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Review Article

Virtual health care for adult patients with intellectual and developmental disabilities: A scoping review



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ABSTRACT

Background: The COVID-19 pandemic led to an abrupt shift to virtual health care for many patients, including adults with intellectual and developmental disabilities (IDD). Approaches to virtual care that are successful for people without IDD may need to be adapted for adults with IDD.

Objective: The aim of this scoping review was to examine what is known about virtual health care for adults with IDD and in particular, the impact of virtual delivery on access to care for this population.

Methods: A comprehensive search was conducted of the academic and grey literature. A two-stage screening process was conducted by two independent reviewers and a structured data extraction template was populated for each included study. Findings were analyzed thematically using Access to Care Framework domains.

Results: In total, 22 studies met inclusion criteria. The majority were published in the past three years and focused on specialized IDD services. A subset of 12 studies reported findings on access to care for adults with IDD. Participants generally reported high acceptability of virtual care, though some preferred face-to-face encounters. Initial results on effectiveness were positive, though limited by small sample sizes. Challenges included internet quality and technical skill or comfort.

Conclusions: This review suggests that it is possible to deliver accessible, high quality virtual care for adults with IDD, however, relatively little research has been conducted on this topic. Due to COVID-19 there is currently a unique opportunity and urgency to learn when and for whom virtual care can be successful and how it can be supported.

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Introduction

The COVID-19 global pandemic has led to an abrupt change in how health care is delivered in countries around the world. Almost overnight much of care delivery shifted from in-person to virtual.^{1–4} The term virtual care has been defined in many ways and is often used interchangeably with other terms such as telehealth, telemedicine, ehealth, mhealth and digital health.^{5–7} In this study, virtual care is defined as technology supported interactions between health care providers and patients in different locations. These interactions may be synchronous or asynchronous and may utilize video, telephone or text messaging technologies. The rapid

expansion of virtual care during the pandemic has raised questions about the quality and accessibility of virtual care for patients.

Although wide scale availability of virtual health care is new, approaches to remote delivery of health care have been available and studied for decades.⁵ In considering how to adapt systems and processes to deliver high quality accessible care remotely, it is important to review what is already known about virtual care for different patient populations.

Adults with intellectual and developmental disabilities (IDD) are one group that may require additional consideration to ensure that the increased use of virtual modalities does not compromise access to care. IDD is an umbrella term that includes individuals with a

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wide range of conditions of childhood-onset that impact cognitive and adaptive functioning across the lifespan.⁸ This includes, for example, intellectual disabilities, autism spectrum disorders (ASD), Down syndrome, and fetal alcohol spectrum disorders.

One potential barrier for adults with IDD is access to internet enabled devices and the skills or supports to use these devices. Many adults with IDD live in congregate care settings where they may have limited access to technology and the staff who support them may not have the skills or experience to support a virtual visit.^{9,10} Adults with IDD living with family are often supported by older parents who may not be comfortable using technology.^{11,12} Adults with IDD living independently may have difficulty navigating virtual care without a support person. They are also more likely to have low income¹³ making the costs of high-speed internet and internet enabled devices potentially prohibitive.¹⁴

Additionally, even with the necessary technology in place, virtual clinical interactions may be challenging. Some individuals with IDD rely on facial expressions, lip reading, sign language or communication devices for effective communication.^{15,16} These strategies may be difficult to use remotely, especially if communicating by phone or if the video is delayed or fuzzy.

Conversely, the shift to virtual care may also be an opportunity to improve access for patients with IDD. Health care clinics are not always accessible spaces.¹⁷ Travelling to the health care appointment can be costly, time consuming and disruptive to daily routines.^{18,19} Waiting in the waiting room can be a stressful and overwhelming experience which can lead to negative interactions with health care providers, rushed and unproductive appointments, and anxiety for future health care interactions.^{17,19–22} Conducting health care visits remotely, from a space where the patient is most comfortable, may lead to improved health care experiences for patients with IDD.

Most prior reviews on virtual care for people with IDD have been disorder-specific focusing on people with ASD^{23–28} or attention deficit hyperactivity disorder (ADHD).²⁹ It is important to recognize that people with IDD are a heterogeneous group with a wide range of health care needs and experiences. Findings from reviews specific to people with ASD or ADHD cannot be used to support policy decisions for individuals with IDD more broadly. Two reviews were identified with broader populations included but they were limited to specific health care services: Madhavan³⁰ focused on telepsychiatry for individuals with intellectual disabilities, and Valentine et al.³¹ focused on virtual services to assess or treat neurodevelopmental disorders. A trend across all these reviews is they predominantly focus on children. The common clinical issues for children with IDD, such as initial childhood screening and assessment, are different than the issues predominantly facing adults, which include chronic disease management, preventative cancer screening, and issues related to aging. The clinical interaction can also look different for adults who may be interacting with health care independently or with the support of paid staff, rather than family members.^{32,33}

