Intellectual and Developmental Disabilities

Parental Perceptions of Service Access for Transition-aged Youth with Autism during COVID-19

--Manuscript Draft--

Manuscript Number:	IDD-D-21-00070R2
Article Type:	Research
Keywords:	service access; COVID-19; parents' perceptions; transitional youth; autism spectrum disorder
Corresponding Author:	Meghan M Burke, PhD University of Illinois at Urbana-Champaign Champaign, IL UNITED STATES
First Author:	Meghan M Burke, PhD
Order of Authors:	Meghan M Burke, PhD
	W. Catherine Cheung, PhD
	Chak Li, M.S.
	Leann DaWalt
	Jordan Segal
	Julie Lounds Taylor
Manuscript Region of Origin:	UNITED STATES
Abstract:	Services are critical for youth with autism spectrum disorder (ASD) – especially during the transition to adulthood. Under the best of circumstances, though, it can be difficult to access needed adult services. With COVID-19, services were more difficult to obtain and retain. In this study, we explored parent perceptions of accessing new services and maintaining current services during the first year of the COVID-19 pandemic. Interviews were conducted with 65 parents of transition-aged youth with ASD living in three states. None of the participants reported receiving new services during the pandemic, and many struggled to access services via online applications. Participants reported that service suspensions and changes in modality were spearheaded by professionals. Implications for research and practice are discussed.

Parental Perceptions of Service Access for Transition-aged Youth with Autism during COVID-19

Parental Perceptions of Service Access for Transition-aged Youth with Autism during COVID-19

Abstract

Services are critical for youth with autism spectrum disorder (ASD) – especially during the transition to adulthood. Under the best of circumstances, though, it can be difficult to access needed adult services. With COVID-19, services were more difficult to obtain and retain. In this study, we explored parent perceptions of accessing new services and maintaining current services during the first year of the COVID-19 pandemic. Structured interviews were conducted with 65 parents of transition-aged youth (aged 16-26) with ASD living in three states (IL, TN, and WI) in the U.S. None of the participants reported receiving new services during the pandemic, and many struggled to access services via online applications. In addition, participants reported that service suspensions and changes in modality (e.g., from in-person to telehealth) were spearheaded by professionals and not families. Participants, especially those in TN, were more likely to pay out-of-pocket for services during the COVID-19 pandemic to compensate for service disruptions. Implications for research and practice are discussed.

Keywords: service access, COVID-19, parents’ perceptions, transitional youth, autism spectrum disorder

Parental Perceptions of Service Access for Transition-aged Youth with Autism during COVID-19

For all students, the transition from school to adulthood can be difficult. For students with autism spectrum disorder (ASD), the transition can be especially tenuous. Transition-aged youth with ASD and their families often face systemic barriers in accessing adult services (e.g., vocational rehabilitative services, supplemental security income [SSI]) upon transitioning out of school-based services (Benevides et al., 2017). Such barriers include: difficulty navigating the adult service delivery system, lack of knowledge about adult services, and long waiting lists for services (Burke & Heller, 2016; Taylor et al., 2017). When transition-aged youth with ASD do not receive needed services, they are less likely to live in the community (Myers, Davis, Stobbe, & Bjornson, 2015), participate in the workforce (Alverson & Yamamoto, 2017), or attend post-secondary education (Migliore et al., 2012).

While COVID-19 interfered the lives of everyone, for youth with disabilities - including those ASD, the pandemic was especially disruptive. Many in-person services were either suspended or shifted to telehealth (e.g., Ameis et al., 2020; Bellomo et al., 2020; White et al., 2021). Individuals with ASD who often benefit from a structured schedule were left without supports in an unpredictable world (den Houting, 2020). While the pandemic may be a once in a lifetime experience, it presents an opportunity to understand how a crisis impacts service delivery. Even after the pandemic ends, it is important to explore how services were interrupted so that we can prepare for the next emergency and offer compensatory services for youth with ASD who were affected. Further, there may be changes to the service delivery system that are maintained after the pandemic ends. To this end, the purpose of this study was to explore perceptions of service access among parents of transition-aged youth with ASD during COVID-

19. To have a more holistic understanding of service access during the pandemic, we probed about families' experiences pursuing new services and changes in access to pre-existing services.

First, it is important to explore access to new services during COVID-19. Prior to the pandemic, parents of youth with ASD often struggled with accessing accommodating, acceptable, available, and affordable adult services (Marsack-Topolewski & Weisz, 2020). Parents must contact separate departments for services related to employment, independent living, and post-secondary education. Moreover, they must then advocate that the program meets the needs of their offspring. Many youth with ASD require assistance in employment and activities of daily living (Billstedt, Gillberg, & Gillberg, 2005; Eaves & Ho, 2008; Howlin, Goode, Hutton, & Rutter, 2004); when they are unable to access these needed services, youth may face poor outcomes (Taylor & Hodapp, 2012; Taylor & Mailick, 2014; Taylor & Seltzer, 2011). It is important to understand whether the COVID-19 pandemic made accessing services more difficult than under typical circumstances. Conversely, some changes during the pandemic (e.g., offering services via telehealth, providing online applications) may be preferred by families. Research is needed to explore aspects of access to new services during the pandemic including challenges as well as facilitators to service access. Further, research has not examined how COVID impacts access to new services. This is critical as the need for services is dynamic and does not become dormant during a pandemic.

