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Family carer and professional perceptions of the potential use of telehealth for behavioural support

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Abstract

Background Telehealth (i.e. the use of technology across distance) is widespread in many fields. Although its use for behavioural support for people with intellectual or developmental disabilities (IDD) is emerging, there are no known studies examining stakeholder perceptions of this.

Methods A four-round Delphi consultation was conducted with 11 professionals and six family carers of children with IDD to generate consensus on what would influence participants' use of telehealth for behavioural support. Data were collected prior to the coronavirus pandemic.

Results Thirty-six items reached consensus for professionals (26 advantages and 10 disadvantages/barriers) and 22 for family carers (8 advantages and 14 disadvantages/barriers). A range of solutions were also identified for the disadvantages/barriers.

Conclusions Participants were willing to use telehealth for behavioural support. However, disadvantages/barriers need to be addressed, and guidelines relating to the use of telehealth in this field are needed. We report a number of practice recommendations including combining telehealth with in-person supports where possible, incorporating video technologies, and considering client perspectives and confidence with telehealth methodologies.

Keywords carers, intellectual disability, parents, treatment and services

Background

Telehealth is defined as 'the use of telecommunications and information technology to provide access to health [or behavioural health] assessment, diagnosis, intervention, consultation, supervision, education, and information across distance' (Nickelson 1998, p. 527). Benefits, including increased access to hard-to-reach populations, reduced travel time and increased efficiency for professionals, lower costs and increased patient satisfaction (e.g. Hilty *et al.* 2002; Lindgren *et al.* 2016; Gajarawala & Pelkowski 2021; Madigan *et al.* 2021), have led to telehealth becoming widespread in many fields. In behavioural services (i.e. services that support people via behavioural approaches to develop skills or reduce the occurrence and impact of behaviours that challenge), telehealth use (prior to the coronavirus pandemic) was less common, although with some positive examples (e.g. Tomlinson *et al.* 2018). The use of telehealth within behavioural support (both during and outside of the context of the pandemic) is an important area of investigation given that demand for behavioural services is mismatched with available resources particularly for those with intellectual or developmental disabilities (IDD). Within this field, telehealth may increase access to behavioural support where it would otherwise be inaccessible, enable knowledge and skills transfer to

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support networks such as families or paid support staff (e.g. Tomlinson *et al.* 2018; Ferguson *et al.* 2019; Unholz-Bowden *et al.* 2020), and facilitate generalisation and maintenance of support over time. Demonstrations of the use of telehealth for behavioural support focused on people with IDD have highlighted the effectiveness of support provided in this manner (e.g. Tsami *et al.* 2019; Schieltz & Wacker 2020) and applications of telehealth in this context have increased dramatically in recent years due to the impact of the coronavirus pandemic (as evidenced in the increase in reports of telehealth work within the literature, particularly those highlighting its use during the pandemic, e.g. Crockett *et al.* 2020). It is likely that the use of telehealth within behavioural support will continue to some extent post-pandemic and ongoing considerations of the acceptability, effectiveness and appropriateness of the use of telehealth in this field therefore continue to be important.

Uptake of telehealth services is an important area to consider. Evidence suggests a number of factors are likely to influence uptake of telehealth, including technology requirements, preference for in-person support, concerns about the client-professional relationship, perceptions about the type and quality of support, access for clients, and use of resources such as staff time (e.g. Swinton *et al.* 2009; Brewster *et al.* 2014; Taylor *et al.* 2015; Collier *et al.* 2016). In particular, it has been highlighted that clinician acceptance is the most important factor influencing the use and success of telehealth within a service (Wade *et al.* 2014). The application of telehealth to behavioural support for people with IDD is, however, a relatively unique situation as this often involves a mediator (e.g. a family carer) supporting a focal person (e.g. their relative) with IDD. Here, telehealth support largely involves guidance and coaching from a clinician to a mediator, rather than the clinician supporting the person with IDD directly (although there are some notable examples of telehealth behavioural support being provided directly to individuals with IDD since the pandemic, see Araiba & Čolić 2022). Whilst this collaborative model may have unique advantages (e.g. in supporting knowledge and skill development amongst stakeholders of individuals with IDD), it also means that some of the issues affecting uptake as previously identified may have limited generalisability to

telehealth-based behavioural support. Identifying factors unique to telehealth use in this context, along with ways to maximise uptake of telehealth-based behavioural support, is therefore important and this requires consultation with those utilising telehealth support (e.g. family carers) as well as professionals who would provide such support.

Where evaluated, telehealth-based behavioural support for people with IDD is reported as acceptable to family carers, teachers and therapists who have received this (e.g. Gibson *et al.* 2010; Wacker *et al.* 2013b; Fisher *et al.* 2014; Tsami *et al.* 2019; Boutain *et al.* 2020). However, there are no known studies evaluating perceptions of the potential use of telehealth for behavioural support amongst those who have not yet received or delivered this. This is important to explore given the influence that stakeholders' (e.g. family carers and clinicians) perceptions may have on their likelihood of adopting telehealth for behavioural support.

