


BMJ Open Exploring experiences with telehealth-delivered allied healthcare services for people with permanent and significant disabilities funded through a national insurance scheme: a qualitative study examining challenges and suggestions to improve services

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ABSTRACT

Objectives In people with a disability, or their caregivers, who reported suboptimal experiences, the objectives were to explore: (1) challenges with telehealth-delivered allied health services during the COVID-19 pandemic and (2) suggestions to improve such services.

Design Qualitative study based on an interpretivist paradigm and a phenomenological approach.

Setting Participants who accessed allied healthcare via telehealth during the pandemic.

Participants Data saturation was achieved after 12 interviews. The sample comprised three people with permanent or significant disabilities, and nine carers/partners/family members of people with permanent or significant disabilities, who were funded by the Australian National Disability Insurance Scheme and had suboptimal experiences with telehealth. Semistructured one-on-one interviews explored experiences with telehealth and suggestions on how such services could be improved. An inductive thematic analysis was performed.

Results Six themes relating to the first study objective (challenges with telehealth) were developed: (1) evoked behavioural issues in children; (2) reliant on caregiver facilitation; (3) inhibits clinician feedback; (4) difficulty building rapport and trust; (5) lack of access to resources and (6) children disengaged/distracted. Five themes relating to the second study objective (suggestions to improve telehealth services) were developed: (1) establish expectations; (2) increase exposure to telehealth; (3) assess suitability of specific services; (4) access to support workers and (5) prepare for telehealth sessions.

Conclusions Some people with permanent and significant disabilities who accessed allied healthcare via telehealth during the pandemic experienced challenges, particularly children. These unique barriers to telehealth need customised solutions so that people with disabilities are not left behind when telehealth services become more mainstream. Increasing experience with telehealth, setting expectations before consultations, supplying resources

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Strengths include the fact that we interviewed both carers and people with a disability across a range of different age groups, and that interview invitations were specifically targeted at those who had less than optimal experiences with telehealth to better understand why and how the challenges that they experienced could be overcome.
- ⇒ Only people in Australia who received support from the National Disability Insurance Scheme were included in the research, which limits the transferability of findings to other populations outside of Australia or supported by other healthcare schemes.
- ⇒ Most of our cohort had neurological disabilities, which potentially limits the transferability of our findings to other disabilities.
- ⇒ We did not use strategies like member checks or data triangulation, which may have had an impact on the credibility and dependability of our findings.

for therapy and assessing the suitability of clients for telehealth may help overcome some of the challenges experienced.

INTRODUCTION

COVID-19 pandemic and subsequent social distancing restrictions had a significant impact on the delivery of healthcare across the world. Many services that were traditionally delivered in-person were required to rapidly pivot to telehealth delivery, whereby patients and clinicians could consult remotely via telecommunication technology.¹⁻³ Most clinicians and patients in Australia were inexperienced with telehealth at the time,⁴ and,

as such, were forced to adapt their care. Although telehealth services were initially introduced to facilitate the continuity of care throughout the pandemic, the strong uptake and perceived success of these services within the wider community means that they are likely to remain an option into the future for many people.^{5 6}

The rapid and unexpected turn to telehealth during the pandemic had a particularly profound impact on people with permanent and significant disabilities, being among the highest users of allied healthcare.⁷ People with disabilities use internet services less often than those without disabilities, and are less likely to own computers, smart phones or tablets.⁸ Some may also experience challenges communicating via, or accessing/using, more complex technologies (eg, videoconferencing software) than the general population.^{8 9} For example, those with auditory or visual problems, or sensory sensitivity issues, may experience more difficulty using the technology and communicating effectively with the clinician,¹⁰ and those with physical disabilities and dexterity problems may experience difficulty with assessment or movement tasks via telehealth.¹⁰ These unique barriers to telehealth need customised solutions so that people with disabilities are not left behind when telehealth services become more mainstream.⁹

Over the past decade, evidence to support the effectiveness of telehealth-delivered allied healthcare for people with disabilities has been growing. There is some evidence that telehealth services are clinically equivalent to traditional in-person services among people with stroke,^{11 12} traumatic brain injury,^{12 13} neurodevelopmental disorders,¹⁴ physical disabilities^{12 15 16} and autism.^{16–19} There is also evidence to support the acceptability of telehealth within these populations, with the majority of patients reporting overall positive experiences.^{20–25} However, these studies have been conducted in the research setting, often as part of a clinical trial. As such, it is not clear whether the existing evidence reflects user experiences with telehealth in ‘real-world’ settings.

