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## REVIEW

# Child, family and professional views on valued communication outcomes for non-verbal children with neurodisability: A qualitative meta-synthesis

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## Abstract

**Background:** There are many children with neurodisability who are unable to rely on speech to communicate and so use a range of augmentative and alternative communication (AAC) methods and strategies to get their message across. Current instruments designed to measure the outcomes of speech and language therapy interventions lack specific attention to communication outcomes that are valued by non-verbal children with neurodisability, their families and support networks. This qualitative meta-synthesis was conducted to identify valued communication outcomes to inform the next stage of developing a novel outcome measure.

**Aims:** To systematically identify and synthesise the qualitative evidence about which communication outcomes non-verbal children with neurodisability, their family members, healthcare professionals and educators think are important to achieve, specifically which communication outcomes are most valued by: (1) non-verbal children with neurodisability; (2) parents or other family members of non-verbal children with neurodisability; and (3) professionals who work with non-verbal children with neurodisability.

**Methods & Procedures:** A systematic search of bibliographic databases and the grey literature was undertaken to identify qualitative studies that included evidence of views expressed by children, family members, healthcare professionals and educators on outcomes in relation to the communication of non-verbal children with neurodisability. All papers meeting the inclusion criteria were quality appraised using the Critical Appraisal Skills Programme Qualitative checklist, although none were excluded on this basis. The data synthesis involved organising coded data into descriptive themes which were then synthesised into analytical themes.

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**Main Contribution:** We found 47 papers containing qualitative data meeting the inclusion criteria from research situated in 14 countries. The views of 35 children, 183 parents, six other family members, 42 healthcare professionals and 18 educators are represented in the review. The included studies contained very few data reported by children themselves; most data were provided by adults, especially parents. Three main analytical themes were identified: Experiences of communication and expectations; adapting to and acceptance of AAC; and becoming an autonomous communicator.

**Conclusions & Implications:** This meta-synthesis brings together the limited qualitative research findings about what parents, professionals and children consider are important communication outcomes for non-verbal children with neurodisability. The synthesis identifies key gaps in our knowledge about the perspectives of children and their siblings. This synthesis will inform primary research to understand valued communication outcomes in this group, and ultimately the development of a patient-reported outcome measure (PROM) that can be used to demonstrate the effect of interventions, at both clinical and service levels.

#### KEYWORDS

children, neurodisability, non-verbal, outcomes, qualitative meta-synthesis

#### WHAT THIS PAPER ADDS

*What is already known on the subject*

- Studies of children with cerebral palsy and autism spectrum disorder indicate that at least 25% of children with these conditions are non-verbal. Studies on the health outcomes of children with neurodisability have identified that communication is rated as important by parents and health professionals. There is an evidence gap about which communication outcomes are important to non-verbal children, their families and the people who work with them.

*What this paper adds to the existing knowledge*

- This is the first synthesis of data that relates to communication outcomes for non-verbal children with neurodisability. This qualitative meta-synthesis identifies from previous research studies the communication outcomes valued by children who are non-verbal, their parents or other family members, and the professionals who work with them. The findings will be used to shape further primary research and the development of a novel patient-reported communication outcome measure for non-verbal children with neurodisability. It is anticipated that this will be used by clinicians to measure the effect of their interventions.

*What are the practical and clinical implications of this work?*

- Clinicians should reflect on parents' experiences of communication with their child before discussing potential outcomes with them. Gaining insight into the lived experience of communication for non-verbal children and their families

will help healthcare professionals to understand which goals are important to them and why. Few studies have specifically asked which communication outcomes are important for non-verbal children with neurodisability. Further exploration is needed to determine which communication outcomes non-verbal children and their families would like to see included in outcome measures used by clinicians.

## INTRODUCTION

Developmental disabilities, including neurodevelopmental disorders and congenital conditions, are common in children, with an estimated prevalence of between 8% and 34% worldwide (World Health Organisation (WHO) 2023). Neurodisability is a term used to define:

A group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour. (Morris et al., 2013: 1105–1106)

Neurodisability encompasses conditions such as cerebral palsy (CP), autism spectrum disorder (ASD), acquired brain injury (ABI) and epilepsy (Morris et al., 2015). Some children have co-occurring conditions associated with multiple limitations in functioning (WHO 2023). For example, 30% of children affected by CP 'are unable to walk, 30% have a severe intellectual impairment, 28% have impaired or no speech, and 12% are blind' (Sewell et al., 2014: 1). A prevalence study conducted by the Centres for Disease Control (CDC) found 38% of children with ASD to have an intellectual disability (ID) (Baio et al., 2018). Communication is a key issue for children with neurodisability. In a study of children and young people with neurodisability and their parents, communication was seen as 'fundamental to making choices, decision-making, independence and social interaction' (Allard et al., 2014:5). Professionals also rated communication as a key area of importance (Janssens et al., 2014). Barriers to communicating with those who are not family members affect potential to gain independence, participate in school activity, and interact with the wider community (Allard et al., 2014; Rezende et al., 2022; Raghavendra et al., 2012). Children who are unable to rely on speech to communicate use a range of methods including facial expressions, natural gesture, vocalisations and sign language; some use

paper-based or electronic augmentative and alternative communication (AAC) systems (Moorcoft et al., 2019; Sennott et al., 2016).

Speech is just one element of the multifaceted domain of communication. Speech is a complex process combining the interaction of the cognitive–linguistic and motor systems (Hanley et al., 2022). Studies of children with CP and ASD indicate that about 25–30% with these conditions do not speak (Mei et al., 2016; Norrelgen et al., 2015). Prevalence data are not available for the total population of children with neurodisability. Some children have unintelligible speech due to a motor disorder (Pennington et al., 2013). Others have cognitive, linguistic, social and sensory impairments as well as reduced speech intelligibility impacting on communication (Chadwick et al., 2019; Mei et al., 2015; Norrelgen et al., 2015; Watson & Pennington, 2015). There is no single factor or mechanism to identify why some autistic children do not develop functional speech (La Valle et al., 2021; Posar & Visconti, 2022; Tager-Flusberg & Kasari, 2013). It has been suggested that autistic children who remain non-verbal are more likely to have an ID than autistic children who use speech (Norrelgen et al., 2015).

There has yet to be a consensus about how to describe children who express themselves using methods other than speech (Potter, 2016). Terms such as 'non-verbal' and 'minimally verbal' are applied inconsistently across research studies causing difficulty in making inferences about the broader population of children with neurodisability (Bal et al., 2016; Koegel et al., 2020; Posar & Visconti, 2022; Tager-Flusberg & Kasari, 2013). Other terms used to distinguish children who speak from those who do not include 'nonvocal' (Mei et al., 2020a), 'with limited speech' (Costantino & Bonati, 2014), 'who do not use speech for communication' (Rabiee et al., 2005b), 'minimally verbal' (Bal et al., 2016; Mei et al., 2020b; Tager-Flusberg & Kasari, 2013) or 'non-speaking' (Murray et al., 2020; Rezende et al., 2022). However, the term 'non-verbal' has frequently been used in a clinical context and research studies to describe children who do not have intelligible speech (Alsayedhassan et al., 2021; Mei et al., 2016; Pickering et al., 2023; Raffety et al., 2019; Ryan & Renzoni, 2019). In this

report, we will use the term 'non-verbal' to describe a heterogeneous population of children with neurodisability who use no or few consistent verbal words (Koegel et al., 2020; Norrelgen et al., 2015; Posar & Visconti, 2022).

Speech and language therapists often perform a key role in the delivery of interventions to non-verbal children with neurodisability which may take the form of direct therapy, training of communication partners and environmental modifications (Goldbart et al., 2014; Pennington et al., 2005; Sutherland et al., 2005). However, measuring the effect of interventions in this population is problematic. Outcome measures are designed to capture whether a person using a service has experienced meaningful change following an intervention. Such measures can also be used to provide information for funders and commissioners on the efficacy of the interventions used and whether service objectives have been met (Allied Health Professions Outcome Measures Working Group, 2019; Enderby & John, 2015; WHO, 1988). A patient-reported outcome measure (PROM) is used when the patient's perspective is sought on the effect of a treatment (Food and Drug Administration (FDA), 2009). Previous research has highlighted the paucity of tools designed to evaluate the effect of interventions on communication outcomes in children with neurodisability (Morris et al., 2015). We identified one communication outcome measure for pre-school children, the Focus on the Outcomes of Communication Under Six (FOCUS) (Stonell et al., 2010) which included the views of parents of children with ASD, CP and Down syndrome during its development but the authors of this tool did not state whether any of the children were non-verbal.

The aim of this review was to synthesise the evidence about what communication outcomes for non-verbal children with neurodisability were most valued from the perspectives of non-verbal children, parents, carers and professionals, to inform the development of a PROM that can be used to measure the effect of speech and language interventions. We have followed guidelines on best practice for developing a PROM, which recommend initial gathering of information from a literature review, followed by concept elicitation with individuals from the target population (Matza et al., 2013). In this context, parents or other adults caring for a child may provide proxy reports (Matza et al., 2013; Morris et al., 2015). Specifically, we aimed to understand the literature in relation to which communication outcomes are most valued by:

- Non-verbal children with neurodisability.
- Parents or other family members of non-verbal children with neurodisability.
- Professionals who work with non-verbal children with neurodisability.

## METHODS

### Research design

The review protocol was registered on the Prospero Database, Record CRD42020182158. We conducted a qualitative meta-synthesis using the approach developed by Thomas and Harden (2008). Qualitative meta-synthesis is a term used to describe a process of combining and comparing findings across different studies to result in a higher order interpretation of these (Centre for Reviews & Dissemination, 2009; Herber & Barroso, 2020). This approach could provide a new perspective on the views of non-verbal children and the people involved in their lives, given its congruence with a critical realist stance, whereby we accept 'knowledge of reality is mediated by our perceptions and beliefs' (Barnett-Page & Thomas, 2009).

### Search strategy

We sought only studies that included qualitative findings either in qualitative research, mixed methods studies, surveys or case studies. In keeping with the aim for this to be a qualitative meta-synthesis, we searched for studies that contained evidence of views expressed by children, parents, other family members, healthcare professionals and educators on outcomes in relation to the communication of non-verbal children with neurodisability aged 4–18 years. Studies of siblings' perspectives had not been included in the protocol. We then included studies containing siblings' views having received feedback from a public involvement group for the planned subsequent primary research project following protocol registration.

The PICo (Population, Phenomena of Interest, Context) format for reviews of qualitative data (Munn et al., 2018) was used to guide the search strategy: Population: non-verbal children with neurodisability; Phenomena of Interest: opinions and views of children or parents, other family members, health and education professionals; Context: Valued communication outcomes.

The original search was completed on 24 August 2020. We updated the search in September 2023. The databases searched were MEDLINE, Embase, AMED, CINAHL, PsycINFO and Web of Science, from their inception.

MeSH headings or keywords were adapted for use in each database; an example of the search strategy used is given in Appendix A:

- Group 1 shows MeSH and keywords for children with neurodisability. This included 'Disabled Children', 'Cerebral Palsy', 'Autistic Spectrum Disorder', 'Autistic Disorder', 'Developmental Disabilities', 'Brain

Injury', 'Movement Disorders', 'Congenital, Hereditary, and Neonatal Diseases and Abnormalities', 'Nervous System Diseases' and 'Genetic Diseases'.