Second, we need to examine the effect of COVID-19 on the receipt of current services for youth with ASD. White and colleagues (2021) found that during COVID-19, students with ASD experienced substantial loss of services. For example, a potential reason for loss in services may be due to health insurance. Because of COVID-19, many families lost their jobs and, subsequently, lost their insurance benefits which impacted some of the services their youth received (Bellomo et al., 2020). COVID-19 may also have impacted residential services. Individuals with ASD who lived in congregate care settings (e.g., long-term care facilities or group homes) often struggled with higher rates of transmission of the virus (Ameis et al., 2020). Correspondingly, many residential services were restricted (e.g., the youth could not leave the home and could not have visitors for months on end). Yet, little research has explored parent perceptions of the receipt of current services during the pandemic, especially among transition-aged youth with ASD who are often still living in their family homes.

Studies have shown that youth with ASD are particularly vulnerable to the negative consequences of the COVID-19 pandemic (den Houting, 2020). For youth with ASD, the service interruptions relate to increased challenging behaviors (Colizzi et al., 2020), more sleep disruptions (Bellomo et al., 2020; Manning et al., 2020), greater ASD symptoms (Manning et al., 2020), and increased caregiver stress (White et al., 2021). However, for the most part, research has focused on school services. To learn more about how services for youth with ASD might be impacted by the COVID-19 pandemic, we conducted interviews with parents of youth with ASD to address two research questions: (1) How did the COVID-19 pandemic impact families' pursuits of new adult services?; and (2) How did the COVID-19 pandemic impact families' receipt of current services?

Method

Participants

A total of 65 participants were included in this study. Participants were drawn from a larger, randomized controlled trial to test the effectiveness of a services advocacy intervention for parents of transition-aged youth with ASD. To be included in the larger study, participants were required to: (a) have a child aged 16-26 with ASD, (b) be willing to participate in an advocacy training intervention, and (c) agree to all study procedures. Participants lived in three states in the U.S. (TN, IL, and WI).

Participants for this analysis included only those individuals in the control group who had completed an interview six months after the treatment group finished the intervention. As opposed to treatment group participants, who had participated in the 12-week group-based program (REFERENCE BLINDED), control group participants only received written information about adult services. Excluding treatment group participants allowed us to minimize the impact of intervention on parent perceptions of service access during COVID-19.

Parent participants were, on average, 51.3 years of age (*SD* = 6.2, range from 37.6 to 66.1). The majority of the participants was female (90.8%, *n* = 59). Most participants were White (84.6% or *n* = 55), with the remainder of participants reflecting racial minority backgrounds. Most participants reporting having college degrees (84.6%, *n* = 55). On average, the youth with ASD were 20.82 years of age (*SD* = 2.70, range from 16.6 – 27.3). Most youth were male (73.8%, *n* = 48). The youth with ASD had documentation from a medical provider indicating an ASD diagnosis. In addition, 39.6% of the youth with ASD had co-morbid intellectual disabilities. See Table 1.

Recruitment

Participants were recruited in a variety of ways across the three states, including through research registries, disability agencies, schools, and parent support groups. Recruitment information was available via social media blurbs, flyers, and announcements on websites. For their participation in this particular interview, participants received $25.

Procedures

University Institutional Review Board approval was received for this study. The larger study is a longitudinal experimental design; this analysis focuses on the six-month follow-up interview (i.e., six months after the intervention group received treatment), as this timepoint coincided with the COVID-19 pandemic. Specifically, all six-month interviews were conducted between January of 2021 and June of 2021. All interviews were conducted remotely over the phone or via zoom by trained interviewers. Each interviewer completed a qualitative training as well as a mock interview. When an interviewer reached 100% fidelity on the mock interview, they began conducting interviews for this study.

At the beginning of the interview, the research team member introduced themselves. All interviews were recorded. Questions analyzed in this study were part of a larger interview focused on service access and vocational and educational activities. On average, each interview lasted 30 mins (range 20-45 mins). At the end of each interview, as a member check (Brantlinger et al., 2005), the participant had the option to revise any of their input. Fidelity to the interview protocol was 100% such that each participant was asked all of the questions on the interview protocol.

Instrumentation

The COVID-related service questions in the interview protocol were developed based on a review of the literature about services and transition-aged youth with ASD (e.g., Burke & Heller, 2016; Taylor et al., 2017). The interview protocol was reviewed by experts in ASD research and adult services as well as parents of individuals with ASD. It was also piloted with a parent of a young adult with a disability. Revisions to the interview questions based on this feedback were made, and the protocol was finalized. See Appendix A.