The rapid pivot to telehealth during the pandemic has provided a unique opportunity to evaluate experiences with telehealth outside of the research setting. We recently conducted an Australian-wide survey that investigated the experiences of 2391 people with permanent and significant disabilities who accessed allied healthcare (including physiotherapy, dietetics, occupational therapy, speech pathology, audiology, exercise physiology and psychology) via telehealth during the pandemic.²⁶ Although most of those who completed the survey indicated that they were satisfied with the safety, efficacy and ease of using telehealth, some had suboptimal experiences when compared with in-person consultations. In addition, around half indicated that they would be unwilling to use telehealth services beyond the pandemic. From our survey alone, it is not clear why this is. Further exploration is needed to better understand why some people with disabilities had less than optimal experiences and may be unwilling to use telehealth services in the

future. This information would help inform the development of telehealth services for people with disabilities in the future, and ensure that people with disabilities are not left behind when telehealth services become more mainstream. As such, the aims of this study were to explore (1) challenges with allied health services conducted via telehealth (telephone and/or video conferencing) during the COVID-19 pandemic and (2) suggestions to overcome these challenges, from the perspective of people with a disability, or their caregivers, who reported suboptimal experiences.

METHODS

This study is reported in accordance with the consolidated criteria for reporting qualitative research guidelines.²⁷

Design

A qualitative design based on interpretivist paradigm and phenomenological framework²⁸ was used to explore participants’ perspectives of allied healthcare consultations delivered via telehealth. An interpretivist paradigm was used as it centres on the belief that knowledge about a phenomenon is formed by gathering perceptions and interpretations of individuals who experience it.²⁹ A phenomenological framework focuses on the lived experiences of people involved with the issue being researched.²⁸

Public and patient involvement

This study, and research question, was designed based on the findings of our public survey,²⁶ where people with permanent and significant disabilities shared their experiences accessing allied healthcare via telehealth. The barriers that were identified in our survey helped inform the development of our interview guide for this qualitative study. Patients were otherwise not involved in the design, recruitment, or conduct of the study. Findings from this study will be disseminated via the National Disability Insurance Agency, who are partnered on this research, and who provide support to almost 400 000 Australians with disabilities.

Participants and recruitment

Participants were purposively sampled from the 2391 people who completed our cross-sectional survey investigating the experiences of National Disability Insurance Scheme (NDIS) participants (or their caregivers) who accessed NDIS-funded allied healthcare support during the COVID-19 pandemic (between March and August 2020).²⁶ The NDIS supports more than 391 000 Australian residents with permanent and significant disabilities by providing access to healthcare services, information and connections to community services. Eligible individuals for the survey study had, or were caregivers of, an individual with a disability registered to receive support from the NDIS in 2020. For this qualitative study, survey respondents who had indicated that they were happy to

be contacted for future research and who indicated that telehealth was worse, or much worse, than in-person care were sent an invitation to participate. Recruitment continued until theoretical data saturation was achieved across the whole cohort,³⁰ defined a priori as the point at which no new themes or sub-themes were identified from two consecutive interviews, after a minimum of 10 interviews had been conducted. This was assessed by iteratively coding data after each interview was completed to determine whether new themes and subthemes were emerging or not. Data saturation was achieved after the 12th interview.

Interviews

Semistructured one-on-one telephone interviews were performed by SF, a female physiotherapist and postdoctoral researcher with qualitative research experience who had not met the participants prior to interview nor was involved in the broader survey study. Telephone interviews were audio recorded using conference recording software (HotAir Conferencing) and transcribed verbatim by an external transcription service. One interview was performed using video conferencing software at the request of the participant, and this interview was audio-recorded and transcribed using the same transcription service. Transcripts were deidentified during the transcription process, and an alias was assigned to each participant. The length of interviews ranged from 11 to 38 min.

The semistructured interview guide (online supplemental appendix 1) was designed to allow iterative adaptation, and to elicit relevant information from participants using prompting, probing and open-ended questions.³¹ Content was informed by our survey results²⁶ and was developed in consultation with representatives from the National Disability Insurance Agency, the body that administers the NDIS. It was pilot tested with two people with disabilities. At the end of the interview, participants had the opportunity to contribute additional information if they wished.