- Group 2 shows the MeSH or keywords in relation to non-verbal: 'Communication Disorders', 'Language Disorders' and 'Language Developmental Disorders'.
- Group 3 shows the MeSH or keywords in relation to communication outcomes: 'Attitudes' which captures thoughts, perceptions, opinions, feelings or beliefs.

We searched the grey literature (including theses) in the following search engines: Open Grey, Mednar, King's Fund, JISC library, Google Scholar, CORE, BASE.

We also examined reference lists from all papers identified for inclusion to identify additional studies (backward searching).

## Inclusion and exclusion criteria

We sought studies about children with neurodisability using the definition provided by Morris et al. (2013). Studies were considered for inclusion if they referenced in the title or abstract: non-verbal children, minimally verbal children, non-speaking children, children who do not use speech to communicate, or AAC users. We included studies where participants had a hearing impairment as well as neurodisability. We included studies relating to children and young people aged 4–18, because before the age of 4, children may not have been considered as non-verbal or minimally verbal (Anderson et al., 2007; Norrelgen et al., 2015; Tager-Flusberg & Kasari, 2013). We appreciate that some children may go on to develop functional speech well after this age (McDaniel & Schuele, 2021). Studies were excluded if they related solely to children with hearing disorders who did not have a neurodisability. We excluded studies containing exclusively quantitative data.

## Study selection

The lead review author (K.B.) independently conducted all study searches. Two review authors, the lead author (K.B.) and a second one of the of review authors (either L.F., T.P.H., V.A.) independently screened all titles and abstracts for eligibility against the review criteria. Duplicated studies were removed and full texts were obtained by the lead author for each paper meeting the inclusion criteria and for any for which there was uncertainty. The lead author and two of the review authors (L.F., T.P.H., V.A.) then independently reviewed all full texts to determine eligibility. Disagreements on inclusion were resolved through discus-

sion with a third reviewer (L.F. or V.A.). A record was kept of the decision made for each full text obtained. All papers meeting the study's inclusion criteria were quality appraised using the Critical Appraisal Skills Programme (CASP) Qualitative checklist (Critical Appraisal Skills Programme, 2018) by the lead author and 20% of these by a second author (L.F.). A decision was made at the outset not to have a quality threshold to avoid losing potentially valuable data. We report the findings but did not calculate scores, because the checklists were designed to be used as educational pedagogic tools rather than a scoring system (Critical Appraisal Skills Programme, 2018). The process of quality appraisal gave us an overview of the quality of the included studies (Ring et al., 2011; Williams et al., 2020).

## Data extraction and synthesis

Full texts of included papers were uploaded to NVivo 12 by the lead author K.B. who undertook data extraction, coding and theme development, supported by V.A. K.B. has a clinical background in paediatric speech and language therapy and VA as an occupational therapist. Their different clinical experiences added rigour to the process through challenging and reflecting on each other's views and decision-making, to stay grounded in the data. A summary of the work undertaken was then discussed in supervision meetings with all reviewers (L.F., T.P.H., V.A., D.S.) at least monthly. In some papers there were limited data on individual characteristics of participants; in these cases, based on clinical experience the lead author made a judgment as to whether the quote was more likely than not to relate to a non-verbal child of the age group under consideration. We followed Sandelowski and Barroso's (2002) recommendation of keeping a record as to whether the data coded was a direct quotation from a participant or comment by an author in the results section of the paper. As suggested by Soilemezi and Linceviciute (2018), the relevance of the data was considered in terms of country of origin, age of children, diagnosis and type of participant.

Stage 1, *coding*, involved descriptive categorization of the data (Thomas & Harden, 2008). All text relating to the review questions was coded verbatim, for example 'We would like him to talk as much as any other person' (Pugh, 2015: 88) (parent perspective) was coded under [speech and verbal communication]. Using NVivo's case classification feature, each extract of text was assigned to an individual case set up for each participant in the study. Demographic information was checked for each participant and the case detailed each participant's age group, country, role and, if available, the type of neurodisability of child(ren). Papers that included both verbal and non-verbal children required close scrutiny to distinguish between communication

outcomes for each group. Comments by authors relevant to the review question were also extracted from the results and discussion sections of the publications. Sentences or phrases were coded in NVivo 12 according to meaning and content. The initial codes were created inductively and directly from the data in an iterative process rather than use of a pre-existing framework (Braun & Clarke, 2021).

In stage 2, *developing descriptive themes*, the codes were grouped together to form descriptive codes, and given a full description under 'node properties' (Thomas & Harden, 2008). Further amendments were made to the coding framework over seven months; four different versions were drafted and discussed between the reviewers before the final version was agreed. In stage 3, *generating analytical themes*, two reviewers (K.B. and V.A.) independently examined the descriptive themes and synthesised them into analytical themes, commensurate with the 'third order interpretations' to 'go beyond the content of original studies' (Thomas & Harden, 2008: 7). It was important at this stage to ensure rigour by continually referring back to the coding undertaken in NVivo in the first and second stages. The Concept Map function in NVivo 12 was used to help visualize the themes and discussed as a team over several months, before the final and fourth iteration was consolidated.

## RESULTS

The search yielded a total of 1104 publications from which 70 duplicates were removed and 693 were excluded on the basis of title and abstract. This left 341 publications for which full texts were sought, of which 16 could not be retrieved: seven of these were books, three were reports that were no longer publicly available, and six could not be found even after contacting the authors. A further 52 publications were identified from citation searching. In total, full texts of 377 publications were considered for inclusion. Of these, 47 publications (Table 2) met the inclusion criteria and were included in the review. Figure 1 shows the PRISMA flow diagram (Page et al., 2021).

In total, 285 participants were represented in the 47 papers (35 children, 183 parents, five siblings, two other family members, 34 speech and language therapists, five other therapists, three nurses, and 18 teachers and teaching assistants). Data from 41 authors were also analysed.

Table 1 summaries the types of neurodisability among the parent and child participants. The most common type of neurodisability was CP. There were 58 parents of children with CP (and 19 children with CP), 36 parents of autistic children (and only one autistic child), and eight parents of children with learning or ID (5 children with moderate or severe learning disability) included across the

studies. However, when comparing the data across these participant groups, the analysis found that the views of parents of children with CP, ASD or ID were similar and so we were confident that the perspectives of parents could be combined.

The 47 studies were carried out in 14 different countries: Australia (6), Austria (1), Brazil (1), Canada (3), Finland (1), Hungary (1), Kenya (1), Korea (1), Malaysia (1), Malta (1), Sri Lanka (1), Sweden (1), UK (21) and United States (7). Table 2 provides a description of the 47 studies in terms of aims, analysis, and participants. Eight of the papers, by Allard et al. (2014); Clarke et al. (2011); Gona et al. (2014); Janssens et al. (2014), Morris et al. (2014); Mei et al. (2015); Morris et al. (2015); and Beresford et al. (2018), used the ICF (WHO, 2001) or children and youth version (ICF-CY; WHO, 2007) in the study design or mapped their data to these.

Table S1 in the Supporting Information section shows the results of quality assessment of the included papers. The quality of the studies was moderate to high. We encountered many different terms to describe participants in the studies, including: non-verbal (Cowan, 2013), children who do not use speech for communication (Rabiee et al., 2005a), non-speaking (Murray et al., 2020; Rezende et al., 2022), complex communication needs (Hettiarachchi et al., 2020; Moorcroft et al., 2019; Park, 2020), minimally verbal (Trembath et al., 2021), and children who use little or no speech (Gona et al., 2014; Marshall & Goldbart, 2008). In few studies were the terms clearly defined or the inclusion criteria clear.

The synthesis resulted in the generation of three themes and nine sub-themes. The three main themes were: Experiences of communication and expectations; adapting to and acceptance of AAC; and becoming an autonomous communicator. Table 3 sets out the themes, sub-themes and concepts and lists the studies contributing to the development of each concept.

### Theme 1: Experiences of communication and expectations

This theme set the scene for understanding the nature and impact of a communication disability. The development of speech remained a goal for many parents. The first sub-theme provided accounts of what it is like to have or be a child who does not use speech to communicate (1.1 being a non-verbal child). The second sub-theme outlined what was important for non-verbal children to be able to communicate (1.2 understanding the child's views). The third sub-theme provided participants' opinions on how they saw communication developing in the long term (1.3 aspirations for the future).

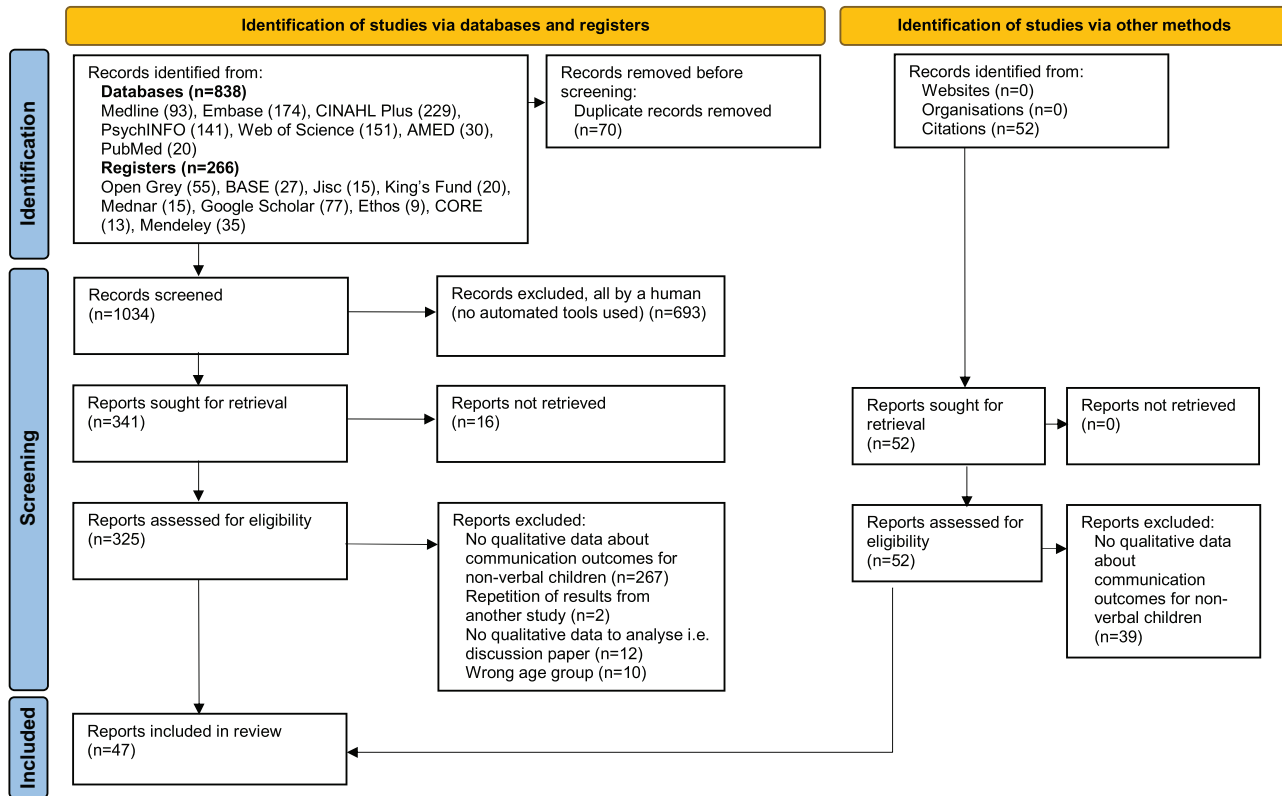


FIGURE 1 PRISMA flow diagram.