Data Analysis

First, interviews were transcribed and two research team members read each transcript multiple times to familiarize themselves with the data (Tesch, 1990). The research team used constant comparative analysis (Glaser & Strauss, 1967) and emergent coding (Patton, 2002) to code the transcripts. Specifically, each team member independently coded the interviews. Using a word-by-word approach, they individually coded all text related to services. Each piece of data was compared with the other data, highlighted, and annotated with a specific phrase (Creswell, 2003). Each new piece of data was then compared with previously coded data to check if the new data were considered a new idea or can be an existing code. The research team then met to compare codes and resolve differences. Once all data were coded, the research team created a codebook. Then, same team members used the codebook to re-examine the data. During this process, they determined whether new codes should be added to the codebook. The codes were grouped into categories and organized into themes grounded in the data. During the coding process, if there were any coding disagreements, team members discussed codes until consensus was reached. During data analysis, the team also searched for patterns among the themes in relation to the support needs of the youth with ASD and the state of residence of the parent/youth. Regarding the frequencies of themes, two research team members independently assess the 65 participants’ transcripts to count on the frequencies of participants’ responses such as yes, no, missing data, or don’t know. Inter-coder agreement was conducted across the 65 participants’ responses on the frequencies of themes.

Although uncommon in qualitative research, in this study, we included the frequencies of themes. We did this for two reasons. First, by sharing the frequencies, the reader can determine the internal generalizability (Maxwell, 1992) of the themes. Notably, the frequencies do not impact the transferability of our findings. Rather, the frequencies illustrate the extent to which a theme was common among our data. This becomes particularly useful when thinking of implications for service delivery and intervention. If a theme emerges around positive impacts of the pandemic on service access (e.g., telehealth, moving applications online), it may be important to know the extent to which participants experienced that positive effect. In addition, we share the frequencies to show the diversity of certain themes (Shulman, 1990). For many of our guiding questions, there was variability in our responses. Sharing the frequencies of the themes showcases the diversity among participants' perceptions of service access.

Credibility and trustworthiness

The authors made several efforts to ensure the credibility and trustworthiness of the themes. For example, a brief member check was conducted at the end of each interview. By conducting member checking, participants were able to assess the validity of the findings (Guba & Lincoln, 1989). In addition to the member checks, the research team debriefed with one another throughout data collection and data analysis. Further, to refine themes, team members searched for negative cases during data analysis (Brantlinger et al., 2005). Names are replaced with pseudonyms and identifiable information within quotes has been removed.

Results

Pursuit of New Services During COVID-19

Few participants applied for new services; none of the participants received any new services during COVID-19. Although participants had different perceptions of the amount of time it took to apply for services, most participants agreed that the process to apply for services was arduous. See Table 2 for participant responses about access to new services.

Barriers to Applying for New Services During COVID-19

About one-third (32.3%; *n* = 21) of the participants reported pursuing new services during COVID-19, including (but not limited to): vocational rehabilitation, SSI, Social Security Disability Insurance (SSDI), conservatorship, guardianship, Medicare, and Medicaid. Of the 21 participants who sought new services, none of them received any new services during COVID-19.

Reasons for *not* pursuing new services included: parent and youth health issues, lack of professional support, less time to apply for new services, and not having enough works credits to apply for SSDI. During COVID-19, Kristen reported sheltering-in-place and incurring health issues (e.g., contraction of shingles). Kristen discussed how her plans to apply for services were disrupted by the pandemic: “He [Kristen’s son] is turning 18. I had hoped that I would have potentially met with like someone, an attorney, to help us set up a special needs trust for him. I plan to do that, and then I was going to go ahead and apply for SSI and some of those different [services]… But with me being as sick as I've been. And with COVID. I just have not done those things..” Another parent, Alana, similarly considered applying for services for her daughter who had recently graduated from college. Alana wanted to apply for Medicare for her daughter but COVID-19 impacted her plans. She reported, ‘It [COVID] has affected her timeline. I will not apply for programs for a while. Because I started doing research [about Medicare], and then everything stopped with COVID. I am not sure now is the right time to start. Offices are closed and no one can ask [for assistance].” Similarly, Josie reported that COVID-19 resulted in reduced work hours for herself but increased caregiving responsibilities, “It's counterintuitive. You would think because my worked slowed down I would have more time to apply, but I am now a full-time caretaker for both my son and mother.” Jana wanted to apply for SSDI for her youth with ASD but was stopped because of COVID-19 implications. She stated, “We're trying to get more work credit so that she [daughter] could get SSDI. But it's COVID, 2020…so [there are] limited opportunities [for work]."

Perceptions of the Time Parents Had to Apply for Services During COVID-19

There were some differing perceptions about whether COVID-19 freed up parents' time to apply for services or resulted in less time. Nearly half (47.6% of those who applied for services or *n* = 10) of the participants reported no difference in the amount of time to apply for services during COVID-19 compared to pre-pandemic. For example, Jessica, the parent of a high schooler with ASD, reported, "We did not have more or less time [to apply for services]." Some participants (28.6% *n* = 6) reported they had more time to apply for services. Tiffany reported: "I lost my job during COVID [so] that gives me more time to apply for services." Some participants (19.0%, *n* = 4) reported less time. Carol stated: "I have less time and privacy than before because of COVID. Whenever my son hears me talk, he wants my attention. Sometimes he refuses to leave the house. My days feel really short."

