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# “The doctor will see you now”: Direct support professionals’ perspectives on supporting adults with intellectual and developmental disabilities accessing health care during COVID-19

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## ABSTRACT

**Background:** It is critical to consider how rapid changes in health care delivery and the rise in use of virtual modalities have impacted adults with intellectual and developmental disabilities and caregivers. **Objective:** The purpose of this paper is to describe direct support professionals’ experiences assisting adults with intellectual and developmental disabilities in accessing virtual and in-person health care during COVID-19.

**Methods:** A content analysis was conducted on responses obtained from an online questionnaire distributed to 942 direct support professionals in Canada. Descriptive statistics were used to report the type of visits that occurred and open text responses describing these visits were coded.

**Results:** Twenty four percent of direct support professionals reported supporting someone at an in-person medical appointment, 22% reported attending at least one video-based virtual appointment and 58% reported supporting at least one phone based virtual appointment in the first 5 months of the pandemic. They identified several barriers and facilitators with each type of visit which suggests there is no “single way” to provide health care to this group, but that optimal care depends on maximizing the fit between the person’s abilities, the skill set of direct support professionals and health care providers, and the presenting health care issue.

**Conclusions:** Study findings provide insight into the experience of health care for this population during COVID-19 and can be used to support direct support professionals and adults with intellectual and developmental disabilities to adapt to safe, supportive and comprehensive virtual and in-person health care during the pandemic and beyond.

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## Introduction

The onset of COVID-19 has led to a dramatic shift in how health care is delivered and has fueled the need for viable alternatives to in-person care.<sup>1,2</sup> Virtual care, health care that occurs remotely through various forms of communication and/or information technologies, has been positioned as an ideal solution to maintain public safety while continuing to provide high-quality, effective health care. The ability of the health sector to rapidly increase capacity to offer virtual care during the pandemic has been considered a major advance by many health care providers, patient

groups, and researchers.<sup>3</sup>

While there are many that hope that options for virtual care will remain beyond the pandemic, there continues to be a need to learn more about the approach to ensure equitable and accessible health care for all.<sup>4,5</sup> There is an urgent need to understand who are the patients that benefit the most from virtual care and which groups may find it challenging. For example, newly adopted virtual care approaches can place many patients at a disadvantage, especially if they lack access to reliable technology, have complex health needs (e.g., multimorbidity, cognitive or communication impairments) or find it difficult to manage new or different ways of interacting with

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their health care providers. We also need to better understand the experience of receiving virtual care, as well as examine how different virtual care modalities, such as video or phone, meet the needs of more vulnerable groups.<sup>6,7</sup> People with intellectual and developmental disabilities (IDD) are one population that live with complex health conditions and have high health needs, and therefore, may be particularly susceptible to being marginalized in this new virtual care environment. It is critical to consider how rapid changes in health care delivery and the rise in virtual care provision during the pandemic have impacted those with IDD, many of whom are reliant on others to help them with in-person health care navigation, and who may lack the skills or capacity to use digital technology.

With the exception of a small number of opinion pieces exploring the value and limitations of virtual care for this group<sup>6,8–11</sup> there is a shortage of research on how people with IDD are accessing health care during the pandemic. The literature on virtual care and IDD pre-pandemic focused primarily on health care delivery to children, with their parents acting as the mediator in these interactions.<sup>12–14</sup> These studies have highlighted the benefits of virtual care, however, a critical difference in these studies compared with health care during COVID-19 is that participants opted to use virtual care when in-person care was available as part of a research endeavor. This is different than what is occurring now, where health care access has been altered for people irrespective of their interest or capacity to engage in virtual care options. Additionally, studies on virtual care of children, mediated by their parents, do not reflect the experience of many adults with IDD who no longer live with families, and who rely on individuals paid to support and mediate their health care interactions. These paid individuals, sometimes referred to as Direct Support Professionals (DSPs), are not health care providers themselves, and while responsible for facilitating health care appointments, have limited training in this area.

The purpose of the current paper is to describe virtual and in-person health care for adults with IDD during the first five months of the pandemic in Canada from the perspective of the DSPs who facilitated these health care interactions. Lessons learned from these experiences can quickly be applied to improve health care delivery in subsequent waves of the pandemic.