TABLE 1 Summary of participant data (children and parents).

Type of neurodisability of the child	Number of participants: child	Number of participants: Parent
Acquired brain injury	–	7
Autism spectrum disorder	1	36
Cerebral palsy	19	58
Chromosomal/genetic abnormality	2	12
Global developmental delay	–	4
Moderate or severe learning disability	5	8
Other type of neurodisability or more than one condition	–	13
Type of neurodisability not specified for individual participant	8	45
Total	35	183

## Being a non-verbal child

This sub-theme contained data on parents' feelings when it became evident that their child's speech would not follow the typical pattern of development. For some parents, though, the diagnosis of a condition such as CP meant they could plan for the future with more certainty, although a sense of grief and loss ensued when they envisioned their

child's future life. The significance of having a child who does not speak was expressed by parents, for example:

Robin cannot walk cannot use his hands can't feed himself can't dress himself but I would say that pales into insignificance. His communication disability is definitely the biggest one. (Marshall and Goldbart, 2008: 203, parent)



TABLE 2 Description of studies included in the review.

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Agius (2019)	An exploration of factors to improve outcomes in the area of AAC interventions for children with ASC	Malta	Mixed methods: Qualitative focus group (study 4)	To consider decision-making for AAC systems for children with autism spectrum condition	Thematic analysis	ASD	Author Parent	4
Allard et al. (2014)	Key health outcomes for children and young people with neurodisability: Qualitative research with young people and parents	England	Qualitative: Focus groups and interviews	To identify key health outcomes, beyond morbidity and mortality, regarded as important in children and young people with neurodisability and their parents	Thematic analysis supported by the framework approach	ABI Attention deficit hyperactivity disorder (ADHD) ASD CP Developmental delay Down syndrome Duchenne muscular dystrophy Learning disability Other syndromes Unspecified diagnosis	Author Child Parent	2 5
Bailey et al. (2006)	Family members' perceptions of augmentative and alternative communication device use	USA	Qualitative collective case study: Focus groups and observations	To examine families' perceptions of the management and use of AAC devices at home and in junior and high school settings for youths with moderate or severe disabilities	Cross-case analysis	Moderate, severe or multiple learning difficulties	Author Parents Grandparent Sibling	4 1 1

(Continues)

TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Batorowicz et al. (2014)	Social participation of Canada school aged children who use communication aids: the views of children and parents	Canada	Qualitative interview study	To examine the views of children who use aided communication	Thematic content analysis	CP Unspecified diagnosis	Author Child Parent	2 9
Beresford et al. (2007)	Desired outcomes for children and adolescents with autistic spectrum disorders	England	Qualitative interview study	To redress the absence of disabled children's voices in the way outcomes are conceptualized and operationalized	Data were analysed by a process of data reduction, data display, and conclusion drawing and verifying	ASD	Author	N/A
Beresford et al. (2018)	Therapy interventions for children with neurodisabilities: A qualitative scoping study	England	Qualitative scoping study Descriptive case study design using qualitative interviews	(1) To describe the current practice neurodisability; (2) to explore clinical decision-making; (3) to investigate views on outcomes and their measurement; (4) to seek views on the aspects of therapy interventions that have an impact on outcomes; and (5) to elicit stakeholder views on research needs and priorities	Summaries of interviews and focus groups	ABI ASD ADHD Ataxia and dystrophy CP Complex motor disorders Communication and sensory processing needs Congenital and rare syndromes Complex epilepsy Developmental coordination disorder Down Syndrome Dyspraxia Genetic/chromosomal abnormalities Global developmental delay Hemiplegia Hydrocephalus Learning disabilities Metabolic disorders Neuromuscular conditions Spina bifida Spinal injuries	Author Parent SLT	1 2

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Borgestig et al. (2017)	Gaze-based assistive technology used in daily life by children with severe physical impairments—parents' experiences	Sweden	Qualitative interview study	To describe and explore what it means to parents when their non-verbal children with severe physical impairments receive gaze-based assistive technology to use in daily life	Hermeneutical interpretations	CP	Author Parent	7
Clarke et al. (2001)	Views of young people using augmentative and alternative communication systems	England	Qualitative focus groups and interviews	To understand attitudes and opinions of children and young people using communication aids towards the organisation of speech and language therapy, the role of SLT in school and issues about their AAC systems	Data were related to the categories of communicative competence	Moderate and severe learning difficulties	Child	4
Clarke et al. (2011)	Short term outcomes of communication aid provision	England	Qualitative interviews	To explore short-term outcomes of communication aid provision from the perspective of children with complex communication needs	Summary of findings and illustrative case study	CP Global developmental delay Trisomy 8 Worster Drought Syndrome Learning disabilities	Author Child	1
Cowan (2013)	An exploration of mothers' relationships with their young, non-verbal children with an autism spectrum disorder: A case study approach	England	Interviews and observations of mothers and children	To explore the reported relationship and observed behaviours of mothers with their young, non-verbal children who had undergone a multidisciplinary assessment for ASD and factors which may have influenced this relationship	Thematic analysis and case study methods	ASD	Author Parent	4

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
De Bortoli et al. (2011)	Complex contextual influences on the communicative interactions of students with multiple and severe disabilities	Australia	Qualitative interviews	To explore teachers' perceptions and experiences of supports and obstacles to engaging students with multiple and severe disabilities in communicative interactions at school	Interview transcripts were analysed for narrative structure and content themes	Severe learning disability and physical and sensory impairments	Author Teacher	11
Dearden (2005)	Introducing facilitated communication training: An action research project	England	Action research and case studies	To explore how facilitated communication training can be introduced for young people with severe communication impairments	Action research and case study methods	ASD Cornelia de Lange syndrome	Author	N/A
Doak (2021)	Rethinking family disengagement with augmentative alternative communication	England	Qualitative interviews	To explore the perspectives of five families of minimally verbal children on the place of AAC in their child's home communication	Reflexive thematic analysis	ASD	Author Parent	4
Gibson et al. (2017)	Assembling activity/setting participation with disabled young people	Canada	Qualitative: interviews, photo-elicitation and observations	To explore activity/setting participation ('activity' meaning leisure or play)	Multiple readings of the data, iterative coding and memoing cycles, comparative memos, concept mapping	Physical impairments designated as needing 'complex continuing care' 'due to multiple impairments and/or long-term ventilation'	Author Child	2
Goldbart et al. (2014)	Speech and language therapists' approaches to communication intervention with children and adults with profound and multiple learning disability	UK	Qualitative interviews	To explore SLTs' decision-making in communication interventions for people with profound and multiple learning disability	Conceptual content analysis	Profound and multiple learning disability	Author	N/A

(Continues)

TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Goldbart and Marshall (2004)	'Pushes and pulls' on the parents of children who use AAC	England	Qualitative interviews	To explore the lived experience of parents of children currently using, starting to use, or expected to need AAC	Thematic analysis	CP Learning disabilities Epilepsy	Author Parent	6
Gona et al. (2014)	A home-based intervention using augmentative and alternative communication (AAC) techniques in rural Kenya: What are the caregivers' experiences?	Kenya	Qualitative interviews	To explore the effects and development potential of a home-based intervention in AAC for children with complex communication needs characterized by little or no speech	Content analysis	ASD CP Global developmental delay Learning disability	Author Parent	6
Hemsley et al. (2014)	Supporting communication for children with cerebral palsy in hospital: Views of community and hospital staff	Australia	Qualitative focus groups	To explore the views of both community- and hospital-based allied health professionals and hospital nurses on: (1) their role in supporting children with CP and complex continuing needs to communicate in hospital; and (2) the children's communication needs	Thematic analysis	CP	Author SLT Other therapist Nurse	2 2 3
Hettiarachchi et al. (2020)	'Now I am a techie too'—parental perceptions of using mobile technology for communication by children with complex communication needs in the Global South	Sri Lanka	Qualitative focus groups and interviews	To explore the perceptions of parents on the use of mobile technology as AAC devices	Framework analysis	ASD CP Learning disability Developmental delay Microcephaly	Author Parent	10
Huer et al. (2001)	Conversations with Mexican Americans regarding children with disabilities and AAC	USA	Qualitative focus groups	To identify and understand issues influencing AAC practices	Content analysis	Disabilities (conditions not provided)	Author Parent	5

(Continues)

TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Janssens et al. (2014)	Health outcomes for children with neurodisability: What do professionals regard as primary targets?	England	Delphi study using open questions	To identify what aspects of health clinicians target when working with children with neurodisability, and which might be appropriate to assess the performance of health services	Data coded using the WHO International Classification of Functioning, Disability and Health for Children and Youth	Neurodisability (conditions not provided)	Author	N/A
Joginder Singh et al. (2017)	Reflections of Malaysian parents of children with developmental disabilities on their experiences with AAC	Malaysia	Qualitative interviews	To explore parents' perception of AAC and their experience when supporting their children who use AAC	Content analysis	Developmental disabilities	Author Parent	4
Lindsay (2010)	Perceptions of health care workers prescribing augmentative and alternative communication devices to children	Canada	Qualitative interviews	To explore the challenges that clinicians experience in prescribing AAC devices	Thematic analysis	Disabilities (conditions not provided)	Author SLT Other therapist	5 2
Lund and Light (2007)	Long-term outcomes for individuals who use augmentative and alternative communication: Part III—Contributing factors	USA	Qualitative interviews	To identify factors individuals who use AAC and their families and professionals felt had affected their outcomes	Qualitative coding procedures	CP	Author Parent Sibling SLT	7 1 1
Marshall and Goldbart (2008)	'Communication is everything I think.' Parenting a child who needs Augmentative and Alternative Communication (AAC)	England	Qualitative interviews	To explore the lived experience of parents of children currently using, starting to use, or expected to need AAC	Thematic analysis	CP Learning disabilities Epilepsy	Author Parent	5

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
McCord and Soto (2004)	Perceptions of AAC: An ethnographic investigation of Mexican American families	USA	Qualitative interviews and ethnographic observations and review of artefacts	To seek family perspectives regarding: (1) their interactions with and without the device; (2) their relationships with professionals regarding communication strategies developed to support their children's participation; and (3) the role of the AAC devices in community events	Constant comparison method	CP	Author Child Parent Aunt	2 3 1
Mei et al. (2015)	Activities and participation of children with cerebral palsy: Parent perspectives	Australia	Qualitative interviews	To explore parents' views of the activities and participation of children with CP with a range of communicative abilities and the factors (personal and environmental) that influenced these	Thematic analysis	CP	Parent	3
Moorcroft et al. (2021)	I've had a love-hate relationship with these PODD books': Parent perceptions of how they and their child contributed to AAC rejection and abandonment	Australia	Qualitative interviews	To explore parent perspectives on the contribution of factors associated with the family unit to the rejection or abandonment of an AAC system for their child with complex communication needs	Thematic analysis	Angelman Syndrome ASD CP ID Mowat Wilson Syndrome Rubinstein-Taybi Syndrome Undiagnosed neurological disorders	Author Parent	11