The aim of this scoping review was to examine what is known about virtual health care for adults with IDD and in particular, the impact of virtual delivery on access to care for this population. Access to care was defined using the Access to Care Framework developed by Levesque and colleagues.³⁴ In this framework, access is conceptualized as the fit between the needs of the individual and characteristics of the service. The Access to Care Framework identifies five dimensions of service accessibility: *approachability* (patient awareness of the service), *acceptability* (patient satisfaction or comfort using the service), *availability and accommodation* (patient ability to use the service), *affordability* (cost of the service), and *appropriateness* (quality of the service). A scoping review methodology was selected due to the breadth of the research topic and the

limited research conducted on adults with IDD. Scoping reviews are recommended for exploratory studies where the aim is to describe the nature and extent of research conducted in a topic area and identify gaps in the literature.^{35–37}

Methods

This review was conducted and reported based on the scoping review methodology articulated by Levac and colleagues³⁵ and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR).³⁸ The protocol is available by request from the first author.

Search strategy

An electronic database search was performed of Medline, EMBASE, CINAHL PLUS, PsycINFO, and SCOPUS using key words related to IDD (e.g., developmental disability, intellectual disability, mental retardation, neurodevelopmental disorders, learning disability, ASD, Down Syndrome, fetal alcohol spectrum disorders) and telemedicine (e.g., telemedicine, telehealth, digital health, virtual care, mhealth, telepsychiatry). The subject heading 'child' was used as an exclusionary term. Backward and forward snowball techniques were used on key papers. Additionally, a targeted grey literature search was conducted using Google Scholar, Grey Literature Report, and OpenGrey. The initial search was conducted in October 2020 and updated in February 2021. See Appendix A for the detailed search strategy.

All identified citations were uploaded into Covidence, a review management software. The final included studies were selected through a two-phase process. Two reviewers (A.S. and N.B.) independently conducted a screening of title and abstract, followed a full text review. Any disagreements were resolved through discussion.

Inclusion and exclusion criteria

Studies were included if they evaluated delivery of virtual health care that included adults, over the age of 18 years, with IDD.

Population: To be included, at least a portion of the study population had to have IDD and be over the age of 18 years old. This review used the Ontario definition of developmental disabilities which includes individuals with intellectual disabilities and other conditions that impact cognitive and adaptive functioning that onset in childhood, persist across the lifespan and affect areas of major life activity.⁸ This definition is narrower than the US definition of which also includes physical disabilities such as hearing loss, vision loss and cerebral palsy.³⁹ Studies that focused exclusively on physical disabilities, mental illness or acquired brain injury were excluded.

Concept: Health care was broadly defined as any health-related service including medical care, therapies, and psychosocial interventions. Virtual delivery was defined to include remote interactions, conducted synchronously or asynchronously, through phone, video and/or text exchange. Studies that did not include interaction with a health care provider (e.g., electronic health care resources, mobile applications or electronic surveillance) were excluded.

Context: Studies had to include adults with IDD as the recipient of care; studies focused on training caregivers or virtual consultation between health care providers were not included. Study data could be collected from patients, caregivers or health care providers, as long as the focus was on care delivered to a patient with IDD.

Study designs: All study designs that contained original data about experiences of using or delivering virtual health care to

