” it is necessary to take stock of the present moment. In March 2020, the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) began gathering information in real time from disabled people,¹ providers of disability services, researchers, and other system partners regarding the importance of person-centered practices in times of crisis. Hearing directly about these experiences enlightens us about current realities while simultaneously highlighting potential paths forward.

¹ Within disability communities there are a variety of linguistic preferences. Some people prefer the use of “identity-first” language, while others prefer “person-first.” To honor these different preferences, we will alternate between using “people with disabilities” and “disabled people” in this article.

In this article, members of the NCAPPS community—which

includes people with disabilities as well as people presently without disabilities—offer a summary of these lessons. We discuss the individual, systemic, and collective challenges and opportunities presented by the pandemic, based on personal reflections solicited by NCAPPS and submitted as short videos by 16 NCAPPS collaborators during the first 6 months of the pandemic. These personal reflections came from people with disabilities, service providers, researchers, and person-centered planning experts (see the appendix for their names, affiliations, and brief biographies). This “Pandemic Wisdom” series has been publicly released and shared through the NCAPPS website and social media channels throughout 2020. In our content analysis of the video transcripts, person-centered practices emerge as an “anchor” to keep us steady while we cope with the challenges brought on by the pandemic, and a “beacon” to illuminate the path forward for those who seek to (re)establish more person-centered and equitable human service systems in the future.

In March 2020, as the severity of the COVID-19 pandemic became clear, there was immediate concern within the disability community about the ways that disruptions caused by the pandemic would put us/them² at risk. As case numbers swelled, professionals and advocates raised concerns about governmental guidelines and the potential for medical rationing on the basis of disability (Andrews & Rogers, 2020). At the same time, professionals in the mental health community expressed concerns about how the pandemic

would be especially stressful and traumatic for people with disabilities (Lund et al., 2020). Service providers and disabled people alike compiled long lists of these concerns, ranging from the everyday difficulties of communicating about the importance of masks, to concerns about medication supplies, to unmet health care needs (Tromans et al., 2020). Some researchers have argued the pandemic merely highlights long-standing weaknesses in our existing systems for providing supports to people with disabilities, and thus advocated for changes to make these systems more agile, responsive, and safe (Bradley, 2020).

² This article is authored by a mix of people with and without disabilities. Therefore, when referring to people with disabilities, we are using the pronouns “them” and “us” throughout the manuscript. Using only “they” risks erasing the involvement of disabled people; however, using only “our” incorrectly includes nondisabled team members in our group.

As communities and human service systems moved to enact policies and processes to respond to the pandemic, these changes prompted concerns that people with disabilities would be disproportionately impacted by the resulting staffing shortages and limitations on physical contact or proximity, and by support systems lacking the flexibility to accommodate the shifting environment and needs of all people.

In light of these concerns, NCAPPS sought to contribute knowledge and strategies to support disabled people and the

families of people with disabilities. NCAPPS support activities took many forms, including development and compilation of COVID-specific resources (<https://ncapps.acl.gov/covid-19-resources.html>), adjustments to technical assistance approaches to support states to continue their systems change efforts (Croft et al., 2020), and creation of the “Pandemic Wisdom” series of short videos. In the Pandemic Wisdom videos, the focus of the present paper, subject-matter experts provided diverse perspectives and insights on how person-centered approaches can be used to solve problems, make use of existing resources, and prepare people and systems for new challenges that may emerge.

This study presents common themes in a series of 16 videos solicited by NCAPPS from subject matter experts with professional and lived experience of disability and human service systems. The themes were established using content analysis of video transcripts (Hsieh & Shannon, 2005; Pope et al., 2000). Content analysis is a method of systematically analyzing text data to identify themes to provide deeper knowledge of a topic (Hsieh & Shannon, 2005). Although it is not a participatory action research study, the work was informed by participatory action approaches. The community under study (in this case, people with disabilities and other experts with experience of long-term support service systems) were invited to be part of the team that developed questions, gathered data, analyzed and interpreted the video transcripts, and wrote this manuscript (Cashman et al., 2008; Greenwood

et al., 1993). Of the 16 experts featured in the videos, 8 elected to participate in the creation of this manuscript.

Our analysis illuminates the role and importance of person-centered practices—such as person-centered planning, peer support, and self-direction—in the lives of people with disabilities and those who support disabled people as they navigate the unforeseen pandemic. The impact of COVID-19 is expansive. The pandemic directly affects individual people, the service systems, and the larger society. People and systems interact in dynamic ways. The social ecological model (Bronfenbrenner, 1977)—which organizes factors at multiple nested levels (e.g., individual, community, society) and allows for examination of the interplay of factors between those levels—provided a structure for organizing the themes that emerged from the videos.

Methods

Recruitment Process and Participants

At the start of the Pandemic Wisdom project, NCAPPS staff (AB, BC, CB, and MK) wrote a letter explaining the purpose and vision of the project and requested recipients to consider participating by submitting a video answering all or any of the following questions.

1. What do person-centered thinking, planning, and

practices look like in times of crisis?

2. How do we hold on to—and even promote—person-centered thinking, planning, and practices at this time?
3. How do we balance collective public health with person-centered, individual well-being?
4. What lessons can we apply from person-centered thinking, planning, and practices to get through this pandemic?

The letter indicated that participation was voluntary, that there would be no compensation for participation, and that the videos would be shared on the NCAPPS website and social media platforms. The letter also included tips and guidelines on how to record the videos. NCAPPS staff also offered to provide filming support if needed. NCAPPS staff then sent the letter via email to 37 people between March 2020 and September 2020. The 37 people were chosen because they are members of the NCAPPS Person-Centered Advisory and Leadership (PAL) Group; had been involved with NCAPPS as subject matter experts for technical assistance efforts or webinars; or served as faculty for NCAPPS' Brain Injury Learning Collaborative. Each email addressed the recipient personally by their first name, and one of the NCAPPS staff sent at least one follow-up email. Of the 37 people who received the request, 16 people contributed to the project. The 16 people have various professional backgrounds and lived experiences—ranging from people with disabilities who are

involved in advocacy work, service providers, researchers, and person-centered planning experts. The table in the Appendix provides the name, affiliation, and biographic information of the subject matter experts who created Pandemic Wisdom videos.

Data

Video transcripts from the 16 NCAPPS Pandemic Wisdom Shorts served as the data for this analysis. Videos were transcribed using Otter.ai. The transcripts were then reviewed and edited by NCAPPS team members. All videos and transcripts are publicly available at <https://ncapps.acl.gov>.

Analysis

The analytic process was adapted from the Pope et al. (2002) content analysis method and consisted of six steps: (1) Familiarization, (2) Identifying a Thematic Framework, (3) Sorting, (4) Mapping and Interpretation, (5) Writing, and (6) Reviewing and Refinement.

In the first step (familiarization), nine team members (BC, CB, CS, MB, MFS, MK, NL, KL, SR) read through all transcripts and were instructed to list what they saw as themes that appeared across the data. This process resulted in nine lists, each containing 9 to 39 potential themes. To initiate the second step (identifying a thematic framework), one team

member (CB) compiled all identified themes into a spreadsheet and created an initial set of thematic groupings. Then, five team members (AB, BC, CB, CS, MK) engaged in two hour-long working meetings to discuss the thematic groupings and arrive at an initial framework consisting of 17 themes. Two other team members (KH and SR) reviewed the initial thematic framework to provide impressions, comments, and suggestions for revision. Team members identified Bronfenbrenner's social ecological framework as useful for structuring the themes. During the third step (sorting), six team members (AB, CB, MB, BC, MFS, and MK) coded all lines of text using the draft thematic framework using an Excel spreadsheet. After an initial meeting to share impressions and experiences from the coding process, the six team members identified candidate themes for condensing and revising, resulting in a final framework of 12 themes. To prepare for the fourth step (mapping and interpretation), team members reorganized all lines of text by theme. After reading through the reorganized data, six team members (CB, BC, KH, MK, KL, SR) met to discuss relationships between the themes, points of agreement and disagreement, and lessons that we may draw from the data. Another team member (MFS) provided written reflections. The team created a graphic (Figure 1) depicting nested levels, with themes arranged within or across levels. Finally, the team wrote and revised the manuscript using a collaborative, iterative process. Individual

team members first wrote specific sections, then other team members reviewed and provided comments and edits to drafts.

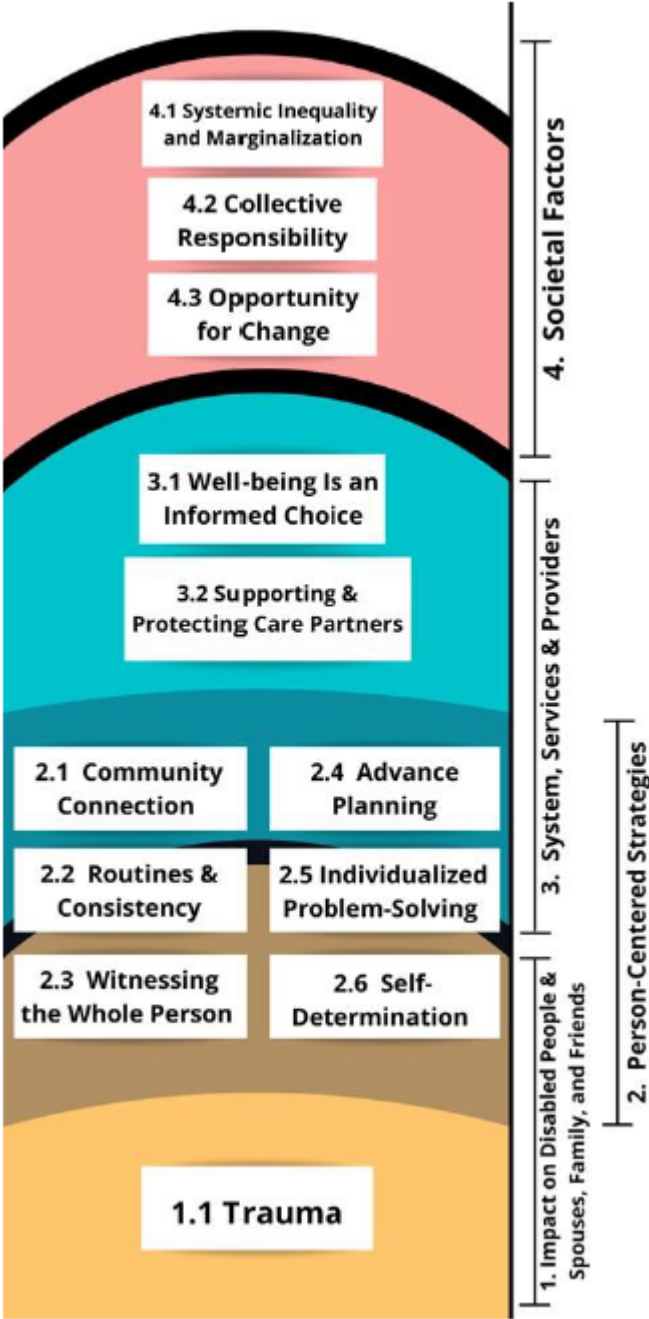


Figure 1

Organization of Pandemic Wisdom Themes at Four Levels

Results

The social ecological model informed the organization of themes to identify both specific factors within each of the levels and the interplay between each of the factors or levels (Bronfenbrenner, 1977). For this paper, we created a four-level model: (1) individual disabled people and spouses, family, and friends;³ (2) person-centered strategies employed by disabled people with support from spouses, family, friends, and service providers; (3) systems, services, and providers; and (4) society (Figure 1). We have nested the themes across these four levels to illustrate that themes at the outer levels (e.g., system, society) ultimately impact those at the inner levels, and always impact individual people with disabilities. The first grouping involves people with disabilities and the friends and families of people with disabilities. It contains one theme. The second grouping, which has the greatest concentration of themes, concerns strategies and considerations that are undertaken by disabled people and the supporters of people with disabilities. The third grouping contains themes related to systems considerations. The fourth grouping contains themes at the societal level.