The current study therefore used a Delphi panel methodology (Linstone & Turoff 1975; Adler & Ziglio 1996) to examine perceptions of the use of telehealth for behavioural support amongst family carers (of children with IDD) and professionals who had not yet experienced telehealth directly for this purpose, and identify key practice recommendations for the use of telehealth for behavioural support. Given the collaborative way behavioural support is mediated via telehealth, the views of both family carers and professionals were sought, with separate panels formed to allow for exploration of issues specific to each stakeholder group. Research questions for this study were

- 1 What are the advantages and disadvantages/barriers perceived by family carers and professionals regarding the potential use of telehealth to provide behavioural support?
- 2 How might any disadvantages/barriers to the potential use of telehealth in this field be overcome?

Method

Study design

Delphi panel methodology (Linstone & Turoff 1975; Adler & Ziglio 1996) was utilised to generate

consensus within a professionals panel (panel A) and a family carer panel (panel B) about the most important factors influencing potential adoption of telehealth for behavioural support. The Delphi consultation consisted of three rounds focused on generating consensus, and a fourth focused on ranking items (see Kobus & Westner 2016; Halvorsrud *et al.* 2018) and identifying potential solutions to identified disadvantages/barriers. Data collection occurred in 2017–2018, prior to the coronavirus pandemic, and informed consent was obtained via email for all participants.

Participants

Participants were recruited via advertisements circulated on social media platforms. The only inclusion criteria were that participants had experience of providing or receiving behavioural support for an individual with IDD and were based in the United Kingdom. No attempts were made to match participants across panels or sample participants purposively given the exploratory nature of the study.

Panel A consisted of 11 professionals with experience of providing support to caregivers of people with IDD about their relative's behaviour (see Table 1), and panel B consisted of six family carers of children with IDD who had previously received behavioural support from a professional in relation to

their child's behaviour (see Table 2). It was not expected that participants in each group would be known to each other, and recruitment of each group occurred independently. A proportion of participants in both panels had experience of telehealth, although not in relation to behavioural services (see Table 1 and Table 2). Participants were recruited through advertisements on social media, via charities, and professional networks. Whilst no consensus exists regarding the optimum number of participants per panel in Delphi studies, Akins *et al.* (2005) cite common panel sizes of 10–100 members and research suggests that panels of 10–15 individuals are sufficient to obtain stable results (Ziglio 1996). The limitations of the small sample for both panels are discussed below.

Data collection and analysis

A series of questionnaires (designed for the purposes of the study and available upon request) were created for each panel and distributed using Google Forms. Responses were kept anonymous using a unique participant code generated by participants themselves. Varying numbers of participants took part in each round due to participant drop out in some rounds; therefore, the number of participants contributing to each round is stated within each section of the results.

Table 1 Participant characteristics for panel A (professionals)

Characteristic	Category	No. of participants (%)
Gender	Male	2 (18.2%)
	Female	9 (81.8%)
Age	26–35 years	6 (54.5%)
	36–45 years	2 (18.2%)
	46–55 years	3 (27.3%)
Professional background [†]	Behaviour analyst	7 (63.6%)
	Speech and language therapist	2 (18.2%)
	Learning disability nurse	1 (9.1%)
	Teacher/educational staff	2 (18.2%)
	Support worker	1 (9.1%)
Years' experience supporting family carers	1–5 years	3 (27.3%)
	6–10 years	4 (36.4%)
	More than 10 years	4 (36.4%)
Previous use of telehealth for professional practice (for any purpose)	Yes	6 (54.5%)
	No	5 (45.5%)

[†]Participants could select more than one answer for this question, therefore totals do not equal 100%.

Table 2 Available demographics of participants in panel B (family carers)

Characteristic	Category	No. of participants (%) [†]
Gender	Male	0 (0%)
	Female	5 (83.3%)
Age	36–45 years	2 (33.3%)
	46–55 years	3 (50%)
Relationship to person with IDD	Parent	5 (83.3%)
Support received via telehealth (for any purpose)	Yes	3 (75%)
	No	1 (25%)

[†]Demographic information was only available for family carers who completed questionnaires in rounds one and two (i.e. for 5/6 family carers in the panel), therefore the number of participants selecting each category is presented alongside the percentage of the total panel (i.e. including those who did not complete demographic questions) that this represents. % refers to % answering that question, rather than % of total panel.

Round one

The round one questionnaire for both panels asked about participants' characteristics, their past use and willingness to use technology, and included a series of open-ended questions about advantages and disadvantages/barriers to the use of telehealth. Participants were provided with Nickelson (1998) definition of telehealth and asked to use this throughout the study. The frequency and percentage of participants selecting each category for closed ended questions were recorded. Qualitative responses were grouped conceptually for each panel.

Round two

The round two questionnaires consisted of all advantages and disadvantages/barriers (using participant's own words) identified by the relevant panel in round one. Participants were asked to rate how influential each item was to their willingness to use telehealth for behavioural support on a five-point Likert scale (1 = not influential to 5 = extremely influential) with an additional option of 'not specific' (i.e. not specific to telehealth), or '?' (if the item meaning was unclear). If two or more participants rated an item as unclear the item would have been modified for round three (this never occurred), and any item rated by two or more participants as 'not specific' to telehealth was removed from the item pool (this occurred for one item in round two for panel B). Participants were also asked to identify additional advantages and disadvantages/barriers that had not been listed in the questionnaire and these were

extracted and included in the round three questionnaire.