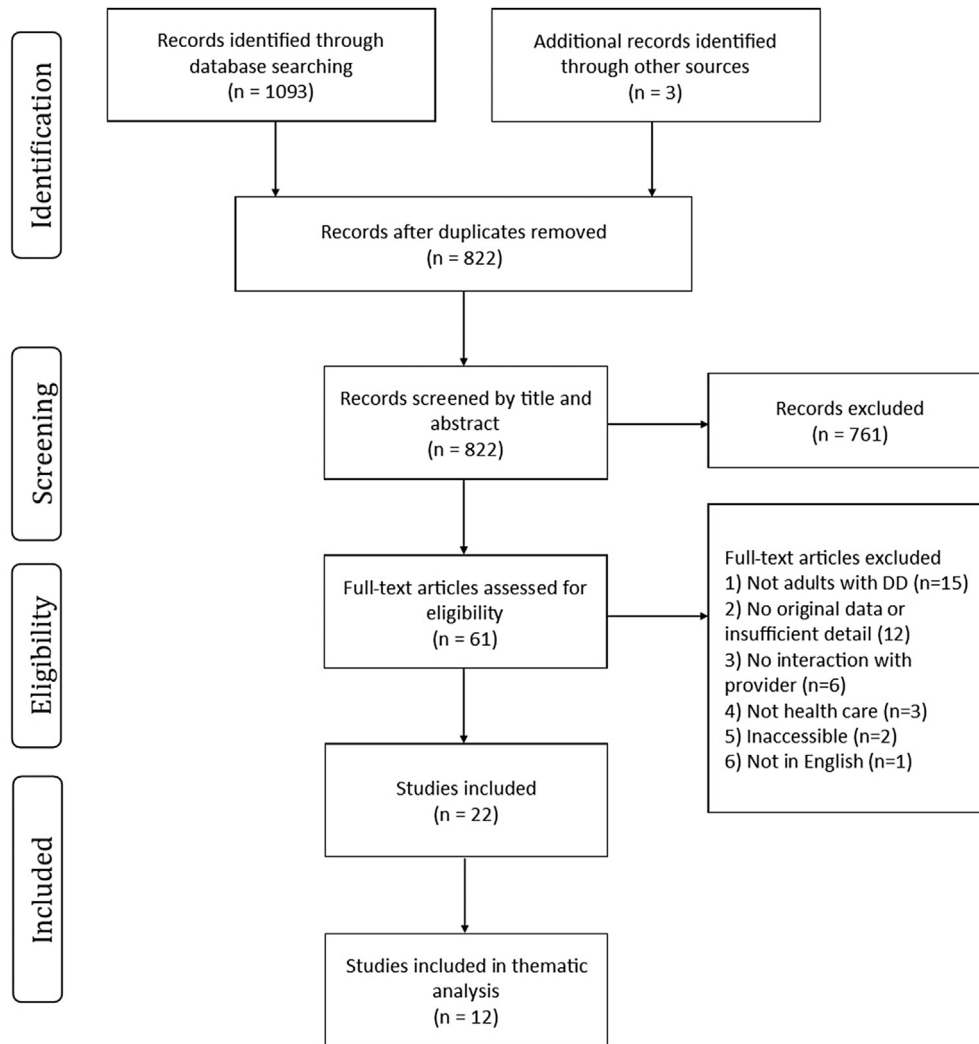


Fig. 1. Study selection process (PRISMA flow diagram).

adults with IDD were included. Commentaries, discussion papers and papers not in English were excluded. Prior literature reviews were not included but were reviewed as potential sources of additional relevant primary studies.

Data extraction and synthesis

A structured data extraction template was developed and populated for each of the included papers. The template captured the study purpose, study design, virtual care modality, health care service, participants, and study findings. Initial extraction was conducted by one author (A.S.), with a subset of studies reviewed by a second author (N.B.) for accuracy and completeness. Given the exploratory nature of this review and the limited research in this field, no formal quality assessment was conducted.

In alignment with the scoping review methodology, two levels of analysis were conducted.³⁵ First, a descriptive numerical summary was provided for the full body of research identified. Descriptors included the study designs, virtual care modalities, health care services, and study populations. Second, thematic analysis was used to synthesize findings related to access to care.⁴⁰ This analytic approach is recommended when including diverse types of data,^{41,42} as is the case in this review. Only the subset of studies that reported findings on access to care specific to adults with IDD were

included in this second analysis. Studies were excluded if they did not report on access to care or if findings specific to adults with IDD (>18 years of age) could not be isolated as they were reported in aggregate with findings from other populations. Findings from the subset of relevant studies were coded deductively based on the Levesque Access to Care framework domains.³⁴

Results

Describing the literature

In total, 819 unique studies were identified in the academic databases and an additional 3 studies were identified through supplemental searches (see Fig. 1). Twenty-two studies met inclusion in this review, describing 18 service models or interventions (see Table 1). All 22 studies were published after 2006, the majority (n = 15) since 2018. Five studies were conducted during the COVID-19 pandemic. Most studies were conducted in the US (n = 9), with the remaining studies conducted in Sweden (n = 4), Canada (n = 4), Australia (n = 1), the Netherlands (n = 1), UK (n = 1), India (n = 1) and internationally (n = 1).

Of the 22 included studies, 13 focused exclusively on adults with IDD. Among the remaining studies, three focused on transition aged youth with IDD (age ranges between 15 and 32 years old), four

Table 1
Characteristics of included studies.