³ We recognize that there are many ways to refer to the people

who are important in disabled peoples' lives. In this paper, we use "spouses, family, and friends" to encompass romantic partners, family members, friends, and other people within one's circle of support.

The themes discussed below were primarily identified based on the number of instances that a theme appeared in the video content and the number of speakers for whom the theme was observed. All of the themes identified appeared across a significant number of the individual videos—at least 6, and as many as 11 of the 16 total. Each theme is framed in the discussion below by a single illustrative quote; however, each theme appears many more times both within the referenced video and across the other videos in the series.

Level 1: Impact on Disabled People and Spouses, Family, and Friends

The overarching theme throughout the videos was trauma. Ideas related to trauma appeared in many of the phrases and words the commentators used to describe the impact of COVID-19 on disabled people and the friends and family who make up their/our circles of support. This level reflects how people with disabilities are nested within the other levels of the environment and highlights how trauma was the interconnecting factor across all levels.

Theme 1.1: Trauma

Nearly every commentator discussed one or more of the negative effects the pandemic has had on the lives of disabled people and their/our friends and family. The pandemic has caused fear, grief, uncertainty, disruption, and social isolation—and all of these experiences are traumatizing. Martha Barbone, a certified peer specialist and advocate who has lived experience in the mental health system, said “[*Fear*] has the power to deeply disturb and limit us. Worst of all, fear can erode our trust in ourselves, in the goodness of others, and in the joy of living.” Several commentators framed their distressing pandemic-related experiences as losses and said that coming to terms with the traumatic experiences will be a lengthy process requiring care and support.

Level 2: Person-Centered Strategies

At this level, themes focused on the interactions, direct practices, and strategies between people with disabilities and those who support them/us. Our team identified six themes at this level.

Theme 2.1: Community Connection

As a response to the trauma of social isolation affecting many people with disabilities, some commentators emphasized the importance of community connections. Person-centered

practices are founded in the belief that connection, communication, and relationships are necessary for thriving. Positive connections to supporters (both paid and unpaid) are valuable and give people power. Commentators noted that rebuilding and strengthening community connections should be prioritized by people providing supports, and they described additional ways to establish connections during the pandemic. Janis Tondora, a nondisabled researcher with expertise in mental health recovery supports, highlighted that these connections often take the form of giving as well as receiving support:

In many cases those strategies include finding meaningful ways to connect and give back to others. And, despite our physical distance, COVID-19 has certainly presented a wide range of ways for people to do just that. I hear stories every day of people grocery shopping for elderly neighbors, making masks for healthcare workers, or simply checking in on a friend that they know is having a hard time. In these simple acts of connection people are at once finding ways to serve others while also building their own sense of agency and value.

Theme 2.2: Routines and Consistency

Reestablishing routines and consistency despite the current uncertainty is another strategy that builds on existing person-centered practices to counter the traumatizing effects of the pandemic. Routines that disabled people have chosen for

themselves/ourselves gives them/us a sense of grounding and helps to retain their/our self-determination. Predictable routines can also make things easier: people may not have to think or work as hard just to accomplish basic life tasks. Person-centered planning provides a way to reestablish routines and regain consistency. Anntionete Morgan, an experienced person-centered thinking trainer who became sick with COVID, noted that routines can allow us to “[keep] some sort of control over our lives during a time where it seems like we have none, [in] which we’re scared, [and] some of us are sick.”

Theme 2.3: Witnessing the Whole Person

While the pandemic’s effects can be isolating and traumatizing, it can also be isolating and traumatizing for people to interact with a service system that does not recognize or honor their culture or values. A number of the commentators described how these systems fail to acknowledge and address culture—despite the critical importance of doing so. They argued that it is essential for service providers to listen with compassion and respect, and seek to understand disabled people’s experiences, values, and culture—even and especially if it is uncomfortable. Eric Washington, an advocate and brain injury survivor who is Black, provided a succinct example of this theme: “*So, if you’re culturally uncomfortable having certain conversations, can you truly be person-centered?*” In addition to attending to cultural differences, experts spoke to the importance of providing information—particularly

medical information—in formats that are clear and accessible to people with language-related or cognitive disabilities and people who are not fluent in English.

Theme 2.4: Advance Planning

Experts highlighted the value of planning for crises in advance and described ways in which person-centered planning helps to do that. While no one can predict every possible crisis, experts stressed the importance of putting systems in place to manage known uncertainties. They endorsed the value of advance planning to reduce anxiety and minimize the negative impacts of future emergencies. Nicole LeBlanc, an autistic disability advocate, said,

This crisis shows why we need to devote much more effort in supporting adults with disabilities to prepare for emergencies and ensure that the community can accommodate our needs during a major crisis.

Theme 2.5: Individualized Problem-Solving

Because of the way life has changed for all people during the pandemic, disabled people and service provision organizations alike have had to figure out new ways to handle formerly easy tasks and processes. Because supporting self-determination is the end goal of person-centered practice, many kinds of person-centered practices are designed to provide tools or frameworks for people with disabilities—with support as

needed—to make decisions for themselves/ourselves. The current uncertainties mean these kinds of practices are especially valuable right now. Problem-solving involves creativity and adaptability to meet individualized and changing needs. It should be expansive and collaborative, incorporating different kinds of options including paid and unpaid supports, technology, and more. Michelle Reynolds, a nondisabled family advocate and researcher, said,

[Person-centered practice] helps ground us in the day-to-day problem-solving we can make about anything that’s happening in our lives. It gives us an opportunity to calm down, recognize the value of the voice, and understand what that person wants.

Theme 2.6: Self-Determination

The remarks on the theme of self-determination often reflected fear that the pandemic would induce changes that unnecessarily limit choices for and the autonomy of people with disabilities. Experts stressed that self-direction and person-driven approaches that promote choice and autonomy are all especially necessary right now. Each disabled person is the expert on their own life and should make their own decisions. Marian Frattarola-Saulino, a nondisabled founder of a community-services provider organization, noted:

Person-centered thinking, planning and practice are means to an end—the end being one that is determined by the

person accepting support, who is, as we all are, the expert of their own life. What holds true during this time of COVID-19 is what matters at any other time and in any other context: the amount of control a person has over their own life, not just their planning and their services.

Level 3: Systems, Services, and Providers

The two themes in the third level—which relates to systems considerations—center on the ways in which disability or long-term services and supports (LTSS) systems are organized and how they affect disabled peoples’ experiences during the pandemic.

Theme 3.1: Well-Being Is an Informed Choice

Many commentators noted that there has been a shift in the balance of what is important to and important for disabled people and the people who support them/us during the pandemic. Because of the heightened focus on physical health and safety (factors that are “important for” disabled people), many have experienced extreme restrictions on activities that give their lives meaning and purpose (things that are “important to” disabled people). When these two focuses are out of balance, we undermine self-determination and risk. Or, as Diana Blackwelder, a volunteer researcher and advocate

with dementia, put it: “*sacrificing the person in order to keep the body alive.*” Experts described how the pandemic has highlighted the importance of viewing outcomes through a person-centered lens and beyond the narrow scope of physical health, as well as the importance of promoting dignity of risk and informed choice. Blackwelder asserted her right to this autonomy.

I should be the one making the decisions.... What kind of care do I want to receive? At what point in my life would I prefer to take on additional risk of injury, to include death, if that meant continuing to live the life I want to live?

Theme 3.2: Supporting and Protecting the Care Partners

Another theme involved supporting and protecting people who provide care and support to people with disabilities from the impact and trauma of COVID-19. These include direct support providers, family members, and others who provide paid and unpaid supports (referred to here as “care partners”). Experts recognized that many people who provide paid support and care are people of color and people with lower socioeconomic status, and that they experience disproportionate impacts from the pandemic. Thus, Lydia X. Z. Brown, a disabled advocate, organizer, strategist, and attorney, stressed that it is important to

...protect and ensure fair working conditions for the people

that are providing these types of services, many of whom are often disabled themselves, often low income, immigrants, and/or people of color.

In this way, systems of support must not only support the person with a disability but also those people that the person with a disability relies on for their well-being.

Notably, self-direction is one avenue for facilitating access to needed services and supports. In self-direction, the disabled person decides how to structure their/our own home and community-based services by hiring their/our own staff, and in some cases managing a budget that can be used for a range of goods and services (Mahoney, 2020). People who are self-directing have the freedom to compensate care partners—including spouses, friends, and family members—who may be providing critical support in the absence of direct-support professionals. Kevin Mahoney, a nondisabled self-direction researcher, emphasized that with self-direction, *“you have a way to receive care from people and provide them something in return.”*

Level 4: Societal Factors

The final three themes reflect the opportunities and barriers within society that have come about because of the COVID-19 pandemic.

Theme 4.1: Systemic Inequality and

Marginalization

Many commentators reflected on systemic inequalities, injustices, and marginalization based on people's social identities such as race and disability, which the pandemic has deepened and exacerbated. According to Janis Tondora:

The crisis and our country's response to it have laid bare structural inequities—with the virus hitting certain communities particularly hard. Whether you are a person who is homeless and you can't get a COVID test because you lack an address or a cell phone, or a person with a disability who may be in need of critical care who needs to worry about medical rationing of ventilators, or a person with a mental illness confined to a psychiatric hospital who has absolutely no control of the six feet of physical space around them, or a person of color who lives each day in fear knowing that they are more than twice as likely to die from the virus should they contract it. In all of these situations, COVID-19 has reminded us that the playing field is not level.

Experts cautioned that some people's lives are seen as having less value than others, and that policymakers are reducing people to statistics during the period of crisis. While this dynamic is not new, the COVID-19 pandemic has sharpened this reality. Tondora insisted,

If our goal in person-centered systems is to help all people live a good life in their chosen community, we cannot remain silent in the face of these injustices.

Theme 4.2: Collective Responsibility

Collective responsibility emerged as a theme that offers a method of correcting systemic inequalities, injustices, and marginalization. Commentators spoke about the importance of shared responsibilities and working to make sure no one gets left behind. These responsibilities encompass those between and among the various levels (see Figure 1), including disabled people, their service providers, and the government entities that fund and regulate services. These responsibilities include communicating accurate information honestly and in accessible ways so that all can be included, specifically those who use alternative communication methods. We all hold responsibility for sharing our expertise to protect each other and to ensure access to emergency planning and preparedness, and community resources, not just specialized services, for the greater community. These responsibilities highlight the importance of our interdependence as well as mutual respect and accountability for each other's actions. Shain Neumeier, a disabled lawyer, activist, and community organizer, stated:

It would be a mistake to pretend like collective care and person-centered care are a big dichotomy or somehow in opposition to one another because the collective is made out of all of us. The collective loses something when it loses any one of its members, so we can't be forgetting right now that every one of those members matters.