Greater Difficulty in Applying for Services During COVID-19

Most participants (52.4% or *n* = 11 of the 21 participants who applied for services) reported that it was harder to apply for services during COVID-19. When asked why it was harder to apply for services, participants often spoke about the lack of professionals working in disability offices and unclear online application processes. However, when asked about whether the online application process made it easier or harder to apply for services, a minority of participants (n = 4 or about 19% of those who applied for services) reported that the online process made applying for services easier.

Lack of In-person Support. Many participants struggled with the lack of in-person support during the online application process for services. May, the mother of a youth with ASD who was attending a school transition program, described applying for SSI for her son: “There's some things we did wrong online. It would have been, if we had been in-person, it might've been easier.” Kelly applied for SSDI for her daughter with ASD. She reported, “[I] can’t talk to a real person when you have questions. Everybody doesn’t fit into a standardized form. [I] didn’t get guidance.”

Unclear Online Application Process. About one-half of the participants who reported the process for applying for services was “harder” cited the confusing online application process as a reason (*n* = 5 of the 11). For example, Sean applied for vocational rehabilitative services for his high school-aged daughter. He reported: "Finding out how to send it [the application] to the right place -- and some of it you had to print off, and some was online...was difficult.” Similarly, Caroline reported struggling with the online Supplemental Nutrition Assistance Program (SNAP) application for her son with ASD: “The questions were confusing. They didn't seem like they applied to my child who was born with disabilities. It gets pretty tricky. I don't feel I can do anything online because it isn't applicable. I wasn’t able to finish the online application because the questions were confusing.” Rosemary similarly struggled with the lack of in-person support and confusing online application when applying for SSI for her son. She reported, “ [It was] confusing to apply online. [I was] not sure which part to apply online and which part to apply over the phone. It was very difficult connecting to the state website and state phone number. It was hard to get in touch with a human.”

Some Advantages of the Online Application. Four participants reported some advantages of the online application process, including not needing to leave the house or apply for services during typical office hours. For example, Lane reported, “They [the office] did it all electronically--even the intake and initial interview. All time sheets are electronic. It has been wonderful." Similarly, Claire reported that the online application process for Medicaid was easy. She stated, "It's much easier than trying to go into an office and get an appointment. It is easier on my own availability." Tammi applied for SSDI for her son with ASD. When asked about the online applications, she reported, "[It was] easier because I could take my time." There were no patterns related to study site (IL, WI, TN) or type of service (e.g., Medicaid, SSI) in relation to the ease in which particicpants reported applying for services online.

Implications of COVID-19 on Access to Current Services

More than half of the participants (53.8%, *n* = 35 of the 65 participants) reported that their services continued during COVID-19. However, for many of the participants who continued receiving services, they reported major disruptions (e.g., switching from in-person to telehealth). Further, the changes made to services were decided by professionals—not families. Perhaps as a result, some families paid out-of-pocket for services to offset the disrupted or missed services. See Table 3 for parent perceptions of maintaining current services during the pandemic.

Many Service Suspensions During COVID-19

Approximately 37% (*n* = 24 of the 65 participants) of the participants reported experiencing service suspensions due to COVID-19. Further, 70.8% (*n* = 17 of the 24 participants who experienced service suspensions) of those reported that the suspensions were determined by the professional (not the family). For example, Elaine reported that her service provider for her son "shut down" for months. With respect to service hours, about one third of the participants (35.4% or *n* = 23 of 65 participants) reported receiving fewer services during COVID-19. Similar to service suspensions, almost all (95.7% or *n* = 22 of 23) of the reductions in service hours were chosen by professionals (not families). For example, Rebecca reported, "They [the provider] are not able to fill the slots in [my son's] plan. Trouble finding a care provider, so it is still in the plan but they cannot fulfill it." Approximately 30% of participants (*n* = 19 of 65) reported they had experienced greater challenges (compared to pre-COVID) finding providers or services, especially in behavioral or mental health services, applied behavior analysis, tutoring, recreational services, caregiving and respite. Colleen reported, "During [the] pandemic, people [agencies] were not taking new clients, [they were] risk adverse to in-home visits."

Differential Impact of Shifting Services from In-person to Virtual

When asked about the impact of COVID-19 on the mode of service delivery, the majority (76.9% or *n* = 50 of 65 participants) of participants reported that their services shifted from in-person to telehealth. Overwhelmingly, 86.0% (*n* = 43 of the 50 participants who switched to telehealth) of the decisions to shift to telehealth were spearheaded by professionals. Correspondingly, 54.0% (*n* = 27 of the 50 participants) of participants reported that services via telehealth were difficult. Upon closer examination, it seems that telehealth may have been less acceptable for youth with more (versus less) support needs. For example, Alana reported that telehealth appointments were arduous for her non-verbal daughter with ASD: "I think that with it being telehealth, it made it that much harder for her-'cause I think it made her feel kind of uncomfortable on the screen." Beth, the mother of a youth with minimal verbal skills, similarly reported: "It was difficult for him to engage and participate through the computer."