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Moorcroft et al. (2019)	Speech pathologist perspectives on the acceptance versus rejection or abandonment of AAC systems for children with complex communication needs	Australia	Qualitative interviews	To explore the experiences and perceptions of speech and language pathologists about factors that contribute to the acceptance versus rejection or abandonment of AAC systems by parents of young children with complex communication needs	Thematic Analysis	Disabilities (Conditions not provided) and Complex communication needs	Author SLT	8
Morris et al. (2015)	Meaningful health outcomes for paediatric neurodisability: Stakeholder prioritisation and appropriateness of patient reported outcome measures	England	Delphi study	To appraise which multidimensional PROMs could be used to assess health domains	Q-sorting task to discuss and rank aspects of health	ASD Neuromuscular conditions CP Epilepsy Learning difficulties	Author	N/A
Morris et al. (2014)	Informing the NHS Outcomes Framework: Evaluating meaningful health outcomes for children with neurodisability using multiple methods including systematic review, qualitative research, Delphi survey and consensus meeting (this is a full report on Morris et al., 2015)	England	Focus groups and interviews	(1) To identify key outcomes of health care for children with neurodisability from the perspectives of children, parents and professionals; (2) to critically appraise existing generic multidimensional PROMs; and (3) to examine whether or not the key outcomes might be measured by existing PROMs	Framework analysis	Neurodisability (conditions not provided)	Author Child Parent	3 8

(Continues)





TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Murray et al. (2019)	Professionals' decision-making in recommending communication aids in the UK competing considerations	UK	Qualitative focus groups	To understand the factors that specialized AAC professionals consider when recommending high-tech communication aids	Inductive thematic analysis	CP Learning disability ASD Physical disability and medical condition	SLT Other therapist Teaching assistant	7 1 1
Murray et al. (2020)	The decision-making process in recommending electronic communication aids for children and young people who are non-speaking the I-ASC mixed-methods study	UK	Qualitative focus groups and interviews	To describe symbol communication aid decisions and their impact over time (work package 3)	Framework analysis	ABI ASD CP Cerebellar atrophy Global developmental delay Mild, moderate and severe learning disability	Author SLT Teacher Teaching Assistant	1 2 1
Parette et al. (2000)	Giving families a voice in augmentative and alternative communication decision-making	USA	Qualitative focus groups and interviews	To gather information that enabled the voices of families to be heard in regard to AAC process	Theme identification and constant comparative method	Disabilities (conditions not provided)	Author	N/A
Park (2020)	Parents' experiences and acceptance factors of AAC intervention for children with complex communication needs	Korea	Qualitative interview study	To explore factors that facilitated parent acceptance of AAC intervention to identify approaches for encouraging acceptance and implementation	Constant comparative method	ABI ASD ID Language disorder Multiple disabilities	Author Parents	12
Pickl (2011)	Communication intervention in children with severe disabilities and multilingual backgrounds: Perceptions of pedagogues and parents	Austria	Qualitative study using observations and interviews	To highlight facilitating and limiting factors for effective communication interventions in school and within the family	Open coding followed by axial coding	Severe and multiple disabilities and complex communication needs	Author Parents Teacher	2 1

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Pugh (2015)	Family perspectives on augmentative and alternative communication: A constructivist grounded theory	England	Qualitative interview study	To explore, from the perspective of the child and family, the use of different AAC systems in the home and the benefits and challenges faced by children and families in integrating these into their daily lives	Followed constructivist grounded theory guidelines (initial short different AAC systems in codes, focused coding, theoretical coding)	ABI ASD Chromosomal abnormality CP Global developmental delay Learning disabilities	Author Child Parent Sibling	4 19 3
Rabeee et al. (2005a)	Desired outcomes for children and young people with complex health care needs, and children who do not use speech for communication	England	Qualitative interview study	To identify desires and aspirations of children and young people with complex health care needs as well as those who do not use speech for communication and their parents	Data reduction and display, conclusion drawing, and verification	Communication impairments Complex health care needs Severe learning disability Multiple impairments including cognitive difficulties	Author Parent	1
Rezende et al. (2022)	Parents' perceptions about the participation and communication of their children with non-speaking cerebral palsy	Brazil	Qualitative interview study	To describe aspects of participation and communication of non-speaking children and adolescents with CP in the family environment	Thematic analysis	CP	Parent	4
Salminen (2000)	Computer augmented communication in the daily life of severely disabled speech impaired children	Finland	Case studies using interviews, observations and record review	To study in greater depth the process and outcomes of computer augmented communication in real life	Narrative analysis of each individual case, followed up with a cross-case analysis	CP	Author Children Parent SLT Teacher	6 6 2 2
Schladant and Dowling (2020)	Parent perspectives on augmentative and alternative communication integration for children with Fragile X Syndrome: It starts in the home	USA	Qualitative study using interviews, observations and record review	To explore how four mother-child dyads used AAC in the home	Constant comparison Fragile X syndrome	Fragile X syndrome	Parent	4

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Serpentine et al. (2011)	Decision-making of parents of children with autism spectrum disorder concerning augmentative and alternative communication in Hungary	Hungary	Qualitative interview study	To investigate the perspectives of parents of children with ASD concerning decision-making processes about communication intervention decisions for their children	Five-step analysis procedures)	ASD	Author Parent	10
Sloper et al. (2009)	Every Child Matters outcomes: What do they mean for disabled children and young people?	England	Qualitative interview study	To explore: (1) how the components of the Every Child Matters outcomes drawing and verification are described by disabled children and their parents; and (2) whether the framework omits any aspects of disabled children's lives or aspirations	Data reduction and Every display, conclusion	ASD Cognitive and physical conditions Complex health care needs Degenerative conditions Learning disabilities	Author Child Parent	1 4
Sousa (2015)	'Crying doesn't work': USA Emotion and parental involvement of working class mothers raising children with developmental disabilities	USA	Ethnographic case studies	To explore the relationship between income and parental involvement in the education of children with developmental disabilities	Grounded theory approach	Severe developmental disabilities	Author Parent	2

(Continues)



TABLE 2 (Continued)

Author (year)	Title	Location of study	Study design	Aim of study	Analysis	Type of neurodisability	Participant role	Sample size
Tasgal (2021)	Mothers who listen with more than ears	UK	Qualitative interview study	To explore what the internal world and life experiences of the mother is like, in relation to the complex non-verbal communication with CP children	Moustakas' framework for analysis	CP	Author Parent	8
Trembath et al. (2021)	Clinician proposed predictors of spoken language outcomes for minimally verbal children with autism spectrum disorder	Australia	Qualitative focus group study	To explore insights from clinical practice that may inform efforts to understand and account for factors that predict spoken language outcomes for children with ASD who use minimal verbal language	Framework analysis	ASD	SLT	5
Wickenden (2010)	Teenage worlds, different voices: An ethnographic study of identity and the lifeworlds of disabled teenagers who use augmentative and alternative communication	England	Ethnographic study using observations and interviews	To explore identity and the 'lifeworlds' (experiences, identity, interactions) of disabled teenagers who use AAC	Themes generated iteratively	CP	Author Child Parent SLT	8 5 1



TABLE 3 Themes, subthemes and concepts.

Theme	Sub-theme	Concepts included	Studies contributing to the concept
1. Experiences of communication and expectations	1.1. Being a non-verbal child	The impact of the diagnosis and experiencing a communication disability	Batorowicz et al. (2014); De Bortoli et al. (2011); Goldbart & Marshall (2004); Gona et al. (2014); Joginder Singh et al. (2017); Lindsay (2010); Marshall & Goldbart (2008); Moorcroft et al. (2019); Moorcroft et al. (2021); Morris et al. (2014); Parette et al. (2000); Park (2020); Pugh (2015); Sloper et al. (2009); Wickenden (2010)
		Wanting the child to be able to use speech and communicate verbally	Agius (2019); Beresford et al. (2018); Cowan (2013); Doak (2021); Goldbart & Marshall (2004); Gona et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Lindsay (2010); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2019); Moorcroft et al. (2021); Park (2020); Pickl (2011); Pugh (2015); Rezende et al. (2022); Serpentine et al. (2011); Trembath et al. (2021); Wickenden (2010)
		Perspectives on 'normality'	Cowan (2013); Gona et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Lindsay (2010); Lund & Light (2007); Mei et al. (2015); Moorcroft et al. (2019); Moorcroft et al. (2021); Pickl (2011); Pugh (2015); Rabiee et al. (2005a); Sloper et al. (2009); Wickenden (2010)
	1.2. Understanding the child's views	Desire for a child to be able to express their basic needs, feelings and emotions	Agius (2019); Allard et al. (2014); Bailey et al. (2006); Borgestig et al. (2017); Clarke et al. (2001); Cowan (2013); De Bortoli et al. (2011); Doak (2021); Gona et al. (2014); Hemsley et al. (2014); Joginder Singh et al. (2017); Marshall & Goldbart (2008); McCord & Soto (2004); Mei et al. (2015); Morris et al. (2014); Murray et al. (2020); Pickl (2011); Rabiee et al. (2005a); Rezende et al. (2022); Salminen (2000); Schladant & Dowling (2020); Sloper et al. (2009); Wickenden (2010)
		'Reading the child's mind' and understanding their communication	Bailey et al. (2006); Batorowicz et al. (2014); Borgestig et al. (2017); Clarke et al. (2001); Clarke et al. (2011); Cowan (2013); Goldbart & Marshall (2004); Hemsley et al. (2014); Lund & Light (2007); Pugh (2015); Tasgal (2021); Wickenden (2010)
		Desire for child to be able to make choices and communicate yes/no for these	Allard et al. (2014); Batorowicz et al. (2014); Beresford et al. (2018); Borgestig et al. (2017); Dearden (2005); Gibson et al. (2017); Goldbart & Marshall (2004); Gona et al. (2014); Hemsley et al. (2014); Marshall & Goldbart (2008); Moorcroft et al. (2021); Morris et al. (2014); Murray et al. (2020); Pugh (2015); Rabiee et al. (2005a); Rezende et al. (2020); Tasgal (2021); Wickenden (2010)
	1.3. Aspirations for the future	Parent and child long-term expectations	Allard et al. (2014); Bailey et al. (2006); Beresford et al. (2018); Borgestig et al. (2017); Cowan (2013); De Bortoli et al. (2011); Dearden (2005); Doak (2021); Goldbart & Marshall (2004); Gona et al. (2014); Hettiarachchi et al. (2020); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Moorcroft et al. (2019); Morris et al. (2014); Murray et al. (2019); Pugh (2015); Rezende et al. (2020); Salminen (2000); Serpentine et al. (2011); Sousa (2015); Wickenden (2010)

(Continues)



TABLE 3 (Continued)

