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Family and Practitioner Perspectives on Telehealth for Services to Young Children with Autism

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Abstract. Telehealth offers the potential to address inequalities in autism service access for young children living in regional and rural areas with limited access to autism specialists. Our aim was to explore parent and practitioner uses of technology, and views about telehealth, including perceived barriers, for autism early intervention service delivery in a regional town in Australia. Fifteen mothers and 19 front-line autism practitioners completed surveys distributed by local autism service and support providers in the regional town; eight front-line practitioners from one service participated in interviews. Mothers and practitioners had access to technology that could be used for video-communication, but had little or no experience with telehealth. Mothers appeared more willing to try telehealth for receiving autism services than practitioners appeared to believe, and practitioners preferred to use it for consulting with other professionals and professional development. Barriers to telehealth included limited experience and practitioners not knowing what a telehealth service would look like, poor access to reliable and high speed internet, lack of skill and technical supports, and practitioners believing families preferred face-to-face services. The success of telehealth in this regional town will rely on better infrastructure, and upskilling practitioners in evidence-based autism interventions so they can provide the required support remotely. Use of telehealth to upskill practitioners in evidence-based practice could provide a first step in ensuring equitable access to expert autism services to regional and rural families.

Keywords. Telehealth, autism, early intervention, rural service delivery, evidence-based practice

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Introduction

Early intervention for children with autism is essential for ameliorating pervasive social-communication and behavioural impairments [1]. Yet, globally, few children access early interventions, particularly those based on current best evidence [2]. At particular risk are children living in low-income countries [2] and/or rural areas [3, 4] because of limited access to autism expertise. Telehealth could provide a solution. A recent projection that 6 billion smartphone users will be from developing nations by year 2020 [5] together with an initiative by Google to increase internet access for all [6] means that telehealth could be a key resource across communities. The feasibility of using telehealth to deliver autism services has been demonstrated in a number of studies [7-10], including those in which remotely located specialists have coached parents in evidence-based strategies while in their homes [4, 9].

Barriers to telehealth service delivery

Despite the promise, current access to the required technologies and associated costs can impede the widespread use of telehealth, particularly in rural communities [11, 12]. In previous telehealth evaluations for children with autism, families needed good internet access [7-9]. Such access may remain problematic for disadvantaged communities, despite overall increases globally. In particular, people in rural areas, even within middle-to-high income countries, continue to be disadvantaged by lack of mobile coverage, resulting in greater costs for smaller data packages in comparison with people in metropolitan locations [13].

A further barrier to the use of telehealth appears to be reluctance on the part of practitioners [11, 12, 14]. This reluctance has been found to stem from limited experience with telehealth, concerns about disrupting the dynamic of interactions, and relationships with children and their parents, and a belief that parents would reject it as a form of service delivery [11, 12, 14]. Recent research has started to debunk these beliefs [15].

Aims

Access to services and technology, and concerns and considerations of service providers and families of children with autism are features of the real-life context for translating research findings about autism evidence-based interventions, and the potential role of telehealth in supporting their implementation. We aimed to explore readiness for telehealth in terms of parent and practitioner uses of technology, and views about telehealth, including perceived barriers, for autism diagnostic and early intervention service delivery in a regional town in Australia. The results presented here were part of a larger study that focused on understanding the community context of this regional town for a planned program to embed evidence-based early autism intervention [16]. In particular, we aimed to explore the potential role of telehealth in this program.

1. Methods

1.1 Design and Ethics Approval

Data were obtained from practitioner and family surveys, and interviews of practitioners. Approvals were obtained from three Human Research Ethics Committees (References FHEC 14-063, FHEC 14-237; LNR/14/BHCG/58; Scope #89/15).

1.2 Study Setting

As documented in our related study [16], 14 services from five organisations served families with autism from a population of 185,000 across a geographic area of 7,486 km^2. This area was characterised as having a high level of disadvantage [17]. As has been found in a large Australian study [18], children with autism in this town tended to be diagnosed late. Families travelled up to 2.5 hours to access autism services (on average 50 minutes each way) [16], which were limited to one hour a fortnight on average, dramatically short of the 15-20 hours recommended to achieve optimal outcomes [19].