Analysis

The analysis was performed using an inductive thematic approach,^{32 33} based on phenomenological framework,²⁸ facilitated by NVivo V.12 software.³⁴ Transcripts were first read multiple times, with and without accompanying audio.³⁵ Next, transcripts were coded to identify topics and patterns of ideas in the data. Codes were then organised and grouped into multiple categories of similar or related topics.³² The coding structure was iterative and data-driven, performed without reference to a pre-existing coding structure.^{32 35} After the initial coding into categories, these were later refined, adapted, merged, and sorted into a hierarchical structure representing themes and subthemes. To ensure external heterogeneity and internal homogeneity within themes and an accurate representation of the entire dataset, the themes and subthemes were reviewed multiple times. To ensure

credibility of the data, a second researcher (BL) independently coded all transcripts, and a consensus meeting was held which showed a high level of agreement between researchers. Themes and subthemes will be described in the results section, with accompanying quotes from participants.

RESULTS

Participant characteristics

Of the 12 individuals that participated in an interview, 9 (75%) were a parent/caregiver of an individual with a disability. Of the NDIS participants who took part in the interview or were represented by a parent/caregiver, 50% were male and 50% were aged 14 years or younger (table 1). A range of disabilities were represented among NDIS participants, including autism spectrum disorder, attention deficit hyperactivity disorder, cerebral palsy, developmental delay, epilepsy, hearing difficulty, inclusion body myositis, intellectual disability, muscular dystrophy, obsessive-compulsive disorder, Rubenstein Taby syndrome and Tourette syndrome. A number of participants had coexisting disabilities.

Exploring challenges with allied health consultations delivered via telehealth

The key challenges experienced during allied health consultations delivered via telehealth are summarised in six themes (figure 1). Exemplary quotes are shown in table 2.

Inhibits clinician feedback

A common issue raised by clients and caregivers was that clinicians could not provide effective feedback due to difficulties observing the client's behaviour and performance of specific tasks via telehealth. Some participants felt that telehealth made it difficult for clinicians to demonstrate exercises or provide hands-on feedback.

And my speech pathologist likes to see how my throat muscles are working which they were a bit difficult when you're just looking at a person on the screen. ...You're sitting in front of a camera. You don't—you can't communicate exactly what your problems are because sometimes you need to show people rather than just—physically show them rather than just visually show them, if that makes sense. P10, 45-64 year-old client with a neuromuscular disability

Difficulty building rapport and trust

Participants who had not previously met their clinician in-person struggled to build a relationship and trust via telehealth. Additionally, a number of caregivers expressed that their children benefited from in-person interactions, and that allied healthcare consultations via video conferencing had a negative impact on their ability to communicate and build rapport with the clinician.

Table 1 Participant characteristics and telehealth experience

Alias	Perspective	NDIS participant age, sex	Disability type	Allied healthcare telehealth services received
P1	Parent/carer (female)	0–6 years, males	Developmental	Occupational therapy, speech therapy, physiotherapy
P2	Parent/carer (female)	0–6 years, female	Developmental	Occupational therapy, speech therapy, physiotherapy
P3	Parent/carer (male)	0–6 years, male	Neuro-developmental	Occupational therapy, speech therapy, Psychology, Speech therapy, psychology
P4	Parent/carer (male)	7–14 years, female	Neurological, intellectual	Occupational therapy, speech therapy, psychology, Occupational therapy
P5	Parent/carer (female)	7–14 years, male	Neuro-developmental, psychosocial	Occupational therapy, speech therapy
P6	Parent/carer (female)	7–14 years, male	Neurological, intellectual	Occupational therapy, speech therapy
P7	Parent/carer (female)	15–24 years, male	Neuromuscular	Speech therapy, psychology
P8	Parent/carer (male)	15–24 years, female	Neuro-developmental, intellectual	Speech therapy, exercise physiology
P9	Parent/carer (female)	15–24 years, male	Neuromuscular	Occupational therapy, physiotherapy, exercise physiology
P10	NDIS participant	45–64 years, female	Neuromuscular	Psychology
P11	NDIS participant	45–64 years, female	Neuromuscular	
P12	NDIS participant	45–64 years, Female	Neuromuscular	

NDIS, National Disability Insurance Scheme.

