

mHealth apps delivering early intervention to support parents of children with autism: a scoping review protocol

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To cite: Bharat R, Uzaina U, Yadav T, *et al.* mHealth apps delivering early intervention to support parents of children with autism: a scoping review protocol. *BMJ Paediatrics Open* 2022;**6**:e001358. doi:10.1136/bmjpo-2021-001358

► Additional supplemental material is published online only. To view, please visit the journal online (<http://dx.doi.org/10.1136/bmjpo-2021-001358>).

RB and UU are joint first authors.

Received 26 November 2021
Accepted 18 February 2022



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ABSTRACT

Objective This review aims to identify the mhealth apps delivering early intervention to support parents of children with autism spectrum disorders (ASD). We aim to explore the concept, context and methodology of implementation that is, theoretical framework, feasibility, quality of evidence, for such apps.

Background To improve outcomes for children with autism, early intervention has been found to be promising. Parental training, parent psychoeducation and parent-mediated intervention are regarded as the gold standard, to achieve early childhood development goals. Digital health technologies like tele-health, web-based services, have been used to deliver this at a reduced cost. There is little evidence about their use and efficacy in empowering parents of children with ASD.

Inclusion criteria The studies reporting the use of mhealth apps to support parents of children with ASD, in community settings, school settings, special schools, clinics, hospitals or child development centres. There will be no exclusion based on region, gender or sociocultural factors. The types of studies included will be quantitative, qualitative, mixed-methods study designs, case reports, grey literature, systematic reviews, clinical trials and studies reporting feasibility of digital mhealth applications. **Method** Using the NICE Healthcare Databases Advanced Search, we will search the following databases: MEDLINE, PUBMED, CINAHL, EMBASE, PsycINFO, Cochrane Library, EbscoHost, Sabinet, SAGE Journals, Directory of Open Access Journals, BioMed Central, Scopus, ScienceDirect. Furthermore, grey literature will be searched through Google Scholar, ShodhGanga, JSTOR, CORE, EBSCO, DOAJ, BASE. The searches will be limited to the age range of children between 2 and 6 years with ASD, and the date range is from the inception of the database to the current date. The terms for the ASD will be combined with terms for parent, early intervention and digital mhealth to identify eligible studies.

INTRODUCTION

'Autism spectrum disorder (ASD) is characterised by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, non-verbal communicative

What is already known on this topic?

- ⇒ The increasing prevalence of autism spectrum disorder can be attributed to increased awareness.
- ⇒ Early intervention and supporting parents are regarded as the gold standard to help parents in understanding the treatment and prevention of their child's various behavioural problems.

What this study hopes to add?

- ⇒ This scoping review will identify what mhealth apps are available to support parents in early intervention, including their methodology, theoretical framework, quality of evidence and what outcome measures have been evaluated.
- ⇒ This study will help identify the current gaps and future development of mhealth apps for parents of children with autism between 2 and 6 years.

behaviours used for social interaction and skills in developing, maintaining and understanding relationships (the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition).¹ The symptoms are present from early childhood and affect daily functioning, posing a greater challenge for parents and carers of children with ASD.² With continuously increasing prevalence, there are about 52 million people with autism across the globe, affecting 1%–2% of the world's population.^{3,4} This could be attributed to increased awareness among parents, carers and professionals and early identification, resulting in increased demand for services, and highly unaddressed needs pre and postdiagnosis for 70% of the children with ASD.^{5–8}

Autism research suggests that early detection and appropriate early intervention is the best way to help children with ASD.^{9,10} Early intervention can lead to improved development, behaviour and reduced symptoms.^{11,12}