Regarding access to the internet, a National Broadband Network (NBN) is being rolled out across Australia, but the timeline for completion and strategies for connecting individual homes and businesses have been debated for some time [20]. The timing for the roll out for this town remains unknown, resulting in reliance on mobile wireless technology, satellite broadband, and for some, telephone dial-up through copper wires [21].

1.3 Participant Recruitment

Autism service providers and a support group in the town distributed surveys to their front-line practitioners and families. Interview participants were practitioners recruited from one intervention service. This service was chosen for interviews because the installation of a new videoconference unit in their workplace provided a timely opportunity to further explore the study aims.

1.4 Surveys

Parents and professionals completed separate surveys (available online and in hard copy). The family survey comprised 35 questions regarding demographic information, access to services (previously reported [16]), use of and attitudes towards technology and telehealth, and information about internet access (reported here). The professional survey comprised 29 questions regarding demographic information, assessment and intervention practices, and professional development needs (previously reported [16]), and use of and attitudes towards technology and telehealth.

1.5 Interviews

Structured interviews were conducted face-to-face or over the phone and lasted approximately 30 minutes. The questions focused on the study aims (see Appendix). Interviews were audio-recorded and transcribed verbatim.

1.6 Analysis

Survey data were analysed and reported descriptively. Interview data were analysed by coding according to broad explicit themes of relevance to our aims [22]: that is, use of technology, views about telehealth for delivering services, and perceived barriers.

2. Results

2.1 Participant Description

Survey participants were 15 mothers of children with autism (aged up to 6 years) and 19 front-line practitioners. Most mothers were full-time carers (*n*=9, 64%), and 20% (*n*=3) were single parents. Practitioners were mostly speech-language pathologists (*n*=5, 26%) and occupational therapists (*n*=4, 21%); others were psychologists, social workers, early childhood teachers and a mental health nurse. They had practiced from 1 to 34 years (mean=10 years, 10 months, sd = 9;11).

Eight early intervention practitioners participated in interviews. Three were early childhood advisors, two were occupational therapists, and three were speech-language pathologists. They had worked in early intervention for 1-25 years (mean=13 years).

2.2. Access to and use of technology

2.2.1 Surveys

All 15 mothers reported having access to a device that could be used for video-communication: mobile phones (*n*=7, 46.7%), tablet devices (*n*=10, 66.7%), laptops (*n*=5, 33.3%) or desktop computers (*n*=2, 13.3%). Some respondents had never used video calls (*n*=6, 40%); those who had, rated the quality of the connection as poor (median score of 2.5 on a scale of 1, very poor to 5, very good). Most had some form of broadband internet connection (*n*=12, 80%) (not NBN); one mother had data on her mobile phone only, and another used a pre-paid mobile with wireless capability. Only three (20%) were on plans providing unlimited data, with the others having 2-200 gigabytes (average = 100.8). Most were on monthly plans, which ranged in cost from AUD$40 to $120 (average = $89).

Most practitioners reported some experience with video-conferencing (*n*=11, 57.9%) using freely available programs, such as Skype® *n*= (5, 26%) and FaceTime® (*n*=3, 15.8%), as well as dedicated videoconference units (*n*=4, 21%). Telehealth was used by few practitioners for assessments (*n*=1, 5.3%) or client reviews (*n*=2, 10.9%), but more used it for intervention (*n*=2, 15.7%) and consultations with other professionals (*n*=4, 21%). None of the practitioners used freely available videoconference programs for assessment or intervention services, but rather for consultations with other professionals and follow-up with families.

2.2.2 Interviews

Technology usage for work purposes for these practitioners included (a) emails to families to set up appointments and send information; (b) digital cameras, picture-making computer software, and Google® images to create materials for therapy and reports; and (c) iPads® with apps for therapy tasks, child reinforcement, and to video-record clinic sessions. Consistent with the survey data, some practitioners used videoconference software, Skype® and FaceTime® for conversations with friends and family members, but none used these for communication with client families. Most had smartphones, but tended to use them for personal use in limited ways, such as to take photos or videos.