Experts emphasized that by focusing on the whole of society,

we can emerge whole from the crisis with our shared values intact—meaning that everyone has the inherent right to self-determination, that each of us has control over our lives and over the support we want to make informed decisions that affect our lives, such as where and with whom we live; that each of us is afforded the dignity of risk, and that we are all free to contribute to our chosen communities in ways that are meaningful to us; that each of us is treated equitably, and has equal access to resources such as technology and health care.

Theme 4.3: Opportunity for Change

Finally, commentators expressed hope that the pandemic presents an opportunity for positive change, innovation, and long-awaited reforms. They mentioned a wide range of areas for change, including moving away from institutional and congregate care, providing a greater level of flexibility in employment, promoting self-direction, expanding telehealth and tele-support, and collecting data to document lessons learned. Moreover, commentators expressed an urgency for policymakers, service providers, and advocates to act on the opportunities presented by the pandemic. Marian Frattarola-Saulino, a nondisabled founder of a community-services provider organization, described the opportunity for change this way:

We need to see this as an opportunity to overcome the institutionalized resistance to person-directed, family-

centered supports, and enable everyone using services to be healthier and safer, not just in times of public health crisis, but every day. This opportunity must become the mandate to shift the system. What else do we need to convince us that in no other time is the use of person-centered approaches more impactful and necessary? If not now, then when?

Discussion

Analysis of the NCAPPS Pandemic Wisdom Shorts videos revealed 12 themes across four nested levels that we aligned within a framework informed by the social ecological model. These themes highlight critical aspects of person-centered practices and provide important guidance for transformational change for systems, policy, and practices.

Trauma was the overarching theme in all of the video submissions. The COVID-19 pandemic undoubtedly has traumatized everyone in many ways. However, commentators described the ways in which many people with disabilities face heightened challenges. Challenges included not only the health ramifications of the virus but also the impact of social isolation, disruptions in day-to-day routines, and decreased access to needed supports and services. Additionally, many people with disabilities have lost jobs and access to activities in the community that enabled meaningful connection to community. The isolation and exclusion experienced by many

disabled people during this time will have far-reaching and long-lasting negative effects.

Equally important, however, is the commentators' assertions that person-centered practices such as person-centered planning, peer support, and self-direction, enable us to respond to and cope with the traumas caused by the pandemic. The themes that emerged at the second and third levels illuminate ways in which the commentators have been using person-centered principles to mitigate trauma and their desire to incorporate person-centered principles for a better future after the pandemic.

Necessary public health and safety measures related to the pandemic only highlight the need to advocate for the self-determination of disabled people. All commentators—as well as the authors of this paper, a group that includes people with disabilities—agreed that all people must have control over their lives, and that service providers must respect people with disabilities as the experts on our/their own experiences who know best what we/they need. Taken further, some participants pointed out that people who lead more self-determined lives are actually safer from at least some of the negative impacts of the pandemic because they live independently (as opposed to living in congregate settings). Living independently gives people with disabilities more capacity to structure their lives in ways that can mitigate the trauma and social isolation brought on by the pandemic. Through self-direction, disabled people have more flexibility

to arrange their/our services and supports to meet unique needs during the pandemic.

Although no one predicted the full scope of the pandemic, having person-centered strategies in place provided a foundation for an immediate response to the changes while ensuring services and supports remained consistent with what was important to the person. Person-centered planning is designed to provide a structure that recognizes disabled people within the context of each individual's culture, strengths, and relationships, and that provides disabled people with choice and control over services and supports. The pandemic has reinforced the importance of person-centered planning for ensuring choice and control, particularly during emergencies and periods of uncertainty. To be effective, person-centered planning must be flexible, ongoing, and informed by the issues that arise, including the changes to people's routines and in their lives. Person-centered planning strategies should include a disabled person's partners, family, friends, and support workers. Additionally, disabled people can make use of modern technology to safely make and sustain social connections.

For many disabled people and care partners, peer support—a practice grounded in person-centered values—has been effective in coping with the traumas associated with the pandemic. Peer support can involve either trained peer specialists working with organizations or informal interactions among others with shared experiences. To harness the benefits

of peer supports in the broadest sense, people who provide peer support should be valued for their full lived experience—not just those experiences attributed to a diagnosis. Increasingly, mental health, aging, and other social services professionals recognize the value of connection and support through shared lived experience. Peer support also bridges important gaps in the shared decision-making and informed consent processes by facilitating clear communication using plain, everyday language and accounting for different learning needs and styles. Peer-support providers have been instrumental in the development of self-management and self-directed recovery tools and, during recent months, the use of digital peer support—which is a promising advance in technology (Fortuna et al., 2020). The increasing prominence of peer support during the pandemic is evident in the fact that, in many communities, peer supporters have done outreach and provided connection to those in need, often expanding the scope of services to those who would not have traditionally received peer support (Adams & Rogers, 2020).

At the systems level, the themes revealed clear opportunities for abandoning outdated practices and rebuilding the service system in a more person-centered manner. Thus, the pandemic is not just a calamity but also a potentially transformative moment. Commentators envisioned a system that acknowledges and responds to trauma in the lives of people with disabilities and the paid and unpaid people who

support us/them. They/we noted that the pandemic further exacerbated gaps and inequities in our service systems, including disparities in access, utilization, and quality of supports for people of color as well as the unrecognized and undervalued role of direct support professionals as essential workers. They stressed the importance of creating and sustaining systems that attend to equity throughout their practices and policies. Commentators stressed the importance of welcoming every opportunity for change. We must use our time, resources, and information to eliminate systemic inequality and marginalization of disabled people, families of people with disabilities, and the workforce that supports them/us.

Finally, at the societal level, commentators rejected the notion that the health of the individual and of the collective are at odds. Instead, commentators argued that a society that strives for collective responsibility and well-being and leaves no one behind will generate the interdependence necessary to weather disasters like the COVID-19 pandemic. These insights will apply equally well to the current pandemic and future challenges that we may collectively face.

Conclusion

As human service systems throughout the U.S. begin the process of reestablishing themselves in coming years, the Pandemic Wisdom series from the NCAPPS community

offers person-centered practices as both an anchor for weathering the pandemic and a beacon for rebuilding lives, service systems, and communities. Through the use of principles of self-determination, equity, and social justice, we may correct long-standing inequities and ensure people with disabilities experience systems as truly person-centered. At the person, provider, system, and societal levels, person-centered practices such as planning, peer support, and self-direction are tools to navigate future disruption and uncertainty.

Of note, the perspectives represented here are those of 16 individual people at one moment in time. A wider array of voices and experiences would have generated even more wisdom. Similarly, though we employed participatory approaches in the data analysis, interpretation and writing for this article, our efforts were limited by time and resource constraints. Additional time and resources would have resulted in a wider and deeper inquiry and more expansive results. Nonetheless, the authors attempted to respond to a pivotal moment in the history of disability and human service systems.

Building on the guidance presented here, future work must explore additional questions related to specific methods for enhancing person-centered thinking, planning, and practice. Critically, leaders in the field must monitor and document their innovations, successes, and failures to continue to expand our knowledge. The unique circumstances we find ourselves in as a society have opened a portal to engage in deep systems

change that could result in more person-centered systems for those of us with disabilities.

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Appendix

**Name, Affiliation, and Biographic Information of Subject
Matter Experts Who Created Pandemic Wisdom Videos**

Name	Affiliation	Biographic Information
Martha Barbone	NCAPPS PAL Group	Martha Barbone served in the U.S. Air Force before being sidelined by a diagnosis of depression and PTSD. She has provided peer support on an inpatient unit, in a peer-run organization, directed the Certified Peer Specialist training program, and has worked for the National Association of Peer Supporters.
Diana Blackwelder	NCAPPS PAL Group	Diana Blackwelder is a volunteer researcher at the University of Maryland studying technology and dementia, serves on the Dementia Alliance International (DAI) Board of Directors, represents DAI to the Leaders Against Alzheimer’s Disease (LEAD) coalition, is a National Alzheimer’s Association Early Stage Advisor Alumni, and consults to the Smithsonian and US Botanical Garden Access Programs for people living with dementia.

Name	Affiliation	Biographic Information
Valerie Bradley	Human Services Research Institute	Valerie Bradley is the founder and president emerita of the Human Services Research Institute. With more than 40 years of experience, Val is a nationally recognized expert in the intellectual and developmental disabilities field. She has devoted her career to working with public agencies and other researchers to strengthen services, improve programs, and inform policy—all as an early and staunch advocate for the direct participation of people with disabilities in these efforts.
Lydia X. Z. Brown	NCAPPS PAL Group	Lydia X. Z. Brown is a disabled advocate, organizer, strategist, and attorney. For over a decade, their work has focused on interpersonal, institutional, and state violence against multiply-marginalized disabled people, especially at the intersections of race, gender, class, and sexuality. They are core faculty in Georgetown University’s Disability Studies Program and Director of Policy, Advocacy, & External Affairs for the Autistic Women & Nonbinary Network.

Name	Affiliation	Biographic Information
Marian Frattarola-Saulino	Values into Action	Marian Frattarola-Saulino is the co-founder and CEO of Values Into Action, an organization dedicated to self-direction and co-production of services and supports. Marian is also one of the founders of The Alliance for Citizen Directed Supports, a membership organization led by disabled people and focused on advancing self-direction.
Karyn Harvey	Park Ave Group	Karyn Harvey has worked in the field of intellectual disabilities as a psychologist for over 30 years and has published two books on the topic. She is director of programs and training for the Park Ave Group and speaks throughout the country on trauma-informed supports for people with intellectual disabilities.
Kelly Lang	NCAPPS PAL Group	Kelly Lang’s brain injury advocacy career began after she and her 3-year-old daughter were injured in a horrific car accident in 2001. Kelly has served on the Board of the Brain Injury Association of Virginia and is a member of the Brain Injury Association of America’s Brain Injury Council.

Name	Affiliation	Biographic Information
Nicole LeBlanc	Human Services Research Institute	Nicole LeBlanc is the coordinator of the Person-Centered Advisory and Leadership Group (PAL Group) for NCAPPS. Nicole has a keen ability and interest in public policy and excels at communicating the needs of people with developmental disabilities to public officials.
Kevin Mahoney	Boston College School of Social Work	Kevin Mahoney is a professor emeritus at Boston College School of Social Work. He is best known for his research on participant direction of home and community-based services and supports for people with disabilities, and financing of long-term care. He serves as the director of the National Resource Center for Participant-Directed Services at Boston College.
Anntionete Morgan	NCAPPS PAL Group	Anntionete Morgan is a Certified Person-Centered Thinking Trainer (CPCTT), and has over 17 years of experience as a social worker. Her experience includes behavioral health with an emphasis on substance use, medical discharge planning, HIV case management, service coordination, managed care and clinical training.

