

Autistic People and Telehealth Practice During the COVID-19 Pandemic: A Scoping Review

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ABSTRACT

Restrictions during the COVID-19 pandemic necessitated changes to health and social care services, including the use of telehealth. Prior to COVID-19, there was interest in telehealth for autistic people; however, little is known about its use during the pandemic. This scoping review focused on telehealth for autistic people during the pandemic. It was pre-registered on PROSPERO, and the PRISMA extension for scoping reviews was followed. Ten databases identified 45 sources, which were categorised into two themes: (1) the nature of the shift to telehealth during the pandemic and (2) service evaluations. Large disruptions were reported across settings, and experiences were variable. New areas were developed, including telehealth with autistic children and adults, autistic people with intellectual disabilities, and minimally verbal autistic people.

Autistic People and Telehealth Practice During the COVID-19 Pandemic: A Scoping Review

The COVID-19 pandemic significantly reduced in-person appointments, introducing, or expanding telehealth technologies (NHS England, 2020). A recent European policy review noted that interruptions to standard health and social care left over 70% of autistic people without everyday support (Oakley et al., 2021). In the decade prior to the pandemic, there was growing research interest in telehealth for autistic people¹ (Valentine et al., 2021). Despite experiencing higher rates of physical and mental conditions (Cashin et al., 2018; Lai et al., 2019; Kinnear et al., 2020), autistic people face barriers accessing healthcare (Calleja et al., 2020; Mason et al., 2021; Nicolaidis et al., 2015; Pellicano et al., 2020). Telehealth may be one way to increase healthcare accessibility (Alfuraydan et al., 2020).

Research on telehealth feasibility for autistic people showed some positive results. A review of 16 pre-COVID studies on child diagnostic and screening assessments, supported video evaluations, observations, and online or phone technology (Dahiya et al., 2020). Several studies that modified existing autism assessment tools (Chambers et al., 2017; Gabrielsen et al., 2015) indicated good diagnostic accuracy, sensitivity, and user satisfaction (Dahiya et al., 2020). Further, systematic reviews suggest telehealth may be effective in improving caregiver competence, child participation, communication, and reductions in ‘problem behaviour’ (Valentine et al., 2021; Ferguson et al., 2019; Hall et al., 2016; Tomlinson et al., 2018; Unholz-Bowden et al., 2020). However, samples were small (Valentine et al., 2021) calling generalisability and replicability into question.

Most studies provide training to parents/carers (Unholz-Bowden et al., 2020; Antezana et al., 2017; Parsons et al., 2017; Sivaraman et al., 2020), or professionals (Ferguson et al., 2019; Tomlinson et al., 2018), with less attention paid to direct delivery to autistic people (Sutherland et al., 2019). The focus has been on varying forms of behaviour therapy, including Applied Behaviour Analysis (ABA) (Ferguson et al., 2019; Hall et al., 2016; Tomlinson et al., 2018; Unholz-Bowden et al., 2020).

In addition, language, cultural and educational-history barriers have been identified (Tomlinson et al., 2018; Sivaraman et al., 2020; Dai et al., 2018). There are concerns about accessibility for people with intellectual disability (ID), or those minimally verbal (Tomlinson et al., 2018). Practical barriers include cost, logistics, and technical issues (Tomlinson et al., 2018; Sivaraman et al., 2020). Furthermore, lack of clinicians’ confidence and

Footnote¹ This paper will use identity-first language. From a disability rights, equality and diversity framework, autism is considered a central, identity-defining feature, which is argued cannot be separated from the individual. Furthermore, the use of person-first language has been considered to perpetuate stigmatizing views.

expertise in remote delivery may act as a barrier (Valentine et al., 2021), alongside ethical concerns around confidentiality and informed consent (Barkaia et al., 2017; Fischer et al., 2017).

In the context of increasing telehealth relevance and gaps in knowledge and practice, this review examined telehealth delivery to autistic people during the COVID-19 pandemic. Given the dynamic nature of the situation, a scoping review examined the extent, and range of research available. The following research questions were asked: (1) what is the state and quality of telehealth literature carried out during the pandemic, relating to autistic people? and (2) what are the gaps in this research?

Methods

Following creation of a review protocol, the PRISMA extension for scoping reviews checklist (PRISMA-ScR) was followed (Tricco et al., 2018), see Table 1. The review was pre-registered on PROSPERO (registration number: CRD42021244901).

Search strategy and selection criteria

The systematic search was carried out with terms listed in Table 2 using a two-pronged approach. Databases for published papers included: MEDLINE, Embase, PsychINFO, EMcare, Web of Science, Scopus, and the Cochrane Library. Given the novelty of this area, 'grey literature' (theses, dissertations, conference articles, pre-prints and government advice) was included from the following sources: MedNar, ProQuest, the COVID-19 Portfolio, and autism organisations, including the National Autistic Society (NAS), Autistica, Ambitious About Autism, and Autistic Women and Nonbinary Network (AWN).

Eligibility Criteria

Studies meeting the following criteria were included:

- Full-text publications reporting primary data relating to telehealth and autistic individuals.
- Studies including one or more individual of any age, who are either autistic, or supporting an autistic person. Where studies included autistic and non-autistic participants, autistic people had to make up at least two thirds of the sample or results had to be clearly disaggregated.
- Studies reporting on any remote health or social care service, including via videoconferencing, telephone, e-mails, apps, and web-based training.
- Studies focusing solely on educational services, or where professionals were the sole focus were not included.
- Written in English.

- Published between January 2020 to March 2022, conducted during the COVID-19 pandemic and clearly mentioning COVID-19.