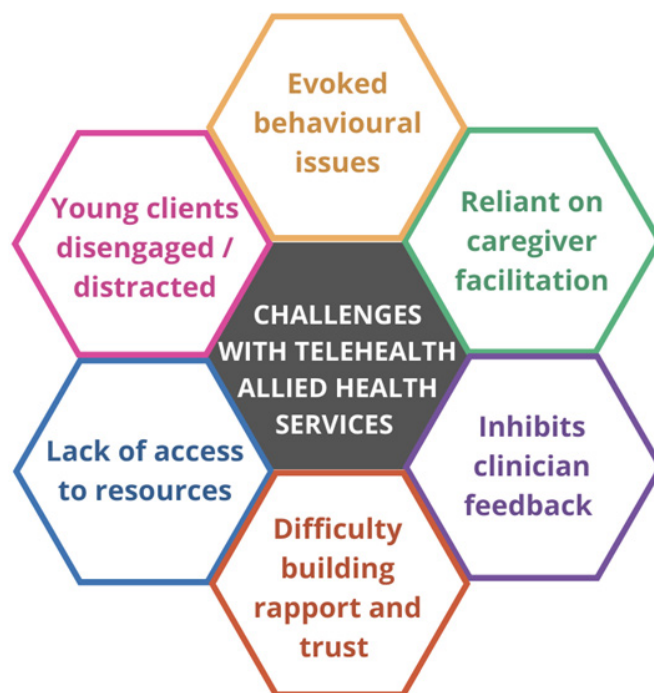


Figure 1 Themes summarising challenges with allied health consultations delivered via telehealth.

She's a very social person so she loves the interaction with people. And the computer, she doesn't get that same level interaction. I was watching her using Zoom but I could see the frustration that because Zoom tends to be a little bit more structured that she doesn't get to ramble on... ..she just connects better with therapists face-to-face. She gets a bit more, she's just probably a little bit more frustrated with the Zoom meeting that it doesn't flow as freely for her so she definitely prefers face-to-face. P8, cares for a 15–24 year-old with a neuromuscular disability

Lack of access to resources

A perceived barrier to effective telehealth sessions was a lack of access to resources. This included access to necessary telehealth infrastructure (eg, web cameras and a reliable internet connection) to allow effective visual and auditory communication, as well as access to additional equipment and resources that were required to facilitate a therapy session (eg, exercise equipment and therapy aids that are normally available in the clinic when attending in-person). Typically, such equipment was not provided by allied healthcare clinicians for telehealth consultations, and it was the participants' responsibility to purchase equipment or improvise with the resources available to them in their home environments.

We basically just discussed what exercises I was doing and how I was going physically but she couldn't actually see to see how I was doing. It was a bit difficult to do. I didn't have the equipment or anything available