Author, year	Country	Title	Study design	Study participants	Virtual health care program			Conducted during COVID-19?	Included in thematic analysis?
					Virtual care modality	Health care service	Setting		
Backman, 2018	Sweden	Internet-delivered psychoeducation for older adolescents and young adults with autism spectrum disorder (SCOPE): An open feasibility study	One-group pretest-posttest design	n = 28 youth with ASD; age 16-25	Online platform with chat function	Psychoeducation	Home	No	No
Gentile, 2018	US	Reaching rural Ohio with intellectual disability psychiatry	Retrospective observational study	n = 120 patients with ID; all ages	Phone or video	Psychiatry/mental health care	Multiple	No	No
Gowda, 2018	India	A study on collaborative telepsychiatric consultations to outpatients of district hospitals of Karnataka, India	Retrospective file audit	n = 139 patients, 14% of whom had an ID; all ages (mean = 31)	Video	Psychiatry consultations	Local hospital	No	No
Goyal, 2020	Canada	Cognitive profile of adults with intellectual disabilities from indigenous communities in Ontario, Canada	Retrospective file audit	n = 60 adults with ID (37 via video-conference); age 18-58	Video	ID specialty services	Local community agency	No	No
Guerra, 2019	US	Feedback and strategies from people with intellectual disability completing a personalized online weight loss intervention: a qualitative analysis	Qualitative evaluation	n = 15 adults with mild-moderate ID; age > 18 (mean = 33)	Phone + online resources	Weight-loss intervention	Home	No	Yes
Harper, 2021	US	A comparative evaluation of telehealth and direct assessment when screening for spasticity in residents of two long-term care facilities	Within subject crossover study	n = 62 long term care residents (includes patients with IDD, % not specified); mean age = 70	Video	Spasticity assessment	Long-term care	No	No
Jeste, 2020	International	Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions	Survey	n = 818 caregivers of individuals with syndromic IDD; 24% > age 18	Not specified	Health care (range of services)	Home	Yes	No
Lunsky, 2021	Canada	"The doctor will see you now": Direct support professionals' perspectives on supporting adults with intellectual and developmental disabilities accessing health care during COVID-19	Survey	n = 942 paid caregivers of adults with IDD; age >18	Phone and video	Health care (range of services)	Home	Yes	Yes
Parmanto, 2013	US	An integrated telehealth system for remote administration of an adult autism assessment	Formative and summative usability studies	n = 10 adults with ASD; age >17	Video	Autism Diagnostic Observation Schedule assessment	Telemedicine site	No	Yes
Pellegrino, 2017	Sweden	Using telehealth to teach valued skills to adults with intellectual and developmental disabilities	Experiment	n = 2 adults with ID; age >18	Video	Skills teaching	Home	No	Yes
Rawlings, 2021	UK	Exploring how to deliver videoconference-mediated psychological therapy to adults with an intellectual disability during the coronavirus pandemic	Survey	n = 22 adults with ID; age 18- 57	Phone and video	Psychological therapy	Home	Yes	Yes
Schutte, 2015	US	Usability and reliability of a remotely administered adult autism assessment, the Autism Diagnostic Observation Schedule (ADOS) Module 4	Within subject crossover study	n = 23 adults with ASD; age 19-30	Video	Autism Diagnostic Observation Schedule assessment	Telemedicine site	No	Yes
Sehlin, 2018	Sweden	Experiences of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorder: a qualitative study	Qualitative evaluation	n = 16 youth with ASD; age 15–32 (mean = 23)	Internet-based chat program	Coaching and psychoeducation	Home	No	No
Shawler, 2021	US	An intensive telehealth assessment and treatment model for an adult with developmental disabilities	Single subject experiment	n = 1 adult with IDD; age 20	Video Video	Treatment and assessment for challenging behavior	Home Clinic	Yes No	Yes Yes

Table 1 (continued)

Author, year	Country	Title	Study design	Study participants	Virtual health care program			Conducted during COVID-19?	Included in thematic analysis?
					Virtual care modality	Health care service	Setting		
Spaan, 2020	the Netherlands	Feasibility and reliability of screening on mild to borderline intellectual disabilities using SCIL through video-administration	Within subject crossover study	n = 89 adults with ID; age 18-63		Screeners for Intelligence and Learning Disabilities (SCIL)			
Szeftel, 2012	US	Improved access to mental health evaluation for patients with developmental disabilities using telepsychiatry	Retrospective chart audit	n = 45 patients with IDD; age 2–61 (mean = 19)	Video	Psychiatry consultation	Primary care clinic	No	No
Tang, 2020	Australia	Development and feasibility of MindChip™: a social emotional telehealth intervention for autistic adults	pragmatic RCT	n = 25 autistic adults (intervention = 11, control = 14); age > 18 (mean = 24)	Video	Social emotional skills	Home	No	Yes
Temple, 2010	Canada	A comparison of intellectual assessments over video conferencing and in-person for individuals with ID: preliminary data	Within subject crossover study	n = 19 adults with ID; age 23–63 (mean = 39)	Video	Wechsler Abbreviated Scale of Intelligence; Beery-Buktenica Test of Visual-Motor Integration	Local community agency	No	Yes
Temple, 2015	Canada	Diagnosing FASD in adults: The development and operation of an adult FASD clinic in Ontario, Canada	Retrospective file audit	n = 93 adults was FASD (10 via video-conference); age > 18	Video	FASD assessment, short-term treatment, consultation	Local community agency	No	No
Wentz, 2012	Sweden	Development of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorders: a pilot study	Pilot study, pre/post evaluation	n = 12 youth with ASD/ADHD; age 15–23 (mean = 19)	Internet-based chat program	Coaching and psychoeducation	Home	No	No
White, 2021	US	Impact of COVID-19 on individuals with ASD and their caregivers: a perspective from the SPARK cohort	Survey	n = 3502 parents of dependents with ASD; 411 (12%) over age 18	Unknown	Health care (range of services)	Home	Yes	Yes