However, even though most families did not elect to switch to telehealth, some participants reported positive experiences with services via telehealth. Indeed, 24.0% (*n* = 12 of the 50 participants) of participants reported that switching to telehealth made services easier to access. Rosemary, the mother of a 22-year-old son who graduated high school with a regular diploma, reported: “[Telehealth] made it easier for me to be in two places at once.” Rebecca, the mother of the youth with ASD and anxiety, said: “[Telehealth was] easier because sometimes hard to get him [son] to leave the apartment [due to increased anxiety].” Notably, there were no patterns with site and type of service in relation to perception of telehealth.

State Differentiation in Paying Out-Of-Pocket for Services

Nearly half (46.2% or n = 30) of the participants reported paying out-of-pocket for services. Notably, 53% (n = 16) of these participants were from TN (26.7% were from Illinois and 20% were from Wisconsin). Such services included: tutoring, psychologist, speech therapy, occupational therapy, social skills and supports, job coaches, in-home care, and applied behavior analysis. Participants chose to pay privately for services because their services were suspended or reduced. For example, Alana, whose daughter with ASD was in college, reported: “More services are needed for her. Supports increased because she needed more help when she wasn't learning in a classroom anymore.” Similarly, Rebecca, the mother of a youth with ASD, cognitive impairment, and anxiety, reported paying for services out-of-pocket during COVID-19: “We are paying $30/hr for college students to help him for his online learning. [It was] tough to find people when the government program only pays $15/hr.”

Discussion

The purpose of this study was to explore perceptions of services access among parents of transition-aged youth with ASD during COVID-19. There were three main findings. First, about one-third of parents applied for services during COVID-19 and, most alarmingly, none of those parents received any of the services for which they applied. Services are critical for the outcomes of youth with ASD (Alverson & Yamamoto, 2017; Migliore et al., 2012; Myers et al., 2015). Especially during COVID-19 wherein youth with ASD were more likely to face mental and physical health challenges (Bellomo et al., 2020; Colizzi et al., 2020; Manning et al., 2020), it is surprising and unfortunate that parents' efforts did not lead to greater service access. Implications of this finding suggest there may be greater negative impacts on the health and outcomes of youth with ASD due to the loss of needed services.

Second, consistent with prior research (e.g., Bellomo et al., 2020; Colizzi et al., 2020), many youth with ASD did not receive their current services during the pandemic and, if they did receive services, received services via telehealth (versus in-person). While the switch from in-person to telehealth services is consistent with prior research (Ameis et al., 2020; Bellomo et al., 2020; White et al., 2021), not yet found in prior research is that most of the decisions to transition from in-person services to telehealth services were spearheaded by professionals (not families). This finding is concerning as families reported little involvement in the decision-making to change modalities. Prior research has emphasized the importance of family-professional partnerships (Summers et al., 2005), especially in the context of transitioning from school to adult services (Kim & Turnbull, 2004). To ensure that the needs of the youth are met, it is often deemed critical to invite the family and the youth to help make decisions about services. This study found that families and youth were often excluded in such decision-making during the COVID-19 pandemic. This may have impacted family and youth buy-in into the telehealth services as well as the trust between the family and the provider and, ultimately, the family-professional partnership itself. Research should examine whether this lack of family involvement in decision making about aspects of services such as modality were a by-product of the extraordinary social circumstances of the COVID-19 pandemic, or whether this reflects long-standing patterns.

Third, there were differential effects on service access. These effects varied with respect to the: application process, the state of residence, and the support needs of the youth with ASD. Regarding the former, participants had different perceptions of the online application process as well as of telehealth itself. Especially for the participants who identified advantages of online applications and telehealth, this finding suggests that some changes made during COVID-19 should be maintained after the pandemic ends. However, the caveat is that not all families appreciated these changes. Taken together, service delivery systems may consider embedding more flexibility and choice for families in relation to services. For example, online applications may be available in addition to in-person support for families applying for services. Telehealth and in-person services could both be offered as options for youth and their families. This finding underlines that one size does not fit all in relation to service access.

Further, research is needed to examine service access in relation to youth (e.g., support needs) and parent (e.g., state of residence) characteristics. Parents of youth with ASD with more significant support needs seemed to struggle more with telehealth. Future research should identify ways to ensure telehealth is uniformly effective for all youth,regardless of support needs. In addition, there were differences regarding the state in which the family resided -- particularly with respect to paying out-of-pocket for services. This pattern raises two issues. First, research about service access should always consider the context of the services. State policies and regulations seem inextricably linked to service access (Grossman, 2019). Second, this raises issues of equity. Parents of youth with ASD (versus other types of disabilities) already spend significantly more money for out-of-pocket for services (Buescher et al., 2014). This finding shows that there may be inequity among parents of youth with ASD with families with greater resources having more access to fund services and families without resources suffering.