Data from round two were analysed by calculating a group median score and recording the frequency of participants selecting each score for consensus calculations. Consensus was defined in line with other Delphi studies (see Diamond *et al.* 2014 for review) as at least 80% of participants indicating that the item was influential (i.e. a score of four or five). Where greater than 60% of participants rated the item as influential and less than 30% indicated that it was not influential (i.e. a score of one or two), the item was identified as having nearly reached consensus and was re-presented in round three. Items where responses were highly varied or where the item met consensus criteria as being 'not influential' were removed. Where a participant indicated that an item was not specific to telehealth this was converted to a score of one, as it suggested that this item would not be influential to their use of telehealth. If a participant indicated that an item needed clarification their score for that item was removed as it suggested that they did not understand the item.

Round three

The round three questionnaire involved presenting new items identified in round two for rating (as described earlier), and re-presenting items that had almost reached consensus in round two (see above). Via the use of individualised surveys linked to a unique code (see below), each participant was provided with the group median and their previous

score for re-presented items and were advised that they could modify or retain their original score.

Round four

The final questionnaire for each panel involved asking participants to select the five most influential advantages (from those reaching consensus) to their likelihood of using telehealth, and then to select the top two from these five to give an indication of the advantages that were most important to participants in each panel. This twofold process was included to assist participants in narrowing down the items. In addition, they were asked to suggest solutions to the disadvantages/barriers that had reached consensus which were grouped thematically to reduce the number of questions and maximise the likelihood that participants would respond fully to each question. Data from this round were analysed by calculating the frequencies with which items were selected as one of a participant's top five or top two most influential, and summarising solutions for the disadvantages/barriers identified.

Results

Round one

Eleven professionals (panel A) and four family carers (panel B) took part in round one. Ten panel A participants (90.9%) and all panel B participants indicated that they would be willing to use telehealth for behavioural support, with the most common methods being videoconferencing, email and telephone.

Answers to open-ended questions were combined and synthesised for each panel as described earlier. For panel A, four conceptual categories were identified relating to direct work (four subcategories: assessments, intervention, monitoring and review, and training), logistics (six subcategories: cost, location, speed of contact, technology, time/scheduling and travel), interpersonal factors (four subcategories: communication, lack of in-person contact, emotional implications and rapport/relationship) and the wider context (four subcategories: access, choice/preferences, ethics and group collaboration). Further detail about these along with summarised participant comments can be seen in Table S1. For panel B, two categories were

identified relating to logistics (nine subcategories: access, location, records, speed of support, time/scheduling, travel, family burden, security, technology) and support provided (eight subcategories: communication, emotional implications, quality of support, relationship, professional skill, professional scope, relative's engagement, lack of in-person contact). Further detail about these including summarised participant comments can be seen in Table S2.

Based on responses in round one, a pool of 84 items (47 advantages, 37 disadvantages/barriers) were identified for panel A, and 36 items (15 advantages, 21 disadvantages/barriers) were identified for panel B.

Rounds two and three

In rounds two and three, participants rated the pools of advantages and disadvantages/barriers according to how influential each item was in relation to their likelihood of using telehealth for behavioural support. Ten panel A participants took part in rounds two and three, whilst five panel B participants took part in round two, and three took part in round three. Table 3 displays the number of items at each stage for rounds two and three for both panels.

Across both rounds, 36 items reached consensus as influential for panel A (26 advantages, 10 disadvantages/barriers) and 22 items reached consensus for panel B (8 advantages, 14 disadvantages/barriers). Table 4 and Table 5 provide an overview of the items achieving consensus in each round for panels A and B respectively.

Round four

In round four, participants were asked to select the top five advantages most influencing their likelihood of using telehealth, and then to further select their top two from these five. Ten panel A and four panel B participants took part in round four. For panel A, the joint items selected most frequently in the top five were 'increased convenience for family carers' ($n = 6$) and 'reduced waiting times for support' ($n = 6$), and the item selected most frequently in the top two was 'increased access to support for family carers who cannot travel, live far away, or cannot leave home' ($n = 3$). For panel B, the item selected most frequently as one of the top five ($n = 4$) and as one of the top two ($n = 3$) most influential was 'less time wasted due to

Table 3 Results of rounds two and three for both panels

	Panel A	Panel B
Round Two		
Number of items presented	84	36
Items reaching consensus	19	16
New items identified	3	10
Items meeting criteria to be re-presented	16	3
Round Three		
Number of items presented	19	13
Items reaching consensus	17	6
Total number of items reaching consensus across both rounds	36 (26 advantages and 10 disadvantages/barriers)	22 (8 advantages and 14 disadvantages/barriers)

attending lengthy or ill-informed meetings'. The full results for this stage of round four can be seen in Tables S3 and S4.