*Autism Spectrum Disorders (ASD); Intellectual Disabilities (ID); Fetal Alcohol Spectrum Disorders (FASD); Intellectual and Developmental Disabilities (IDD).

included individuals with IDD of all ages, and two included adults with and without IDD. Most studies (n = 13) focused on or included patients with intellectual and/or developmental disabilities generally. The remaining diagnosis specific studies focused on patients with ASD (n = 7), Down syndrome (n = 1) and fetal alcohol spectrum disorder (n = 1).

Most of the studies focused on specialized services aimed at individuals with IDD rather than general health care services. Exceptions included one study on spasticity assessments,⁴³ one general psychiatry program,⁴⁴ and three surveys on general health care utilization during COVID-19.^{45–47}

Over half of the included studies were trials testing the feasibility or validity of conducting assessments virtually (n = 6) or delivering multi-week programs (e.g., psychoeducation, therapy) (n = 7). Five were observation studies evaluating consultation or multiservice programs, and four were surveys on utilization of virtual care during COVID-19. The five observation studies reported on four existing programs: a telepsychiatry program in California for patients with IDD open to all ages, but predominantly treating children⁴⁸; a telepsychiatry program in Ohio for patients with intellectual disabilities, with varied age eligibility by county⁴⁹; a telepsychiatry program in India that treats patients of all ages with

Table 2

Study findings related the Access to Care Framework.

Author, date	Approachability	Acceptability	Availability and accommodation	Affordability	Appropriateness
Guerra, 2019			X		
Lott, 2006					X
Lunsky 2021		X	X		X
Parmanto, 2013		X	X		
Pellegrino, 2017		X			X
Rawlings 2021		X	X		
Schutte, 2015		X	X		X
Shawler, 2021		X	X		X
Spaan, 2020		X	X		X
Tang, 2020		X	X		X
Temple, 2010		X			X
White, 2021		X	X		

a range of psychiatric disorders, including patients with intellectual disabilities⁴⁴; and a specialized agency in Ontario for adults with IDD that includes a telemedicine clinic.^{50,51}

Across the 22 studies, care was offered most frequently by video (n = 13), in three cases via online chat, and in six cases through multiple methods. Patients accessed care from a range of locations with varied levels of support. In nine studies patients accessed care from a clinic (e.g., telemedicine clinic, primary care office) where there was a clinician or assistant present to support the interaction. In twelve studies, the patients accessed care from their residence where support ranged from no support, to intensive family or staff support. In one study participants accessed care from multiple settings. In studies published prior to the COVID-19 pandemic, services accessed at home were more likely to be multi-week online programs, while assessments and consultations were more likely to be accessed in clinics.

Findings related to access to care

Of the 22 included studies, 12 reported results related to access to care specific to adults with IDD. Four of these studies were conducted in the first few months of the COVID-19 pandemic: three surveyed patients or caregivers about their perceptions and experiences using virtual care, and one tested the feasibility of delivering intensive virtual treatment for challenging behavior. The remaining eight studies were trials where the virtual care intervention was delivered as part of a research project: five tested the use of assessment tools via telemedicine where the patient participated from a clinic, and three tested or evaluated multi-session virtual treatment programs where the patient participated from their home. Findings from these 12 studies are reported below organized by the Access to Care Framework Domains: *acceptability, availability and accommodation, and appropriateness*. No studies reported findings related to *approachability* or *affordability* (see Table 2).

Acceptability

Ten studies reported findings related to the acceptability of the virtual service for users. This domain refers to comfort or satisfaction with the service. For this review, focus was given to acceptability of the virtual platform rather than the content of the program. The six studies conducted prior to COVID-19 all found that patients were generally positive about receiving care virtually, though in a few studies a subset of participants preferred face to face interactions. The four studies conducted during COVID reported more mixed findings.