Screening, Selection, and Data Extraction

Independently, two reviewers screened titles and abstracts and full texts. Initially, there was 88% agreement between reviewers for published papers (154/175 studies) and 86% for grey literature (23/27 studies). Following discussion, 35 published papers and 10 grey literature sources were agreed.

Two reviewers extracted and cross-checked data independently for all full-text articles. We used the Mixed Methods Appraisal Tool (MMAT) (table 3) (Hong et al., 2018) to evaluate methodological rigour. All studies were independently rated by two reviewers, with any disagreements resolved via discussion including a third reviewer. Literature were then categorised based on the following variables: literature type, methodology, participant characteristics, technology used, service provided and outcome.

(INSERT FIGURE 1 HERE)

Results

Literature was sorted into two themes: (1) nature of the shift to telehealth during the COVID-19 pandemic and its impact on autistic people and (2) types of services evaluated during the pandemic. One study (Samadi et al., 2020) was included in both themes.

Nature of the Shift to Telehealth and its Effects on Autistic People

Fifteen published papers and one grey literature source relate to this theme (see Table 4). Studies reported large disruption, with some services moving to telehealth, others shutting down entirely. In a study of American carers, 78% reported moderate to severe disruption (Bhat et al., 2021). Similarly, in a UK-based study, 65% of professionals reported major services disruptions (Spain et al., 2021). Disruptions were widespread, including for speech and language therapy, physical and occupational therapies, ABA services, and respite care (White et al., 2021a; Jacques et al., 2021). A longitudinal US survey conducted during initial stages of the pandemic (March – June 2020), saw a greater disruption in services at Time 2 (T2) (May/June 2020) than Time 1 (T1) (March/April 2020), suggesting a cumulative effect of disruption as the pandemic progressed. In this study, online services did not significantly predict distress. However, those who perceived less benefit from remote services at T1 reported significantly more distress at T2 (Bal et al., 2021).

There was large variability in accessing telehealth, ranging from the majority not having accessed any (White et al., 2021a) to 66% accessing online support (Aranki et al., 2022). When telehealth was offered, there was also variability in acceptance. In one study, 40% of families initially declined telehealth-delivered ABA, resulting in a gap in support during the pandemic (Aranki et al., 2022). Across studies, there was general preference for in-person contact. However, where telehealth was an option, some were grateful for services' continuation (Pellicano et al., 2022; Johansson et al., 2021; Thang et al., 2021), and reductions in (sensory) stressors (Spain et al., 2021; Pellicano et al., 2022; Harris et al., 2021). Nearly half the families in one study requested to continue with telehealth or a hybrid model following the pandemic (Johansson & Bulkeley, 2021). A survey completed by Italian carers identified telehealth interventions to have been a protective factor for their child's quality of life during lockdown (Logrieco et al., 2022).

Across literature, there were potential age-related differences in telehealth use. While some professionals viewed telehealth as more appropriate for younger people (Spain et al., 2021), studies conducted directly with autistic people found results to the contrary. One study saw 100% of adults aged 41-50 feeling able to communicate effectively over telehealth, while 85.7% of 21–30-year-olds felt unable to do so (Adamou et al., 2021). More younger-aged adults disagreed with telehealth being offered in future consultations (Adamou et al., 2021). Elsewhere, parents reported a greater proportion of dependent adults (68%) significantly or moderately benefited from online services, compared to school-aged (54%) or preschool-aged children (22%) (White et al., 2021a). Age correlated significantly with parental perceptions of telehealth benefits in a separate study, indicating younger children benefited less from telehealth compared to older children (Bhat et al., 2021). Parents also felt that younger children had faced greater service disruptions (Bhat et al., 2021). Age-related differences were also found in parental satisfaction, with older-aged parents reporting more positive ratings following completion of an intervention than younger parents (Samadi et al., 2020).

Alongside age, studies investigated other impactful demographics (Bhat et al., 2021; Aranki et al., 2022). While one study found no differences in a variety of demographic variables (socioeconomic data, gender, age, ethnicity, language and household size) between those who accepted remote ABA and those that declined (Aranki et al., 2022), this was not consistent across studies. Bhat et al (2021) saw parents from lower-income households reporting greater negative impact of the pandemic on their child's "ASD-related behaviours". Income also correlated with parental perceptions of telehealth benefits, with parents from lower income households not only perceiving telehealth as more beneficial, but a higher likelihood of accessing such services in the future.

Communication ease over telehealth varied. Some autistic people felt able to effectively communicate (Johnsson & Bulkeley, 2021; Harris et al., 2021; Adamou et al., 2021; Gibbs et al., 2021). Others highlighted increased social communication difficulties (Bundy et al., 2022; White et al., 2021b), with more pressure placed on non-verbal communication, including eye contact, conversational cues, and interpreting body language. Enhanced sensory sensitivities were also perceived (Pellicano et al., 2022; Bundy et al., 2022). Some professionals felt telehealth was potentially inappropriate for people with ID and recalled a general preference for audio calls with these clients (Spain et al., 2021). Practitioners also identified additional barriers for families with English as a second language (Johnsson & Bulkeley, 2021).

Concerns were also raised by professionals that telehealth could exacerbate systemic inequalities for the autistic community including waiting-times (Spain et al., 2021). Indeed, participants in a qualitative study did report an exacerbation in waiting times for in-person autism diagnostic clinics during early stages of the pandemic (Bundy et al., 2022).

. Limited access to provisions required to engage with telehealth were proposed as potential barriers at both an individual and provider levels. Authors identified areas including diagnostic services, and acute care for autistic people as being potentially vulnerable to limited-service provisions (Spain et al., 2021).