In addition, participants were asked to suggest potential solutions to the disadvantages/barriers that had reached consensus, grouped conceptually as outlined above. Table S5 gives an overview of the solutions identified, and these are discussed further below. A summary of the full results for each panel (including an overview of the main solutions identified to address the disadvantages/barriers) can be seen in Figures 1 and 2.

Discussion

Consensus was reached on several items (36 for panel A and 22 for panel B) representing advantages and disadvantages/barriers for family carers of children with IDD and professionals relating to the use of telehealth for behavioural support. Notably, results between panels varied considerably both in relation to the types of items identified (i.e. advantages versus disadvantages) and their content. Family carers reached consensus on fewer items overall than professionals, and on more disadvantages/barriers than advantages, although all family carers indicated that they would be willing to receive support via telehealth suggesting that the critical issue is that support should be provided in a way that mitigates barriers. In contrast, professionals identified more advantages than disadvantages/barriers, suggesting a generally positive perception of the use of telehealth for behavioural support in their professional practice.

This is an important finding, given evidence that clinician acceptance is a key variable influencing uptake of telehealth (Wade *et al.* 2014).

The variation in content of items identified by the two panels suggests that different elements of telehealth may be important to different stakeholders, although it may be the case that professionals were also considering the impact on the families they support when responding about advantages/barriers. Both panels identified advantages relating to logistics such as improved time/scheduling and reduced waiting times, reflecting some of the benefits from the use of telehealth cited in the literature (e.g. Lindgren *et al.* 2016; Gajarawala & Pelkowski 2021; Madigan *et al.* 2021). However, some differences also emerged between panels. Professionals focused almost entirely on logistics, additionally identifying reduced travel and cost, improved access to the service, and aspects of the technology itself (e.g. the ability to record sessions). They also felt that the use of telehealth would facilitate stakeholder involvement and multidisciplinary work. In contrast, family carers identified advantages relating to the nature of support received such as being able to receive support more quickly and in a manner that reduced disruption to their relative's routine, as well as being able to revisit advice provided to them.

Considerable differences also emerged in the disadvantages/barriers identified by both panels. Here, professionals focused mainly on practicalities such as difficulty delivering specific types of intervention via telehealth and ethical issues relating to data security or providing advice without meeting

Table 4 Items reaching consensus (in round two or three) as influential for panel A

Item	% rating as influential (round two) [†]	% rating as influential (round three) [†]	Group median [‡]
Advantages			
The possibility of using video observations	90%	80%	4.5
Ability to train families in support methods before the full behaviour plan development	80%	-	4
Minimised/removed travel costs for you as a professional	80%	-	4.5
Minimised/removed travel costs for family carers	80%	-	4.5
Ability for family carers to join sessions from their own home	80%	-	4
Ability for others to be in situ (e.g. in the service setting) with all necessary resources during sessions	80%	-	4
Ability to offer appointments more quickly	80%	-	4
Ability to offer more appointments overall	80%	-	5
Increased ability to gather information from family carers without waiting for in-person clinic appointment	90%	-	4.5
Increased ability to monitor procedural fidelity via video recordings	80%	-	4
Flexibility for family carers in relation to fitting appointments around their other commitments	90%	-	5
Reduced travel for you as a professional	80%	-	5
Reduced travel for family carers and others involved in the client's support	80%	-	5
Increased access to support for family carers who cannot travel, live far away, or cannot leave home	90%	-	5
Ability to involve more people in the client's support	90%	-	4
Increased ability to record sessions	90%	80%	4
Ability to share recordings of sessions	90%	80%	4
Ability for family carers to contact professionals quickly using email	70%	90%	4
Ability to share emails and other permanent products with others	60%	80%	4
Ability to arrange multi-disciplinary meetings more easily	90%	80%	4
Reduced waiting times for support	60%	80%	4
Increased time to deal with administration tasks	60%	80%	4
Increased choice for family carers about what information they are given and how	90%	80%	4
Increased convenience for family carers	50%	90%	4
Ability for family carers to access group or peer support	50%	80%	4
Clients/families have a known point of contact to develop rapport with	-	80%	4
Difficulty with modelling specific intervention strategies via telehealth	80%	-	5
Difficulty with delivering specific intervention strategies via telehealth, for example, ABA therapy	90%	-	5
Disadvantages			

Table 4. (Continued)

Item	% rating as influential (round two) [†]	% rating as influential (round three) [†]	Group median [‡]
Family carer preference for meeting in-person	90%	-	4.5
Ethical issue of offering support/advice without seeing situation in-person	80%	-	5
Potential for mistakes to be made in assessment/advice given	50%	80%	4
Lack of confidence using technology for family carers	60%	80%	4
Possibility of misinterpreting communication for example, via email	60%	90%	4
Difficulty for family carers to get point across via technology	50%	80%	4
Difficulty related to checking misunderstandings	50%	90%	4.5
Difficulty in understanding family carer's reactions to suggestions	50%	90%	4

[†]Refers to percentage of responses in the round, rather than percentage of total panel.

[‡]Group median presented for round in which the item reached consensus.