## Methods

### Design

The current paper is part of a wider research study aimed at understanding the impact of COVID-19 on the mental health of DSPs working with adults with IDD in Canada. This paper reports on a subset of survey findings focused on health care utilization, specifically the experiences of DSPs supporting individuals with IDD to attend health care visits during COVID-19. This work is situated within a pragmatic paradigm, where multiple analytic strategies were used to examine both closed and open text questions from an online survey.

Researchers on this team included three members who were regulated health professionals, as well as family members (YL, NB, MIJ). Researchers engaged in an iterative analytic process that included critically reflexive dialogues to identify the experiences and expertise of the team, and capture both personal and professional insights into the provision and use of health care services for this population. These team discussions helped to highlight each team member's positionality in relation to the data, inform the analytic process and overall conceptualization and interpretation of the data. All members contributed to the analysis and writing of this paper.

### Participants

DSP participants (N = 942), the majority of whom lived in Ontario (92%) ranged in age with almost half (44.5%) being 45 years or older. Most respondents were women (85%), and 13% identified as a racial minority. Seventy-five percent of respondents had over five years of experience working in the sector, and 82% worked in residential settings such as group homes or supported living environments.

### Instrument and procedure

An online survey was developed by study investigators to examine the impact of COVID-19 on the mental health of DSPs. Study data were collected and managed using REDCap electronic data capture tools hosted at [Hospital].<sup>15,16</sup> REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies. The survey was distributed nationally through social media and IDD community agencies over a 5-week period from July 2nd to Aug 10th, 2020. All DSPs were provided with a link to an online letter of information and consent form and once completed they were directed to the survey. The survey asked a range of questions regarding mental health, workplace supports, as well, a brief section examining the experiences of DSPs supporting people with IDD attending health care visits during COVID-19 which is the focus of this paper. DSPs indicated (Yes/No) whether they had supported individuals to access in-person health care, virtual telephone-based care, or virtual video-based care since the onset of COVID-19 and were able to provide open-text responses reflecting on these experiences.

### Ethics

This study was approved by the hospital Research Ethics Board.

### Analysis

Survey data were exported from REDCap to Microsoft excel. Descriptive statistics were used to capture the number of participants who reported each of in-person, telephone-based, and video-based care. A content analysis was the primary analytic approach used to examine the open-text responses.<sup>17</sup> First, one author (MIJ) categorized the open text responses under types of health care delivery modalities (in-person, telephone-based, video-based care). When it was not clear what type of health care a comment referred to, this comment was excluded from the analysis (154 comments). These more general comments were a combination of positive, negative, and mixed or neutral responses. Nine DSPs commented on their own health care, and these responses were also excluded. Each member of the research team (YL, AS, MIJ, NB) completed an initial reading of all the remaining data to familiarize themselves with the types of responses collected under each care modality. The research team met to discuss their initial impressions and develop preliminary codes. Additionally, the first ten responses in each category were reviewed by the whole team to ensure agreement and consistency between coders. A primary coder was then assigned to each unique health care delivery modality (in-person (NB), telephone (MIJ), video-based care (AS)). Each response was categorized as positive, negative or neutral experience and assigned code(s). The lead author (YL) acted as an independent secondary coder for all sections. Raters agreed on 96% of ratings at this stage. The research team then met again to review the codes and to discuss key findings in each category. Any disagreements between the primary and secondary coder were discussed with the full research team until consensus was reached (e.g., if the visit was

described “good, but my client wasn’t really engaged”, it was coded as neutral/mixed.)

## Results

### In-person office visits

Two hundred and twenty-five DSPs (24%) reported attending at least one in-person office visit with an adult with IDD during the first five months of the pandemic. Of those, 24 DSPs provided comments related to these visits, of which 21% were positive, 29% were negative and 50% were neutral. DSPs provided examples of the types of health care issues requiring in-person visits which included: *dental care, bloodwork, and routine injections*. Some DSPs appreciated when the visit was “*very professional*” and when, “*precautions were in place*”. They also highlighted challenges related to adhering to safety protocols and noted that additional personal protective equipment (PPE), combined with changes in office procedures, could be complicated. As one DSP noted, “*it is hard to keep my client from going through check points to soon, to wear their mask properly, to not touch all surfaces, and for me to have goggles on during*”. Several DSPs reported challenges with the people they supported not tolerating masks and described additional efforts needed to ensure compliance with safety protocols, “*the client had to wear a mask for the entire visit which he didn’t totally understand and I had to keep reminding him to keep it on*”. Concerns with physical environment/space were also raised; it was challenging to manage physical distancing when appointment rooms were small or there were no waiting areas.