Table 2 Themes and exemplary quotes

Theme	Exemplary quote
Challenges with telehealth	
Inhibits clinician feedback	We actually messed around with trying to do video conferencing and unfortunately that was diabolically bad no matter what our best intent was. We actually ran a two-camera system—one so that we could see so we had to use a laptop for [him] to be able to review the information on. So we had one laptop that was capturing what [he] was, hopefully what [he] was going to point out on the screen what his selection was. And another one to, I think it was to measure his facial gestures. So we effectively had two cameras working at the same time and it was just horrendous. ...Yeah, you just couldn't get the nuances, so it ended up that I had to be interpreting [his] responses for the therapists because they weren't there to see them themselves. And so you lost depth on the screen, you lost the nuances of [name], the movements of [his] hands, and if his hand waivered before, so you lost so much information. Unfortunately it was really, really tough.'P3, cares for a 0–6 year-old with a neuro-developmental disability
Difficulty building rapport and trust	Yeah, so for my son in particular... eye contact is an incredibly important aspect to relationship rapport, trust, communication. And he wasn't getting that. Not in the way that he needed to. So, it was already a barrier to effective communication for him. Additionally, he's quite sociable, so in-person is the way that he gets his validation and feels supported. So, for both those reasons, communication and validation, it just wasn't effective at all. P7, cares for 15–24 year-old with a neurological and intellectual disability
Lack of access to resources	Probably the other difficulty was not having what we needed for the therapies. So the different tools and things that the therapist either brings to our house or have at their place. So I find myself having to buy a lot of things so we can do those games and those things that I probably wouldn't necessarily have bought otherwise because we don't use them every day. ...and if it doesn't work we don't necessarily use it again. So I was just buying something to try that she didn't like. So I found that that was probably the other difficulty, was I guess getting the necessary equipment and therapy aids to help during that time. P2, cares for a 0–6 year-old with a developmental disability
Young clients disengaged/distracted	...he was hiding under the computer because he's worked out that if I hide I don't need to do it. And we had to do every single thing with him one on one. So that was extremely taxing so basically we were all doing OT and it took two adults to help him go through this. So I would highly discredit that for our case. It didn't work at all. ...there's nothing like face to face, and especially he didn't associate being at home with doing OT. He was with mum and dad and a person who's not here can't really tell him what to do. To him it made no sense. He tried to engage but he just couldn't. It's the whole routine it was very difficult, just the actual change of routine and not being able to go to school. So then you add therapy at home as well and it just was hell. P6, cares for a 7–14 year-old with a neuro-developmental and psychosocial disability
Evoked behavioural issues	We did attempt to do that over a Zoom video conference call, and it was a disaster, to be optimistic. Yeah, he's a 7 year-old who can't sit still at the best of times. So to be taking instruction and engaging with someone over a video call, yeah, it was really a waste of time; hence we didn't do many more. I mean he struggles with communication as it is, anyway. So yeah, communication and attention, behaviour, they're all the things that we're working on. You need to have really strong skills in those areas I think to focus on a Zoom conference, which it wasn't suitable for him at all. P5, cares for a 7–14 year-old with a neuro-developmental disability
Reliant on caregiver facilitation	And also when she moves around the room I felt like I was a dog, and I'd start following her around with the iPad to try and show whoever we were dealing with that, yeah, this is what she's doing, or if they wanted her to move somewhere else to try something different. So it definitely put a lot more complexity into just the process by having to do it online. ...It's hard to get a two year-old to be engaged with therapy at the best of times, especially, obviously, things that they don't want to do. So it just added I think more pressure for me because I had to be really present. Whereas if the therapy happens face-to-face, I can step back and watch how they're doing it and learn a bit more, and get her to interact with someone else. And obviously, that wasn't happening, so I have to be hands-on ...but I don't think it's necessarily the best thing for my daughter to have me do some of the stuff because she doesn't like it. And so I think sometimes having someone else do it, she's a bit more tolerant of certain things. P2, cares for a 0–6 year-old with a developmental disability
Suggestions to improve telehealth	
Prepare for telehealth sessions	And I think the other thing that helped was just having everything set up, having everything ready to go. So we would set them up with their tables and chairs, for example, and have everything sitting there ready to do. I think that was another I guess enabler to the sessions. P1, cares for 0–6 year-olds with a developmental disability

Continued

Table 2 Continued

Theme	Exemplary quote
Establish expectations	I think particularly for the clients, especially when we're looking at assessment, tutorials, and simple tutorials at the outset will probably go a long way to helping. How much to assist your child without breaking the assessment. How do you guide without answering, and things like that. P3, cares for a 0–6 year-old with a neuro-developmental disability
Increase exposure to telehealth	A lot of it was practice, so if we were thrown into that situation again I think it would be a little bit different. So I think having them consistently and the boys getting used to them – if that was what we chose to do—then that would help. P1, cares for 0–6 year-olds with a developmental disability
Assess suitability of specific services	What I actually concluded for us, was that those sessions were appropriate for training of support workers and communication partners and other people in(my son's)life. So, it was about rethinking what we needed to do. So, if we were locked down and we're not getting access to services and supports, then those services and supports that we do have needed to step up in terms of being, as I said, communication partners or almost therapy assistance in a way, so it was more effective for us to get the support workers up to speed on what we were trying to do with [my son] in terms of speech, OT, behaviour, then for the session to be with [my son]. So, it's more about rethinking and repackaging what you're using the sessions for. P7, cares for 15–24 year-old with a neurological and intellectual disability
Access to support workers	Look, certainly from our end the support workers; that made it a lot easier because then it wasn't just me. At least then they did have someone else to engage in. ...I think certainly, we were lucky because we did have the support workers. And on a global sense, I guess if you didn't have that that will be very hard. So that would be my number one thing that would help any family I think, would be just having that extra support there that were able to come. I know for some ladies they weren't able to have anyone, so that was really tricky, but for us, that made a really big difference.P1, cares for 0–6 year-olds with a developmental disability

to do in front of a computer. P10, 45-64 year-old client with a neuromuscular disability

Children disengaged/distracted

A common experience shared by caregivers of children was that their children were disengaged and easily distracted when allied healthcare sessions were delivered via video conferencing. This resulted in the perception that the telehealth sessions were ineffective and unsuitable for their children. This was experienced by parents of children of a variety of ages, spanning 2 to 11 years.