Types of Services Evaluated During the Pandemic

The second theme comprised of twenty-six published papers and four grey literature sources (see Table 5).

Assessments

Five studies focused on an delivering diagnostic assessments. Across studies, several standardised tools were used, including the TELE-ASD-PEDS (Ludwig et al., 2021; Nasir et al., 2021; Wagner et al., 2020), the Brief Observation of Symptoms of Autism (BOSA) (Nasir et al., 2021; Jonathan & Watson, 2021) and the Naturalistic Observation Diagnostic Assessment (NODA) (Matthews et al., 2021). These were often used in combination with developmental histories, behavioural observations, measures of adaptive and intellectual functioning (Ludwig et al., 2021; Matthews et al., 2021) and speech and language assessments (Jonathan & Watson, 2021).

The studies administering the TELE-ASD-PEDS reported benefits including provider comfort, advantages of observing children in their natural environment, continuation of services and reductions in waiting times (Ludwig et al., 2021; Nasir et al., 2021; Wagner et al., 2020; Jonathan & Watson, 2021). In a study

comprising of 204 TELE-ADS-PEDS assessments with families, 71% of children received an autism diagnosis (Wagner et al., 2020). This study however, excluded children with complex presentations, impacting on the sample's representativeness. One study (Ludwig et al., 2021) administered TELE-ASD-PEDS to 1/3 young people. A provisional diagnosis was given, however, and an in-person appointment was required for diagnostic certainty (Ludwig et al., 2021). Two grey literature sources (conference abstracts) detailed TELE-ASD-PEDS assessments with young children at UK-based clinics, in combination with the BOSA for older children (Nasir et al., 2021) and speech and language assessments (Jonathan & Watson, 2021). However, information was limited, including, sample characteristics and diagnoses.

Two studies assessed older-aged clients; a case series with an adolescent (Ludwig et al., 2021) and clients across the lifespan (Matthews et al., 2021). The case series involved a hybrid model of telehealth and in-person assessment (neuropsychological, behavioural and speech and language) (43). In (Matthews et al., 2021), clients over age 8 underwent remote developmental history, behavioural observation, adaptive and intellectual functioning assessments. For children under 8, NODA assessments were also administered. Diagnostic determination was made for 91% (Matthews et al., 2021).

Combined Assessments and Interventions

Three studies investigated the delivery of assessments and interventions. All studies aimed to reduce 'problem behaviour' through functional analysis (FA) and functional communication training (FCT). Results indicated reductions in 'challenging behaviour' and high levels of treatment fidelity (87-98% for assessment and 81-94% for treatment in two studies (Gerow et al., 2021a; O'Brien et al., 2021). A follow-up appointment completed 6-months post intervention suggested sustained improvements (O'Brien et al., 2021). However, studies contained small samples, and limited information on controlling confounds. Lacking control groups, it is unclear if improvements were due to the interventions alone.

Interventions

Twenty studies investigated, mostly behavioural, interventions.

ABA and Other Behavioural Therapies

Nine studies delivered ABA via telehealth. Three consisted of FA and FCT; four involved more comprehensive ABA and two delivered Discrete Trial Training (DTT). Using archival data, one study reported on 17 autistic children and adults that transitioned from in-person to remote ABA (Pollard et al., 2021). Despite the transition, participants continued to access similar amounts of treatment, and either maintained or improved

on the tasks set. Improvement or maintenance on tasks was also reported by other studies (Kunze et al., 2021; Shanok et al., 2021; Turan et al., 2020). Two studies delivered DTT directly to children (Ferguson et al., 2020; Nohelty et al., 2021). Across both studies, participants were considered to have achieved set goals.

A further eight studies investigated interventions delivering other forms of behavioural support. Caregiver delivery demonstrated improvements in adaptive behavioural skills (Gerow et al., 2021b), social communication (Ura et al., 2021; Wood de Wilde et al., 2022) and targeted “problem” behaviours (Boutain et al., 2020; Marino et al., 2022; Matano et al., 2021; Sivaraman et al., 2021). Four of the eight studies reported high treatment fidelity (Gerow et al., 2021b; Boutain et al., 2020; Marino et al., 2022; Sivaraman et al., 2021). Across studies, sample sizes were small. There was lack of control over confounders in most.

A single-case experimental design investigated telehealth consultations with professionals, via a behavioural support plan and a mindfulness-based intervention, ‘Soles of Feet Programme’ (SOF) (Sing et al., 2021). The goal was to reduce self-injurious behaviour (SIB) in autistic adolescents. SIB reduction was significant only with the SoF programme, not the behavioural support plan. Across the behavioural studies, sample sizes were small and lacked diversity, in Intelligence Quotient (IQ), language ability and demographics. There were no control groups and only two studies included follow-up appointments.

Two further studies explored a combination of ACT and behavioural parent training (Andrews et al., 2021; Yi & Dixon, 2021) to improve parental adherence to behavioural programmes. Both studies reported positive outcomes on adherence, reducing experiential avoidance and stress (Andrews et al., 2021). Initially, both studies included control groups but there was significant drop-out in these, resulting in an altered study design in one (Andrews et al., 2021) and incomplete dataset in the other (Yi & Dixon, 2021).

Other Interventions

Other interventions included two social skills intervention with autistic children (Cihon et al., 2022) and parents (Sengupta et al., 2021); dance psychotherapy with an autistic adult with Downs Syndrome (Rothman et al., 2021), two parenting support interventions (Samadi et al., 2020; McDevitt, 2021) and a telehealth learning platform (Vallefuoco et al., 2021).