[†]A dash indicates that the item was not presented in that round, either because consensus had already been reached in round two or because it was a new item identified as part of round two and therefore was only presented in round three.

the focal person, mirroring some of the concerns reported in the literature relating to telehealth (e.g. Lee *et al.* 2015; Pollard *et al.* 2017; Baumes *et al.* 2020). They also emphasised the potential for communication difficulties and issues for those who lack confidence with technology or prefer in-person support. In contrast, family carers again focused on the nature and quality of support. They highlighted concerns that receiving support via telehealth might mean additional work and management for them. They also felt that the quality of support might be reduced and there might be issues relating to professional practice (factors also highlighted as concerns in the literature from other fields, e.g. Gordon *et al.* 2020) such as professionals lacking skills, not being proactive, having limited influence via telehealth, or diagnostic overshadowing. They additionally emphasised issues due to the professional being less able to get to know their relative. Both panels were able to suggest solutions to these barriers/disadvantages, and these most often involved combining telehealth with in-person support in some format. Other solutions focused on involving others (e.g. keyworkers, others who know the focal person and additional professionals), modifying support (e.g. modifying communication, using training videos and specific technologies), providing or seeking additional training in the use of telehealth, and seeking stakeholder feedback. Family carers additionally highlighted system-wide solutions such as national guidance for telehealth, policy changes, and an emphasis on their rights to complain. These solutions are further discussed within the practice recommendations below.

This is the first study to the authors' knowledge that prospectively (i.e. prior to the delivery or receipt of telehealth for this purpose) explores the social acceptability of providing behavioural support to family carers of children with IDD via telehealth. It is important to note, however, that some participants did have experience of the use of telehealth for other purposes meaning that their views may have been informed by this. These tended, however, to be relatively basic forms (e.g. telephone and email) that, at the time of the study, were widespread within key services (e.g. health and industry). The use of telehealth for behavioural support (as explored) requires more sophisticated technology (e.g. videoconferencing) and is still therefore likely to

Table 5 Items reaching consensus in either round two or three for panel B

Item	% rating as influential (round two) [†]	% rating as influential (round three) [†]	Group median [‡]
Advantages			
Increased ability to revisit any advice that was provided	80%	- [§]	4
Ability for support to be provided more quickly as issues arise	80%	-	5
Ability to arrange appointments more easily	80%	-	4
Reduced disruption to your relative's routine	80%	-	4
Less time wasted due to attending lengthy or ill-informed meetings	80%	-	4
Quicker response times	-	100%	4
No need to attend appointments to deal with admin	-	100%	5
Increased ability to plan ahead, for example, preparing an email or document to be sent in advance	-	100%	4.5
Disadvantages/barriers			
The possibility that professionals might provide generic or inappropriate advice when providing support via telehealth	80%	-	5
The potential that support provided via telehealth might mean you have to oversee and manage this more than support provided in-person	80%	-	5
Professionals not meeting your relative in-person	100%	-	5
Professionals being unable to directly observe your relative	80%	-	5
Professionals being unable to influence other people who support your relative	80%	-	5
Professionals having limited ability to effect change	80%	-	5
Professionals lacking the skills to provide support	80%	-	5
Professionals not being proactive	80%	-	5
Support being less in-depth or less well informed	100%	-	5
Possibility that professionals might not get to know your relative as well	100%	-	5
Possibility that professionals might not see your relative often enough to notice changes or issues	80%	-	5
Lack of focus from professionals as they may be dealing with multiple clients and might mix people up or not go into much depth	-	100%	4
Concerns about trusting whether professionals know your relative well, are complying with legislation (e.g. the Mental Capacity Act, quality Act) and are not diagnostically overshadowing due to your relative's disability	-	100%	5
Additional work for families who are already tired	-	100%	4

[§]Refers to percentage of responses in the round, rather than percentage of total panel.

[†]Group median presented for round in which the item reached consensus.

[‡]A dash indicates that the item was not presented in that round, either because consensus had already been reached in round two or because it was a new item identified as part of round two and therefore was only presented in round three.