Theme	Sub-theme	Concepts included	Studies contributing to the concept
		The desire to maximize communication potential	Allard et al. (2014); Bailey et al. (2006); Beresford et al. (2018); Beresford et al. (2007); Borgestig et al. (2017); Cowan (2013); De Bortoli et al. (2011); Dearden (2005); Goldbart & Marshall (2004); Gona et al. (2014); Moorcroft et al. (2019); (Murray et al. (2019); Murray et al. (2020); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Schladant & Dowling (2020); Tasgal (2021); Trembath et al. (2021)
		The importance of achieving emotional well-being	Allard et al. (2014); Beresford et al. (2018); Clarke et al. (2011); Cowan (2013); Goldbart & Marshall (2004); Marshall & Goldbart (2008); Morris et al. (2014); Salminen (2000); Sloper et al. (2009); Tasgal (2021)
2. Adapting to and acceptance of AAC	2.1. Getting the message across	The desire to help the child communicate in the way they want	Bailey et al. (2006); Borgestig et al. (2017); Cowan (2013); De Bortoli et al. (2011); Hemsley et al. (2014); Hettiarachchi et al. (2020); Lindsay (2010); McCord & Soto (2004); Mei et al. (2015); Moorcroft et al. (2021); Pugh (2015); Rabiee et al. (2005a); Sloper et al. (2009); Tasgal (2021); Wickenden (2010)
		General attitudes towards use of AAC	Bailey et al. (2006); Beresford et al. (2018); Dearden (2005); Goldbart & Marshall (2004); Hemsley et al. (2014); Hettiarachchi et al. (2020); Joginder Singh et al. (2017); Lindsay (2010); Marshall & Goldbart (2008); Moorcroft et al. (2019); Moorcroft et al. (2021);); Morris et al. (2014); Park (2020); Pugh (2015); Serpentine et al. (2011)
	2.2. The value attached to different AAC methods	Communication books, boards, symbols and PECS	Batorowicz et al. (2014); Clarke et al. (2001, 2011); Cowan (2013); Hemsley et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Lund & Light (2007); Marshall & Goldbart (2008); Moorcroft et al. (2021); Moorcroft et al. (2019); Murray et al (2019); Pugh (2015); Salminen (2000); Serpentine et al. (2011); Tasgal (2021)
		Sign language	Doak (2021); Goldbart & Marshall (2004); Gona et al. (2014); Hemsley et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2021); Moorcroft et al. (2019); Pickl (2011); Pugh (2015)
		Use of communication aids/technology	Agius (2019); Bailey et al. (2006); Batorowicz et al. (2014); Beresford et al. (2018); Borgestig et al. (2017); Clarke et al. (2001, 2011); De Bortoli et al. (2011); Gibson et al. (2017); Goldbart & Marshall (2004); Hemsley et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2019); Moorcroft et al. (2021); Morris et al. (2014); Murray et al. (2020); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Schladant & Dowling (2020); Sloper et al. (2009); Tasgal (2021); Wickenden (2010)

(Continues)



TABLE 3 (Continued)

Theme	Sub-theme	Concepts included	Studies contributing to the concept
	2.3. Becoming a proficient AAC user	How the amount of time needed for communication impacts on outcomes	Bailey et al. (2006); Batorowicz et al. (2014); Borgestig et al. (2017); De Bortoli et al. (2011); Clarke et al. (2001); Gibson et al. (2017); Hemsley et al. (2014); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2021); Moorcroft et al. (2019); Murray et al. (2019); Park (2020); Pugh (2015); Salminen (2000); Sloper et al. (2009); Wickenden (2010)
		The impact of environmental barriers on AAC outcomes	Bailey et al. (2006); Beresford et al. (2018); De Bortoli et al. (2011); Goldbart et al. (2014); Hemsley et al. (2014); Joginder Singh et al. (2017); Lindsay (2010); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2021); Moorcroft et al. (2019); Pickl (2011); Pugh (2015); Salminen (2000); Sloper et al. (2009)
		The desire to achieve 'communication competence'	Bailey et al. (2006); Beresford et al. (2018); Borgestig et al. (2017); De Bortoli et al. (2011); Dearden (2005); Goldbart & Marshall (2004); Huer et al. (2001); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Moorcroft et al. (2021); Alison Moorcroft et al. (2019); Morris et al. (2014); Murray et al. (2019); Murray et al. (2020); Pickl (2011); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Serpentine et al. (2011); Sloper et al. (2009); Trembath et al. (2021)
3. Becoming an autonomous communicator	3.1. Connecting with the wider community	Desire to increase independence	Allard et al. (2014); Bailey et al. (2006); Batorowicz et al. (2014); Borgestig et al. (2017); Clarke et al. (2011); De Bortoli et al. (2011); Hemsley et al. (2014); Hettiarachchi et al. (2020); Lindsay (2010); Lund & Light (2007); Mei et al. (2015); Morris et al. (2014); Murray et al. (2020); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Schladant & Dowling (2020); Sloper et al. (2009); Tasgal (2021); Wickenden (2010)
		Desire to participate in society	Bailey et al. (2006); Batorowicz et al. (2014); B (2018); Beresford et al. (2007); Borgestig et al. (2017); Clarke et al. (2001, 2011); Cowan (2013); De Bortoli et al. (2011); Goldbart & Marshall (2004); Lund & Light (2007); Mei et al. (2015); Morris et al. (2014); Murray et al. (2019); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Sloper et al. (2009); Wickenden (2010)
		Desire to take part in conversation and social interaction	Bailey et al. (2006); Batorowicz et al. (2014); Beresford et al. (2007, 2018); Borgestig et al. (2017); Clarke et al. (2011); Cowan (2013); De Bortoli et al. (2011); Doak (2021); Goldbart & Marshall (2004); Lund & Light (2007); Mei et al. (2015); Morris et al. (2014); Murray et al. (2019); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Schladant & Dowling (2020)

(Continues)



TABLE 3 (Continued)

Theme	Sub-theme	Concepts included	Studies contributing to the concept
	3.2. The role of communication partners	How a familiar communication partner affects outcomes	Bailey et al. (2006); Batorowicz et al. (2014); De Bortoli et al. (2011); Goldbart & Marshall (2004); Gona et al. (2014); Huer et al. (2001); Marshall & Goldbart (2008); McCord & Soto (2004); Morris et al. (2014); Pickl (2011); Pugh (2015); Sloper et al. (2009); Wickenden (2010)
		The effort needed to communicate with a non-verbal child	Agius (2019); Allard et al. (2014); Bailey et al. (2006); Batorowicz et al. (2014); Beresford et al. (2007); Clarke et al. (2011); Cowan (2013); De Bortoli et al. (2011); Gibson et al. (2017); Goldbart & Marshall (2004); Hemsley et al. (2014); Hettiarachchi et al. (2020); Joginder Singh et al. (2017); Lund & Light (2007); Marshall & Goldbart (2008); McCord & Soto (2004); Mei et al. (2015); Moorcroft et al. (2021); Morris et al. (2014); Murray et al. (2019); Park (2020); Pickl (2011); Pugh (2015); Rabiee et al. (2005a); Salminen (2000); Serpentine et al. (2011); Sloper et al. (2009); Tasgal (2021); Trembath et al. (2021); Wickenden (2010)
	3.3. The team around the child	The role of parents in supporting communication outcomes	Agius (2019); Allard et al. (2014); Bailey et al. (2006); Batorowicz et al. (2014); Beresford et al. (2018); Borgestig et al. (2017); Cowan (2013); De Bortoli et al. (2011); Dearden (2005); Goldbart & Marshall (2004); Hemsley et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Marshall & Goldbart (2008); McCord & Soto (2004); Moorcroft et al. (2019); Moorcroft et al. (2021); Morris et al. (2014); Murray et al. (2020); Parette et al. (2000); Pickl (2011); Park (2020); Pugh (2015); Schladant & Dowling (2020); Sousa (2015); Tasgal (2021); Wickenden (2010)
		The role of professionals in supporting communication outcomes	Bailey et al. (2006); Beresford et al. (2018); Clarke et al. (2001); Cowan (2013); De Bortoli et al. (2011); Doak (2021); Goldbart & Marshall (2004); Gona et al. (2014); Hemsley et al. (2014); Hettiarachchi et al. (2020); Huer et al. (2001); Joginder Singh et al. (2017); Lindsay (2010); Lund & Light (2007); Marshall & Goldbart (2008); Moorcroft et al. (2019); Park (2020); Pickl (2011); Pugh (2015); Salminen (2000); Sousa (2015); Tasgal (2021); Wickenden (2010)
		Decision-making about communication priorities/goals	Bailey et al. (2006); Dearden (2005); Goldbart & Marshall (2004); Lindsay (2010); Lund & Light (2007); Marshall & Goldbart (2008); Moorcroft et al. (2019); Murray et al. (2019); Parette et al. (2000); Pugh (2015); Salminen (2000); Serpentine et al. (2011); Sloper et al. (2009); Sousa (2015)



Communication is a big part of what it means to be human for me. It is an area with Gary that I have invested hours and hours of time. I wanted to reach my son across the abyss of his brain injury. (Tasgal, 2021: 125, Mandy)

Several studies referred to the concept of being or feeling 'normal' and the notion of 'normality' (Hettiarachchi et al., 2020; Moorcroft et al., 2021; Rabiee et al., 2005a; Sloper et al., 2009; Wickenden, 2010). For instance:

I was in a position of, you could probably call it grief of not having a normal child. (Moorcroft et al., 2021: 74, parent 12)

The problem for her was that the teachers at her old school had perceived her personhood in a way that mismatched her selfhood. They were trying to make her 'normal' (e.g., write fast, talk and do not use VOCA [Voice Output Communication Aid]) in ways which she could not do, and at the same time were denying her autonomy to do other things that she felt she could. (Wickenden, 2010: 259)

One author hypothesised that for a 'child to be 'normal' involved communicating like other children' (Pugh, 2015: 250). As shown in Table 3, being able to talk was expressed as a desired outcome by parents in 15 of the studies. Not being able to talk was seen by some parents as a bigger disability than not been able to walk and they wanted to put all their efforts into helping their child achieve the goal of speech.

They say speech production will happen once the child turns 10. [...] There are mothers who hold onto hope that their children will start speaking even late. (Park, 2020: 325, #11)

My biggest wish is for him to be able to walk and talk. They told me he won't be able to walk. But they never said he won't be able to speak. And I believe he will be able to speak. (Rezende et al., 2022): 9, M3)

Interviews undertaken by Gona et al. (2014: 35–36) with caregivers in Kenya revealed how highly they valued the development of speech under the theme of 'normality' in that study.

I want her to be like others. I want her to talk. (P2)

I expect her to talk and the madness change and be able to understand. (P5)

You wake up one morning and you start talking with him and he is able to reply to you [...]. (P1)

Data from professionals also contributed to this sub-theme. Speech therapists acknowledged that they found it difficult to answer questions from parents about whether a child would speak in the future (Beresford et al., 2018; Moorcroft et al., 2019; Lindsay, 2010). They recognised that individual parents were likely to be at different stages in the grief cycle and this affected their decision-making about the optimum time to introduce AAC, which is explored further in Theme 2.