Four of the pre-COVID studies focused on testing the usability, reliability and/or feasibility of using assessment tools over video-conference. Two studies^{52,53} evaluated the delivery of the Autism Diagnostic Observation Schedule via videoconference and found that most participants were comfortable with the process and would be willing to do it in the future, though a portion of participants reported they would still prefer face-to-face visits. Spaan et al.⁵⁴ reported on the feasibility and reliability of using the Screener for Intelligence and Learning Disabilities through video-administration compared with in-person. They found that most participants (n = 89) were satisfied with both ways of being assessed though almost half preferred face-to-face. A small number of participants (10%) preferred remote assessment, finding it less distracting and appreciating the distance from the clinicians. Temple et al.⁵⁵ looked at the validity of virtual intellectual assessments and reported informal positive feedback from participants.

The remaining two pre-COVID studies focused on ongoing health interventions. Tang et al.⁵⁶ reported results from a

randomized pragmatic pilot trial of a ten-week virtual social emotional skills program for autistic adults which included an online computer-based intervention and weekly video meetings with a psychologist. All seven participants who completed the follow up questionnaire were satisfied with the program and most found it enjoyable. Pellegrino and Reed⁵⁷ tested the efficacy of a telehealth intervention to teach new skills to two adults with intellectual disabilities via video. Both participants strongly agreed with the statements: "I liked the way I learned new skills over video calls" and "I would recommend others to learn new skills through video calls."

The four studies conducted during the first few months of COVID reported more mixed findings. White et al.⁴⁷ surveyed 3502 parents of dependents with ASD, of which 411 were parents of autistic adults. Among parents whose adult children received virtual services, only a relatively low proportion reported benefit across service categories (physical/occupational therapy = 22%; speech/language = 37%, applied behavioral analysis = 52%, medical = 64%, mental health = 68%). Lunsky et al.⁴⁶ surveyed paid caregivers and reported both challenges and benefits to virtual care. Respondents identified that while there were benefits for some patients, others found it distressing, rushed and impersonal. Shawler et al.⁵⁸ tested the feasibility of virtual delivery of high intensity caregiver mediated treatment for an adult with behavioral challenges and reported very high acceptability from the caregiver. Rawlings et al.⁵⁹ surveyed existing patients with intellectual disabilities in a psychological therapy clinic on their willingness and readiness to receive care virtually. They found that half of the 22 patients surveyed were unable or uninterested in receiving care virtually. Those willing to participate were generally more comfortable with the idea of virtual care when delivered by a known therapist and when delivered by phone rather than video.

Availability and accommodation

Nine studies reported findings related to availability and accommodation. This domain refers to how easy it is for patients to get to and use the health care service. The main challenges raised were related to technical issues using the virtual platform. The extent of challenge varied across studies and appears to be influenced by the availability of a support person to manage the technology and the technical skills of the participants. The other three studies that did not explicitly report on this domain all noted the presence of a second person to support the technology.

Among the three studies which tested the usability or reliability of conducting virtual assessments, one reported that most participants found the system intuitive and simple to use and experienced no technical issues;⁵³ the other two reported only occasional minor technical glitches.^{52,54} In all three studies the assessment was conducted in a controlled supported setting where an assistant was present to set up the technology and troubleshoot any issues. Technical support for the patient was identified as an important component of the model. It was also noted that the provider administering the assessment must also have sufficient comfort and skill with the virtual platform to effectively administer remote assessments.⁵²

Two studies evaluated ongoing online programs supported by phone or video coaching sessions.^{56,60} The first, a social emotional skills program for autistic adults,⁵⁶ reported that most participants (86%) found the system easy to use, though some experienced technical issues due to poor internet connection. One participant had difficulties with verbal expression and was able to use the chat box function to communicate. Study participants were required to have sufficient computer skills to use the program and an IQ over 70. The second study, a weight loss intervention for adults with

intellectual disabilities,⁶⁰ reported that many of the participants experienced challenges using the online platform, including connection issues due to slow internet and trouble navigating the website. In one case, access to a computer was a challenge for a participant in a single computer household. The study found that caregiver support, good quality internet, consistent scheduling and a quiet space to participate in the coaching phone calls were important for success. Participants were required to have access to a computer with internet and any legal guardians had to be willing to participate.

One study that used video to support daily five hour caregiver-mediated therapy sessions for an adult with challenging behavior, reported only minor technical issues that did not interrupt treatment.⁵⁸ Though this study was conducted during the pandemic, the providers had prior experience delivering virtual care and there were two caregivers present with the individual at all times (one to deliver care, one to manage the technology).

The final three studies conducted patient or caregiver surveys during the early months of the pandemic. White et al.⁴⁷ found that across a range of services only a small proportion of autistic adults using the service prior to lockdown were accessing that service virtually in the first months of the pandemic (medical = 21%, physical/occupational therapy = 32%, applied behavior analysis = 36%, speech/language = 44%, mental health = 53%). It should be noted that the reason for this decline was not reported and may be a reflection of either service availability or patient utilization. Rawlings et al.⁵⁹ found that patients had mixed to low prior experience with technology and concluded that using virtual care would likely be challenging. Lunsky et al.⁴⁶ found that virtual care was in some cases more accessible than in-person care. It saved time and was easier to access for patients who find waiting in the waiting room or social distancing challenging. However, they also identified frequent technological challenges including internet connection issues and lack of familiarity with the many virtual platforms used by different health care providers.