Thus, imposing an increased need for dissemination and implementation of early interventions, to support children with ASD and their families.^{13–16} Early intervention has been defined as ‘the term used to describe the services and supports that are available during early years to babies and young children with developmental delays and disabilities, who are at risk of poor outcomes and their families’.^{17 18} Its primary goal has been to facilitate the acquisition of critical developmental skills and allow children to achieve independence across different environments. The time period from birth up to 6 years is considered to be the most crucial for brain development. (For detailed brain development process, refer to Human brain development. Charles A. Nelson, University of Minnesota). By intervening during this period, children will be able to meet their individual developmental and learning goals.¹⁹ Direct benefits of Early Intervention include improvement in child’s outcomes like physical, cognitive, behavioural and social and emotional development.^{17 20} Other reported benefits included increment in verbal and non-verbal abilities of children with ASD, along with improved parents and caregivers’ ability to manage and understand their child’s needs.^{21 22}

To achieve these outcomes and support, various theoretical models like Developmental Systems Model, Unified Theory Approach and Integrated Framework Model have been used for the implementation of early intervention.^{23–25} The developmental systems model is a framework for implementing community-based early intervention services. It supports children and families by addressing potential stressors related to risk and disability conditions. This allows parents to engage in positive parent–child interactions, which in turn helps children develop skills and abilities. A unified theory approach looks at the broader contexts in which families and programmes exist. As families and homes are primary nurturing contexts, strengthening relationships (parent–child, child–child, parent–practitioner, etc) is crucial to early childhood intervention. This approach emphasises the importance of adults providing children with positive experiences, so that they may learn by both acting on and observing their environment. Early childhood intervention practices informed by the unified theory approach are, therefore, individually and dynamically tailored to meet the unique needs of each child and family. The later; integrated framework model, not just focuses on parents, but on combining independent interventions, programmes and theories, into one, at different levels like in social setting, school setting and home to maximise intervention exposure, resulting in improving the targeted outcome in children. Although there is no fixed approach to the implementation of early intervention, it has been reported to be an amalgam of various theories and approaches.²⁶ Community-based early intervention through parents or carers, based on an integrated framework theory, is reported to be helpful in building a solid base for the developing brain during the most crucial period of infancy and early childhood.^{27 28}

Parent education and training (PET) is emphasised to be the priority during the early intervention and care for their children with ASD²⁹ and has resulted in significantly improving the children’s desirable behaviours, increasing children’s language/communication and cognitive abilities and reducing autism symptoms.^{30–35} PET programmes along with parent-mediated early intervention have since rapidly increased, focusing on imparting knowledge of child development, supporting parenting self-efficacy, improving communication skills, cognitive and behaviour improvements.^{36–40}

Despite the reported effectiveness of early intervention programmes at the community level, in schools and parent-based groups, it was found that there were still limitations such as a lack of trained professionals, unavailability of such services in remote areas, the time factor, cost-effectiveness, etc.^{41 42} With recent advancements made through information technologies like E-Health Services, early interventions programmes’ reach expanded and training programmes like Triple-P, IMPACT Online, etc emerged.^{43 44} These web-based programmes helped by delivering these workshops individually or together, providing more personalised care while also cutting down costs due to reduced needless time spent travelling between locations.⁴⁵

However, people depended on immobile devices such as desktop computers, network access, web cameras, to access these services.^{46 47} There are studies that found telehealth to be an effective method for promoting children’s healthy behaviours and supporting parents.^{48 49} In a recent systematic review done by Ferguson *et al*, they concluded while telehealth can be used for both diagnosis and treatment for ASD, still due to methodological problems, telehealth did not meet the criteria for being considered a true evidence-based treatment and suggested the need for more research to determine the efficacy of telehealth as a treatment model.⁵⁰

A little more than a decade ago, the term ‘mobile health’ (mhealth) was coined to describe a subset of eHealth that uses mobile technologies, including advancements in innovative applications also called mhealth apps to address health priorities.⁵¹ Although this term has been in use since 2003, few experts in the field agree on its scope and definition. According to the WHO Global Observatory for eHealth, mhealth is a ‘medical and public health practice supported by mobile devices (MD), such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices’.⁵² In addition to the MDs mentioned in this definition, smartphones, portable media players and tablet personal computers have essential applications in mhealth.⁵³ With the emergence of smartphones, and reported efficacy and feasibility of telehealth programmes, there has been seen a shift from e-health or web-based programmes to mhealth apps.⁵⁴