### Understanding the child's views

This sub-theme outlined the importance of a child being able to communicate their basic needs, feelings and emotions, and establish a way of communicating 'yes' and 'no'.

And they can make choices. [...] Teach them to say yes or no. [...] Just a big thing is yes and no. It's a huge thing is yes or no [...]. (Morris et al., 2014: 105, FGP1)

As shown in Table 3, 23 studies contained data from parents stating that they wanted their child to be able to express that they were hungry, thirsty, needed the toilet, felt ill, needed repositioning, or were in pain, for example:

My expectation is that anywhere, anytime, he (Joe) will be able to express basic needs, greetings, and responses to questions. (Bailey et al., 2006: 56, Bob)

Showing he needs toilet [Makaton sign], which is such a massive [thing], definitely there is no worries about being in shopping centre and then suddenly having a little incident. (Doak, 2021: 203, Albert's Mother).

Parents remarked on how distressing they found it not to be able to ascertain what their child wanted or what was upsetting them. They saw it as an important part of their role to be able to do this and a failure when they could not (Cowan, 2013; Gona et al., 2014; Morris et al., 2014; Mei et al., 2015), for example:

I just thought me being a mum for him was pretty pointless, because I couldn't comfort him I didn't know what he wanted and I didn't make him feel better. So what was my point. (Cowan, 2013 p. 170, Sally)

Parents sought a reciprocal interaction with their child in which they wanted the child to acknowledge that their presence and role in their life was important. Mothers wanted their child to be able to express the emotion of love to strengthen the bond of the relationship between them:

I would desperately love for him to turn round and say 'mummy I love you'. (Cowan, 2013 p. 202, Sheila)

I want him to say Mamma so badly I am like Mamma, Mamma, and he looks at the lips and he kind of like, but without any sound. I am like come on do it. Say something. (Doak, 2021: 206, Albert's Mother)

Nurses and allied health professionals working with children with CP and complex communication needs in hospitals expressed how important it was for children to convey that they needed the toilet or were in pain. They reported feelings of ineptitude when they could not determine what a child was trying to tell them and often needed the involvement of a parent:

One child [...] was able to use eye gaze to say she was in pain; and she had a broken bone. And that took a long time before anyone actually paid attention to the fact that she was grimacing and she was really tense. (Hemsley et al., 2014: 160, PT)

## Aspirations for the future

This sub-theme encompassed data on expectations for a child's communication development. Marie, aged 12, gave her views on what she wanted to improve:

I like my legs, I would change my talking, TALK more, then I wouldn't need the VOCA, I would like to write—letters to boys (book and signs). (Wickenden, 2010: 225, Marie)

Many parents spoke about the wish for their child to maximize their communication potential. They wanted others to see what their child was capable of as they felt this

would increase their acceptance in society (Bailey et al., 2006; Beresford et al., 2018; Rabiee et al., 2005a). There was, though, a tension evident between therapists and parents. Some therapists felt that parents prioritised physical skills such as walking over communication (Moorcroft et al., 2019) and some parents thought that speech and language therapists had low expectations of their children (Allard et al., 2014). A teacher in one study stated the importance of not making assumptions about what a non-verbal child is capable of understanding:

If we have the expectation that there's not a lot of ability there, then that's where we're going to pitch our interactions. (De Bortoli et al., 2011: 426, Sally)

When Hungarian parents of autistic children were asked for their views on potential communication interventions, five of ten parents expected their child's speech to develop but other parents in the same study held a broader aim, for example:

We expected to be able to communicate better with our child. (Serpentine et al., 2011: 226, Barna)

The emotional well-being of their children was identified as a key concern by many parents and therefore an important outcome in several studies (Allard et al., 2014; Beresford et al., 2018; Clarke et al., 2011; Goldbart & Marshall, 2004; Marshall & Goldbart, 2008; Morris et al., 2014; Salminen, 2000; Sloper et al., 2009), for example:

I just want him to be happy. (Allard et al., 2014: 9, IP6)

## Theme 2: Adapting to and acceptance of AAC

Theme 2 contained participants' opinions on how AAC systems would impact on communication outcomes. The theme included parents' concerns that AAC would hinder speech development. It also included data about children's idiosyncratic ways of communicating and the reasons for parents' rejection or acceptance of AAC (2.1 getting the message across). Participants discussed the pros and cons of different types of AAC (2.2 the value attached to different AAC methods) and what it meant to achieve communication competence (2.3 becoming a proficient AAC user). Many papers included high-technology AAC users; there were fewer papers about users of low-technology AAC.

## Getting the message across

Parents in six studies described how they intuitively understood what their child wanted to communicate and so did not think AAC added value to their interactions (McCord & Soto, 2004; Rabiee et al., 2005a; Bailey et al., 2006; Hettiarachchi et al., 2020; Moorcroft et al., 2021; Pugh, 2015).

Around the house I always knew her little noises and body language and I knew what she wanted. (Pugh, 2015: 99, F4I1: Mother)

The amount of effort and time involved in using AAC systems was a barrier to implementation when parents felt their child communicated well using natural gesture, vocalisations, facial expression and body movement (non-symbolic means) (Beukelman & Light, 2020). By the time an AAC device had been prescribed, parents and children had often developed their own way of communicating with each other (Lindsay, 2010; Pugh, 2015). Some parents were concerned that the introduction of AAC would hinder their child's speech development, so they considered this a temporary measure until a child became verbal (Hettiarachchi et al., 2020). However, there were many parents who valued the introduction of AAC (Bailey et al., 2006; Joginder Singh et al., 2017; Marshall & Goldbart, 2008; Moorcroft et al., 2019; Pugh, 2015;) and felt that this had enhanced communication with their child, for example:

We know what he wants nowadays, we understand him so much more. It makes communication. (Joginder Singh et al., 2017: 114, parent)

The aim of parents of children with degenerative conditions with deteriorating speech intelligibility was for them to hold onto some way of communicating, using AAC while they were able to. Later, as the condition progressed, parents wanted to become skilled at interpreting their child's subtle movements or facial expression (Sloper et al., 2009).

## The value attached to different AAC methods

This sub-theme includes data from participants about different types of AAC namely: communication books, boards, symbols, sign language and assistive technology for communication. The implementation of a particular type of AAC seemed to be influenced by positive or negative attitudes towards it. Communication books were commonly

cited as being onerous to prepare. Parents felt this was an added pressure to their already busy lives and were frustrated that they did not always contain the vocabulary needed (Joginder Singh et al., 2017; Marshall & Goldbart, 2008; Moorcroft et al., 2021; Pugh, 2015). One young AAC user was frustrated by his need to rely on a communication partner when he used his book as he wanted to use his own voice:

[using a symbol book means someone else speaks the words, it is] not my voice. (Clarke et al., 2001: 111, child using AAC)

The use of sign language was contentious; some parents felt that it was easier to use than other methods of AAC and wanted to learn it (Goldbart & Marshall, 2004; Huer et al., 2001; Joginder Singh et al., 2017; Moorcroft et al., 2019; Moorcroft et al., 2021; Pugh, 2015). Other parents were embarrassed by use of sign language (Joginder Singh et al., 2017; Hettiarachchi et al., 2020; Pickl, 2011;), for example:

My husband just wants him to talk. He cannot see it as success when our son has learned new signs to tell us something. The teachers have explained to me how important it is that he has a way to express himself, but for my husband communication is only verbal speech. He argues that our son is not deaf, so why should he use sign language. (Pickl, 2011: 238, mother of son with Downs Syndrome)

There were more data on the use of high-technology (electronic or computer-based speech generating devices) than any other methods of AAC. Parents anticipated that high-technology AAC would open the doors to communication beyond the immediate family even though identified barriers were outlined: cost, programming, reliability, limited vocabulary, storage of the device, access methods and set up (Bailey et al., 2006; Borgestig et al., 2017; Goldbart & Marshall, 2004; Gona et al., 2014; Hemsley et al., 2014; Huer et al., 2001; Joginder Singh et al., 2017; Lindsay, 2010; Lund & Light, 2007; Marshall & Goldbart, 2008; Moorcroft et al., 2019; Moorcroft et al., 2021; Rabiee et al., 2005a; Salminen, 2000; Pugh, 2015; Wickenden, 2010). These children explained how crucial their communication aids were to them:

I use this communication device to help me talk. I can't do it myself (C8Y), Well, if I don't have my communication device on, it is hard to understand me (C5O), It has been a miracle!

(C5O), Awesome! (C2O). (Batorowicz et al., 2014: 243)

On the other hand, there were examples in this sub-theme that recalled data in sub-theme 1.1 (Being a non-verbal child) and 2.1 (Getting the message across): there was concern that use of AAC system would hinder a child from talking, as speech was seen as the overriding goal:

Maybe he might get lazy to speak. Instead of saying the word he might press [the cell on the VOCA]. (Agius, 2019: 277, James' mother)

After the first consultation with us the family decided against continuing on with AAC [devices]. The dad told me that he was afraid that it would impede her speech development. He really wanted her to speak. (Lindsay, 2010: 218, #10, speech language pathologist)

### Becoming a proficient AAC user

Communication competence is a term used to describe the attainment of communication goals (Light, 1997). The desire for a child to achieve communication competence was specifically mentioned by authors in two studies (Bailey et al., 2006; Borgestig et al., 2017). This parent explained what he felt becoming a competent communicator using AAC meant for his child:

Well, I figured that there would be some huge learning curve. And once we got in front of it, we'd be able to have a device that he could access for all of his immediate needs and be able to also participate in the classroom environment using his augmentative device as well as at home or any social areas that he's involved in. (Bailey et al., 2006: 52, Bob)

Both health professionals and parents acknowledged that children need to develop their linguistic skills—language understanding, vocabulary knowledge, grammatical ability and literacy as well as operational skills to use AAC (Beresford et al., 2018; Borgestig et al., 2017; Joginder Singh et al., 2017; Lindsay, 2010; Moorcroft et al., 2021). Parents in five studies stated that they valued achievement in curriculum areas: reading, writing, literacy and numeracy separately from specific communication goals (Goldbart & Marshall, 2004; Joginder Singh et al., 2017; Lund & Light, 2007; Rabiee et al., 2005a; Sloper et al., 2009), for example:

These teachers, their whole focus was on communication. My feeling was, 'well he could be learning as he's communicating as well'. I understand that communication is a big part of it, but it shouldn't be at the expense of other things. (Lund & Light, 2007, Anthony's mother: 328)

Social competence was viewed by professional participants as a prerequisite for successful AAC use (Lindsay, 2010), as was strategic competence. When communication breakdown could not be repaired, participants reported frustration and what was described in several studies as challenging behaviours, including biting, throwing, punching, slapping and tantrums (Allard et al., 2014; Cowan, 2013; Hettiarachchi et al., 2020; Marshall & Goldbart, 2008; Morris et al., 2014; Mei et al., 2015; Moorcroft et al., 2019; Pugh, 2015). Parents wanted communication interventions to reduce their child's level of frustration and lead to changes in behaviour:

I was hoping his attention would improve, his behaviour would change, in fact, that his behaviour would get better (Geza). We hoped the behaviour problems would end, finally no more tantrums (Peter). (Serpentine et al., 2011: 226).