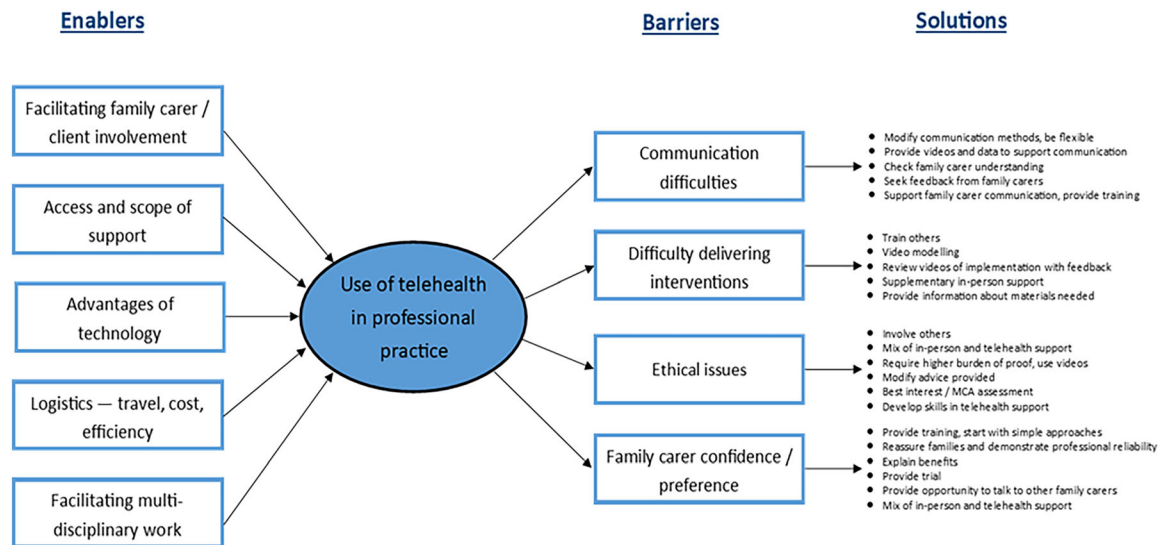


Figure 1. Model of enablers and barriers (with solutions) for panel A.

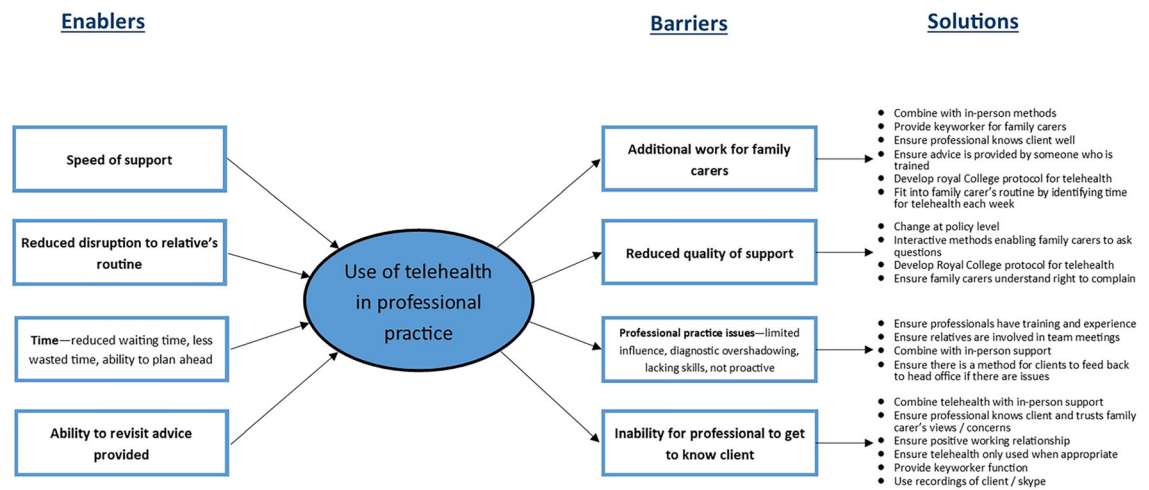


Figure 2. Model of enablers and barriers (with solutions) for panel B.

represent a unique service delivery format for participants (notwithstanding the impact of the pandemic as described below).

The inclusion of both family carers and professionals represents a particular advantage by considering perspectives of both parties involved in any future telehealth-based behavioural support (although the inclusion of participants with IDD was beyond the scope of the study and represents a limitation as discussed below). As noted above, the

provision of behavioural services via telehealth differs from the use of telehealth in other fields given that support is required to be more collaborative and facilitate knowledge and skills transfer, rather than providing services directly to a focal person (Tomlinson *et al.* 2018; Ferguson *et al.* 2019; Unholz-Bowden *et al.* 2020). The finding that both professionals in the field and family carers view telehealth favourably is therefore particularly significant.

Consideration of advantages and barriers for families is also particularly important, given that unique factors may influence uptake within this group. For example, as noted by participants in this study, the ability to receive support in their own home (minimising disruption to their relative) may be an influential consideration for family carers given the demands of their caregiving role. In contrast, concerns raised by participants in this study about professional conduct may represent unique barriers for this group, particularly given that many families may have previously had negative experiences of support provided by professionals with significant impact for them and their relative (e.g. Baker *et al.* 2021). This study therefore provides insight into the unique perspective of families, albeit the small sample size represents a significant limitation as discussed below.

Whilst this study evaluated prospective social acceptability amongst stakeholders, previous studies in this field (prior to the pandemic) have instead focused on evaluating acceptability following delivery of support via telehealth (e.g. Wacker *et al.* 2013a; Lindgren *et al.* 2016; Wacker *et al.* 2016). However, similar findings are reported here to those in retrospective evaluations of social acceptability. The majority of participants in this study reported being willing to use telehealth for behavioural support, echoing findings in previous studies in which families report they would recommend the use of telehealth (e.g. Fisher *et al.* 2014). One participant in the professional panel (representing 9.1% of the panel) was unwilling to use telehealth (although all of the participants in the family carer panel reported being willing to use telehealth). This may suggest that there is variability in willingness to use telehealth as in other fields (e.g. Subramanian *et al.* 2004; Sanders *et al.* 2012; Choi *et al.* 2013; Gorst *et al.* 2014; Fischer *et al.* 2020), although this conclusion remains tentative as it is based on one participant only. Concerns reported by participants in this study also mirrored issues reported in retrospective evaluations in the literature. For example, a number of authors identify ethical issues as a concern for professionals and difficulties delivering some interventions via telehealth (e.g. Machalicek *et al.* 2010; Wacker *et al.* 2013a, 2013b; Suess *et al.* 2014; Fischer *et al.* 2016; Barkaia *et al.* 2017), both of which were highlighted here also.