### Virtual video-based visits

Virtual video-based visits were the least common type of encounter reported, identified by 204 DSPs (22%). Thirty comments related to video-based visits, of which 12 (40%) were positive, 9 (30%) were negative, and 9 (30%) were neutral. Reasons for virtual video visits included: *general medication queries, toe fungus, and assessment by psychiatrist*. The benefit of this modality was evident with several DSPs commenting on the value of such visits for people who have challenging behaviours that would make in-person visits complicated, particularly with waiting, and social distancing requirements. As one participant reported, “*the video and zoom call appointments are actually better for us as our clients are non-verbal and highly aggressive-this saves us the time, staff and stress and can still accomplish what we need from a medical appointment for the most part*”. DSPs also commented on the benefit of accomplishing the same outcome but saving time relative to an in-person visit.

DSPs also commented on the benefit of “being seen”. Compared to a phone-based visit, video-based visits allowed the doctor to assess the patient’s context in a way that could not be communicated by phone and would not be evident outside of the home context. As noted by one DSP, “*Video calls are awesome. Doctors saw things they don’t normally see in the office*”.

Challenges with technology were reported by several respondents. DSPs reported difficulties with connectivity and the visits were “*challenging as the virtual platform was glitching*”. There was also some confusion when the platform the doctor used was unfamiliar to the DSPs and they noted “*technology is frustrating because each doctor’s office uses different systems*”. Both DSPs and health care providers needed a degree of technical literacy to navigate the platform successfully. “*The virtual video-based care option wasn’t set up to handle multiple people with one email address, so we had to take the person into the office to see the doctor in-person*”. DSPs described these visits as “different,” and doing

something unfamiliar to people with IDD could be quite distressing as one DSP described, “*my client never liked the experience and started crying*”.

### Virtual phone-based visits

Phone visits were the most frequently reported type of health care interaction since the onset of COVID-19 with 549 DSPs (58%) reporting at least one phone-based interaction with someone they supported.

DSPs offered 220 comments related to these visits of which 94 (43%) were positive, 57 (26%) were negative, and 69 (31%) were neutral. Examples of the types of health care issues discussed over the phone included: *prescription renewals, rashes, ear complaints, filling forms, aging, seizure activity, eye irritation, blood pressure, and COVID-19 testing results*. DSPs reported that phone-based visits were “*easy and efficient*” with many reporting that they “*prefer it over waiting for hours in a crowded waiting room*”. Having experience interacting with health care providers over the phone prior to COVID-19 appeared to help make the visits more successful. As well, proper preparation before the visit and guidance on how to follow-up after the visit was critical and DSPs reported “*it was easier as I was able to gather all the required information as directed by the nurses and the person did not have to suffer from the anxiety of an appointment*”. Depending on the nature of the health issue, being able to share a photo with the health care provider to illustrate the health issue also assisted, as one DSP noted: “*I had to send pictures to the doctor so that they could diagnose without needing to see a client in-person. It was difficult but manageable to do a ‘doctor’s visit’ this way*”. DSPs reported appreciating the opportunity to speak briefly with the health care provider to discuss an issue or renew a prescription and avoid going into the office with the individual. When the provider was familiar with the patient, phone meetings were easier.

Barriers identified by DSPs included the timing and organization of these visits, as well as the challenge of not seeing or being seen by the doctor. As one DSP reported, the “*time with doctor felt rushed and impersonal, the inability of the person with IDD to see the provider, and to be seen. It is hard to receive proper medical advice due to the medical fragility of the people we support without a doctor seeing them*”. Also, certain types of health complaints were noted to require being seen in-person: “*It can be difficult for a doctor to diagnose issues over the phone, for example, a rash needs to be seen as every one’s idea of severe and not severe differ greatly*”. Inclusive, collaborative visits were difficult to orchestrate by phone and it is easier to include the person with IDD in the interaction when they can “see the doctor” by visiting the doctor in-person. Phone calls also have more restrictive time limits, “*which means we don’t necessarily have the time to talk everything out with our client during the appointment*”. There is the risk that someone could feel excluded, either the DSP “*Its harder to be an advocate over the phone*” or the person with IDD “*Short phone calls and very to the point. Not as focused on the patient*”.