### Theme 3: Becoming an autonomous communicator

This theme encompassed views on how a child can be supported to become independent in their communication and what the barriers may be to this. It explored participation in society (3.1 connecting with the wider community), the importance of people familiar with the child's communication methods (3.2 the role of communication partners) and the influences on a child's communication development (3.3 the team around the child).

#### Connecting with the wider community

This sub-theme emphasized the aspirations held for and by non-verbal children in their transition to becoming an adult. Parents described how their children wanted to interact and develop friendships but explained how there were barriers to communication with peers (Beresford et al., 2007; Goldbart & Marshall, 2004; Pugh, 2015). Development of communication skills, often linked with the proficient use of AAC, was seen as key to gaining

independence (Allard et al., 2014; Bailey et al., 2006; Borgestig et al., 2017; Lund & Light, 2007; Mei et al., 2015; Morris et al., 2014; Pugh, 2015; Rabiee et al., 2005a; Salminen, 2000; Sloper et al., 2009; Wickenden, 2010).

Although we are a long way from a conversation [using AAC] I have faith and hope he will get there and I would like him to live independently and get a job in Tesco or whatever but I would love him to be independent. (Pugh, 2015: 109, F9I1: Mother)

Participants mentioned the practicalities of functioning in the world independently. Developing life skills such as going shopping and ordering food in restaurants were mentioned by participants in four studies (Bailey et al., 2006; Rabiee et al., 2005a; Sloper et al., 2009; Wickenden, 2010). Parents wanted their child to be able to initiate communication, make decisions and organise their own schedules, thus developing at least some degree of autonomy (Bailey et al., 2006; Beresford et al., 2018; Borgestig et al., 2017; Mei et al., 2015; Morris et al., 2014; Salminen, 2000; Sloper et al., 2009; Pugh, 2015). Being able to use a Voice Output Communication Aid (VOCA) to converse outside the home was an outcome cited as important by parents and siblings, for example:

I would actually like him to use it more in the community. We went to the dentist and he had money in his wallet and if I had done quick thinking, I would have recorded a message exchange on his device. (Bailey et al., 2006: 55, Penny: mother)

Like he can order his own French fries. You know, that kind of thing, and it's nice for him, especially because then he doesn't have to be so reliant on people, and he feels independent. That's important. (Bailey et al., 2006: 55, Melissa: sister aged 15)

Children reinforced the notion of independent communication, for example:

Now that I've got my voca (and can spell) I can be independent, I can go shopping on my own. I can order food and drink if I go out. if I'm ill, I can tell the doctor what is wrong with me. (Wickenden, 2010: 232 Kate: age 13)

Similarly, a speech and language therapist implied that one goal of AAC might be to foster independent communication with peers:

My idea is that, when Noel gets into school, he'll be using the system to interact and to do some of the social stuff with it. (Murray et al., 2019: 172, specialist SLT)

## The role of communication partners

This sub-theme highlighted how the success of communication was heavily influenced by the attitudes of other people towards a child and this affected the goal of independent functioning. The data demonstrated that whilst there was a strong desire among parents for non-verbal children to become as independent as possible, children were reliant on family members or skilled carers who could 'translate' their communication to others in the wider community. This eye gaze user summarized how crucial the role of his parents was to support communication with others:

Because the parents can understand what the people are saying and understand them as well. (Morris et al., 2014: 106, ICY1)

Parents reported that siblings played a crucial role as 'interpreters' for their brother or sister, as due to the close relationship, they developed a special way of understanding them (Batorowicz et al., 2014; Pugh, 2015; Wickenden, 2010):

Because they have been brought up with him they understand him better than anybody. You know when he is frightened, when he is happy and when he is a pain in the butt. (Pugh, 2015: 117 F3I1: Mother)

Breakdowns in communication could occur when strangers made assumptions about a child's cognitive abilities (Batorowicz et al., 2014; Clarke et al., 2011; Wickenden, 2010). This communication aid user explained how that affected autonomous interactions with strangers:

They treat me like I'm a baby. I absolutely hate it. (Batorowicz et al., 2014: 246, C50)

Having in-depth knowledge of a child's idiosyncratic ways of communicating was reported to require long periods of familiarisation, thereby necessitating a dependency on skilled communication partners such as family members, teaching staff or long-term carers (Goldbart & Marshall, 2004; McCord & Soto, 2004; Bailey et al., 2006; Marshall & Goldbart, 2008; Sloper et al., 2009; Wickenden,



2010; De Bortoli et al., 2011; Batorowicz et al., 2014; Gona et al., 2014; Morris et al., 2014; Pugh, 2015). One child described new people she met as ‘goodies’ or ‘baddies’ (Wickenden, 2010: 190, Marie, aged 12) depending on how much effort they were prepared to listen to what she wanted to say using her VOCA or communication book. This impacted on her decision about whether to bother communicating with them. Communication was most successful with her younger sister and familiar staff at school.

## The team around the child

This sub-theme drew attention to the myriad of stressors faced by the parents of children with neurodisability. Mothers featured in the data more frequently than fathers, providing accounts of how communicating with a non-verbal children took a toll on their emotional health. Much data related to parental well-being and coping with the care of a disabled child (Bailey et al., 2006; Beresford et al., 2018; Goldbart & Marshall, 2004; Gona et al., 2014; Hemsley et al., 2014; Huer et al., 2001; Lindsay, 2010; Moorcroft et al., 2019; Moorcroft et al., 2021; Pugh, 2015; Wickenden, 2010). These data were relevant to the systematic review question in explaining whether parents had the capacity to support the desire they had for their children to become independent communicators. This example from a parent-child dyad sums up the influence of parental support on communication outcomes:

Chad credited much of his success to his mother. He stated, ‘She taught me to use my voice (“SGD”)’. His mother added, I pushed him to use it [SGD] more and more [...] I pushed him to be more independent. (Lund & Light, 2007: 239)

Despite a desire by parents for their children to be more independent, they had limited capacity to implement the interventions recommended by healthcare professionals. There were reports from parents about the disappointment felt when they were unable to communicate well with their child embodying a host of emotional responses including depression, guilt, reduced self-esteem, anger, anxiety, resentment and hopelessness (Borgestig et al., 2017; Cowan, 2013; Goldbart & Marshall, 2004; Gona et al., 2014; Pugh, 2015). The pressure on parents to use AAC that had been recommended by professionals was an added burden when they were already overwhelmed by the care needs of a child with a disability (Goldbart & Marshall, 2004; Huer et al., 2001; Moorcroft et al., 2021; Pugh, 2015).

I don’t think I had the patience, I don’t think I had the resilience, emotional resilience to you know, make that part of the family routine. (Moorcroft et al., 2021: 75, parent 11)

When a parent was able to invest in supporting AAC, they found that their child’s ability to communicate autonomously increased and they were less frustrated. Parents enjoyed the interaction with their child when they could understand their views (sub-theme 1.2):

From the moment we could communicate, there was a reduction in aggressive, self-harming, and violent behaviours and an improvement in impulse control. (Park, 2020: 323, #1)

Communicating with my child is such a delightful experience, and the more I communicate with my child the more I want to do it. (Park, 2020: 323, #3)

## DISCUSSION

The range of studies and participants (children, parents, family members and professionals) included in this qualitative meta-synthesis enabled us to compare different perspectives on communication outcomes. However, the views of parents and other adults were more evident in the studies conducted so far. The predominance of participation from parents highlights the gap in literature on the views of non-verbal children regarding their expectations, hopes and goals of therapy. As other reviewers have identified (Pennington et al., 2004b), we found that studies relating to children within the definition of neurodisability include those with a wide range of cognitive and linguistic skills. The frequent co-occurrence of ID and neurodisability in some non-verbal children could explain why we found relatively few papers capturing the views of non-verbal children directly. The studies we found were more likely to include children with CP rather than ASD, even though a similar if not higher percentage of autistic children are non-verbal (Mei et al., 2016; Norrelgen et al., 2015). This suggests that non-verbal autistic children may encounter more barriers to participation in qualitative research studies than other non-verbal children because of difficulties in social interaction and ID. Few studies included the views of siblings. A recent qualitative meta-synthesis by Berenguer et al. (2022) also found few data from siblings. Sibling perspectives are important because in families of children with a disability, sibling interac-

tion may influence communication participation (Hansen et al., 2016; Chase & McGill, 2019).

The synthesis provided insight into how parents experienced communication with a non-verbal child. Most striking were feelings of grief and loss, and uncertainties for a future in which their child may not speak. A small ethnographic study conveyed the joy parents felt when they found ways to support their child's communication, but many parents struggled to understand their child's needs or feelings (Raffety et al., 2019). Some parents in this synthesis remained focused on hearing their child speak but SLTs found it difficult to answer questions about whether this outcome could be achieved. While there were commonalities, there were also dissonant views across parents and therapists on AAC. Given the amount of time devoted to caregiving for children with significant disabilities (Leiter et al., 2004), it is not surprising that our synthesis found parents lacked the energy to make AAC part of the daily routine. Berenguer et al. (2022) found similarly that parents' multiple responsibilities impacted on the time they were willing to devote to supporting AAC. The synthesis identified that many children need family members or skilled caregivers to translate for them to others in the wider community, a finding also of a systematic review by Noyek et al. (2020). However, relying on family members and paid carers can lead to a restricted social network, limiting interaction with peers and opportunities to participate (Thirumanickam et al., 2011).

The main objective of this synthesis was to seek out data which represented an 'outcome'. However, we found that this word itself was not commonly used by participants in research studies. This was similarly reflected in a previous synthesis on the experiences of people who use AAC (Broomfield et al., 2022). Both syntheses highlight how the words used to represent some concepts differ between researchers, clinicians and individuals who access health or education services. Our analysis found that professionals were more likely to use the words outcome or goal, whereas parents expressed an outcome as desire, hope, wish or expectation. Researchers in studies seeking children's views recognised that they would find it difficult to understand the concept of outcomes and adapted their methods to account for this. For instance, Clarke et al. (2001), Rabiee et al. (2005a), Sloper et al. (2009), Clarke et al. (2011) and Pugh (2015) used symbol cards or Talking Mats (Murphy & Cameron, 2008) to include the perspectives of children. Most of the data on communication outcomes from children in this synthesis originated from users of electronic communication aids and a smaller amount from those using communication books, symbols or sign language. Although, as other reviewers have found the type of AAC used by an individual was not always clearly stated (Berenguer et al., 2022).

## Key limitations

The search strategy proved difficult to refine because of the variable use of terminology. This made it complex to decide which studies to include. We recognise that we may have inadvertently included some verbal users of AAC who used AAC to give their views because their speech was too unclear to be understood by an unfamiliar person. The current interchangeable use of labels and the meaning attributed to them is a problem for researchers and clinicians as it makes comparison of studies and services difficult. We excluded quantitative studies which could have contributed to the review question. The combining of a meta-synthesis of quantitative studies with this meta-synthesis of qualitative studies could further enhance our understanding. The data from this synthesis were not mapped to the ICF and it would have been useful to explore which outcomes were linked to the activity/participation and body function components of this.