It was fine from my perspective, but it was really hard for the boys. They weren't able to really engage normally. ...They have difficulties communicating and engaging at the best of times, let alone over a screen. ...I guess they found it difficult not to have a person there. It's very much just like watching the TV. Like I said, they have trouble engaging at the best of times so they're certainly going to have a lot more trouble...P1, cares for 0-6 year-olds with developmental disabilities

Evoked behavioural issues in children

For some children, in addition to being disengaged and distracted, video consultations resulted in a deterioration in behaviour and exacerbation of behavioural issues. This stemmed from difficulties understanding why the clinician was not in the room with them, and difficulties listening and taking direction via telehealth. There was subsequent resistance from these children, and from their carers, to continue with telehealth consultations.

The second session, he hated it, and his behaviour was terrible, and he was acting out and hitting and really trying to communicate that he didn't want to do it. He wasn't enjoying it. He didn't understand what was happening. He didn't know why his therapist was on the computer and why he wasn't in the room, and he just opted out of the session. And at that point, we decided not to continue with them. P7, cares for 15-24 year-old with a neurological and intellectual disability

Reliant on caregiver facilitation

Caregivers of children with disabilities felt that telehealth sessions placed a lot of responsibility on them to facilitate and run the allied healthcare sessions. Some described certain therapies being more difficult to facilitate, including physiotherapy, which they found to be particularly hands on and technical. Some parents described this as exhausting, others struggled to manage this on top of other parenting responsibilities, and some felt that their children were less receptive to parental facilitation of the session compared with therapist facilitation.

I'm already fairly involved with facilitating it but I guess from a secondary perspective where I'm shown and then I help them. And I guess because the boys have so much therapy it was a little bit more tiring for me because it is nice for somebody else to be facilitating it and me just helping along... ...I had to always make sure I had a support worker with me to do them otherwise, it was pretty much impossible. ... the level of facilitation from the parent end definitely

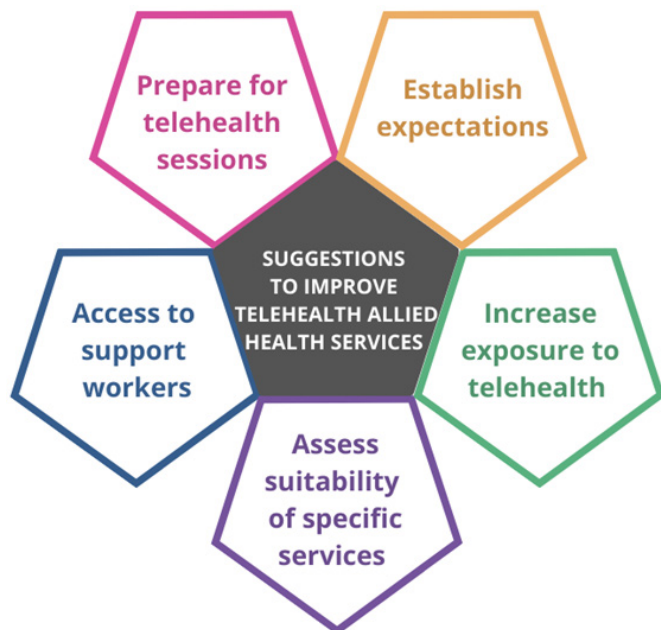


Figure 2 Suggestions to improve telehealth allied healthcare services for individuals with a disability.

increased when you did a telehealth, yeah. P1, cares for 0-6 year-olds with developmental disabilities

Suggestions to improve telehealth allied healthcare services for individuals with a disability

Suggestions to improve telehealth allied healthcare services for individuals with a disability are summarised in [figure 2](#). Based on the experiences of participants, strategies could be employed to improve the suitability of telehealth services to better meet the needs of more individuals with a disability, and thereby provide these individuals with more healthcare options in the future.

Establish expectations

Several participants highlighted the importance of the clinician setting expectations before the telehealth session, to enable the participant and/or caregiver to be adequately prepared.