The social skills intervention with autistic children, involved implementing the ‘Cool vs not cool’ intervention online. This is a discrimination program which consists of an ‘interventionist’ first demonstrating via role play with a staff member, the target behaviour both appropriately (cool) and inappropriately (not cool) while the learner observes (Milne et al., 2017). The dependent measure was teaching the children to change the

conversation when someone is bored. No comparison group was used. All children reached the mastery criterion in four to eight sessions (Cihon et al., 2022). The intervention aiming to train parents to promote social communication, play and language acquisition for their children with autism, (project ImPACT) (Sengupta et al., 2021) used a quasi-experimental pre-post design with mixed methods approach to investigate the fit of the intervention to the context. Culture and context-specific adaption were made. Results indicated a high level of completion rates, improvement in fidelity to the model and in child socio-communication skills.

However, while one reported the intervention to have been acceptable and effective, only 1/3 parents returned the measure investigating this (Cihon et al., 2022). Furthermore, authors reported interrater agreement was high, although the measure was only collected on the primary dependent variable on 37.5% of all sessions. There was no mention of outcome measurement blinding or how confounders were controlled for in either study, and, in both, there was no control group.

In dance psychotherapy, the practitioner gradually transitioned to videocalls, and an easy-read guide was sent to the client prior to sessions (Rothman et al., 2021) Barriers included technical issues impacting on communication fluidity, and the clinician feeling loss of control in protecting the client's privacy. Overall, the intervention was considered beneficial: the clinician observed an increase in the client's confidence, which they felt had been encouraged by the medium of telehealth.

In the two parenting interventions (Samadi et al., 2020; McDevitt, 2021) parental satisfaction was generally high. However, in one, when children had more than one diagnosis, parental reports were less positive (Samadi et al., 2020). Barriers included technical problems, financial burden, concerns about confidentiality, and lack of personalisation. Transcultural barriers between trainers in the US (who had immigrated from China) and parents in China were highlighted (McDevitt, 2021). Differences across the social and cultural contexts between the two countries, namely, lack of disability awareness and stigma associated with autism in China were reported. This differed to the US conceptualisation of autism as part of personal identity. Social pressures and structural barriers in the parents' cultural context often impacted the intervention. In both studies, information on data analysis was limited (McDevitt, 2021) or entirely absent (Samadi et al., 2020).

Finally, an Italian study created a digital telehealth platform to promote information sharing between autistic peoples' families, health services and schools, known as "SUPER". A preliminary-user test showed the system to be user-friendly and aid communication and collaboration between services and services-users (Vallefuoco et al., 2021) However, the sample was small (12 parents).

Risk Management

Risk was mentioned primarily when targeting ‘problem behaviour’. Participants were often excluded based on the perceived severity of their challenges or self-injury. There was limited information on how risk was assessed. Two studies outlined steps to assess risk prior to the telehealth intervention. In one, a ‘safety interview’ was conducted with parents (Gerow et al., 2021a). In the other, risk analysis based on a tiered system determined behavioural plans and the level of support needed by families (Yi & Dixon, 2021).

Quality Appraisal

As it is discouraged to calculate an overall score (Hong et al., 2018), presentations of the ratings are noted in the discussion (also, see Table 3).

(INSERT TABLE 4 HERE)

(INSERT TABLE 5 HERE)

Discussion

What happened to healthcare services for autistic people during the pandemic?

Large disruptions were reported across services. Studies varied on the proportion of autistic participants accessing telehealth services. This likely reflects multiple factors, including the number of services that transferred to telehealth; the point in the pandemic at which studies were conducted; and sampling strategy and bias. It may also reflect variability in autistic people’s preferences. There was a general preference for some degree of in-person contact. Of those that engaged with telehealth, for some, it provided a level of consistency, and continuity of care (Mason et al., 2021). Across studies, some autistic people and caregivers felt telehealth should be incorporated into future practice. Future studies should continue evaluating the nature and effect of these changes, to gauge autistic people’s healthcare delivery needs and preferences.

Who were healthcare services aimed at?

Prior to the pandemic, there was little focus on telehealth delivered directly to autistic people (Sutherland et al., 2019). Within this review, most studies involved parents/carers. However, some studies did explore supports given directly to autistic people. Given general lack of control groups and social validity data, future studies should seek feedback from autistic participants when evaluating any intervention, aim to include control groups, and involve autistic people in guiding research goals.

Prior to the pandemic, studies exploring telehealth delivery to autistic people with additional needs, including those with ID (Tomlinson et al., 2018), and mental and physical health conditions, were lacking. No studies relating to mental or physical health were found, highlighting two continuing gaps. While selection bias against ID is seen in surveys for autistic people (Russell et al., 2019), two surveys with caregivers did include autistic children with ID and language impairment. Similarly, while intervention studies were heavily dominated with people without ID, three case studies involved autistic people with Down Syndrome, ID, and language impairments. Of these, a case study outlined steps that helped facilitate therapy which may be valuable to all autistic people across the spectrum of abilities and difficulties.

Given autistic people's high rates of mental and physical conditions, future studies should prioritise those with IDs, language and speech difficulties, and physical and mental health difficulties, to reflect this reality.

How did different groups respond to telehealth services?

Age-related differences were noted in relation to perceptions of telehealth effectiveness. Older autistic peoples' telehealth experiences were more favourable than younger adults', or children's, consistent with age-related differences found in telehealth-use with the general population (Hoffnung et al., 2021). In the general population, in has been suggested pragmatic support via telehealth may be more amenable for children (Hoffnung et al., 2021). The dominance of behavioural interventions could be consistent with this. Future research should evaluate what form such pragmatic support should take, by consistently engaging with autistic people and their families.

What kind of services were delivered via telehealth?