Appropriateness

Eight studies reported findings related to appropriateness. This domain refers to the fit between services provided and patient needs and includes findings related to service quality and effectiveness. Findings generally showed that health care can be successfully delivered virtually to patients with IDD. However, most studies were small, limiting their ability to draw definitive conclusions.

Four studies looked at whether assessments can be conducted remotely, including the Autism Diagnostic Observation Schedule,⁵² intellectual assessments⁵⁵ Alzheimer assessments,⁶¹ and the Screener for Intelligence and Learning Disabilities.⁵⁴ The studies generally found only minor differences between virtual and in-person administration, though a number of limitations were flagged related to study design, sample size and sample composition suggesting the need for further research. Temple et al.⁵⁵ reported informally that clinicians generally found virtual administration acceptable but were concerned about the loss of more subtle body language that can inform clinical judgement. Schutte et al.⁵² similarly noted that, though it did not impact scores, clinicians felt that some aspects of the interaction were missed when assessed remotely. Additionally, an element of the assessment that required a physical interaction with the assessor could not be replicated virtually and was therefore excluded.

Three studies evaluated ongoing virtual programs to teach social emotional skills,⁵⁶ manage challenging behavior,⁵⁸ and teach life skills.⁵⁷ They all reported positive findings on program effectiveness (i.e., that the programs were able to achieve their intended

outcomes), though their conclusions were limited by very small samples ($n = 11$ in intervention group;⁵⁶ $n = 1$;⁵⁸ $n = 2$;⁵⁷).

A survey of paid caregivers conducted during COVID-19 reported mixed feedback related to the impact of virtual modalities on quality of care.⁴⁶ An identified benefit of video-based care was that it allowed the provider to see the patient in their home environment, providing clinically important information and potentially improving the quality of care. Challenges identified were largely related to phone-based visits, the most common type of virtual care reported, including diagnostic accuracy and the feasibility of including the patient in the interaction.

Discussion

The aim of this scoping review was to examine what is known about delivering virtual health care to adults with IDD. Most of the research on virtual care and people with IDD has focused on children and only 22 studies were identified that included adults. Most of these 22 studies focused on services delivered by specialists in the field of IDD; fewer studies focused on services provided by mainstream health care providers. In many cases participants received care from a clinic where a trained staff member was present to facilitate the virtual interaction. This limits the applicability of findings to the current experience during the pandemic where patients and caregivers are accessing health care services from home. Most of the included studies were small trials or pilot studies, almost half of which had fewer than 30 participants.

Twelve of the 22 included studies reported findings on access to care specific to adults with IDD. Study findings were summarized based on the Access to Care Framework.³⁴ No findings were reported related to two of the framework domains: *approachability* and *affordability*. This is a substantial gap in the literature. *Approachability*, or the patient's awareness of the service, is the first prerequisite for accessing care. Especially as restrictions have shifted throughout the COVID-19 pandemic, it is possible that patients and families are unaware of virtual care options which may inhibit utilization. *Affordability*, or the cost of virtual services for patients, has important equity implications that should be considered in service planning. Some studies have suggested that virtual care may eliminate or reduce costs related to travel and missed work which may benefit low income patients and their caregivers.^{26,62} Conversely, studies have also found technology costs (e.g., internet-enabled devices, high speed internet) to be a barrier to accessing virtual care.^{10,63} Additionally, the time cost for caregivers may be substantial if caregiver support is needed to facilitate virtual participation that would not have been necessary for in-person services. For example, Shawler et al.⁵⁸ described an intensive five hour daily intervention that required continual caregiver presence. Costs may also be a relevant consideration on the supply side when considering how to most efficiently deliver care. For example, some studies have shown reduced service costs due to avoided travel time for providers who traditionally conduct home visits.^{62,64} This is likely especially relevant for interprofessional models of care that require the presence of multiple providers.

For the three access domains that were addressed in this review (*acceptability*, *availability and accommodation*, and *approachability*), findings were generally positive. Regarding *acceptability* of virtual services, most studies reported positive feedback from patients and caregivers, though a subset of participants preferred face-to-face interactions. The exception to this trend was the three surveys conducted with patients and caregivers during the pandemic.^{46,47,59} While some survey respondents expressed satisfaction or interest in virtual care, others were uninterested, reported low benefit or perceived virtual care as rushed and

impersonal. It is not surprising that in studies where patients volunteered to participate and services were generally well supported, feedback was more positive. It should be noted, however, that the survey studies were conducted during the early months of the pandemic and it is possible that as providers, patients and caregivers become more experienced utilizing virtual care, acceptability will increase.