Together, these findings related to disproportionate service access in relation to youth and parent characteristics suggest challenges around equity. Prior research has shown that COVID-19 has exacerbated existing inequity especially in relation to racial minority families (White, Liburd, & Coronado, in press) and low-resourced families (Lund, Forber-Pratt, Wilson, & Mona, 2020). This study extends the literature by suggesting that the geographic location of an individual also raises concerns about equity. Indeed, the combination of socioeconomic status and state of residence seemed to impact access to services. Thus, service disparities due to COVID-19 go beyond racial and ethnic background to include geographic location.

Limitations

Although this study has important findings, there were a few limitations. First, this study was based on cross-sectional data. Without longitudinal data asking the same set of questions before, during, and after the pandemic, we cannot examine perceptions of service access over time, and whether these perceptions truly worsened due to COVID-19. Second, this study was based on a primarily White, convenience sample of parents of youth with ASD who were interested in completing a parent advocacy training. These parents may not be reflective of the population and the transferability of our findings may be limited. Third, the COVID-19 pandemic fluctuates with rising and declining rates of COVID. Data for this project were collected over a period of months such that there may have been changing regulations regarding social distancing at any given time. Thus, we are unable to characterize the nature of the pandemic in relation to service access.

Implications for Practice

Practitioners should offer more than just online applications for services. There are many benefits of applying for services via an online platform including: the ability to complete the application during off hours (Szymanski & Hyse, 2000), no transportation barriers (Liao & Cheung, 2002), and limited exposure to others (Meuter et al., 2000). However, practitioners should also be mindful of this study's findings that in-person, individualized support may still be needed by some families. To this end, practitioners may consider pairing online applications with a helpline. Further, when transitioning an application to an online format, practitioners should also consider equity in access to technology (e.g., a computer) and the internet to complete the application. Accordingly, practitioners may consider providing an online application as well as continuing to allow phone and/or in-person applications.

Practitioners may also consider continuing to offer services via telehealth. Although there were barriers to accessing services via telehealth, some families reported enjoying the benefits of telehealth (e.g., not leaving the house, no transportation barriers). Similar to online applications, practitioners may include telehealth as an option (but not the only option) to receive services. In addition, practitioner may continue to offer in-person services as well as hybrid services (e.g., in-person and online) as a way to meet youth needs.

Implications for Future Research

Research is needed to examine the effect of limited service access during COVID-19 on youth and family outcomes. This study suggests that none of the participants received new services. Further, the majority of participants reported impacts on the type of services they received (including suspensions and switching to telehealth). However, the effects of these changes are unknown. Research is needed to longitudinally examine the effects of these changes to service access on youth physical and mental health as well as youth outcomes (e.g., employment, independent living).

Further, research is needed to determine the effect of service access on the family. This study suggested that parents experienced many challenges as direct (e.g., health challenges, youth staying at home due to shelter-in-place orders) and indirect (e.g., losing job opportunities) implications of COVID-19. In addition, unmet service needs can increase caregiving burden (Burke & Heller, 2017). It is critical to determine whether service access impacted the health and well-being of parents of youth with ASD and, if so, to identify and deliver supports to caregivers.

References

Alverson, C. Y., & Yamamoto, S. H. (2017). Employment outcomes of vocaational rehabilitation clients with autism spectrum disorders. *Career Development and Transition for Exceptional Individuals*, *40*, 144-155. https://doi.org/10.1177%2F2165143416629366

Ameis, S. H., Lai, M. C., Mulsant, B. H., & Szatmari, P. (2020). Coping, fostering resilience, and driving care innovation for autistic people and their families during the COVID-19 pandemic and beyond. *Molecular Autism*, 11(1), 1-9. https://doi.org/10.1186/s13229-020-00365-y

Bellomo, T. R., Prasad, S., Munzer, T., & Laventhal, N. (2020). The impact of the COVID-19 pandemic on children with autism spectrum disorders. *Journal of Pediatric Rehabilitation Medicine*, (Preprint), 1-6.

Benevides, T. W., Carretta, H. J., Ivey, C. K., & Lane, S. J. (2017). Therapy access among children with autism spectrum disorder, cerebral palsy, and attention- deficit–hyperactivity disorder: a population- based study. *Developmental Medicine & Child Neurology*, 59(12), 1291-1298. https://doi.org/10.1111/dmcn.13560

Brantlinger, E., Jimenez, R., Klingner, J., Pugach, M., & Richardson, V. (2005). Qualitative studies in special education. *Exceptional Children*, *71*, 195-207. https://doi.org/10.1177%2F001440290507100205

Buescher, A. V., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics*, *168*(8), 721-728.