In line with pre-pandemic literature (Ferguson et al., 2019; Antezana et al., 2017) most telehealth services delivered interventions, with a bias towards child studies (Pellicano et al., 2014). However, five studies evaluated the delivery of diagnostic processes. In line with past systematic reviews (Dahiya et al., 2021; Valentine et al., 2021), results were favourable. However, as in previous research, sample representativeness was questionable (Dahiya et al., 2021; Valentine et al., 2020) with more complex presentations requiring in-person appointments.

Where standardised diagnostic tools were employed, samples consisted only of children, particularly younger-aged. There appear to be limited tele-diagnostic tools that have been evaluated for use with adults. Although a recent study has found BOSA showing promise (Dow et al., 2022), more research is required. Future research should evaluate tele-diagnostic tools with autistic adults and more diverse samples, including those with complex needs and IDs.

Intervention studies were dominated by behavioural therapy, including ABA. This reflects past telehealth research (Hall et al., 2016; Tomlinson et al., 2018; Unholz-Bowden et al., 2020), and clinical trends (Denne et al., 2018). Studies delivering forms of ABA were all conducted in America, where ABA is considered ‘treatment as usual’ (Keenan et al., 2015). Most behavioural studies evaluated intervention effectiveness, largely concluding interventions were successful in improving target behaviour (Gartlehner et al., 2006), consistent with pre-pandemic systematic reviews (Tomlinson et al., 2018; Unholz-Bowden et al., 2020). It is increasingly recognised that ‘acceptability’ should be taken into account when evaluating and implementing healthcare, to achieve the best clinical outcome in the context of available resources (Sekhon et al., 2017) and to attain ethical standards respectful of clients. One indicator of acceptability is dropout rates in interventions, which, across studies included in this review, were generally low. A few studies used social validity measures, determining acceptability for individuals (Winett et al., 1991).

However, ABA literature has high prevalence of conflict of interest in published studies (Bottema-Beutel & Crowley., 2021; Devita-Raeburn, 2016; Wilkenfeld & McCarthy, 2020) and autistic people and allies caution about harmful ABA experiences (Kirkham et al., 2017). Given the high prevalence of ABA studies in this review, it is imperative any future behavioural studies follow rigorous scientific methods, and that autistic people’s experiences are foregrounded and researched. Any research should include ways of evaluating autistic peoples’ experiences. Engagement with the autistic community, individuals and families is paramount.

How was risk managed?

There was limited information on risk management. Although risk management via telehealth has been given some consideration in literature with the general population (Edmunds et al., 2017; Kramer et al, 2016), there exists no universal framework. To our knowledge, prior to the pandemic, there were no publications on managing risk with autistic people via telehealth. With this in mind, the guide published by (Yi & Dixon, 2021) could be disseminated to services working with autistic people over telehealth. There should be efforts to co-create up-to-date ethical guidelines.

What were the barriers to telehealth services?

Potential autism-specific access barriers were suggested. Two studies highlighted perceived increases in social communication difficulties over telehealth, including, heightened pressures on non-verbal communications, increased sensory difficulties and cognitive factors including information processing. These studies reflect many

of the barriers previously identified in literature investigating in-person healthcare (Nicolaidis et al., 2015; Mason et al., 2019; Mason et al., 2021;)

Professionals shared concerns telehealth delivery could exacerbate healthcare disparities, with lack of provisions resulting in further marginalisation of autistic people (90). On a wider scale, services could see an exacerbation in pre-existing challenges, including delays for autism services (Jones et al., 2014). Given the current reliance on telehealth, it is essential that more research is conducted in a timely manner to investigate the exacerbation of systemic barriers.

The authors met to discuss the findings presented in this paper alongside the findings from an interview study on the same topic (Ali, et al. 2022) conducted contemporaneously. The study authors included researchers, clinicians and health policymakers who collaboratively produced a list of recommendations which may help inform service design, and these are presented in Table 6.

[INSERT TABLE 6 HERE]

Methodological Quality of Studies

Coinciding with a pre-pandemic review (Ferguson et al., 2019), the methodological quality of studies was generally low, especially in studies evaluating interventions. Sample sizes were small and lacked diversity. Other than one RCT, which lost its control group (Yi & Dixon, 2021), no other studies included controls. In the absence of this, it is difficult to conclude whether changes are due to the intervention, or other factors. There was also limited information on how confounders were controlled for.

Limitations

Firstly, although grey literature sources provide beneficial insights, it is important to acknowledge that they have not been peer reviewed. Secondly, MMAT indicated variability in research quality. Although scoping reviews are less restricted by methodological quality, it would be beneficial for a systematic review to follow this paper. Lastly, most studies were carried out in high-income countries (United States of America and to a lesser degree, the UK), impacting on generalisability.

[INSERT TABLE 3 HERE]

Conclusion

This scoping review explored the evidence base related to telehealth services with autistic people during the COVID-19 pandemic. There was large disruption to services. The most evaluated interventions were

behavioural (including ABA). However, studies appeared of poor quality, and little attention was paid to how autistic people experienced these interventions. Due to variability in autistic people's needs, and the barriers identified, telehealth for autistic people should be considered on an individual basis, regularly reviewed. Future studies should include diverse samples and explore telehealth-delivered physical and mental health services. Engagement with autistic communities in this research is essential in creating effective and efficient healthcare.

Table 1. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	4
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	4-5
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	4
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	4
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	5
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	5
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	5

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	MMAT - see table 5
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	5
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	Figure 1 (page 5 / 18)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	5
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	MMAT - see table 5 for a full copy of assigned codes
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	Tables 2 and 3 (page 12 / 19-24)
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	6-12
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	13
Limitations	20	Discuss the limitations of the scoping review process.	17
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	17
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	17

Table 2.