Name	Affiliation	Biographic Information
Shain Neumeier	Committee for Public Counsel Services, Mental Health Litigation Division	Shain M. Neumeier is a lawyer, activist, and community organizer, and an out and proud member of the disabled, trans, queer, and asexual communities. They are a passionate advocate for the autonomy of young, disabled, and queer people, and focus on ending abuse and neglect of disabled youth in schools and treatment facilities. Shain has worked with the Intersex and Genderqueer Recognition Project, the Autistic Women & Nonbinary Network, and the Community Alliance for the Ethical Treatment of Youth.
Michele C. Reynolds	University of Missouri, Kansas City	Sheli Reynolds is the associate director at the University of Missouri-Kansas City (UMKC) Institute for Human Development, where she advocates for and alongside people with disabilities and their families, working to create policy, practice, system, and community change. She is the lead developer of the Charting the LifeCourse framework and directs the LifeCourse Nexus.

Name	Affiliation	Biographic Information
Carole Starr	Brain Injury Voices	Carole Starr has been a brain injury survivor since 1999 when she was in a car accident. The injury ended Carole’s career as an educator and her hobby of classical music performance. One small step at a time, Carole has reinvented herself. She is now a national keynote speaker, the author of <i>To Root & To Rise: Accepting Brain Injury</i> and the founder/facilitator of Brain Injury Voices, an award-winning survivor volunteer group in Maine.
Janis Tondora	Yale University School of Medicine	Janis Tondora is a professor and researcher at the Yale University School of Medicine whose work focuses on services that promote self-determination, recovery, and community inclusion among individuals diagnosed with serious behavioral health disorders.

Name	Affiliation	Biographic Information
Eric Washington	Brain Injury Association of Missouri	Eric Washington is a former football player for the University of Kansas. His football career ended on September 30, 2006 due to a concussion and spinal cord injury. After recovering from the neck injury, he returned to graduate with a bachelor’s degree in Applied Behavioral Sciences. Today, Eric’s life mission is to advocate for people like him – people with TBI, especially those who are also homeless.
Janet Williams	Minds Matter LLC	Janet Williams has been working for people with brain injuries and families since 1982. She is the founder of Minds Matter LLC, an organization grounded in person-centered practices that provides supports to people with brain injury.

16.

ASSESSING AND MITIGATING RISK FOR APPLIED BEHAVIOR ANALYSIS PROVIDERS DURING A PANDEMIC

Joshua B. Plavnick PhD; Krista Clancy; and
Sharon Milberger

Plavnick, J. B., Clancy, K., & Milberger, S. (2020). Assessing and Mitigating Risk for Applied Behavior Analysis Providers During a Pandemic. *Developmental Disabilities Network Journal*, 1(2), 210–220. <https://digitalcommons.usu.edu/ddnj/vol1/iss2/17/>

[Assessing and Mitigating Risk for ABA Providers PDF File](#)

Plain Language Summary

The COVID-19 pandemic presented many barriers to delivery of behavioral health services. Applied

behavior analysis (ABA) for children with autism spectrum disorder (ASD) is one example. Yet it is important to maintain ABA services for people with ASD to help them achieve long-term life goals. This paper describes a toolkit that helps ABA providers decrease risk during a pandemic. Three providers used the toolkit with 20 children who had ASD. The toolkit helped providers make decisions that maintained safety from COVID-19. The results showed the toolkit can be useful to ABA providers. The toolkit could also be useful in other situations that provide close-contact therapies.

The novel Coronavirus of 2019 (COVID-19) created massive international shutdowns of almost all basic services across many countries in the early stages of 2020, and these shutdowns sporadically continued throughout the year across the globe (Dawood, et al., 2020). The effects of the loss of services varied from inconvenient (e.g., fitness centers and bars) to potentially debilitating (e.g., mental and behavioral health). In situations where loss could be serious, providers required procedures and tools to deliver essential services without placing the consumer or service provider at excessive risk of contracting COVID-19 or suffering severe symptoms if they were to contract the illness. Early stages of the pandemic saw relatively limited direction for safe delivery of essential services, with guidance increasing as it became clear that the U.S. would

be navigating peaks and valleys of infections throughout the summer of 2020 and beyond.

One essential service that struggled in the beginning of the pandemic to optimize care was behavioral health treatments for individuals with autism spectrum disorder (ASD; Cox et al., 2020; Columbo et al., 2020). Although many mental and behavioral health providers pivoted to delivery of services via telehealth, such an approach was not always possible as a direct treatment for individuals with ASD (see Cox et al., 2020, and Rodriguez, 2020, for an explanation of telehealth barriers in ASD treatment). In addition, although some children in daycare settings could quickly learn to wear a mask and distance from others, such safety measures may not have been readily understood or feasible for some children with ASD, who often have communication and social skill deficits and who sometimes experience heightened sensitivity to physical stimuli, such as straps around their ears or coverings over their nose and mouths (Kojovic et al., 2019). As such, the ability to maintain safety for both consumers (i.e., the individuals with ASD and family members) and providers, while also delivering effective services, was particularly challenging for treatment of individuals with ASD during the pandemic shutdowns.

The present paper describes a process for assessing and mitigating health risks to individuals with ASD and their families while trying to fulfill behavioral health needs during the COVID-19 pandemic. Although specific to one group of providers and clients, we believe it offers useful guidance to

the broader community of behavioral health providers (e.g., occupational therapists, speech and language pathologists, physical therapists) who may be responsible for devising and delivering therapies to individuals with ASD and related developmental disorders during a major public health emergency, such as a pandemic.

Background

Among the most prevalent and empirically supported treatments for ASD are those therapeutic techniques based on the scientific concepts and principles of applied behavior analysis, or ABA (Leaf et al., 2016). It is not uncommon for people with ASD to engage in behavior that can be very challenging for caregivers and service providers, including aggression and self-injury. In addition, these behaviors can be exacerbated by changes in environment and routine (Cohen & Tsiouris, 2020). As the pandemic shutdowns continued, and many consumers experienced restrictions in services in both the schools and community, the importance of consistently delivering ABA to individuals with ASD increased. Therapeutic interventions based on ABA often directly target challenging behaviors and as part of those interventions, behavior analysts provide guidance to families on how to best handle challenging behaviors in the home. These services most often include staff who work directly with the client in their home or clinic, which can also offer much needed respite for

families whose other services have been disrupted, reducing additional stressors on families already experiencing higher levels of stress than normal (James, 2012). Although in cases where therapeutic interventions based on ABA were deemed necessary to continue, mechanisms for doing so safely continued to lag, leaving ABA providers guessing about how to safely continue to serve clients and families in need of care.

Among the most important ethical tenets in delivering behavioral health services is “do no harm” (Koocher & Keith-Spiegel, 1998), which raises several new considerations during a global pandemic. For example, providers might be concerned that delivering in-person treatment during a pandemic puts clients and families at risk of harm. Such a concern is unlikely when not experiencing a pandemic. In addition, the Behavior Analyst Certification Board (BACB, 2016) outlines conduct of a behavior analyst in the *Professional and Ethical Compliance Code for Behavior Analysts* to include practicing in areas where they are competent (codes 1.01 and 1.02) and considering their responsibility to their clients and the parties involved with therapy, such as the staff and family who work with that client (2.02, 2.04). It is also necessary to consider the integrity of the treatment and when services need to be discontinued or interrupted for a period of time (2.09 and 2.15). Within the context of the COVID-19 pandemic, behavior analysts and others who provide services to individuals with ASD and related disorders could benefit from a process for assessing risks at the individual level and making

treatment decisions based on that assessment to adhere to professional and ethical standards of care.

Risk assessments are used in considering choices for life, health, finances, and many other situations where it is important to consider options that will provide the best outcome during times of uncertainty (Wilson & Crouch, 2001). Experts in the field of ABA recommend using a decision-making framework to determine the risks and benefits of the situation and determine the best course of action. Bailey and Burch (2016) discuss a process for a risk-benefit analysis that includes (a) assessing the general risk factors, (b) assessing the benefits of treatment, (c) assessing the risks for the procedure, and (d) reconciling the risks with the parties involved. This advice for risk analysis is best when considering if treatment is possible and the types of treatment that should be considered. The process can then be used to objectively review and discuss potential risks and risk mitigation strategies with the client and their family to determine the best choice for each individual client.

Following the widespread shelter-in-place orders that were instituted across the country, Colombo et al. (2020) offered a decision model to determine if ABA services are warranted during a time of crisis. They advised behavior analysts to review the setting, the risk of exacerbating behavioral issues to the point where a client might experience imminent harm or hospitalization, the ability to utilize telehealth services, and the possibility of reducing service intensity for a period of time. In

April 2020, the Association of Professional Behavior Analysts (APBA) also offered guidance for ABA practitioners on using ABA during the COVID-19 pandemic that defined terms such as “essential,” reviewed legal responsibilities that behavior analysts should consider and recommended that risk mitigation strategies be used when services are necessary. Unfortunately, the risks associated with COVID-19, along with mitigation strategies to reduce risks, are not “common knowledge” for all behavior analysts. In addition, the risks and mitigation strategies are likely to vary from one service provider to another based on where and how they provide services, as well as for the clients receiving services.

Behavior analysts are trained to consider decisions about safety of the client and others in relation to the need to continue therapy, but it has not been until recent times that a behavior analyst would have to make such decisions during a pandemic. Even those with extensive experience in the field found themselves questioning what the best way was to evaluate the need for treatment in such a novel situation (Cox et al., 2020). Many states across the country issued shelter-in-place orders for its citizens in March of 2020. ABA providers were identified as essential workers, but it was unclear from state to state how that role was defined and how providers should respond with treatment during that time (Cox et al., 2020). Some providers chose to stop services for all clients, some continued services or quickly reopened services and added precautionary measures such as the use of personal

protective equipment (PPE) for staff, utilization of health screens, social distancing, and increased sanitization of workspaces and hygiene practices (Kornack, et al., 2020). Local government agencies, the Centers for Disease Control and Prevention (CDC), and other various health and human services agencies produced ongoing new information, making it difficult to competently navigate the information while considering the conflicting responsibilities to the client and other parties involved.

In the current situation, many behavior analysts, including the authors, did not feel like they had the knowledge in disease management or the ability to keep up with the changing information to carry out a competent risk analysis. In response to this challenge, a task force was established through our state's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) network, with experts in specialty areas including practicing behavior analysts, medical experts in pediatric care and epidemiology, and community and advocacy leaders in ABA and the treatment of ASD. Questions regarding information necessary to conduct a risk analysis were presented to the task force. Each expert gathered supporting documentation in their area of expertise from local and national governmental agencies and published research. The information collected and discussed included the most up-to-date recommendations for safety measures for direct care workers from a variety of areas (medicine, childcare, etc.; CDC, 2020; Michigan Department of Health and Human

Services, 2020), recently published articles on COVID-19 (health risks for different populations, comorbid disease-related health concerns, and the populations most at risk; Ludvigsson, 2020; Mullen et al., 2020), and governmental websites with daily and weekly data regarding cases, hospitalizations, and deaths related to COVID-19 (Michigan.gov, 2020a, 2020b; Mi Safe Start Map, 2020; Whitmer, 2020).

The product developed by the task force was a toolkit that behavior analysts could use to assess individual client risk and devise corresponding risk mitigation strategies to increase the likelihood of maintaining client and staff safety while delivering behavioral health services to clients (see Clancy et al., 2020). Although specific to behavior analysts, the toolkit was informed by and modeled after a similar resource from the Johns Hopkins Bloomberg School of Public Health (Mullen et al., 2020), which was intended for the broader business community in its return to operations during COVID-19. The task force adapted this broader resource to meet the specific needs of ABA providers and children with ASD. At minimum, we believe our toolkit (i.e., Clancy et al., 2020) could be adapted for use across many behavioral health providers, and likely also has applicability in educational and recreational settings where individuals with intellectual and developmental disabilities (I/DD) may receive services. The following case study describes our first use of the toolkit for a

behavioral health center and discusses the broader implications of this work.