Burke, M., & Heller, T. (2016). Individual, parent and social–environmental correlates of caregiving experiences among parents of adults with autism spectrum disorder. *Journal of Intellectual Disability Research*, 60(5), 401-411. https://doi.org/10.1111/jir.12271

Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zoccante, L. (2020). Psychosocial and behavioral impact of COVID-19 in autism spectrum disorder: an online parent survey. *Brain Sciences*, 10(6), 341. https://doi.org/10.3390/brainsci10060341

Den Houting, J., Adams, D., Roberts, J., & Keen, D. (2020). Brief report: Investigating the impact of anxious symptomatology in autistic children. *International Journal of Disability, Development and Education,* 1-10. https://doi.org/10.1080/1034912X.2020.1727420

Hanley-Maxwell, C., Whitney-Thomas, J., & Pogoloff, S. M. (1995). The second shock: A qualitative study of parents' perspectives and needs during their child's transition from school to adult life. *Research and Practice for Persons with Severe Disabilities*, *20*, 3-15. https://doi.org/10.1177%2F154079699502000102

Kim, K. H., & Turnbull, A. P. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning.

Liao, Z., & Cheung, M. T. (2002). Internet-based e-banking and consumer attitudes: an empirical study. *Information & management*, 39(4), 283-295. https://doi.org/10.1016/S0378-7206(01)00097-0

Lund, E. M., Forber-Pratt, A., Wilson, C., & Mona, L. R. (2020). The COVID-19 pandemic, stress, and trauma in the disability community: A call to action. *Rehabilitation Psychology, 65*, 313-322. https://doi.org/10.1037/rep0000368

Manning, J., Billian, J., Matson, J., Allen, C., & Soares, N. (2020). Perceptions of Families of Individuals with Autism Spectrum Disorder during the COVID-19 Crisis. *Journal of autism and developmental disorders*, 1-9. https://doi.org/10.1007/s10803-020-04760-5

Marsack-Topolewski, C. N., & Weisz, A. N. (2020). Parents' perceptions of access to services for their adult children diagnosed with autism spectrum disorder. *Families in Society, 101*, 190-204. https://doi.org/10.1177%2F1044389419881273

Maxwell, J. A. (1992). Understanding and validity in qualitative research. *Harvard Educational Review, 62*, 279-300.

Migliore, A., Timmons, J., Butterworth, J., & Lugas, J. (2012). Predictors of employment and postsecondary education of youth with autism. *Rehabilitation Counseling Bulletin, 55*, 176-184. https://doi.org/10.1177%2F0034355212438943

Meuter, M. L., Ostrom, A. L., Roundtree, R. I., & Bitner, M. J. (2000). Self-service technologies: understanding customer satisfaction with technology-based service encounters. *Journal of marketing*, 64(3), 50-64. https://doi.org/10.1509%2Fjmkg.64.3.50.18024

Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders, 45*, 2373-2381. https://doi.org/10.1007/s10803-015-2403-z

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilitiess, 117*, 48-66. https://doi.org/10.1352/1944-7558-117.1.48

Shulman, L. S. (1990). *Paradigms and programs*. New York: Macmillan.

Sturges, J. E., & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research, 4*, 107-118. https://doi.org/10.1177%2F1468794104041110

Summers, J. A., Poston, D. J., Turnbull, A. P., Marquis, J., Hoffman, L., Mannan, H., & Wang, M. (2005). Conceptualizing and measuring family quality of life. *Journal of intellectual disability research*, 49(10), 777-783. https://doi.org/10.1111/j.1365-2788.2005.00751.x

Szymanski, D. M., & Hise, R. T. (2000). E-satisfaction: an initial examination. *Journal of retailing*, 76(3), 309-322. https://doi.org/10.1016/S0022-4359(00)00035-X

Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training parents of youth with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders*, 47(3), 846-857.

Taylor, J. L., & Seltzer, M. M. (2011). Changes in the mother–child relationship during the transition to adulthood for youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *41*(10), 1397-1410.

White, L. C., Law, J. K., Daniels, A. M., Toroney, J., Vernoia, B., Xiao, S., & Chung, W. K. (2021). Brief report: impact of COVID-19 on individuals with ASD and their caregivers: a perspective from the SPARK cohort. *Journal of autism and developmental disorders*, 1-8. https://doi.org/10.1007/s10803-020-04816-6

White, A., Liburd, L. C., & Coronado, F. (in press). Addressing racial and ethnic disparities in COVID-19 among school-aged children: Are we doing enough? *Preventing Chronic Disease*. https://dx.doi.org/10.5888%2Fpcd18.210084