Related to the *availability and accommodation* domain, the most common challenges raised were related to technical issues using the virtual platform. The presence of a support person, good quality internet, and a quiet and private space to participate seem to be important factors in a successful virtual care interaction. Benefits to virtual care were also identified, including saving time and reducing challenges for patients who cannot tolerate waiting in the waiting room and/or social distancing. It is important to note that these studies almost exclusively represent situations where participation was voluntary or where the patient is supported by family or staff. Little is known about how adults with IDD who live independently have managed the shift to virtual care during the pandemic.

For the final domain, *appropriateness*, findings were generally positive that the health care interventions studied can be successfully delivered virtually, though most studies were not sufficiently robust to draw conclusions on efficacy or effectiveness. In some cases, virtual care may also be an opportunity to improve the quality of care for patients. For example, one study in this review found that virtual care had the added benefit that providers can see patients in their home environment providing important clinical insights.⁴⁶ Though not specific to adults, studies have found that appointments can be more effective when patients with IDD participate from a familiar setting where they are most comfortable.^{65,66} Another study found that for some autistic youth who find face-to-face interactions challenging, online chat-based programs reduced misunderstandings and eliminated memory issues.⁶⁷

One important concern raised was that virtual health care interactions can be dominated by the caregiver, leaving patients with IDD excluded from their own health care.⁴⁶ This has long been identified as a problem during in-person visits,^{68,69} and it is extremely concerning that virtual care may worsen this issue because it is deemed too complicated to include the patient.

Concerns were also raised that in some cases quality was compromised given the limitations of conducting physical exams remotely.⁴⁶ While there may be some types of care that can never be delivered virtually, many innovative programs are being developed to support an increasing range of virtual care interventions. For example, a telehomecare program in Ontario, Canada for patients with heart failure and chronic obstructive pulmonary disease equipped patients with digital touch-screen tablets connected to a weight scale, pulse oximeter and digital blood pressure monitor. Daily self-measurements were monitored remotely by nurses with regular follow up by phone.⁷⁰ Another recent study described an approach spine surgeons can use to conduct remote 'physical' spine assessments by observing a range of prescribed movement patterns over video.⁷¹ These projects suggest that it is possible to deliver a wide range of services virtually, but unfortunately patients with IDD are not typically included in these studies and it is unknown whether these programs would be successful for this population.

Overall, this review suggests that additional availability of virtual care has the potential to support access to health care for adults with IDD; however, existing studies are limited to a narrow segment of the IDD population and range of health care services. Caution is needed in determining the ongoing role of virtual care post-COVID. This review suggests that variables such as the type of health care, whether the provider is known to the patient, patient tolerance for virtual interactions, presence of caregiver support,

access to necessary technology, and skills to use technology can have an impact on the success of virtual care. Some of these variables (e.g., access to technology) can be supported or modified, and others (e.g., patient tolerance for virtual interactions) may be difficult or not possible to modify. As health care providers and policy makers contemplate the ongoing role for virtual care moving forward, a patient centred approach is needed which considers when virtual care is beneficial, when it can be supported, and when it is inappropriate. The most appropriate modality will be dependent on the specific preferences and needs of the patient in combination with the particular reason for the health care encounter.

This review has several limitations that it are important to note. Though efforts were made to develop a broad search strategy, it is possible that relevant articles were missed. Additionally, the review was limited to articles published in English and it is unknown whether relevant studies may be available in other languages. As this review was intended to be exploratory and comprehensive, no formal quality assessment was conducted.

Conclusion

Few studies have been conducted on virtual care for adults with IDD and there are substantial gaps in the literature. Adults with IDD are already an underserved population and it is important that they are not left behind as the system shifts towards virtual care. Preliminary findings suggest that it is possible to deliver accessible, high quality virtual care for patients with IDD, though the accessibility of care may be dependent on the needs and capacities of the patient, supports available, environment from which care is received and the type of health care provided. A common conclusion of the studies in this review was that virtual care should complement and not replace in-person services. A better understanding is needed of which patients, under which circumstances, and with what supports can benefit from virtual care. Due to the ongoing COVID-19 pandemic there is currently a unique opportunity and urgency to learn how virtual care works in practice for populations not typically studied, including adults with IDD. It is critical that future research include the perspectives of patients, family members, paid caregivers and health care providers. This research must consider the full range of health care services, diversity of patients with IDD, and the different dimensions of access.

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Conflicts of interest

There are no conflicts of interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2021.101132>.

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