2.3 Views regarding telehealth

2.3.1 Surveys

Aggregate responses for each service type and whether mothers anticipated problems if they were delivered by telehealth are provided in Table 1. Most mothers were either undecided or willing to consider telehealth for their child's assessment (*n*=12, 80%) or intervention (*n*=10, 67%), and were unsure about potential problems. Most (*n*=9, 60%) thought the reduced need for travel would be an advantage, as well as minimising children's anxiety by being able to stay in a familiar environment (*n*=4, 26.7%) and not having to interact with new people (*n*=5, 35.5%) in a face-to-face session.

Table 2 provides aggregate data from practitioner surveys. Respondents fell along a continuum in terms of seeing the benefits of telehealth, with most agreement clustering around potential benefits to families in relation to travel. Responses about possible benefits aligned with those to a question about barriers they thought families face in accessing services, with nine (47.3% of all practitioners)[2] indicating distance and travel time, with associated costs and disruptions for family. Still, even on the issue of disruptions to families, almost a third of respondents were undecided.

Practitioners tended to rate the quality of videoconference experiences as 3 (1-5 scale). Only one (5.3%) would use it for assessment, four (21%) for regular intervention, nine (47.4%) for reviews, 12 (63.2%) for follow-up support to families, nine (47.4%) for consultation with other professionals with the child and family present at the remote location, and 16 (82.4%) for such consultations without them being present. Most practitioners believed their employing organisation would (*n*=9, 47.4%) or might (*n*=7, 43.8%) be willing to use telehealth for autism services and provide the technology required, but many (*n*=10, 52.6%) were unsure if they would also provide training in using it. Many practitioners (*n*=10, 52.6%) did not think telehealth would reduce their workload; three (15.7%) believed it would increase it and six (31.6%) were unsure if it would increase it.

2.3.2 Interviews

Practitioners who were interviewed valued technology, reporting it had made a difference to how they worked. When asked to consider its possible use in supporting clients at a distance, one practitioner indicated that although she saw benefits, it was not going to change how she or others worked, stating it would not replace the value of "connecting with families, getting on the floor." Further, they were unclear how telehealth could work for them or families. One practitioner suggested telehealth would develop in her practice, and had much potential, but she did not know what that service

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[2] For items in which there was missing data, percentages are reported according to all 19 practitioners.

would look like. It was noted that not having to come into a centre would have advantages for families who had children who could not tolerate even short drives, and competing demands.

Rather than for use with clients, these practitioners indicated that the videoconference equipment would help them access professional development activities without needing to travel. One participant stated "What interested me was the training, for us to go to [name of city] is massive, it's expensive and time consuming and exhausting."

Table 1. Summary of family survey responses (*n* = 15) regarding use of telehealth for receiving autism services

	Response		
Item	**No**	**Maybe**	**Yes**
Would you be willing to use telehealth for assessment?	3 (20%)	7 (46.7%)	5 (33.3%)
Would you be willing to use telehealth for intervention?	5 (33.3%)	5 (33.3%)	5 (33.3%)
Do you think there could be problems in using telehealth for either assessment or intervention?	3 (21.4%)	8 (57.1%)	3 (21.4%)

Table 2. Practitioner views about telehealth for autism service delivery.

Statement	**Rating 5 Strongly Agree**	**4**	**3**	**2**	**1 Strongly Disagree**
Telehealth provides an effective and efficient means to conduct an autism/ASD diagnostic assessment*	0	1 (6.7%)	7 (46.7%)	3 (20%)	4 (26.7%)
Telehealth provides an effective and efficient means to deliver intervention service*	0	3 (20%)	9 (60%)	2 (13.3%)	1 (6.7%)
Telehealth can provide useful addition to face-to-face diagnostic assessment	3 (18.8%)	6 (37.5%)	3 (18.8%)	3 (18.8%)	1 (6.3%)
Telehealth is disruptive to the clinician – client relationship or rapport	1 (6.3%)	6 (31.6%)	4 (25%)	4 (25%)	1 (6.3%)
Telehealth can provide a useful addition to face-to-face intervention	1 (6.3%)	8 (50%)	5 (31.3%)	1 (6.3%)	1 (6.3%)
Telehealth is suitable for the conduct of diagnostic assessments only if there is a local clinician with the child/family^	2 (14.3%)	6 (42.9%)	4 (28.6%)	1 (7.1%)	1 (7.1%)
Telehealth provides a lower quality service for families than does face-to-face	2 (12.5%)	5 (31.3%)	5 (31.3%)	3 (18.8%)	1 (6.3%)