Method

Based on discussions from a series of meetings, the task force developed a toolkit to provide support for behavior analysts in the field to gain knowledge about COVID-19, the necessary background information providers needed to gather about the client and their family, and the unique aspects of the therapeutic environment and the community that influenced risk (Clancy et al., 2020). This knowledge could then be used to complete a risk assessment for each individual client. The toolkit also included extensive considerations for risk mitigation across a range of service options for clients. Together, the risk assessment and risk mitigation options provided the information necessary for a behavior analyst to feel competent in using a decision-making framework similar to what is recommended for complex situations the professionals are likely to encounter.

The toolkit, titled *“Risk Assessment and Mitigation Strategies for Applied Behavior Analysis: Treatment of Children with Autism During a Pandemic”* (Clancy et al., 2020), is divided into two sections (see Table 1). The first section focuses on risk assessment and includes an Individualized Risk Assessment tool that requires the behavior analyst review several aspects of service delivery and assign to specific items

a ranking of minimal, moderate, or more than moderate risk, to make decisions about the overall exposure to COVID-19 as well as a client's risk of a severe COVID-19 infection. Assessment questions targeting the therapeutic environment include the size and number of people in the therapeutic space, the ability for the staff to keep the area disinfected, the ability to keep others out of the treatment area, and access to handwashing in the treatment area. Assessment questions targeting the individual and their family include health questions about pre-existing conditions, age of the client and family members, behaviors that could increase the risk of contamination (e.g., pica, mouthing, eye poking, nose picking), the ability of the client and family to maintain social distance from staff, and the ability for an alternative caregiver to care for the client if the current caregivers were to become ill. There are also questions targeting the staff including age of the staff, comorbid medical conditions, possibility of exposure to COVID-19 outside of work, and the risk of contamination from working with a client with increased contamination behaviors, as discussed above. The risk assessment tool also has an example of a health screen that can be used by the behavior analyst to monitor symptoms in clients, family, and staff, and a flow chart used to guide the behavior analyst in the decision model if they identify items that increase risk on the assessment tool.

Table 1
Contents of the Risk Assessment and Mitigation Strategies for Applied Behavior Analysis: Treatment of Children with Autism During a Pandemic Toolkit

Section	Description	Purpose
1. Individualized risk assessment	Assesses risk pertaining to 3 areas: • Treatment environment • Client and family • Staff members	Allows behavior analyst to identify greatest risk factors for spread of illness or severe response if infected.
2. Health screen	Assess daily health condition of staff, client, and client family if needed.	Make decisions about need for daily cancellation due to report of illness. Must be adapted regularly to align with health guidelines.
3. Mitigation strategies worksheet	List of potential mitigation actions at organization or individual level.	Takes outcomes from assessment and guides provider to optimize mitigation strategies.
4. Parent planning guidelines	Considerations for providers to discuss with parents.	Assists in revising treatment plan to account for health risks.

The second section of the toolkit focuses on mitigation strategies and includes an individualized Mitigation Strategy Worksheet that provides strategies related to physical

distancing between persons and objects, health screenings, sanitation and hygiene measures, agency policy, and communication between the agency and staff as well as between the agency and families (Clancy et al., 2020). These strategies, although not all encompassing, are a summary of many of the risk mitigation strategies compiled in the task force discussions and the documents collected during the task force workgroup. Collecting these strategies into a single toolkit allows providers to complete an assessment and mitigation plan for each client, discuss critical operating procedures with each member of the staff team, coordinate planning and logistics with the client and family, and embed implementation guidelines within a client's treatment plan. Figure 1 is part of the toolkit and depicts a process that providers can use to guide decision making as information is collected using the various assessments within the toolkit.

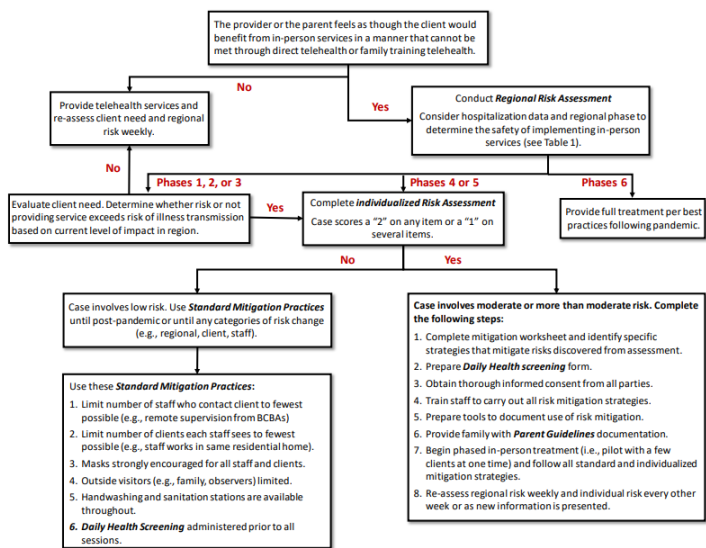


Figure 1

A Sequence for Administering Assessment Tools and
Aligning to Individual Risk Mitigation Strategies

When possible, it is important to involve the client in the planning process. When not possible, the family must be involved to ensure a balance between client or family needs, effective treatment, and overall safety. Also included in the toolkit (Clancy et al., 2020) is a set of parent planning guidelines for the behavior analyst to use with the family or to provide to the family prior to completing the risk assessment with them. This tool helps to educate the parent on the risks of COVID-19 and the expectations and considerations that are made in determining if and how treatment should be continued during this time.

At its inception, the Clancy et al. (2020) toolkit was a collection of resources and practice guidelines the authors believed would be beneficial to providers and families alike. In the time since, a preliminary evaluation of the toolkit was conducted to determine the feasibility of providers utilizing the various components and deriving modified treatment plans as a result. During this pilot evaluation, we sought to evaluate whether the toolkit effectively assessed risk for individual clients and families, as well as risk of behavior technicians in delivering ABA services. In addition, the feasibility of Board-Certified Behavior Analysts (BCBAs) to use the toolkit to develop individualized risk mitigation plans for each client was also evaluated.

The toolkit was piloted following the shutdown—at a time when services for those involved had been temporarily suspended and the providers were working toward restarting ABA services within clients' homes. In order to pilot the toolkit, three BCBAs completed the risk assessment and developed corresponding mitigation strategies for 23 children with ASD. All BCBAs were employed with the same organization, which delivered early intensive intervention based on the principles of ABA to children between 2 and 6 years of age. Each of the providers had a master's degree and had been working as a BCBA for at least 3 years.

Each of the families for whom an assessment and mitigation plan were developed had received services within a clinic setting prior to the COVID-19 pandemic. When the

pandemic began, in-person services were paused, and telehealth was administered when possible. Prior to relaunching in-person services, the organization made the decision to administer in-home services only, as the clinic setting in which services had been provided did not allow for appropriate social distancing. Therefore, the risk assessment and mitigation strategies had to be aligned to each families' unique home environment. Some families had multiple generations living within a single home, with home size ranging from quite small (e.g., one-bedroom apartments) to large (e.g., 3,000 square feet or more).

The BCBA's all completed the same risk assessment toolkit described above. Each BCBA completed all items on the toolkit for each client, assigning a rating of minimal, moderate, or more than moderate for each item. The BCBA's had served all participating clients for at least 6 months prior to the start of the pandemic. For any items the BCBA could not answer on the assessment, they contacted parents of the child to derive a risk rating of low, medium, or high for that item. Once each of the items on the risk assessment had been scored (minimal = 1, moderate = 2, more than moderate = 3), the BCBA's calculated overall risk scores by adding each of the rankings together and dividing the sum by the total possible score to derive a percentage. Although some items may involve greater risk than others, a weighted analysis was beyond the scope of this preliminary evaluation. Instead, the purpose of the overall score was to derive a general profile of the risk each client,

family, and the behavior technicians, may face in delivering services. Higher risk scores were interpreted to mean more precautions and possibly resources were needed, though each item with a moderate risk score was addressed with a corresponding risk mitigation strategy. Risk scores were not used to make decisions about pausing services. All clients continued to receive services unless the family opted out of treatment.

Results

After administering the risk assessment across 23 families, BCBAAs identified a mean risk score of 36.4%, with a range from 13% to 59%. The sample involved in this pilot evaluation demonstrated relatively low overall risk, with some clients and families having very low risk and others demonstrating moderate risk. In what follows, we discuss the use of system-wide mitigation strategies that can contribute to overall reduction of risk for all clients, as well as the importance of individualized mitigation strategies to support health and safety of each client, family, and staff member in the delivery of behavioral services during a pandemic.

Although the sample mean was relatively low, it should be noted that the service provider had already eliminated one major element of risk in that services within the same treatment room had been stopped in favor of delivering treatment within each clients' home environment. This

strategy exemplifies a system-level mitigation effort that was optimal for this specific agency because of spacing issues within the clinic. Although the types of systemic mitigation approaches will vary from agency to agency, providers will likely benefit from incorporating some system-wide mitigation strategies, regardless of assessed risk levels. Similar systemic risk mitigation efforts in the present investigation involved conducting health screenings with all staff, clients, and family members prior to beginning a treatment session, and requiring masks for all staff and families while teaching clients to tolerate wearing a mask as often as possible during treatment sessions. Finally, though the assessment may have deemed clients at a low risk for either contracting or having a severe outcome from COVID-19, this is different than identifying no risk, as in a post-pandemic environment. Thus, developing individualized risk-mitigation strategies can be useful even when overall risk starts at a low level.

The variation of risk scores across clients and families with some very low scores to some moderate risk scores speaks to the importance of an individualized assessment followed by mitigation strategies at the level of individual clients, families, and staff members. For example, one common approach when delivering ABA services within a client's home in the absence of a pandemic is to provide at least two different behavior technicians (one at a time during different times of the day) to promote multiple social partners and interactions. In addition, a BCBA will supervise within the home once per week to

review program implementation and adjust as needed. However, in situations where clients had higher risk scores, one mitigation strategy used was to reduce the total number of people who entered the home. This was accomplished by only pairing one behavior technician with each client and the BCBA conducting supervision sessions via videoconferencing.

Conclusion

The toolkit developed by Clancy et al. (2020) was a useful way for the individual providers and organization to make decisions about delivery of treatment to clients and families during the COVID-19 pandemic. Individual risk factor scores indicated some clients presented greater risk than others. Calculating those scores allowed for a decision-making process that ensured resources were allocated toward clients and families, or staff members with higher risk scores. The authors of this paper believe all clients who consent to treatment should receive services during a pandemic or similar situation, and strongly caution against using risk scores as a mechanism for allocating treatment to some clients and not others. Instead, risk scores should be used to inform the level of support needed for all clients.