While the use of mHealth apps has been reported to improve health services in many medical conditions for over a decade, evidence on its use in delivering early intervention to support parents of children with ASD is limited.⁵⁵ Studies have

reported the use of mobile technology in supporting clinicians and professionals to facilitate the easier identification of autism diagnosis.^{56 57} It has been used to deliver intervention directly to individuals with ASD, for example, to deliver Cognitive Behaviour Therapy, for improving functional communication skills, toilet training, turn-taking, improving sleep routine, as a speech-generating device, for video modelling to train for transitional behaviours in schools, vocational and daily living skills, multiple-step job performance is documented.⁵⁸⁻⁶⁴ All the apps, which have been documented, are delivering a targeted intervention, to be mostly used by individual, and adolescents with ASD. There is a lack of research reporting apps for parents to be used in a community setting as a part of integrated early intervention.

With an increasing prevalence and improving technological platforms, the reach of early intervention programmes can be increased by identifying and reporting these mhealth apps. This review is part of a wider study that focuses on the development, use and feasibility of autism early intervention apps for parents. With limited evidence and very few studies on the usability, feasibility, methodological aspects of key components of such mhealth applications, there is a need for this review. Therefore, the objective will be to conduct a scoping review of mHealth applications, their concept and context of implementation, methodological framework and evidence quality. This paper also aimed to identify gaps in the literature to provide recommendations for future research. Based on the findings and scope of the current evidence, the findings of this review will also lay the foundation for the development of an early intervention app to support parents.

Following the Joanna Briggs Institute (JBI) Scoping Review Methodology, this scoping review will map the available evidence related to the concept and context of the mhealth app and report any gaps.⁶⁵ To address the research objective, we conducted an initial search of PROSPERO, MEDLINE, the Cochrane Database of Systematic Reviews and the JBI Evidence Synthesis on 10 November 2021. We found no ongoing scoping or systematic reviews on our topic of interest.

Review questions

1. What mhealth apps exist for supporting parents of children with suspected or under-diagnosis of ASD between 2 and 6 years of age?
2. Classification of the mhealth applications using National Institute for Health and Care Excellence (NICE) Evidence standards framework for digital health technologies.⁶⁶
3. What type of intervention, context and outcomes are reported and to summarise them using TiDieR checklist.⁶⁷
4. What theoretical framework has been used and reported for the development of the app?
5. What methodology for feasibility, evaluation and implementation has been used?
6. Quality and level of evidence will be reported using the evidence-based practice tool developed by the Center for Evidence-Based Practice.⁶⁸

Inclusion and exclusion criteria

The studies will be selected and excluded specifically related to the following population, concept and context criteria presented in [table 1](#).

Table 1 Predefined inclusion and exclusion criteria for identifying eligible studies

	Inclusion criteria	Exclusion criteria
Population/participants	Studies that include parents and carer of children with autism spectrum disorder between the ages of 2 years and 6 years will be included. As we are interested in reviewing the apps supporting parents in the early years, therefore the age range has been restricted. In our review, we define parents as biological parents, birth parents, carer or foster parents who have children with ASD between 2 and 6 years.	Studies reporting mhealth apps for children above the age of 6 years or adolescents will be excluded.
Concept	We define mhealth applications (apps) as applications developed for use on mobiles or smartphones, tablets, or I pads that can be easily downloaded from the Play Store or App Store. This review will consider mhealth apps that support parents during early intervention.	Web/internet-based programmes or computer-dependent programmes will be excluded.
Type of study	This scoping review will consider quantitative, qualitative, mixed-methods study designs, case reports, grey literature, systematic reviews, clinical trials and feasibility studies of mhealth applications.	Any study not reporting the use of mhealth will be excluded.
Context	This review will consider studies conducted or implemented for parents of children with ASD to provide support during the early intervention in community settings, school settings, special schools, clinics, hospitals, at home a child development centres. There will be no exclusion based on region, gender, socio-cultural or language factors.	No restriction on context
ASD, autism spectrum disorder; mhealth, mobile health; PDAs, personal digital assistants.		