Statement	**Rating** **5** **Strongly Agree**	**4**	**3**	**2**	**1** **Strongly Disagree**
Telehealth is suitable for the provision of regular intervention only if there is a local clinician with the child/family*	3 (20%)	5 (33.3%)	7 (46.7%)	0	0
Telehealth saves the child/family from having to travel	6 (31.5%)	8 (42.1%)	1 (5.2%)	1 (5.2%)	0
Telehealth allows the child to stay in their familiar environment	6 (31.5%)	8 (42.1%)	2 (10.5%)	0	0
Telehealth provides less disruption to other family members	5 (26.3%)	6 31.5%)	5 (26.3%)	0	0
Telehealth provides less disruption to scheduled family activities	4 (21%)	7 (36.8%)	5 (26.3%)	0	0

n=16, **n*=15, ^*n*=14; percentages calculated for 19 participants.

2.4 Perceived barriers

2.4.1 Surveys

Some mothers provided reasons for responses about their willingness to receive telehealth services (Table 1), including concerns about internet access or quality and the need for practitioners to directly interact with their children. Practitioners reported concerns about (a) access to the required technology for themselves and families, skill in using it, and reliability (including of the internet); and (b) the appropriateness of telehealth when working with children with autism, with many indicating it would interfere with building rapport and sustaining the relationship with the child, or it would not be useful for demonstrating clinical strategies. One respondent queried whether telehealth could be rebated under Medicare (the national health scheme), and another noted logistical issues in finding a common convenient time for a remote and local practitioner, and family.

2.4.2 Interviews

Barriers to using technology for service delivery included limited access to equipment and participants' own skill and confidence in using it. Many described problems with poor quality and unreliable connectivity, resulting in frustration and a reluctance to use videoconferencing with families. There was concern that children would act differently if they knew they were being observed remotely, or that a camera would not be able to follow them as they moved around.

Major perceived barriers for families related to their access to resources, including the internet, their skill in using technology, and whether they would see telehealth as equivalent to a face-to-face service or would value it. One practitioner described the differences in the situation of two families on her caseload, who lived a distance from the centre:

> …I have a couple of clients in [name of town] who I think would be great to use [telehealth with], one in particular, they are quite IT-savvy. The other, it wouldn't work, because they are quite poor really, they've often

> not got credit … often they can't even afford petrol to get to [town where centre is located].

Other access issues included many wireless dead spots and slow internet speeds in the area, which would disrupt the signal, and in turn, sessions. It was suggested that families in small communities who had to travel to receive services and were most likely to benefit from telehealth were least likely to have reliable internet because of its lack of availability and cost. One practitioner wondered how much internet data would be required, which was relevant to many people on limited internet usage plans.

Practitioners also reported problems with engaging families in early intervention, broadly, noting further difficulties in encouraging their participation in telehealth. Some families were described as very private, declining home visits. These families, one practitioner suggested, would be unlikely to accept telehealth into their homes. One wondered about some families' ability to think about telehealth in light of the complex challenges they faced, including for some, having more than one child with a disability.

Practitioners also wondered about the support they would receive to use the equipment, given their organisation had only limited technology support staff. Logistical issues were identified in terms of accessing the equipment and having back up support if there were problems. One practitioner was concerned about a family not having skill or support at home, and her own ability to provide the technical support that would be required to assist or to troubleshoot problems.

3. Discussion

The potential for telehealth to provide a means to connect families in this regional town to autism specialists [4, 9] was tempered by a number of factors. These factors related primarily to (a) practitioner experience with, and understanding of how, telehealth could be incorporated into services, (b) practitioner and family access to reliable technology and confidence in using it, and (c) parent and practitioner preferences and views regarding service delivery.

For both practitioners and families, there was little experience in using telehealth, although many had used video-call programs for personal communication. Our findings reflect those found previously, including that practitioners used technology largely for managing work tasks [11, 12] and saw telehealth as a poor alternative to face-to-face interaction [14, 15]. Rather, they saw telehealth as more useful for consulting with other professionals, even though a videoconference may not provide benefits beyond those of a telephone meeting.