The strategies described in this paper were developed for Michigan ABA providers treating children with ASD during the COVID-19 pandemic, though they were based on risk mitigation procedures from a general return-to-work

document written by public health officials at Johns Hopkins University (Mullen et al., 2020). Therefore, these strategies can easily be applied to several other contexts including non-ABA providers, children with disabilities other than ASD, use outside of Michigan, and use with adults as well as children. Moreover, the strategies have potential to be extended beyond the COVID-19 pandemic to address future public health emergencies, and possibly to other barriers to in-person service provision, as well as client and family preferences.

The flowchart shown in Figure 1 can serve as a reasonable framework for many behavioral health providers. The language used in the flowchart is nonspecific to any particular provider or type of disability with one minor exception (an example is given to “use remote supervision from BCBA’s” as a mitigation practice to limit the number of staff who come in contact with the client). Similarly, the *Individualized Risk Assessment* and *Daily Health Screening Tool* are written in a manner that can be used by any provider serving clients in a behavioral health setting. The *Risk Mitigation Worksheet* does make a few references to behavior analysts and behavior technicians, but these terms could easily be substituted with more general words such as “provider” or discipline-specific terminology. In order to make the tools applicable to adult clients, items may need to be revised in a manner that asks the individual to answer on behalf of themselves (or have an option to have the person be supported in answering the questions).

The Parent Guidelines are geared to ABA services and would need modification for other behavioral and nonbehavioral services. The guidelines provided could serve as a template from which to work. These guidelines could also be modified for any family member including those who support an adult with a disability.

Although the strategies focus on our state's Safe Start Plan, which delineates six phases (Phase 1 indicating extreme caution and Phase 6 referring to post-pandemic), they could be applicable to other states. More specifically, the portion of the flowchart following Conduct Regional Assessment can be adapted to refer to state-specified risk levels rather than being organized by phase. Each provider should abide by their particular state's public health requirements.

The strategies identified in this report can be readily used if there is a resurgence of COVID-19 or another pandemic emerges. In addition, the toolkit may be of use when not in a pandemic, as risks to health and safety of consumers are applicable anytime behavioral health providers administer services to individuals with disabilities or mental health disorders. Future research could assess the benefit of using the tools described herein when not in a pandemic and determine whether risk assessments and mitigation strategies decrease general spread of illness or injury during service delivery. COVID-19 led to many innovations that will be essential to incorporate across a range of business and service-delivery entities. The toolkit described herein offers a potential solution

to a number of challenges that could arise in the delivery of behavioral health services.

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17.

USING QUALITY IMPROVEMENT (QI)-FOCUSED EVALUATION TO REDESIGN DIRECT HOME- AND COMMUNITY-BASED SERVICES DURING THE COVID-19 PUBLIC HEALTH EMERGENCY

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[Using Quality Improvement \(QI\)-Focused Evaluation to Redesign Direct Home- and Community-based Services during the COVID-19 Public Health Emergency PDF File](#)

Plain Language Summary

The University of New Mexico is home to the Center for Development and Disability. At the Center, we have many direct service programs. The programs are for people with intellectual or developmental disabilities. They are also for families who are expecting a baby or have a very young child. In March 2020, the COVID-19 pandemic changed our work. To keep our clients and staff safe, we stopped all home and community visits. We moved to using “telehealth”—meaning video (Zoom) and/or phone calls to meet with our clients and families. We then wanted to know how our clients and staff reacted to no longer seeing each other in person. We met with staff and did surveys with clients to find out how this changed things for them. This paper describes what we learned. Below are the questions we asked ourselves:

1. How did clients rate telehealth-based services?

How did clients/families compare telehealth to in-person services?

2. How did staff experience the switch to telehealth? What problems did they face with technology and a new way of working?
3. What changes did program leaders make to support staff and service delivery?
4. How did programs use technology to deliver services? How prepared were our programs to use telehealth? How were problems overcome?

The article ends with four issues that UCEDD's and other agencies delivering telehealth direct services may want to think about moving forward.

Introduction

An estimated five million people receive some form of home and community-based services in the U.S. Approximately 4.7 million receive services through one of the federal Medicaid Waiver or state plan programs, many with intellectual or developmental disabilities (Musumeci & Chidambaram, 2020). Home-visiting programs serving families with pregnant women or young children serve approximately 350,000 families (National Home Visiting Resource Center [NHVRC], 2020), many of whom are from lower socioeconomic groups or minority communities (Sama-Miller

et al., 2018). One factor that clients in all of these programs have in common is that they are members of vulnerable populations, which have been shown to be at higher risk of infection from COVID-19. For example, a recent analysis of 64 million patient records from 547 healthcare organizations found that people with intellectual disabilities were 2.5 times more likely to contract COVID-19 (Gleason et al., 2021). A study by the Centers for Disease Control and Prevention (CDC) found that pregnant women are more likely to both contract the infection and are at greater risk for severe outcomes (Zambrano et al., 2020). A 2020 analysis of over 1 million people who contracted COVID-19 published in the *Journal of Public Health* found that lower socioeconomic status (SES) and race were both significantly positively associated both with initially contracting the virus and side effects (Hawkins et al. (2018).

Using the Association of University Centers on Disability (AUCD) definition for reporting about service programs, home and community-based services are defined as specialized, non-clinical services offered with to enhance the well-being and status of the client or family receiving them. These services are offered by many Centers within the national network of University Centers for Excellence in Developmental Disabilities Education, Research and Service (UCEDDs). These services have been identified as playing “...a crucial role in keeping people...safely at home and in their communities.

During the COVID-19 pandemic, these services are both more important, and under more stress, than ever” (Edwards, 2020).

UCEDDs design and implement home- and community-based direct service programs that reflect the unique needs and target populations within the state or local area they serve, the requirements of evidence-based protocols, as well as specific mandates of funding partners and related federal and state regulatory requirements. The Center for Development and Disability (CDD) at the University of New Mexico (UNM) offers a variety of home- and community-based direct service programs with a diverse range of client populations that include case management, consultation, prevention, and intervention services traditionally delivered via face-to-face, in-person meetings in family homes, and other community settings. These nonclinical programs include the following.

- Family-centered nurse case management services provided statewide for children and adults with developmental disabilities who have been diagnosed with long-term chronic health condition that require skilled care and assessment prior to age 22 (the Medically Fragile Nurse Case Management Program [MFCMP]).
- Consultation services supporting adults with intellectual disabilities who have opted to participate in the state’s Mi Via (“My Way”) self-directed Medicaid waiver program.
- Parents as Teachers (PAT), an evidence- and prevention-

based home visiting program provided by trained parent educators providing services to families from the prenatal period through age 5.

- The Nurse Family Partnership (NFP), in which licensed registered nurses provide evidence-based prevention services to families from the prenatal period through age 2.

Together, these programs serve well over 1,000 families at any given time. Two of the four programs serve families statewide (MFCMP and Mi Via), while the others provide services across multiple counties that include both urban and rural communities. For a variety of reasons, providing home- and community-based services to clients in these programs was challenging in New Mexico even before the pandemic struck. New Mexico is the fifth-largest state by land mass (Economic Development Department, 2021) and the sixth least densely populated state or territory in the U.S. (U.S. Census Bureau, 2021a). This results in service delivery challenges for direct-service programs that rely on delivering services in clients' homes. Before the pandemic, Center staff often drove long distances to serve clients and families.

In addition, lack of access to consistent broadband internet service is common across the state. The U.S. Census Bureau (2021b) ranked New Mexico 48th in the country for the percentage of households with broadband internet connections in 2019. The Executive Director of the state's

Public-School Facilities Authority estimates that nearly 25% of primary and secondary students in New Mexico lack internet access at home (Mckay, 2020). This is especially true in rural, tribal, and more remote areas of the state. In testimony before the U.S. House of Representatives Committee on Energy and Commerce in July of 2020, President of the Navajo Nation, Jonathon Nez, estimated that less than half of Navajo chapters—spread out over 27,000 square miles across three states—have access to broadband internet (Nez, 2020).

New Mexico is also a “minority-majority” state. According to the last U.S. Census, half the population of the state cite Hispanic ethnicity (49%) and 11% of the population report Native American heritage (U.S. Census Bureau, 2021). Both Hispanic and Native Americans in the state have significantly lower incomes (New Mexico Center on Law and Poverty, 2018). The clients and families served by CDD direct service programs are broadly representative of the racial and ethnic diversity of the state with a range of 31% to 60% of clients served in specific programs reporting Hispanic ethnicity and the proportion of Native Americans receiving services in each program ranging from 6% to 16%.

The economic impact of the pandemic has greatly affected the entire population of the state. According to a special report by New Mexico Voices for Children (2021) using data from the *2020 Kids Count Data Book*, as many as 34% of New Mexican children were food insecure in 2020, compared to 24% in 2018; 51% of adults in households with children had

lost employment income since March 2020; and by the fall of 2020, nearly 30% of adults in households with children had little to no confidence in their ability to pay their next rent or mortgage payment on time.

In March 2020, because of the rapid spread of COVID-19, as in many other states across the U.S., New Mexico's governor declared a public health emergency and all in-person home and community services were abruptly halted throughout the state. In the first days and weeks following this declaration, all direct-services programs at the CDD required rapid recalibration to use distance-based technologies and virtual platforms for service delivery. As this transition was taking place, CDD faculty and staff simultaneously designed and implemented an ongoing, hybrid quality improvement/evaluation process with two purposes in mind. The first purpose was to gain real-time knowledge of the realities of program implementation in this new environment—given most program staff and clients had little experience with using distance-based methods. The second was to assess the short- and long-term impact of shifting service delivery from in-person to remote service delivery for both the staff and those served by these programs.

Methods

Using a combination of interviews, focus groups, surveys and programmatic data, this effort focused on four primary topics.

1. How did clients rate the quality and efficacy of distance-based services? How did clients/families compare virtual to in-person services?
2. What were the experiences of service providers as the switch to distance-based services occurred, including barriers revolving around technology and altered service-delivery processes?
3. What adjustments did program leaders make to support staff and service delivery?
4. How did programs use technology to deliver distance-based services? How well equipped were Center programs to operate remotely in terms of technology, and how were obstacles overcome?

Using a hybrid program evaluation and mixed-method research design, qualitative and quantitative data were collected via interviews with program leads, focus groups with key staff, and online surveys of direct-service clients from May through September 2020. A total of 36 staff participated in either interviews or focus groups via videoconference. The purpose of the interviews and focus groups was to assess the efficacy of the distance-based services as opposed to face-to-face services. The interviews and focus groups had similar protocols and included questions on the following:

- Previous experience of program staff with distance-based technologies;

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- Programmatic changes made to accommodate distance-based services;
- Involvement of funding partners in changes made; and
- Training programs conducted for staff in order to provide services remotely.

The online survey of program clients was offered in both English and Spanish. A total of 270 client surveys were completed, including 25 in Spanish. The survey was anonymous and voluntary. Each program's participants were surveyed independently, and the average response rate was 40%. Survey questions focused on:

- Communication methods used by program staff;
- Changes in the amount of interaction with staff;
- Perceived changes in effectiveness of distance-based services;
- Overall satisfaction with distance-based services; and
- Preferences for client services in the future.

Basic descriptive statistics including frequencies and cross tabulations were performed in Survey Monkey and Microsoft Excel. Qualitative data were manually reviewed, categorized, and coded thematically.