## Clinical implications

This meta-synthesis found that speech is a highly valued outcome by the parents of children with neurodisability and remains so past the early years. When children do not speak, this may be associated with lack of progress towards typical developmental milestones leaving parents feeling bereaved. This means that healthcare professionals need to have the skills and the time to support parents as they navigate their way through life with a child who has a neurodisability. Knowledge of a family's coping pattern with regard to disability could be beneficial (Kandel & Merrick, 2007). Conversations with parents about how their child communicates could be highly emotive and need to be handled with sensitivity. Having insight into the lived experience of communication with a non-verbal child will help healthcare professionals gain a greater understanding of the challenges parents face. This could provide a base from which to discuss outcomes and the different evidence based approaches to speech and language therapy, for instance, direct speech language therapy or communication partner training (Pennington & McConachie, 2001; Pennington et al., 2004a, 2020). Further research is needed so that clinicians can answer questions about the possibility of speech with more certainty and advocate for the introduction of AAC for children who may need it from a young age (Pennington et al., 2020).

AAC systems require significant investment by families who already have to manage the extra demands of caring for a disabled child (Berenguer et al., 2022). Before conversations take place about AAC, gaining a deeper understanding of parents' ability to cope with the day-to-



day practicalities will help professionals reflect on parents' readiness for different approaches. Professionals need to take account of the growing body of research indicating that it is unrealistic to expect parents to fulfil the additional roles of therapists and educators. (Currie & Szabo, 2019; Disabled Children's Partnership, 2021; Rosenbaum et al., 2021). The evidence gap in our synthesis highlights that there that may always be some children who are unable to communicate their views about therapy outcomes due to severe cognitive impairments (Morris et al., 2015; Rabiee et al., 2005a). Methods used in research such as Talking Mats (Mitchell, 2011; Rabiee et al., 2005b) show that there are creative ways we can capture children's first-hand views although these may not be suitable for some. For those children with profound and multiple learning disabilities, by observing or videoing behaviours (Pearlman & Michaels, 2019) it may be possible to record their preferences for communication interventions, which can then be considered alongside parent report on outcomes.

## Future directions

This meta-synthesis highlights the need for more primary research that focuses specifically on the identification of valued communication outcomes for non-verbal children with neurodisability to inform the development of a PROM for this population. It is also important to achieve consensus and clarity of terminology in research and clinical practice for non-verbal children, as has been achieved by the multinational and multidisciplinary Delphi consensus study that has provided clarity of terminology for children with developmental language disorders (Bishop et al., 2016). We suggest that the views of children and young people should be sought in addition to those of adults.

## CONCLUSIONS

This meta-synthesis identified the existing published literature on valued communication outcomes for non-verbal children with neurodisability. One of the key findings centred on parental desire for children to develop speech, persisting past the early years. It was considered crucial that children could find a way to communicate their immediate needs, choices and feelings. Developing the ability to communicate autonomously meant that children could interact more easily with people outside of their immediate family and become more independent. Children and family members felt that AAC could support the longer term goal of increasing participation in the community. There were factors which impacted on the successful introduction of AAC, such as parental concerns that it would hinder

speech development and parents' capacity to support a system. Healthcare professionals need to be sensitive to the demands of caregiving before entering into discussion with parents about potential outcomes. The findings from this meta-synthesis will be used to suggest what items could be included in a PROM. Further exploration is needed with stakeholders to pinpoint item content and the constructs to be measured.

## CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. The authors are responsible for the content and writing of the paper.

## DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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## APPENDIX A: EXAMPLE SEARCH STRATEGY USING MESH SUBJECT HEADINGS

Group 1: Subject headings for 'children with neurodisability'		MESH scope note	Entry terms
1	Disabled Children MESH ID D019988	Children with mental or physical disabilities that interfere with usual activities of daily living and that may require accommodation or intervention	Child, Disabled Children with Disabilities Children, Disabled Handicapped Children
2	Cerebral Palsy MESH ID D002547	A heterogeneous group of nonprogressive motor disorders caused by chronic brain injuries that originate in the prenatal period, perinatal period, or first few years of life. The four major subtypes are spastic, athetoid, ataxic, and mixed cerebral palsy, with spastic forms being the most common. The motor disorder may range from difficulties with fine motor control to severe spasticity (see <a href="#">MUSCLE SPASTICITY</a> ) in all limbs. Spastic diplegia (Little disease) is the most common subtype and is characterized by spasticity that is more prominent in the legs than in the arms. Pathologically, this condition may be associated with <a href="#">LEUKOMALACIA</a> , <a href="#">PERIVENTRICULAR</a> . (From Dev Med Child Neurol 1998 Aug;40(8):520-7)	CP (Cerebral Palsy) Cerebral Palsy, Athetoid Cerebral Palsy, Atonic Cerebral Palsy, Congenital Cerebral Palsy, Diplegic, Infantile Cerebral Palsy, Dyskinetic Cerebral Palsy, Dystonic—Rigid Cerebral Palsy, Hypotonic Cerebral Palsy, Mixed Cerebral Palsy, Monoplegic, Infantile Cerebral Palsy, Quadriplegic, Infantile Cerebral Palsy, Rolandic Type Cerebral Palsy, Spastic Congenital Cerebral Palsy Diplegia, Spastic Diplegic Infantile Cerebral Palsy Infantile Cerebral Palsy, Diplegic Infantile Cerebral Palsy, Monoplegic Infantile Cerebral Palsy, Quadriplegic Little Disease Little's Disease Monoplegic Cerebral Palsy Monoplegic Infantile Cerebral Palsy Quadriplegic Infantile Cerebral Palsy Rolandic Type Cerebral Palsy Spastic Diplegia
3	Autistic Spectrum Disorder MESH ID D000067877	Wide continuum of associated cognitive and neurobehavioral disorders, including, but not limited to, three core-defining features: impairments in socialization, impairments in verbal and non-verbal communication, and restricted and repetitive patterns of behaviors. (from <a href="#">DSM-V</a> )	Autism Spectrum Disorders Autistic Spectrum Disorder
4	Autistic Disorder MESH ID D001321	A disorder beginning in childhood. It is marked by the presence of markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interest. Manifestations of the disorder vary greatly depending on the developmental level and chronological age of the individual. ( <a href="#">DSM-V</a> )	Autism Autism, Early Infantile Autism, Infantile Kanner's Syndrome

(Continues)

Group 1: Subject headings for 'children with neurodisability'	MESH scope note	Entry terms
5 Developmental Disabilities MESH ID D002658	Disorders in which there is a delay in development based on that expected for a given age level or stage of development. These impairments or disabilities originate before age 18, may be expected to continue indefinitely, and constitute a substantial impairment. Biological and nonbiological factors are involved in these disorders. (From American Psychiatric Glossary, 6th ed).	Child Development Deviations Child Development Disorders Child Development Disorders, Specific Development Disorders, Child Developmental Delay Disorders Disabilities, Developmental
6 Brain Injury MESH ID D001930	Acute and chronic (see also <b>BRAIN INJURIES, CHRONIC</b> ) injuries to the brain, including the cerebral hemispheres, <b>CEREBELLUM</b> , and <b>BRAIN STEM</b> . Clinical manifestations depend on the nature of injury. Diffuse trauma to the brain is frequently associated with <b>DIFFUSE AXONAL INJURY</b> or <b>COMA, POST-TRAUMATIC</b> . Localized injuries may be associated with <b>NEUROBEHAVIORAL MANIFESTATIONS; HEMIPARESIS</b> , or other focal neurologic deficits.	Acute Brain Injuries Brain Injuries, Acute Brain Injuries, Focal Brain Lacerations Focal Brain Injuries Injuries, Acute Brain Injuries, Brain
7 Movement Disorders MESH ID D009069	Syndromes which feature <b>DYSKINESIAS</b> as a cardinal manifestation of the disease process. Included in this category are degenerative, hereditary, post-infectious, medication-induced, post-inflammatory, and post-traumatic conditions.	Dyskinesia Syndromes Etat Marbre Movement Disorder Syndromes Status Marmoratus
8 Congenital, Hereditary, and Neonatal Diseases and Abnormalities MESH ID D009358	Diseases existing at birth and often before birth, or that develop during the first month of life ( <b>INFANT, NEWBORN, DISEASES</b> ), regardless of causation. Of these diseases, those characterized by structural deformities are termed <b>CONGENITAL ABNORMALITIES</b> .	Congenital Disorders Disorders, Congenital Neonatal Diseases and Abnormalities
9 Nervous System Diseases MESH ID D009422	Diseases of the central and peripheral nervous system. This includes disorders of the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction, and muscle.	Nervous System Disorders Neurologic Disorders Neurological Disorders

(Continues)



	<b>Group 1: Subject headings for 'children with neurodisability'</b>	<b>MESH scope note</b>	<b>Entry terms</b>
10	Genetic Diseases MESH ID D030342	Diseases that are caused by genetic mutations present during embryo or fetal development, although they may be observed later in life. The mutations may be inherited from a parent's genome or they may be acquired in utero	Genetic Diseases Genetic Disorders Hereditary Disease Hereditary Diseases Inborn Genetic Diseases Single-Gene Defects
11	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 (Group 1 terms combined) Group 2: Subject headings for 'non-verbal'	MESH Scope Note	Entry Terms
12	Communication Disorders MESH ID D003147	Disorders of verbal and non-verbal communication caused by receptive or expressive <a href="#">LANGUAGE DISORDERS</a> , cognitive dysfunction (e.g., <a href="#">MENTAL RETARDATION</a> ), psychiatric conditions, and <a href="#">HEARING DISORDERS</a>	Acquired Communication Disorders Childhood Communication Disorders Communication Disabilities Communication Disorders, Childhood Communication Disorders, Developmental Communication Disorders, Neurogenic Communicative Disorders Communicative Dysfunction Developmental Communication Disorders Neurogenic Communication Disorders
13	Language Disorders MESH ID D007806	Conditions characterized by deficiencies of comprehension or expression of written and spoken forms of language. These include acquired and developmental disorders.	Acquired Language Disorders Language Disorders, Acquired (Continues)



Group 1: Subject headings for 'children with neurodisability'	MESH scope note	Entry terms
14	Language Developmental Disorders MESH ID D007805 Conditions characterized by language abilities (comprehension and expression of speech and writing) that are below the expected level for a given age, generally in the absence of an intellectual impairment. These conditions may be associated with <b>DEAFNESS</b> ; <b>BRAIN DISEASES</b> ; <b>MENTAL DISORDERS</b> ; or environmental factors.	Auditory Processing Disorder, Central Auditory Processing Disorder Developmental Disorder, Speech or Language Developmental Language Disorders Language Delay Language Disorders, Developmental Semantic-Pragmatic Disorder Speech Delay Speech or Language, Developmental Disorder
15	12 OR 13 OR 14 (Group 2 terms combined)	Entry Terms
16	Group 3: Subject headings for "desired outcomes"	Attitudes Opinions Sentiment
17	An enduring, learned predisposition to behave in a consistent way toward a given class of objects, or a persistent mental and/or neural state of readiness to react to a certain class of objects, not as they are but as they are conceived to be.	
18	11 AND 15 AND 16 (Group 1, 2 and 3 combined) Limit to: using filters Group 1-3 combined relating to humans, child: birth-18 years, English Language	