As found by Dunkley et al. [12], also in a rural Australian context, families were more open to telehealth than practitioners. Most mothers were, or might be, willing to consider telehealth to receive autism services, with few being certain it would entail problems. Of most concern was the quality of the internet connection, a reality for many residents in this regional town and surrounding areas. Discrepancies in internet access across Australia may be addressed with the roll out of the NBN, but interim solutions, such as government subsidised access to satellite broadband has resulted in high demand, which along with latency problems, has led to poor performance [21]. Further, residents relying on mobile connectivity, as was the case for some families, have had to deal with WiFi deadspots [21], further compromising the potential to rely on telehealth.

Both the survey and interview data indicated that practitioners were uncertain about the usefulness of telehealth in delivering regular services, even if connectivity issues were resolved. Lack of previous experience created uncertainty about how telehealth would work [14, 15]. Access to equipment was not a barrier given that many families had tablet devices, with both video and internet capabilities, but their use for real-time interactions with families were not considered by the practitioners. Concerns about maintaining child attention, rapport or simply being able to follow a child with a camera have not been borne out in research in which telehealth has been used effectively to engage children and parents [7-9].

Although telehealth for autism service delivery is an emerging research area, previous studies have shown that success relies not only on access to reliable equipment and willingness to use it, but also that the delivered interventions are based on strong evidence, and with skilled practitioners providing the remote coaching and support [7-9]. In our previous study, we did not find evidence of skill in evidence-based interventions amongst practitioners, nor opportunities to develop them [16]. In this context, then, rather than using it for training parents, telehealth may be more useful in upskilling practitioners, which has been found feasible and effective in extending delivery of evidence-based interventions to community settings [23]. Extending coaching to parents using telehealth may be the logical next step. However, access to equipment and reliable internet connectivity may be an ongoing barrier, at least until the NBN reaches all parts of Australia [21], thereby contributing to the disadvantage that characterised this regional and rural area [16]. Certainly, families relying on limited usage plans and slow internet will not be able to take advantage of telehealth. These are likely to be the very families who are most reliant on service delivery models other than those available in light of the distance to services and transport costs incurred, or having to rely on infrequent home visits by service providers [16].

3.1 Limitations and Research Directions

The main limitation in the study was that there were few survey respondents, especially families, precluding the generalisability of findings. Interview data did provide greater insight into practitioner perspectives reflected in survey responses, and including families in interviews similarly would have contributed to understanding their attitudes and ability to make use of telehealth. Nonetheless, the combined data converged to provide a picture of limited potential to implement telehealth, albeit with some willingness to do so, and reflect previous findings [11, 12, 14, 15]. Extending the current study across rural and regional Australia would provide more robust and generalisable results. On the other hand, there may be greater value in providing both families and service providers with positive experiences of telehealth [15], and then determining their willingness to use it for delivering services to children with autism. Telehealth does hold potential to increase the availability of evidence-based intensive interventions for young children with autism [4], but there has been a lack of research into using telehealth for diagnosis [4]. Research with other client groups [24] has indicated that assessments conducted remotely can yield reliable and valid results, but accuracy in autism diagnosis is an area ripe for future research with the need to facilitate earlier diagnosis.

Conclusions

The promise of telehealth to redress problems with accessing autism services for young children is unlikely to be realised unless infrastructure, training, and attitudinal issues are addressed. For families in rural and regional Australia, delays in the roll out of a national infrastructure to support efficient and low cost internet access is contributing to their experiences of disadvantage. Children with autism have a small window of time in which to optimise their potential to overcome developmental delays. Those living large distances from specialist autism services rely on upskilling both local practitioners and parents, and telehealth could provide a means to do this effectively if barriers can be overcome.

Appendix

Practitioner Interview Questions

1. Can you tell me about your role and work with young children with autism and their families?
2. How do you utilise information and communications technology in your general work life at present?
3. Have you ever, or do you currently use any form of technology for the delivery of services to families?
4. If not, have you ever thought about using technology in supporting families? How?
5. How do you utilise technology in other aspects of your life at present?
6. If you were to use technology in your role to deliver services to families, what might be some of the barriers that would first need to be overcome?
7. What might be some of the enablers that might help to facilitate use of technology, in your role, to deliver services to families?

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