Published Literature Search Strings (MEDLINE)

First search: All search terms relating to: Autism AND Telehealth. Filtered between 2020 – 2021

Second search: All search terms relating to Autism AND Telehealth AND COVID

Autism Search Terms:

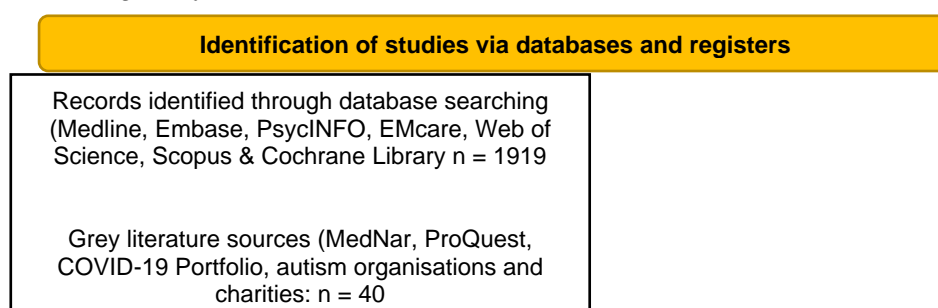
Asperger*, Autis*, child developmental disorders, pervasive/, child development* disor*, ASD, ASC, neurodevelopmental disorders/, neurodevelopmental dis*, Pervasive development*, autism spectrum condition*, development* dis*, development* disability*

Telehealth search terms:

Telehealth, tele-health, telemedicine/, telemedic*, tele-medic* telepractice, teletherapy, telecommunications, telerehabilitation, "remote therapy", "remote medicine", "remote service", remote consultation/, remote intervention, remote rehabilitation, mobile consultation, mobile intervention, mobile rehabilitation, virtual consultation, virtual intervention, virtual rehabilitation, telecare, telepsychiatry, mhealthFh, m-health, ehealth, e-health, digital therapy, digital health, online therapy, online services, teleconsultation, tele-consultation, tele consultation videoconferenc*, video-confernc*, mobile health, telemental, electronic health, m-mental, mmental, or e-mental or emental, digital mental*, electronic mental* , computer-assisted therap*, video conferencing, teleconference, teleconference*

COVID Search terms (NICE, 2020):

exp coronavirus/, COVID-19/, SARS-CoV-2/, severe acute respiratory syndrome*, ((corona* or corono*) adj1 (virus* or viral* or virinae*)), coronavirus* or coronavirinae* or Coronavirus* or Coronovirus* or Wuhan* or Hubei* or Huanan or "2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCov or "HCoV-19" or HCoV19 or CoV or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncover or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese*), (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*") adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)), (outbreak* or wildlife* or pandemic* or epidemic*) and (China* or Chinese* or Huanan*)

Figure 1
PRISMA Flow Diagram of Reviewed Studies


			questions ?					and interpretat ion?
McDevitt	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Rothman	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Turan	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pellicano	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Randomised Controlled Trials (RCT)								
First author	Year	S1. Are there clear research questions?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? Can't tell
Yi & Dixon	2020	Yes	Yes	Can't tell	Yes	No	No	Can't tell
Non Randomised Studies								
First author	Year	S1. Are there clear research questions?	2.1. Is randomization appropriately performed?	3.1. Are the participants representative of the target population?	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	3.3. Are there complete outcome data?	3.4. Are the confounders accounted for in the design and analysis?	3.5. During the study period, is the intervention administered (or exposure occurred) as intended? Yes
Cihon	2021	Yes	Yes	No	No	No	No	Yes
Ferguson	2020	Yes	Yes	No	Yes	Yes	No	Yes
Gerow	2021a	Yes	Yes	No	Yes	Yes	No	Yes
Gerow	2021b	Yes	Yes	No	Yes	Can't tell	No	Yes
Kunze	2020	Yes	Yes	No	Yes	Yes	No	Yes
Shawler	2021	Yes	Yes	No	Yes	Yes	No	Yes
Singh	2021	Yes	Yes	No	Yes	Yes	No	Yes
Sivaraman	2021	Yes	Yes	No	Yes	Yes	No	Yes
Ura	2021	Yes	Yes	Yes	Yes	No	No	Yes
Andrews	2021	Yes	Yes	No	Yes	No	No	No
Boutain	2020	Yes	Yes	No	Yes	Yes	No	Yes
Nohelty	2020	Yes	Yes	No	Yes	Yes	No	Can't tell
Quantitative Descriptive Studies								

First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Adamou	2021	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Bal	2021	Yes	Yes	Yes	No	Yes	Can't tell	Yes
Pollard	2021	Yes	Yes	Yes	No	Yes	Yes	Yes
White	2021a	Yes	Yes	Yes	Yes	Yes	No	Yes
Mixed Methods Studies								
First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
Spain	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
O'Brian	2021	Yes	Yes	Yes	Yes	No	Yes	Yes
Samadi	2020	Yes	Yes	Yes	Yes	Yes	Yes	No
Wagner	2021	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell
White	2021b	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bundy	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jacques	2021	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell

Table 4.*Papers Describing the Shift to Telehealth and its Effects on Autistic People*