## Discussion

This paper focused on describing the experiences of DSPs who facilitated virtual and in-person health care visits for adults with IDD in the first five months of the pandemic. Results suggest that adults with IDD have used both in-person and virtual care during this time with the support of DSPs, with virtual phone-based health care being most common. Importantly, DSPs described both positive and negative experiences with each type of care which suggests that, at least from their perspective, there is no one ‘right’ approach to health care for this group. There are clearly several

contributors to positive health experiences, and depending on the circumstances, each of telephone, video-based and in-person visits were thought to be beneficial. Overall, there was a sense of the importance of assessing for best fit between the need for health services, the types of health care modalities available and the unique characteristics and capacity of the patients who the DSPs were supporting. Below we discuss key issues identified in the study as it relates to DSP experiences of accessing health care during COVID-19 including: fostering the therapeutic relationship, the continued value of in-person visits for people with IDD, the importance of 'seeing and being seen' at health care visits, having the 'time to care', as well as acknowledging what was not found in the data.

**Fostering the therapeutic relationship.** At the core of health care is the relationship between the health care provider and the patient, with facilitation from caregivers as needed.<sup>18</sup> In the current study, DSPs provided examples of how even a brief phone call could be successful if there was an established positive relationship. New relationships however, seemed to be more complex to negotiate virtually and some DSPs spoke about health care providers being rushed or dismissive over the telephone, either not including the patient or not including the DSP. Evidence on the impact of virtual care on the therapeutic relationship is still developing, however, studies suggest it is possible to foster a positive relationship virtually.<sup>19,20</sup> Some studies even suggest that virtual interactions have the potential to foster a stronger therapeutic alliance for some patients who may feel more comfortable, safer or less self-conscious interacting remotely, such as those with autism<sup>21</sup>; though other patients find virtual interactions can hinder effective communication, particularly if there are technical difficulties.<sup>20</sup> Additional consideration may be needed to effectively manage virtual relationships with this patient group, and the DSPs supporting them.<sup>22</sup>

**Time to care.** An advantage identified for both phone and video visits was that they saved time and were more convenient. It is well established in the literature that traveling to health care visits and waiting in the waiting room can be time consuming and disruptive to both DSPs and patients with IDD,<sup>23,24</sup> and virtual visits may be an opportunity to improve this element of the health care experience even after the pandemic. However, there were also concerns expressed that virtual visits could be too short, and therefore miss details or convey a lack of caring for the patient. Additionally, since only the DSP perspective was captured in the survey it is important to ensure that DSP convenience does not supersede the needs of patients with IDD, which may be different. There is a complex balance when supporting patients with IDD in that a thorough visit can take more time, but needs to be sensitive to the tolerance/ability of that person to safely and comfortably participate. It is important to recognize that the necessary time to care can be thought about differently from the patient, provider, and DSP perspective, and the optimal balance may be dependent on the reason for the visit.

**The continued value of in-person visits.** From the perspective of DSPs, in-person visits continue to be viewed as important for some people with IDD. There are a number of reasons why this may be the case. Firstly, it can be hard for someone with an IDD to describe their health problem so being able to see the person and build rapport is important. Body language is easiest to observe in person, as is the health care provider demonstrating how something is to be done. It is also the easiest way to include all members of the health care triad (i.e., healthcare provider, person with IDD, DSP) in the discussion. Additionally, depending on the particular type of health complaint, a physical exam may be necessary in order to complete a proper assessment. For a population that may struggle with communicating symptoms effectively,<sup>25</sup> the physical

exam (e.g., feeling a rash, listening to breathing, observing pain responses when touching a certain area) can provide key information that may not be obtained otherwise. It is important to recognize that although more difficult, some of these issues can be addressed with virtual technology with practice and support (e.g., correct camera positioning, having people from multiple locations join the call). These modalities, however, may have added cognitive demands which can be challenging for the person with IDD.