Prior Research: Using Virtual Platforms to Provide Direct Services in Home

and Community Settings

In the past decade, a significant body of research has focused on assessing the effectiveness of “telemedicine”—providing direct health care services using virtual service-delivery platforms. A 2017 scoping review in the *Journal of Telemedicine* identified over 1,200 studies published between 2013 and 2017 that investigated the efficacy of telemedicine in various medical specialties (Kidholm, 2018). Unlike telemedicine, “telehealth” is a less well-defined term that denotes “the use of telecommunication and virtual technology...outside of traditional health-care facilities” (World Health Organization [WHO], 2018). The term incorporates a range of platforms, including synchronous communication, (individuals communicating in real time using videoconferencing or other technologically based means; Barak, 2018), which is our focus in this article.

While the body of systematic research assessing the use of “telehealth” in home- and community-based services is smaller, it is relatively robust and includes well-planned pilot or feasibility studies, including a number of control group studies that directly compared the efficacy of in-person and telehealth services within one program. Prior research on the feasibility of telehealth has generally focused on four key areas: (1) client satisfaction, (2) comparative effectiveness of telehealth and in-person services, (3) barriers to implementation from both the provider and client

perspective, and (4) a comparison of substantive program goals and outcomes by those receiving services in-person versus telehealth. The CDD's assessment presented here examined the first three.

Prior Findings on Client Satisfaction with Telehealth

In a pilot feasibility study of the PAT home visiting program at the University of Southern California (USC), 74 families participated in telehealth-based services over an 18-month period. Eighty percent reported that they were “very satisfied” with the program (Traube et al., 2020). In a small pilot study of nine families receiving telehealth-based services in the Chicago Health Promotion and Prevention Parent Program, all parents found the telehealth-based services useful and the technology easy to use (Breitenstein & Gross, 2013). A pilot program in Australia that enrolled nine families in a telehealth-based counseling program offered by clinical social workers using computers, tablets, and smartphones reported that, despite technical glitches such as loss of sound and video connections freezing intermittently, parents rated their overall satisfaction as 4.2 on a 5-point scale, with 5 being very satisfied. (Owen, 2020).

Prior Findings on Comparative Effectiveness of Telehealth and In-Person Services and Client Preferences

Eighty-one percent of participating families in the USC PAT pilot reported their experience receiving services via telehealth was the same or better than in-person programs in which they had participated (Traube et al., 2020). All parents participating in the Australian pilot of social work counseling said that they would use telehealth for future counseling. A 2015 study found that some clients actually preferred telehealth to in-person services, particularly when they experience feelings of discomfort when talking about their problems (Stubbings, 2015).

Prior Findings on Barriers to Implementation

Prior studies (Molfenter et al., 2015; see also Adler et al., 2014; Robben et al., 2012) have identified resistance to change by program staff and unfamiliarity of staff with both the technology used and differences in service delivery methods between face to face and remotely as barriers to telehealth service delivery. Within this theme, professionals' negative expectations about the effectiveness of telehealth interventions and their lack of technology experience and training were also cited as barriers (Backhaus et al., 2015; see also Richardson & Simpson, 2015). *Difficulties with reimbursement* for telehealth

from public funding sources such as Medicaid and Medicare as additional roadblocks to implementing telehealth services (Silva et al., (2015). Several studies identified the lack of broadband access for families in rural or remote areas and/or among families with limited means to purchase access to broadband internet services as barriers (Kahn et al., 2014; see also LeRouge & Garfield, 2013). Finally, a number of studies identified privacy and security of information shared during telehealth sessions as a barrier (Cherney & van Vuuren, 2012; see also Sinclair et al., 2013).

From Pilots to Everyday Practice

A key difference between these past studies and the reality of moving to telehealth-based direct services in the spring of 2020 is that, without exception, these prior studies were rigorously planned “pilots” or feasibility studies, and telehealth-based interventions were carefully developed prior to implementation. These studies took place over a predetermined period of time and preparation included support and training for staff implementing these new models. For example, the PAT pilot study at USC included a rigorous training and reflective supervision program for staff that included telehealth-based practice as a topic.

In the midst of the COVID-19 public health emergency, we were faced with little opportunity to engage in planning and preparation before in-person services were abruptly halted,

and telehealth services were initiated out of necessity. In most of the pilot or feasibility programs reviewed, staff and client participation was voluntary, with clients asked to sign informed consent forms before the study began. Further, they included only a subset of staff and clients—some in control group studies—or clients recruited specifically for the telehealth pilot designed and conducted by dedicated experts knowledgeable in research/evaluation methods. Finally, unlike the pilot or feasibility studies reviewed, the move to telehealth by CDD programs required all program staff, regardless of their knowledge of or comfort with technology-based service delivery, to begin offering telehealth services with little to no time for preparation; participation was not voluntary.

However, even with these differences, prior pilot and feasibility studies provide a useful guide to assessing the unplanned move to distance-based service delivery necessitated by the COVID-19 Public Health Emergency across the UCEDD Network.

Findings

The findings presented include qualitative and quantitative data from client impact surveys, one on one interviews with program directors/leads, and group interviews with staff from each direct service program. Generally, our findings are consistent with the results of previous telehealth pilot and feasibility studies reviewed for this article showing clear

efficacy for the use of telehealth as a platform for service delivery across diverse programs. In addition, these findings include infrastructure and support needs required to implement virtual service delivery effectively.

Finding One

Although CDD direct service programs varied slightly in their technological readiness to make an unplanned move to telehealth services, all did so successfully and without interruption in services. All CDD programs had access to the basic technological infrastructure required to provide telehealth services, including laptop computers, access to the Center's servers through the CDD's virtual private network (VPN), and broadband internet services. All direct service staff had access to work-issued smart phones. Some staff needed cameras and upgraded laptops and the Center's Technology Services (TS) Unit worked rapidly to meet equipment needs and provide technology support. The CDD's Medically Fragile Case Management Program Manager noted, "Everyone had the capability to do remote work before the pandemic." In addition, the Nurse Family Partnership home visiting program had previous experience using telehealth as a "special case" strategy when a home visit might create health concern for the client. However, though permitted, these telehealth visits could not be billed as "telehealth was approved but not

allowed as billable [because the funder] considered it supplementary.”

The one consistent need across all direct service programs was individual access to a video-conferencing technology platform to conduct telehealth visits with clients. The University maintained an Enterprise license agreement with Zoom, but prior to the COVID-19 public health emergency, only a handful of CDD employees had designated, individual Zoom accounts. Once the realities of the pandemic became apparent, the University quickly offered access to Zoom accounts to all University staff and by mid-March 2020, all CDD staff had individual accounts. Interviews with program leads and focus groups with program staff revealed that familiarity with videoconferencing and other technology-based work procedures such as using VPN to connect to the Center’s servers varied greatly, confirming findings in other settings discussed above. To overcome this barrier, Center Technology Services staff provided consultation and direct support to program staff regularly.

Finding Two

All programs used multiple methods to provide services. Although eventually, Zoom became the standard platform for most direct service telehealth visits, in the beginning many staff used multiple methods to retain contact with clients and families; they worked diligently by all means available to ensure

there were no significant interruptions in service delivery (see Table 1).

Table 1
Ways in Which Clients Communicated with Program Staff

Response	<i>n</i>	%
Telephone only	22	23
Multiple methods (telephone, Zoom, texting, email)	82	44
Videoconferencing only	83	44

In what way have you met with program staff since face-to-face meetings ended? Though all CDD programs utilized multiple methods to sustain contact with clients, the range varied widely across programs. For example, 67% of Mi Via Consultants supporting adults with intellectual disabilities receiving services under the state’s self-directed Medicaid waiver communicated by telephone only. This was in contrast with the PAT Home Visiting Program serving families with infants and toddlers where the percentage of “telephone only” contact was only 6%. The nature of the populations served, and specific services provided by the two very different programs, likely explain these differences, and speak to the tailoring of service delivery to meet client needs across programs. In some instances, difficulties caused by a lack of reliable broadband internet access for families created initial barrier to using videoconferencing. This was particularly true in rural, remote parts of the state and impacted the Center’s

statewide programs (Mi Via and MFCMP) more so than the CDD’s the Home Visiting programs, which largely serve families in the metropolitan area in and surrounding Albuquerque where internet access is generally more consistently reliable.

Finding Three

The majority of clients (89%) reported that they had the same or more interaction with program staff since the switch to telehealth services (see Table 2).

Table 2
Assessment of Interaction Levels with CDD Program Staff by Direct Service Clients

Response	<i>n</i>	%
Less	90	28
About the same	190	61
More	34	11

Compared to face-to-face visits, how much interaction have you had with program staff since the move to “telehealth”? In fact, across programs, a number of staff noted that many clients and families wanted more contact with them. This was presumably due to the isolation experienced during the pandemic. One program director noted, “It seems that all my participants are happy with [our program] because we’ve had so much more

time with them”, while a second observed that “families want to meet more frequently virtually; they’re eager for services—they felt cut-off from all other services.” Finally, another program lead remarked, “Clients needed the program staff more than ever.” One program began more frequent outreach with single parents after observing that these individuals seemed more socially isolated. It was also noted by program leads that it was in fact possible to increase the number of visits because staff no longer needed to drive long distances to meet in person. One staff noted that using telehealth saved “hours to pack and unpack plus over 100 miles plus in travel.”

Finding Four

Health concerns related to the COVID-19 Public Health Emergency underscored many clients’ desire for virtual services while in some cases others simply preferred them to in-person visits. In many instances, across programs, family members identified health risks for their children and themselves during the pandemic as a major driver of preferring telehealth services. One parent remarked, “During this time, I think it is necessary and appreciate the move to telehealth calls.” A second remarked, “[Telehealth] is a good option if there is a need to not have anyone in my house due to illness. Finally, one noted that “For the time being we do prefer telehealth visits for our safety and the safety of our home visitor.”

Staff across programs also noted the phenomenon that occurred in pilot studies: some clients genuinely preferred telehealth. In fact, an average of 45% of clients agreed with the statement that “I would prefer to have visits using Telehealth rather than face-to-face.” One program staff noted that many clients in their teens preferred using the telephone, which seemed to make it easier to discuss sensitive topics: “Not having visual...contact was beneficial in this case, and the teen was able to open up more without showing their face.”

Clients who supported the continued use of telehealth for visits, even after the public health emergency is over, focused on ongoing health risks faced by their children throughout their lives. One parent noted, “Don’t be in a rush to start face-to-face appointments because it puts the high-risk patients at an even higher risk.” Another commented, “We would appreciate the opportunity to have more telehealth visits. It is so much better for our family.” One client stated that the use of telehealth satisfied their personal preferences: “Yes, due to [me] having issues with people in [my] personal space this helps”, referring to virtual visits.

Finding Five

Clients were satisfied with telehealth services and felt that they were as effective as in-person services. However, most clients said that the interpersonal aspects of in-person, face-to-face meetings

were valuable and should be part of the “mix” of service delivery when the public health emergency is over.

Across programs, 96.5% of clients said they were either “very satisfied” or “satisfied” with the services they received via telehealth. Over three quarters (82%) said that the telehealth services they received were “about the same” in terms of effectiveness, while just under a fifth said they were less effective (see Table 3).