One thing I would suggest, especially with children, is maybe if the providers—and I'm just creating more work for them—if they could set their expectations in the communication with them, just set the expectation around what's acceptable in telehealth appointments... ..I know that those boundaries and those expectations are really good especially with kids. They then know exactly what they are going into. P9, cares for 15-24 year-old with a neuro-developmental and intellectual disability

Prepare for telehealth sessions

Participants described the importance of being prepared for each allied healthcare telehealth session. Preparation included taking the time to set up the treatment environment and equipment for the allied healthcare session.

And I think the other thing that helped was just having everything set up, having everything ready to go. So we would set them up with their tables and chairs, for example, and have everything sitting there ready to do. I think that was another I guess enabler to the sessions. P1, cares for 0-6 year-olds with a developmental disability

Increase exposure to telehealth

COVID-19 necessitated a rapid shift to telehealth services, despite some clients and clinicians having little experience with telehealth. Some participants reported that telehealth sessions were improving with time, as participants became more familiar with the requirements and format of telehealth sessions.

A lot of it was practice, so if we were thrown into that situation again I think it would be a little bit different. So I think having them consistently and the boys getting used to them—if that was what we chose to do—then that would help. P1, cares for 0-6 year-olds with a developmental disability

Assess suitability of specific services

Despite a strong preference for in-person sessions, some participants would consider a hybrid approach in the future, where telehealth sessions were offered as a supplement to in-person sessions. Several participants believed that telehealth was useful for some allied health services (eg, services comprising conversation or education where the clinician did not need to see the participant), and inappropriate for others (eg, services requiring the clinician to observe the participants motor skills, environment, or speech). Additionally, some participants believed that nothing would improve their experiences with telehealth allied-health sessions, and that this mode of healthcare was unsuitable for them.

The only one, potentially, which may have been able to evolve into something that he would engage effectively in is maybe speech because his speech therapy, he does a lot of worksheets and conversation. Whether that was something interactive where he would use the iPad to perhaps complete a worksheet which we would otherwise have face-to-face; that potentially could work with the speech that he was working on, but certainly not the OT. P5, cares for a 7-14 year-old with a neuro-developmental disability

Access to support workers

Participants suggested that a potential solution to reduce reliance on parents/caregivers to facilitate the telehealth sessions, was to have access to trained support workers to facilitate the sessions.

Look, certainly from our end the support workers; that made it a lot easier because then it wasn't just me. At least then they did have someone else to engage

in. ...I think certainly, we were lucky because we did have the support workers. And on a global sense, I guess if you didn't have that that will be very hard. So that would be my number one thing that would help any family I think, would be just having that extra support there that were able to come. I know for some ladies they weren't able to have anyone, so that was really tricky, but for us, that made a really big difference. P1, cares for 0-6 year-olds with a developmental disability

Discussion

This study explored challenges with allied healthcare via telehealth during the COVID-19 pandemic for people with permanent and significant disabilities, and explored suggestions to improve these services in the future, from the perspective of those who reported less than optimal experiences. The key challenges experienced were elicitation of behavioural issues, disengagement by children, increased burden on parents/carers to facilitate the consultation, and inhibition of rapport and trust. Future services may benefit by increasing exposure to telehealth, establishing client/caregiver expectations, supplying resources for therapy, and providing access to support workers to help facilitate the consultation.

Our findings are broadly comparable to previous qualitative studies examining experiences with telehealth services among those with disabilities. Other studies in clients and/or carers have also found that, while convenient, telehealth services increased burden and stress on parents/carers,³⁶ made communication more difficult for some,²⁴ limited clinician/client observation,²⁵ inhibited development of rapport^{24 25} and led to disengagement in therapy among children.^{36 37} Previous studies also found that telehealth services were perceived to be unsuitable for some people with disabilities, such as those who were visual or hands-on learners,^{24 36} or for allied healthcare professions that needed hands-on or in-person contact to provide appropriate care.²⁴ The suggestions to improve telehealth that we identified are also broadly reflected by previous research, including providing access to support workers,³⁸ establishing expectations⁹ and providing educational resources for therapy.⁹ Importantly, previous studies in people with disabilities have found that, as clients/caregivers and clinicians gain more experience in telehealth, their perceptions about the quality and efficacy of these models of service delivery also become more positive.^{25 39} Given that telehealth services were rapidly introduced at the start of the pandemic, with little to no preparation or prior experience by the client/caregiver or by the clinician, some of the challenges with telehealth may be overcome as these services become more mainstream and better established in the future.