In-person care is also the most familiar way of obtaining health care, and learning something new, while difficult for all of us, can be especially challenging to people with IDD. DSP comments remind us that there are other important ways in which traditional visits are helpful. It is important to recognize that the experience of a health care visit is more expansive than the time spent interacting with the health provider alone. The process of traveling to a visit and going home afterwards are opportunities for preparation and celebration, making the visit itself more rewarding. Appointments within the home do not provide that same degree of 1:1 time between the individual with an IDD and the DSP, do not include that built-in preparation time, and may not even be completed in full privacy.

**To see and to be seen.** For a marginalized group who can be excluded from health care decisions and can have decisions made about them as opposed to with them, it is especially important that they be able to be seen by their health provider. There is a risk that these individuals will not be "seen" or will be excluded during phone calls, as suggested by some DSPs in the current study, a concern which has been voiced by adults with IDD even during in-person encounters.<sup>26,27</sup> It would be interesting to explore whether people with IDD feel more seen in-person when everyone is wearing masks, which was listed as a barrier to in-person visits by some DSPs, compared to seeing and being seen fully on video without masks. As the pandemic continues, and with appropriate preparation and support, experiences with masked in-person care, and unmasked video-based care may become easier. Importantly, video-based care, as opposed to in-person or phone-based care, also allows the health care provider to "see the patient" more fully, because they are in their own context, which is helpful for the provider to understand.

**What was not said.** Equally important to reviewing what was shared by DSPs about health care visits is noting topics that were not commented upon. Challenges related to consent were not identified. In fact, some DSPs spoke about their preference for simple and quick discussions with health care providers that did not include the patient. While this may be appropriate when receiving advice generally, the patient or his/her substitute decision maker should be included when it comes to any treatment decisions. How the supported decision-making process occurs virtually or during in-person visits when DSPs are not permitted in the space warrants further consideration. A second concern was the issue of privacy. Many individuals with IDD live in shared or congregate care settings and if either the patient or DSP wanted to discuss something with the health care provider alone during a virtual visit, this might be difficult to accomplish without careful planning and DSP support. In-person visits have a waiting area, as well as separate examination rooms, but homes do not have this same set up.

## Limitations

Despite being the largest study on this topic to date, there remain several limitations which should be considered. First, findings only represent the perspective of DSPs. What a DSP considers to be positive or negative may be perceived differently by the health care provider, who has different responsibilities and

priorities in the health care encounter, as well as the patient, who may also have different priorities. Ideally, it would be important to obtain all three perspectives about the same encounters when possible. Second, only a subset of survey participants provided open ended feedback regarding their health care encounter and, we did not explicitly ask a set of standardized questions about each health care experience. Third, many of the DSPs in this study only experienced one type of visit and were therefore limited to only providing feedback on that type of visit. Fourth, because some of the DSPs participated in multiple types of health care visits, but were asked to provide general comments and not comments specific to each type of visit, this meant that we could not always interpret which type of health care visit a person was referring to from their comment. Such responses could not be included in our analysis. Finally, responses are based primarily from Ontario respondents and may not be reflective of other jurisdictions where health and social care are organized differently, and where technology access may also vary.

## Conclusion

How we deliver health care fundamentally changed during COVID-19 and it is critical that we understand the implications of these changes for individuals with IDD. Simply adhering to guidelines developed for the general population around virtual care will not guarantee good quality care for this unique group, unless adaptations can be made. If we are to learn how to best adapt virtual care, we need to not only examine the DSP experience, but also invest in research focused on the patient perspective and the quality of care.

As we continue to better understand when and how to best deliver virtual care to people with IDD, from multiple perspectives, we can begin making changes based on lessons learned here. Preparation is a key part of capacity-building and is essential for any type of health care visit during COVID-19. Knowing how to wear a mask is essential for in-person visits, as is having the ability to move to a private room where a mask is not required. Knowing what information to have available for a phone call saves time for a phone visit, and understanding how lab requisitions and follow-up appointment information will be shared is required for all virtual care. For health care providers and health care recipients, internet access and skills training to facilitate video appointments is crucial. To enhance virtual health care encounters, tailored tip sheets, checklists and video demonstrations for providers and patients/staff would be useful. Moving forward, we need to carefully consider how to best fit the individual situation to the best suited health care interaction, recognizing that in the same way that in person care can be problematic for certain individuals, virtual care may not be effective for others. This will be relevant both during and beyond the current pandemic.

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