METHODS

Due to the nature of the research question, a scoping review design was chosen to identify what mhealth apps are available for supporting parents with early intervention in children with ASD between 2 and 6 years of age. This scoping review will be conducted per the JBI methodology and the PRISMA extension for scoping reviews checklist and flow diagram to identify and report the findings of the scoping review.^{65 69}

Data extraction and findings of the summary table based on TiDieR checklist will be used to summarise the findings as per the review questions. We will use the Evidence Standards Framework for Digital Health Technologies developed by NICE to report the functional classification of the final mhealth apps selected for review.

Search strategy

An initial limited search of MEDLINE and PsycInfo was undertaken to identify keywords, articles on the topic. The text words in the titles, abstracts and keywords used to describe the articles helped develop a complete search strategy adapted for included databases (see online supplemental appendix I).

The search will include peer-reviewed articles in quantitative, qualitative, mixed-methods study designs, case reports, grey literature, systematic reviews, clinical trials and feasibility studies. In addition, only studies reporting the use of mhealth apps for parents of children limited to the following age groups between 2 and 6 years will be included.

The NICE Healthcare Databases Advanced Search will search the following databases with MEDLINE, PUBMED, CINAHL, EMBASE, PsycINFO, Cochrane Library, EbscoHost, Sabinet, SAGE Journals, Directory of Open Access Journals, BioMed Central, Scopus, ScienceDirect. Furthermore, grey literature will be searched through Google Scholar, ShodhGanga, JSTOR, CORE, EBSCO, DOAJ, BASE.

Study selection

Following the search, all identified records will be uploaded into a data screening sheet developed on Google sheet and searched for duplicates. Following this, titles and abstracts will then be screened by two reviewers independently for assessment against the inclusion criteria. Potentially relevant papers will be retrieved in full and screened against the population, concept and context to adhere to the inclusion criteria. The screening of the reference lists of articles selected for full-text review will be done for additional papers. The scoping review will record and report reasons for the exclusion of full-text papers that do not meet the inclusion criteria.

Patient and public involvement

The review will also consider studies reporting the involvement of parents and carers. We aim to involve parents, carers and guardians of children with ASD in the dissemination of the findings of this review. Based

on the findings, we will conduct a focus group interview involving parents and carers to inform the development of the app.

Data extraction

Data after review of the full paper will be collated using the data extraction instrument (online supplemental appendix II: Data extraction instrument). The table will include specific details about the author of the study, purpose of the study, year, origin, methodology of study including population and sample size, context, concept and target population, outcome variables with measures and key findings that relate to the scoping review question, major strengths and limitations, the parental views/feedbacks and feasibility, the theoretical framework used and reported if any.

A summary of the finding table based on all the included studies will present information as per the TiDieR checklist and will report quality and level of evidence.

The draft data extraction tool will be modified and revised as necessary while extracting data from each included paper. Modifications will be detailed in the full scoping review. Any disagreements that arise between the reviewers will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required.

Data analysis and presentation

Results will be presented visually and descriptively in tables based on the data extraction tool (online supplemental appendix II) and a summary of findings for included papers (online supplemental appendix III). The discussion and conclusions will also address potential areas for evidence synthesis and identified research gaps.

Ethics and dissemination

Ethical approval is not required; the final scoping review paper will be published in a peer-reviewed journal.