Author Country	(year)	Literature Type	Methodology	Participant Characteristics	Technology Used	Service Provided
Adamou et al., UK	(2021)	Peer reviewed, published	Survey	117 service users of autism and ADHD diagnostic pathways	Telephone, videoconferencing and combination of the two	Service- users who had been assessed by autism and ADHD assessment services
Aranki et al., US	(2022)	Peer reviewed, published	Non- experimental , archival	200 autistic children (100 accepted telehealth, 100 declined telehealth adults with autism (18-74yrs)	Not specified	Archival data. All service-users had previously accessed ABA intervention in- person
Bal et al., US	(2021)	Peer reviewed, published	Online Survey	adults with autism (18-74yrs)	Not specified – 'online service'	Not specified. However, the majority reported accessing MH services prior to the pandemic, suggesting MH support are likely to be the services mostly utilised
Bhat US	(2021)	Peer reviewed, published	Online survey	9249 parents of autistic children	Not specified, mention of videoconferencing	Not specified
Bundy et al., UK	(2022)	Peer reviewed, published	Online Survey	133 autistic adults (20-73yrs).	Not specified, but some mention of telephone, videoconferencing and texts	Not specified

Gibbs et al., (2021) Australia	Peer reviewed, published	Online survey	16 autistic adults, 56 carers of autistic children and adults	Not specified, mention of videoconferencing	Tele-assessments
Harris et al., (2021) US	Peer reviewed, published	Interviews	7 autistic adults, 12 caregivers of autistic adults	Not specified, mention of videoconferencing	Not specified
Jacques et al., (2021) Canada	Peer reviewed, published	Online Survey	109 parents of autistic children (2.6–18 years) and 56 autistic children (5.75–18 years)	Not specified	Not specified
Johnsson & Bulkeley (2021) Australia	Peer reviewed, published	Online survey	141 allied health practitioners, 806 autistic people (unclear on age)	Videoconferencing	Tele-therapy with allied health professionals
Logrieco et al., (2022) Italy	Peer reviewed, published	Online survey	243 parents of autistic children (2-15yrs)	Not specified	ABA interventions, Naturalistic Developmental Behavioural Interventions (NDBI), parent training (PT), Parent-mediated interventions (PMIs), non-specific interventions for autism
Pellicano et al., (2022) Australia	Peer reviewed, published	In-depth interviews	131 autistic people and families (35 autistic adults, 80 parents of autistic children and 16 young autistic people aged between 12 and 18 years). 4% ID,	Not specified	Not specified
Samadi et al., (2020) Iran	Peer reviewed, published	Non randomised experimental	336 parents of autistic children. Mean age 8yrs. Dual diagnoses incl. ADHD, CP and ID (45%)	Mobile application	30 day-care centres in Iran

Spain et al., (2021) UK	Peer reviewed, published	Online Survey	Professionals working in clinical educational and academic settings with autistic people – include views of clients and some direct quotes. Professionals: psychologists, SLT, OT, Nurses, psychological therapists, medical doctor, unqualified staff	Not specified, although Zoom mentioned	Not specified
Thang et al., (2021) US	Grey literature, Conference abstract	Interviews	10 essential service providers and 4 clients of the community centre for adults with NDD	Videoconferencing	Mental health support, community and vocational support
White et al., (2021a) US	Peer reviewed, published	Online Survey	3502 parents and carers of autistic people. Mean age 12yrs, 21% ID, 13% non-verbal	Not specified	Not specified
White et al., (2021b) US	Peer reviewed, published	Online Survey	70 caregivers of autistic children and adults. 48.6% minimally verbal, 12.9% nonverbal	Not specified	Not specified

Table 5.

Papers Describing the Type of Services Evaluated During the Pandemic

Author Country	(year)	Literature Type	Methodology	Participant Characteristics	Technology Used	Service Provided
Andrews et al. (2021)	US	Peer reviewed, published	Experimental	4 parent-child dyads	Videoconferencing	ACT plus behaviour training
Cihon et al. (2021)	US	Peer reviewed, published	Experimental	3 children with autism	Videoconferencing (zoom)	Telehealth delivery of the Cool Versus Not Cool social skills intervention
Ferguson et al. (2020)	US	Peer reviewed, published	Experimental	6 autistic children	Videoconferencing (zoom)	Discrete Trial Teaching (a implemented ABA procedure teaching 'tact relations')

Gerow et al., (2021b) US	Peer reviewed, published	Experimental	Four autistic children (5-9yrs) and parents	Videoconferencing	Total-task chaining procedure (ABA)
Gerow et al., (2021a) US	Peer reviewed, published	Experimental	7 autistic children (3-11yrs) and parents	Videoconferencing	Parent implemented Functional Analysis and Functional Communication Training.
Jonathan & Watson (2021) UK	Grey literature, Conference abstract	Descriptive	Children under 5yrs (unclear of sample size)	Videoconferencing	Diagnostic assessments
Kunze et al., (2021) US	Peer reviewed, published	Experimental	6 mother-child dyads (on ASD diagnostic waitlists)	Videoconferencing	Behavioural Interventions for Young Children on the Waitlist for an Autism Diagnosis
Boutain et al., (2020) (2020) US	Peer reviewed, published	Experimental	3 parent-child dyads (child diagnosed with autism)	Videoconferencing (GoToMeeting)	Toilet training intervention
Ludwig et al., (2021) US	Peer reviewed, published	Case series	1 17-month-old male, suspected of ASD. 1 5-year-old female suspected of ASD, 1 17-year-old female, suspected of ASD	Videoconferencing	Telehealth diagnostic assessments of ASD
Marino et al., (2022) Italy	Peer reviewed, published	Experimental	16 parents and children	Videoconferencing	Behavioural skills training
Matano et al., (2021) Japan	Peer reviewed, published	Experimental	1 parent-child dyad	Videoconferencing	Parent-Child Interaction Therapy (PCIT)
Matthews et al., (2021) UK	Peer reviewed, published	Descriptive	121 children, adolescents and adults suspected of ASD	Videoconferencing	Diagnostic assessments
McDevitt (2021) China	Peer reviewed, published	Semi-structured interviews and focus group interviews	4 trainers, 294 parents of autistic children	Mobile application	12-week online Parent education and training programme (PET)
Nasir et al., (2021) UK	Grey literature, Conference abstract	Descriptive	60 Children suspected of ASD		
Nohelty et al., (2021), US	Peer reviewed, published	Experimental	7 autistic children (4-16yrs)	Videoconferencing	DTT and Natural Environment Teaching