Our findings suggest that telehealth was particularly challenging for children with disabilities, who were disengaged with therapy and experienced behavioural issues. This also increased the burden on parents/carers who

were required to facilitate the telehealth session. Other research supports this, also reporting that the loss of established structure and routine contributed to stress for the person with the disability, as well as for the carer or parent.^{36-38 40} Parents and carers of children with disabilities already experience higher levels of stress than those of children without disabilities,^{41 42} which may be further exacerbated by the added strain of facilitating telehealth-delivered consultations. As suggested by our participants, providing access to support workers to facilitate telehealth consultations may help reduce any additional strain on parents/carers.³⁸ In addition, clinicians who use telehealth may benefit by establishing expectations around engagement with therapy ahead of time, or telehealth consultations may need to be shortened and/or increased in frequency to better facilitate children's engagement.²⁴ Introducing methods for evaluating whether telehealth is suitable for each individual client, depending on their needs and preferences, may help ensure that such services are only used for those whom it is most appropriate.³⁶ However, many of these suggestions for improvements to services come with their own challenges in terms of practicality and feasibility. For example, providing consistent access to support workers would require additional funding and/or increased availability of support staff. In addition, changing the length/frequency of telehealth consultations may not be feasible for many, and it is currently unclear how best to evaluate suitability for telehealth or prepare clients for telehealth consultations. It is also important to consider how to maintain long-term quality control of telehealth services in the case of staff changes. Further consideration is needed to determine how these suggested improvements could be feasibly implemented into policy or clinical practice. It is also important to acknowledge that for some people, and in some circumstances, telehealth is not a suitable mode of service delivery, and in-person delivery of care is more appropriate.

Participants in our study found that, at times, communication was difficult via telehealth and that their ability to build trust and rapport with the clinician was inhibited. This reflects the findings of other studies that have reported difficulties communicating and observing non-verbal cues during telehealth consultations between allied healthcare clinicians and people with disabilities.^{24 25} One of those studies recommended that clinicians should ensure their hands are free to make gestures, and that both clients and clinicians are positioned so that as much of the body as possible is captured by their video camera.²⁴ Increased experience with telehealth and upskilling of clinician's verbal and non-verbal communication skills may also help overcome challenges associated with communication, and facilitate rapport and trust between the clinician and client.^{13 24} However, it is also important to note that we specifically interviewed people who had suboptimal experiences with telehealth, which, based on our survey findings,²⁶ was the minority. In fact, our survey findings suggested that only one-quarter of respondents

felt uncomfortable communicating with the clinician via telehealth.²⁶

Our findings have implications for patients, clinicians, policy makers, as well as for the design and delivery of future telehealth services for people with permanent and significant disabilities. Our findings indicate that, for some people, and in some circumstances, telehealth is not a suitable mode of service delivery and in-person delivery of care is more appropriate. As concluded in other studies,^{22 40} telehealth should not be viewed as a replacement for in-person care, but an additional option for those who may benefit from the added convenience and accessibility. Our findings also suggest that health-care clinicians should be aware of the additional barriers that their clients with disabilities (particularly children) encounter when consulting via telehealth.¹⁰ Health-care providers could consider shorter, more frequent, consultations to enhance engagement and reduce the likelihood of behavioural issues.³⁹ Training clinicians in effective communication skills and the delivery of care via telehealth may also ensure that their patients receive high-quality care.⁴⁰ In fact, previous research suggests that less than half of allied healthcare clinicians who provided telehealth during the COVID-19 pandemic had received any training in the remote delivery of care,⁴ highlighting the need for such training programmes.

Study limitations

Only people in Australia who received support from the NDIS were included in the research, which limits the transferability of findings to other populations outside of Australia or supported by other healthcare schemes. Most of our cohort had neurological disabilities, which potentially limits the transferability of our findings to other disabilities. We did not use strategies like member checks or data triangulation, which may have had an impact on the credibility and dependability of our findings.

CONCLUSIONS

Some people with permanent and significant disabilities who accessed allied healthcare via telehealth during the pandemic experienced challenges, particularly children. These unique barriers to telehealth need customised solutions so that people with disabilities are not left behind when telehealth services become more mainstream. Increasing experience with telehealth, setting expectations before consultations, supplying resources for therapy and assessing the suitability of clients for telehealth may help overcome some of the challenges experienced.

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