Contributors UU wrote the original draft. RB, UU, PK contributed to the conception of the study and substantively revised the protocol. RB and UU planned the initial search strategy and carried out the pilot. SN and TY developed the data extraction form. All authors RB, UU, SN, TY and PK have contributed to the scoping review protocol, methodology for screening, final analysis and interpretation of the papers and read and approved the final version.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article or uploaded as supplemental information.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those

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Appendix I: Search strategy

#MEDLINE (NICE Healthcare Databases Advanced Search). Search conducted on 06 August 2021

Search	The search strategy used in MEDLINE (NICE Healthcare Databases Advanced Search)	Records retrieved
#1	Digit* OR exp TECHNOLOGY/ OR exp ELECTRONICS/ OR exp "DIGITAL TECHNOLOGY"/ OR exp "ANALOG-DIGITAL CONVERSION"/ OR digitisa* OR digitiza* OR onlin* OR technolog* OR computeriz* OR digitaliz* OR cell phone* OR mhealth* OR mobile technology* OR smartphone* OR mHealth apps* OR digital health intervention* OR digital health technology* OR e-health* OR telehealth* OR telemedicine*	2,263,054
#2	paren* OR exp PERSONS/ OR paren*or guardi* OR famil* OR Parent training* OR psychoeducation* OR parent education* OR Parent Education Programmes* OR Parent Education Groups* OR Parent Psychoeducation* OR Parent Education Training*	178,797
#3	"AUTISM SPECTRUM DISORDER"/ OR "AUTISTIC DISORDER"/ OR "PDD"/ OR "ASPERGER"/ OR "NEURODIS"/ OR "AUTISM SPECTRUM CONDITIONS"/ OR "AUTISTIC SPECTRUM CONDITIONS"/ OR "AUTISM"/ OR "COMPLEX AUTISTIC SPECTRUM"/ OR "SOCIAL COMMUNICATION DISORDERS"/ OR "NEURODISABILITY"/ OR "AUTISTIC DISORDER"/ OR "AUTISTIC CONDITION"/ OR "ASPERGER SYNDROME"/ OR "SPECTRUM"	461,50
#4	CHILD HEALTH SERVICES"/ OR "PREVENTIVE HEALTH SERVICES"/ OR "EARLY INTERVENTION, EDUCATIONAL"	88604
#5	COMBINED- (1 AND 2 AND 3 AND 4)	879

Appendix II: Data extraction instrument												
<i>Author (s) (Year)</i>	<i>Purpose of study/paper</i>	<i>Origin</i>	<i>Population and sample size</i>	<i>Methodology</i>	<i>Context</i>	<i>Concept</i>	<i>Classification as per the NICE Evidence standards framework for digital health technologies</i>	<i>Outcome variables with Measures</i>	<i>Key findings that relate to the scoping review question</i>	<i>Major strengths and limitations</i>	<i>Parental views/feedbacks</i>	<i>Theoretical framework</i>

Appendix III: Summary of Finding Table reporting mHealth app-based Interventions as per TIDieR Checklist													
	BRIEF NAME	WHY	WHAT		WHO PROVIDED	HOW	WHERE	WHEN and HOW	TAILORING	MODIFICATIONS	HOW WELL		Quality & Level of Evidence
Title	1. Provide the name or a phrase that describes the intervention.	2. Describe any rationale, theory, or goal of the elements essential to the intervention	3. Materials: Describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (e.g. online appendix, URL).	4: Procedures: Describe each of the procedures, activities, and/or processes used in the intervention, including any enabling or support activities.	5. For each category of intervention provider (e.g., psychologist, nursing assistant), describe their expertise, background and any specific training given.	6. Describe the modes of delivery (e.g., face-to-face or other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.	7. Describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.	MUCH 8. Describe the number of times the intervention was delivered and over what period including the number of sessions, their schedule, and their duration, intensity or dose.	9. If the intervention was planned to be personalised, titrated, or adapted, then describe what, why, when, and how.	10. If the intervention was modified during the study, describe the changes (what, why, when, and how).	11. Planned: If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.	Actual: If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.	