O'Brian et al., (2021). US	Peer reviewed, published	Case study (Mixed Methods)	3-year-old autistic non-verbal female, with autism and moderate intellectual disability and parents	Videoconferencing	Functional Analysis and Functional Communication Training
Pollard et al., (2021), US	Peer reviewed, published	Archival data	17 children and adults with autism (3-29yrs)	Videoconferencing	ABA directly to individuals of varying needs.
Rothman, (2021), unclear	Peer reviewed, published	Case study	1 adult with autism and Downs Syndrome female, early 20s)	Videoconferencing (zoom and Microsoft teams)	Dance psychotherapy intervention
Samadi et al., (2020) Iran	Peer reviewed, published	Experimental	336 caregivers of autistic children	Mobile application	Online support and training for parents
Sengupta et al., (2021) India	Peer reviewed, published	Experimental	12 parents of autistic children (1-6 yrs)	Videoconferencing	Parent-mediated intervention (Project ImPACT)
Shanok et al., (2021) US	Peer reviewed, published	Experimental	29 autistic children and families	Videoconferencing	RUBI Parent Training Programme
Shawler et al., (2021) US	Peer reviewed, published	Case study	Caregiver and adult with autism, Downs Syndrome, Intellectual Disability (Severe to profound) and Mixed Expressive-Receptive Disorder	Videoconferencing (zoom)	Functional Analysis and Functional Communication Training
Singh et al., (2021) Unclear	Peer reviewed, published	Experimental	Community-based mental health team and school	Videoconferencing (Zoom)	Behaviour support plan and informed mindfulness-based Soles of Feet programme SOF)
Sivaraman et al., (2021) Belgium, India, Mexico and Costa Rica	Peer reviewed, published	Experimental	6 children with autism and their families and / or therapists	Video conferencing,	Behavioural intervention to teach face mask wearing to children
Turan et al., (2020) Turkey	Peer reviewed, published	Case study	1 autistic child (11yrs male) and family	Mobile application – Special Children Support System (SPCC)	Behavioural analysis: Mobile application providing behavioural support – Special children support system
Ura et al., (2021) US	Peer reviewed, published	Experimental	41 parents of children (2-	Videoconferencing	Naturalistic instruction and behavioural strategies to

			18yrs) with autism		increase social communication skills
Vallefuoco et al., (2021) Italy	Peer reviewed, published	Experimental	30 participants (18 therapists and 12 parents of children with ASD)	Online platform	Preliminary user-test for a digital platform for ASD families, health services and schools
Wagner et al., (2020) unclear	Peer reviewed, published	Experimental	204 Carers and children (under 3 yrs) with developmental concerns	Videoconferencing (Zoom)	TELE-ASD-PEDS evaluation of too for caregiver-medicated evaluation of ASD)- remote observations of ASD in young children
Wood de Wilde et al., (2022) Switzerland	Grey literature, pre-print	Questionnaire	45 families (majority of children diagnosed with ASD, a few suspected)	Videoconferencing	Participation and satisfaction of families as they experienced telehealth interventions
Yi & Dixon et al., (2021) US	Peer reviewed, published	RCT	14 families (7 in ACT group and 6 in control group)	Videoconferencing (Zoom or GoToMeeting)	ACT intervention to improve adherence to telehealth ABA parent training)

Table 6.*Clinical Recommendations***Deciding Whether to Offer Telehealth**

- Is it possible to provide information about telehealth prior to the beginning of the service/treatment? Is the information about telehealth given in easy-to-understand language? Can this information answer frequently asked questions and misconceptions about telehealth?
- Can an initial appointment be offered to discuss mode of delivery, client/family preference, and what is most accessible and appropriate?
- Is the autistic person, especially in the case of children, able to focus and process information for required periods of time via telehealth?
- Does the person have the technology, the internet access, and the confidence to use specified platforms?
- Does the service have the technological access and confidence to provide a telehealth service? Can additional training be sought?
- Is a hybrid approach the most appropriate, combining telehealth with in-person meetings?
- Is the autistic person highly distressed or has any additional communication difficulties that may be exacerbated by telehealth?
- Does the autistic person have privacy from where they can attend telehealth appointments? Does the client have significant concerns around data protection and/or online confidentiality?

Adapting Telehealth Delivery for Autistic Adults and/or Children

- What is the client's preferred communication method? Can writing e.g. chat, and drawing e.g. digital boards, be implemented in the session? In the case of videoconferencing, does the person prefer to have their video on or off?
 - Can clear information about online privacy, confidentiality, and data protection, be provided, as well as answers to related concerns and questions, prior to commencing appointments?
 - Can the clinician support the autistic person in the transition into and from the session (especially in the case of conducting an appointment at home)? Can the clinician provide a graded approach in introducing digital delivery, especially if the client is used to in-person services?
 - Is there a way to regularly gauge feedback from client/s to reflect and act on?
 - How is the service/clinician able to support and involve family members, partners, and friends, who may be assisting the client? How can this be balanced with respecting client's privacy?
 - Is there any background noise or feedback, or any other sound in the service/clinician's environment that may be heard or seen by the client? How can this be minimised?
-

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