However, there are also key differences between this study and findings from retrospective evaluations of the acceptability of the use of telehealth for behavioural support. Technical difficulties have often been reported in the literature (e.g. Machalicek *et al.* 2009; Hay-Hansson & Eldevik 2013; Alnemary *et al.* 2015; Barkaia *et al.* 2017) but were not identified here by either panel. Whilst this may reflect a genuine lack of concern about potential technical difficulties, it may also represent participants' limited experience with the use of sophisticated technology for this purpose. Only half of participants in this study had experience of telehealth and this was often via email or telephone which may be less prone to technical difficulties. In addition, although some studies report reduced costs for behavioural professionals (Lindgren *et al.* 2016; Boydston *et al.* 2022), a variable also identified as important by participants in this study, one study (Lindgren *et al.* 2016) found increased costs for families as a result of equipment requirements. This was not considered by participants in this study. Many of the key variables identified by participants in this study (e.g. facilitating stakeholder involvement, communication difficulties and concerns about the quality of support) have not been mentioned in other studies in this field, likely reflecting the exploration of prospective rather than retrospective use of telehealth here and possibly increased acceptance of technology over time as technology use becomes more widespread. These findings therefore provide a valuable perspective on the social acceptability of the use of telehealth for behavioural support and variables likely to influence stakeholder acceptance and uptake.

It is important to note that data reported here were collected prior to the coronavirus pandemic. During the pandemic, telehealth was adopted at speed within all fields, including behavioural support (e.g. Crockett *et al.* 2020), meaning that both professionals and family carers are likely to now have experience of the use of telehealth for behavioural support. It remains to be seen whether the use of telehealth within the field will continue at this rate post-pandemic. However, the findings reported here are likely to be valuable in enabling practitioners to consider key factors that may influence the uptake and usability of telehealth for family carers whom they support, particularly where use of telehealth for service delivery is offered as a choice (rather than a necessity, as was the case at the height of the pandemic). Furthermore,

even with the increase in research activity relating to telehealth during the pandemic, this remains the only study known to the authors to examine perspectives of the use of telehealth for behavioural support (provided to family carers) prior to this having been provided.

Limitations and directions for future research

Some key methodological limitations should be considered when interpreting results. Firstly, the representativeness of panel B (family carers) is limited for a number of reasons. Whilst the sample size for both panels was small, this was more pronounced for panel B due to difficulties in recruitment and participant non-completion of questionnaires. Caution is therefore required in interpreting the results, particularly from panel B, and the findings here should be considered exploratory only. Akins *et al.* (2005) recommend calculating the necessary sample size for each Delphi study which was not possible here, although they cite varying sample sizes from 10–100 suggesting the sample size of panel A is within acceptable limits. Additionally, whilst the use of an online questionnaire had advantages (e.g. ease of completion), it likely also increased difficulty for participants in identifying protected time to complete questionnaires or remembering to check their email, contributing to participant attrition across rounds. As participation was anonymous, it was not possible to send targeted reminders to non-completers (although general reminders were sent to all participants). The representativeness of the family carer panel was also limited as most were family carers of children who had recently received behavioural support. Future research with family carers is therefore warranted to confirm the findings here with a larger, more representative sample. It was also not possible within the scope of the study to consult people with IDD directly about their views of their family carers receiving support about their behaviour via telehealth. Future studies could usefully explore this to ensure that social validity is considered from the perspective of all stakeholders.

Secondly, the study was advertised and conducted solely via technology. This may mean that participants were familiar with and accepting of technology, resulting in a skewed sample of participants who were willing to use technology in

their everyday lives and potentially also willing to use technology for behavioural support. Whilst the use of technology for the study was necessary to facilitate recruitment, future studies should aim to involve participants with variable experience of technology and consider avoiding the use of technology for questionnaire completion. Thirdly, the definition of telehealth used in the study was broad, including technology which is used regularly in everyday life (e.g. telephone and email) and which most participants had used in the past, potentially increasing the likelihood that participants would be willing to use this technology for behavioural support. Despite this, participants indicated that they would also be willing to use more advanced forms of technology (e.g. videoconferencing).

Fourthly, although participants were asked about their willingness to use telehealth, this was not validated through subsequent behavioural checks, and it is therefore possible that willingness may not align with actual uptake. Furthermore, given the relative scarcity of behavioural expertise in the United Kingdom and changed practices following the pandemic, it is unclear whether family carers would have a genuine choice between telehealth and in-person support in practice. Favourable perspectives may therefore represent participants' willingness to accept any form of behavioural support. Similarly, professionals may be aware of these issues and therefore more open to ways of overcoming them in their professional practice. Future studies could usefully examine uptake of telehealth when offered as a genuine alternative to in-person support. Finally, as noted above, data collection occurred prior to the coronavirus pandemic, reflecting perceptions of telehealth when this was used infrequently. Given the role of telehealth in the pandemic, it is likely that participants would now have greater experience with telehealth both generally and in relation to behavioural support. Future studies could usefully replicate methodology here and explore the impact of the pandemic on stakeholders' decisions about service delivery method and uptake post-pandemic.