Table 3
Perceived Effectiveness of Telehealth Services Compared to Face-to-Face Services by Clients

Response	<i>n</i>	%
Less effective	43	18
About the same	171	73
More effective	21	9

Overall, how effective were the telehealth visits compared to face-to-face? One parent noted that program staff exhibited “the same excellence” when using telehealth as they did in face-to-face visits. A second observed that there had been no interruption in services: “Disruption of communication between us has been virtually non-existent.”

However, the majority of parents did note that not having in-person, interpersonal communication left them feeling something was “missing.” One parent noted that “Practically, telehealth did the same thing but not as fun, rejuvenating and

therapeutic as in person.” Another noted that “[My son] misses seeing [his nurse case manager] in person but technically Zoom visits worked very well for us.” A third comment referenced why the client prefers occasional in-person communications: “[My son] likes to visit with his consultant sometimes in Starbucks where he likes to get hot chocolate.”

One parent commented on the bond that had developed between her child and home visitor, stating, “When you don’t have face-to-face, the quality is reduced. The bond is better with families when you are face-to-face.” Another echoed this sentiment, noting the change in their child with in-person visits: “Our son is more enthusiastic and engaged when meeting in person.” Finally, one program director noted that some staff felt that the switch to telehealth left them unable to read body language and other nonverbal cues as effectively as possible during in-person interactions and this was a disadvantage to using telehealth.

Finding Seven

Given the need to move to telehealth-based services in a one-week period, programs did not have time to search for best practice models for the provision of telehealth services. However, programs directors all increased the frequency of staff meetings for two reasons: to engage in discussions on how to make programmatic

changes to their service delivery models using telehealth and to reduce feelings of isolation among staff.

The director of one program noted, “The heaviest lift was how to support staff. We already had the equipment. It was a huge change programmatically and for our clients.” One program increased their regular staff meeting from monthly to weekly during the initial months of the public health emergency and developed job aids for completing Individual Service Plans that were shared with other programs. Another director noted the importance of ensuring that staff remain connected: “Staying connected is critical. Staff have varying levels of stress; staff meetings keep [people] connected.” Finally, another noted that it was important to build confidence of both staff and clients: “Everything we do in home visiting is relationship based and reflective. We had to embrace the change and build staff confidence. Some staff were more comfortable with the technology than others.” The Center’s Home Visiting programs all increased the frequency of reflective supervision sessions with all staff.

Finding Eight

Finally, program leads and staff had to overcome a number of funding, administrative and regulatory barriers, including barriers to reimbursement from funding sources including Medicaid (Silva et al., 2015).

The state’s Human Services Department (HSD) and Center

for Medicare and Medicaid Services did not allow Medicaid billing for telehealth services prior to the public health emergency. That barrier dissipated quickly when NM HSD almost immediately issued guidance to provider agencies that for the duration of the public health emergency, Medicaid could be billed for virtual and telehealth visits across programs. Additionally, the state agency overseeing NM's Home Visiting programs also assured providers that telehealth "home" visits would be reimbursed, reversing the prior stance that virtual visits were seen as supplementary to in-person visits and therefore not funded. Providers were also assured by state and federal guidance related to the Health Insurance Portability and Accountability Act (HIPAA) compliance when transitioning to telehealth service delivery.

As all CDD direct service staff obtained individual Zoom accounts, funding was assured and many systems barriers were rapidly removed, the somewhat "clunky" need to obtain required "wet" signatures for service consents and other documents persisted as an inconvenience across Medicaid-funded programs. This is an issue that is still not completely resolved, but eventually, the NM Human Services Department sanctioned a number of innovative methods to overcome this barrier, including verbal consent and clients signing a document sent via email and returning a jpg file of the signature back to the program.

Privacy and client confidentiality represented a second area that continues to evolve across programs. Program staff have

begun using headphones for telehealth meetings to maintain client privacy and confidentiality and programs have developed guidelines for staff and families related to boundaries around virtual visits. As programs at the CDD have refined their practices, staff and families now actively define the frame for a telehealth session – in an effort to further support both family and staff privacy.

Conclusions and Recommendations

The results of this preliminary evaluation of the UNM CDD's direct service programs' rapid pivot from in-person home- and community-based visits to virtual encounters provide evidence that telehealth is, in fact, a viable and even robust tool for delivering services across a number of programs and client populations. Prior pilot and feasibility studies examining the use of telehealth to provide direct services also demonstrated that under controlled conditions, using telehealth was a viable tool in lieu of in-person, face-to-face service delivery. By incorporating virtual visits and other technology-supported communication due to the COVID-19 public health emergency, direct service programs at the CDD were able to continue to provide uninterrupted and effective services for the great majority of clients across multiple programs. Clients and families expressed gratitude that, under the circumstances of a pandemic, their safety was prioritized, and services

continued to be offered. The majority felt that using telehealth is effective, but many cited the loss of personal connection afforded by in-person contact as a clear downside and in some instances felt it negatively affected the quality of services provided. With that said, the majority of clients and families strongly supported the continuation of telehealth as a service delivery methodology post-pandemic.

Preparedness related to equipment, access to Zoom accounts and technology support was key in the success of all CDD programs effectively making the rapid shift to telehealth service delivery in spite of limited or no prior experience doing so. Initial barriers related to funding, privacy, and signatures for consent were quickly addressed and clients across all CDD programs have continued to have their service needs met. In addition, telehealth provided a means for clients and families to experience reduced isolation by remaining connected to their home visitors, nurse case managers and consultants during a highly stressful and unprecedented time. Telehealth also allowed programs to offer, when needed, more meeting time with clients in particular need, such as single parents.

For staff, increased meeting time and support was also critical to address and refine administrative, technological, logistical and practice elements of their work in real-time as they gained experience providing telehealth services. Opportunities for extra meeting time and reflective supervision also helped staff remain connected with each other and decrease their own sense of isolation.

While the recent gradual reduction in the number of cases in New Mexico and nationwide offers a glimmer of hope that the pandemic is easing, it is clear there will be no return to regular in-person, face-to-face services soon. While this is distressing to consider, it is positive to know that telehealth is a viable and effective option during this extraordinary time. At some point, the virus will be brought under control and in-person services will resume. In preparation for that time, the key question is this: how can the experiences gained during the public health emergency in providing services remotely be used moving forward? The ongoing willingness of funders, including Medicaid to continue to reimburse direct service programs for telehealth and virtual services will be a critical foundation as we anticipate a future in which direct service programs may offer a hybrid model. The ability, post-pandemic, to offer a combination of in-person and remote services, customized to fit the unique needs and preferences of families is recommended. In a rural state like New Mexico, in which staff regularly travel long distances for visits, this would increase the efficiency of programs and could even allow them to increase their caseloads or services.

Based on the experiences of our Center, four issues stand out that deserve attention as we contemplate a future service delivery platform using a combination of face-to-face and telehealth services. The first is defining and operationalizing practice elements for successful telehealth encounters. Many of the pilot and feasibility studies discussed earlier offer

“lessons learned” about how to successfully conduct telehealth encounters taking both client and program staff needs into account. As mentioned earlier, some national programs such as NFP and PAT, have developed well-structured operating procedures for conducting home visiting via telehealth, which may be applicable beyond these particular programs. Articulation of “best practice” elements for “home and community” based virtual direct services is recommended as we move forward.

The second is the need to make ongoing and systematic professional development investments in program staff to support their skills and comfort in working with clients and families using telehealth and/or hybrid models. This might include developing standard training in telehealth for new staff as part of their onboarding and orientation processes, as well as ongoing professional development/training opportunities for existing staff. In addition, expansion of the use of reflective supervision models currently common to home visiting practice to other direct service programs may also be promising to support best practice in the use of telehealth for service delivery over time.

Third, the need to sustain ongoing investments in technology over time is critical. Prior to the COVID-19 Public Health Emergency, technology purchases at the Center were made on an ad-hoc basis based on individual program needs and the availability of financial resources. The reliance on well-functioning computer equipment and broadband, as well as

the ready availability of technology platforms like Zoom to successfully conduct telehealth direct services, made it clear that a more systematic planning and acquisition process is needed within our Center to ensure that staff have adequate resources to support their virtual work.

Finally, the issue of limited broadband connectivity for some clients (and even some staff) must be acknowledged. There is no easy answer to this problem, as acquiring broadband access in rural and remote areas is a problem requiring a public-private investment strategy to build the technological infrastructure that would allow isolated residences to connect to broadband internet services. Finding a way to provide a family with a “hotspot” is insufficient if there is no broadband with which to connect.

Cases in which broadband internet is available but families do not have the resources to purchase technology to access it may be somewhat less formidable to address. Leadership at the CDD is exploring multiple approaches to access resources for clients and families. These include approaching funders for permission to use program funds to provide families with resources, applying for external grants to purchase technology to be given or loaned to families on a long-term basis, and using simple phone calls when Zoom access is not feasible for clients/families who may consistently or intermittently lack internet access. New Mexico state government and tribal governments across the state are using financial support provided through the CARES Act and subsequent legislation to significantly

increase access to broadband services in rural and hard-to-reach areas of the state.

In summary, our preliminary findings suggest that telehealth is a viable, effective and appropriate strategy for delivery of direct services across a diverse set of home- and community-based programs serving a diverse range of clients and families. Initial client perception of telehealth was overwhelmingly positive. The majority of clients and families reported that the ongoing use of telehealth as part of a hybrid of in-person and virtual visits would be welcome – even after the pandemic is over.

Next Steps: Longitudinal Impact Evaluation and Comparison of Clients Receiving Services by Telehealth with Those Who Received “Hybrid” Services

Center Evaluation Services staff are now engaged in additional activities designed to address three questions.

1. What is the long-term impact of telehealth on substantive program indicators? Moving forward, evaluation of the long-term impact of telehealth services on substantive and individual program indicators for success will be needed. At present, both the NFP and PAT Home Visiting programs have national and state

performance metrics that are embedded in the assumption that services are delivered in-person.

Outcome data is collected for both programs at the state and national levels. We are now in the process of conducting a comparison of program outcomes for these programs, shedding light on whether telehealth services result in the same program outcomes as in-person home visits.

2. What are the medium- and long-term impacts? Given that the current findings only examine the initial response to telehealth direct services, we are unsure of the medium and long-term impacts of using telehealth across programs. The analysis on which findings are reported in this article was deliberately designed as a “rapid cycle” assessment that would capture information on program needs of staff, as well as the immediate impact on clients. We are now implementing a second wave of surveys of clients and interviews with program staff to gauge the extent to which perceptions of both program staff and clients may have changed over time and as the pandemic has continued.
3. How does the impact on clients who had telehealth services only vs. those who received “hybrid” services compare? The CDD direct service programs reported on in this paper have now enrolled two hundred and sixteen new clients since March 2020 when in-person, face-to-face services stopped due to the public health emergency.

This will offer a unique opportunity to directly compare perceptions of those who have received both in-person and virtual services with those who have received only distance-based services. In the language of Don Campbell (Cook & Campbell, 1979), this is an example of a “naturally occurring experiment” that occurs when “...a particular intervention has been implemented but the circumstances surrounding the implementation are not under the control of researchers” (Craig et al., 2012, p. 1182).

We are in the process of preparing a new round of client-impact surveys. These new surveys will measure both the longitudinal impact of telehealth services for those clients who were receiving in-person services before the public health emergency as well as capture any differences in perceived impact between those clients and families who experienced a shift from in-person to telehealth services with those who have only experienced virtual service delivery.

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