Table 1

Participant Demographics

	% (*n*)
Gender	
Female	90.8% (59)
Male	9.2% (6)
Race	
White	84.6% (55)
Black or African American	7.7% (5)
Other	3.1% (2)
Asian	3.1% (2)
More than one race	1.5% (1)
Ethnicity	
Not Hispanic/Latinx	90.8% (59)
Hispanic/Latinx	9.2% (6)
Marital status	
Currently married	70.8% (46)
Divorced	20% (13)
Spouse/partner deceased	3.1% (2)
Never married	3.1% (2)
Separated	1.5% (1)
Other	1.5% (1)
Family income	
$20,000 or less	1.5% (1)
$20,001 – $40,000	13.8% (9)
$40,001 – $60,000	10.8% (7)
$60,001 – $80,000	9.2% (6)
$80,001 – $100,000	7.7% (5)
$100,001 – $125,000	10.8% (7)
$125,001 – $150,000	7.7% (5)
$150,001 – $200,000	18.5% (12)
$200,001 or higher	13.8% (9)
Prefer not to answer	6.2% (4)
Education level	
Received high school degree (or equivalent)	4.6% (3)
Some college	10.8% (7)
Associate degree	7.7% (5)
Bachelors degree	38.5% (25)
Masters degree	27.7% (18)
Ph.D. or professional degree (JD, MD, etc)	10.8% (7)

Table 2

COVID-19 Impact on Families' Pursuits of New Adult Services

Question	Response	% (*n*)
Have you pursued any NEW government programs during COVID-19?		
	Yes	32.3% (21)
	No	67.7% (44)
Did you have more or less time to access or apply for government programs?		
	More time	28.6% (6)
	No Difference	47.6% (10)
	Less time	19.0% (4)
	Missing Data	4.8% (1)
Was it easier or harder to access needed services?		
	Easier	14.3% (3)
	No Difference	9.5% (2)
	Harder	52.4% (11)
	*Don't know	23.8% (5)
Was it easier or harder to apply for programs because of online application process (versus in-person)?		
	Easier	19.0% (4)
	No Difference	19.0% (4)
	Harder	33.4 % (7)
	Missing Data	14.3% (3)
	*Don't know	14.3% (3)
Was the application process much slower or faster than before COVID-19?		
	Faster	9.5% (2)
	No Difference	9.5% (2)
	Slower	38.1% (8)
	Missing Data	9.5% (2)
	*Don't know	33.4% (7)

Table 3

COVID Impact on Families' Receive of Current Services

Question	Response	% (*n*)
Have you experienced any temporary service suspension due to COVID-19?		
	Yes	36.9% (24)
	No	56.9% (37)
	Missing Data	6.2% (4)
who chose to change?		
	Parent	20.8% (5)
	Provider	70.8% (17)
	Other	8.4% (2)
Were there any changes in the number of service hours due to COVID-19?		
	Yes	35.4% (23)
	No	63.1% (41)
	Missing Data	1.5%(1)
who chose to change?		
	Parent	4.3% (1)
	Provider	95.7% (22)
Have you experienced any challenges to finding providers or services due to COVID-19?		
	Yes	29.2% (19)
	No	64.6% (42)
	Missing Data	4.6% (3)
	Don't know	1.6%(1)
Have you experienced any service delivery changes (e.g., telehealth, phone consultation, virtual service) due to COVID-19?		
	Yes	76.9% (50)
	No	23.1% (15)
who chose to change?		
	Parent	8.0% (4)
	Provider	86.0% (43)
	Other	6.0% (3)
has it been easier or harder?		
	Easier	24.0% (12)
	No Difference	12.0% (6)

	Harder	54.0% (27)
	Missing Data	10.0%(5)
Have you ever paid out of your pocket to provide services for youth with ASD during COVID-19?		
	Yes	46.2% (30)
	No	53.8% (35)

Appendix A

Interview protocol

Questions
Have you pursued any NEW government programs we just asked you about (e.g., SSI, SSDI, Medicaid, VR, SNAP, SNT, Conservatorship/Guardianship) during COVID-19?
If yes… Did you have more or less time to access or apply for government programs? - Why did you have more / less time? Was it easier or harder to access needed resources, information, or personnel to apply for government programs? Were there changes to your young adult's eligibility for programs? - For which program(s) did youth's eligibility change? Was it easier or harder to apply for programs because of online application process (versus in-person)? - Why was it easier / harder? Was the application process much slower OR faster than before COVID-19? Were there changes in terms of whether agencies were accepting new applications? - Which agencies and what changes? Has COVID-19 impacted - in any way - your plans for which government programs you will pursue for your son or daughter and/or your timeline for pursuing programs? - If so, what was the impact?
Has COVID-19 impacted your ability to maintain the government programs (e.g., SSI, vocational rehabilitation, etc.) that support your son/daughter? - How so? DIRECT SERVICES: Have you received any new services due to COVID-19? - which services? Have you experienced any temporary service suspension due to COVID-19? - which services?

- Who chose to make changes?

Were there any changes in the number of service hours due to COVID-19?

- which services?
- Who chose to make changes?

Have you experienced any challenges to finding providers or services due to COVID-19?

- which services?

Have you experienced any service delivery changes (e.g., telehealth, phone consultation, virtual service) due to COVID-19?

- which services?
- Who chose to make changes?
- Has it been easier or harder?
- Why?

Have you ever paid out of your pocket to provide services for youth with ASD during COVID-19?

- which services?
- Why?

During COVID-19, have you experienced any OTHER changes in accessing services?

Compared to BEFORE COVID-19, are you...

- Please explain