Practice recommendations

Despite limitations, it is possible to make some preliminary recommendations for practitioners to increase the utility and acceptance of telehealth

support. These recommendations reflect solutions identified by both panels to overcome some of the barriers identified, and therefore may increase the likelihood of telehealth support being utilised by professionals and family carers (although this point will require empirical validation). However, it is important to note that these recommendations are based on perceptions from a small number of participants with data collected before the pandemic. They therefore remain tentative, requiring validation with larger, more representative stakeholder groups and additional consideration of the impact of the pandemic on stakeholder perceptions. Nevertheless, these recommendations are particularly relevant in the context of the pandemic as telehealth was adopted speedily and on a mass scale with a relative lack of support from industry specific guidance and local/national policy. As a result, the importance of studies such as this which generate tentative guidelines relating to the use of telehealth, and of the development of local and national policy governing telehealth use cannot be overstated. The following recommendations are made:

- 1 Consider combining telehealth with in-person support. This may be particularly important for individuals who are hesitant about the use of telehealth or for complex cases which require greater oversight. This may also facilitate rapport.
- 2 Incorporate video technologies. Participants suggested this may facilitate consistency in the implementation of interventions, enable practitioners to provide feedback and training, and facilitate rapport.
- 3 Take advantage of the opportunity to involve multiple stakeholders. Participants felt that involving additional individuals (e.g. other professionals, others who know the focal person well) would supplement support and protect against some of the potential disadvantages of telehealth. In addition, participants reported that telehealth can facilitate training with multiple stakeholders and multidisciplinary working.
- 4 Consider client perspectives and confidence. Participants highlighted that this is likely to be a barrier to the use of telehealth and therefore professionals should consider providing training for family carers in using the technology, seek feedback both formally and informally from clients, and respect client preference. Furthermore, professionals are likely to benefit from training relating to the use of telehealth linked to the barriers identified in this study (e.g. training focused on facilitating effective communication via telehealth, sensitively seeking client feedback etc.).
- 5 Develop guidelines for the use of telehealth. Family carers felt that guidelines should be developed by national regulatory bodies. General guidelines have been published during the coronavirus pandemic for various audiences (e.g. Royal College of Speech and Language Therapists 2020) but there is still no national regulatory framework for the use of telehealth in the United Kingdom or guidance relating specifically to behavioural support services. In addition, local guidance will also be useful to specify what clients can expect from a telehealth service and ensure that all aspects of service delivery conform to frameworks outlining good practice. Guidelines should describe technology requirements, ethical considerations, procedures for telehealth meetings, and feedback mechanisms for clients.
- 6 Ensure that telehealth is part of a wider service package that enables families and professionals to choose the most appropriate delivery format for support. Family carers expressed concern that telehealth may be used to avoid offering alternative support in-person. It is therefore important for services to consider their motives for the use of telehealth and ensure it is part of a service package that can be utilised when appropriate as directed by the unique needs of each family. Services should discuss telehealth with potential clients ensuring that the rationale, potential benefits, and potential disadvantages/risks are described, with clients able to make an informed choice about the use of telehealth. Whilst some services may not be able to offer alternative support in-person, robust referral mechanisms can ensure that clients who do not wish to use telehealth can still receive support.

In addition to these guidelines, other authors have provided further suggestions including those relating to technological requirements or ethical considerations for telehealth-based behavioural support (Lee *et al.* 2015; Wacker *et al.* 2016; Pollard

et al. 2017; Romani & Schieltz 2017; Rios *et al.* 2018; Baumes *et al.* 2020; Rodriguez 2020; Araiba & Čolić 2022) which should also be consulted by practitioners prior to adopting telehealth within their practice.

Acknowledgements

There are no acknowledgements for this work.

Funding information

No funding was received for this work.

Conflict of interest

The authors declare no conflicts of interest in relation to this work.

Ethics statement

Ethical approval for the study was obtained from the researchers' institutional ethical review committee on 13 April 2017.

Data availability statement

Research data are not shared.

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Accepted 22 February 2023

Supporting Information

Additional Supporting Information may be found online in the supporting information tab for this article.

Table S1. Conceptual Categories and Subcategories Identified in Round One Responses for Panel A and Summarised Comments Made by Participants

Table S2. Conceptual Categories and Subcategories Identified as Part of Round One by Panel B Participants and Specific Comments Made by Participants

Table S3. Advantages Selected by Panel Members in Panel A as Their Top Five or Top Two Most Influential

Table S4. Advantages Selected as Panel Members' Top Five or Top Two Most Influential by Panel B

Table S5. Solutions Suggested for the Disadvantages/Barriers Identified by Each Panel as Part of Round Four