

## Rethinking family (dis)engagement with augmentative & alternative communication

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**Augmentative and Alternative Communication (AAC) is a core component of special education for many children with learning disabilities and/or autism who have minimal or no speech. Much literature focuses on implementation of AAC in the classroom or therapy setting, but less is known about how AAC is used in the family home. Few studies are authored by an AAC parent/researcher with reflection on positionality, power and the advantages conferred by ‘insider’ status. This paper addresses this gap by exploring the perspectives of five families of minimally verbal children on the place of AAC in their child’s home communication. Semi-structured family interviews were transcribed and subjected to Thematic Analysis. Formal AAC practices such as Picture Exchange Communication System (PECS) and Makaton were found to play a limited role in the children’s home communication. Findings indicate three possible explanations: the emotional and relationship-building dimensions of family communication; the competing priorities of family life with a disabled child; and the child’s existing multimodal communication strategies including the use of household objects. These findings offer a preliminary starting point for understanding the emic perspectives of AAC families and reasons for their convergence/divergence with professional attitudes to AAC, and warrant further investigation in larger-scale studies.**

### Introduction

Augmentative and Alternative Communication (AAC) is a cornerstone of ‘special education’ for children with limited or no speech throughout the world (McLeod, 2018). It involves the provision of communication modalities to replace or augment spoken language including symbol cards (Frost and Bondy, 2002), speech-generating devices (Van der Meer and Rispoli, 2010) and manual signing systems (Grove and Walker, 1990). AAC is typically

introduced and periodically reviewed by a Speech and Language Therapist (UK) or Speech-Language Pathologist (USA), although day-to-day implementation falls within the remit of classroom practitioners and families. AAC is recognised internationally as an enabler of the right to freedom of expression for disabled children (UN Convention on the Rights of Persons with Disabilities Art.21; UN Convention on the Rights of the Child Art.13).

Effective collaboration with families is increasingly foregrounded in the call for family-centred Speech and Language provision (Klatte et al, 2020). This is particularly important in AAC implementation where it is desirable for new skills to be generalised across multiple settings. However, Speech and Language Therapists (SLTs) report lacking both the time and the training to liaise effectively with AAC families (O’Neill, 2018). It has been suggested that SLTs may subsequently resort to a directive, professional-centred approach that exports an AAC package to the family home with little sensitivity to families’ individual needs (Mandak et al., 2017). This can lead to professional frustration at the subsequent apparent lack of family ‘buy-in’ to AAC (Erickson et al., 2017).

This paper begins by reviewing existing literature on the importance of the professional–family relationship in AAC implementation, before presenting the theoretical framework for the current study which draws upon both ethnography and multimodality. It then presents findings from semi-structured interviews with five AAC families, organised into four themes using Thematic Analysis (Braun and Clarke, 2006). These are the limited role of AAC in the family home, the child’s use of embodied idiosyncratic communication as an alternative to AAC, the competing household priorities of families with disabled children and the emotional significance of communication for parents. These findings are important given the limited existing corpus of qualitative work on AAC (Balandin and Goldbart, 2011), particularly on family experiences and beyond the USA. The findings are also distinctive insofar as the author occupies the extremely unusual position of an AAC parent-turned researcher, and the paper reflects explicitly on the impact of researcher’s

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positionality and disclosure on the data-generation process. This is an important contribution to the literature given the predominance of SLT-led research in AAC and the need for a counterpoint to the dominant clinical perspective, which can pathologise ‘other’ families. Building on these findings, the paper finally identifies some ‘entry points’ for beginning family-based AAC, which professionals may find useful in their dialogue with families.

## Background

Families can be positioned as problematic, reluctant and ‘barriers’ to the efficient implementation of AAC due to their supposed lack of enthusiasm. Johnson et al., (2006) distinguished between parental AAC *rejection* (where AAC is dismissed before any attempt) and AAC *abandonment* (where use of a child’s AAC system is discontinued after introduction). Professionals lament that ‘a common area of struggle is getting parents and clients to buy in beyond the clinic or classroom’ (Erickson et al., 2017). Moorcroft et al., (2019a) illustrate how professionals may ascribe blame to parents:

*“For some reason when we walk out the door it’s [AAC’s] just not being implemented and I don’t know if it’s cause they [the parents] don’t have time or they don’t think it’s important or they just can’t be bothered” (p.196)*

*“They all want the quick fix, they want it done you know ‘if it [AAC] doesn’t work in a week or so it’s no good, we’ll try something else’” (p.197).*

Similarly, Calculator and Black (2010) observe that ‘current AAC principles and practices ... place the onus on professionals to engage rather than take the lead from families’ (p.31), although Culp (2003) concurs that ‘many professionals simply move their lesson plans and direct therapy sessions with the child into the home environment’ (p.5). SLTs may believe themselves to be acting in a family-centred way when they have contact with families, give them information and obtain their agreement to collaboration, but such behaviours ‘lack the key features of true family-centred services’ (Mandak et al., 2017, p.2). It is further contended by Mandak et al. that family resistance or reluctance to AAC seen through a true family-centred lens is a valuable starting point for genuine dialogue about the communication modes, contexts and aspirations valued in the family home and if/how AAC might enhance existing practice.

This positioning of parents as problematic is not new. Three decades ago, Hammer (1998) noted that SLTs can be tempted to frame families as the problem because the profession is schooled in experiment-oriented interventions emphasising cause and effect relationships. Thus, AAC rejection or abandonment must have an identified ‘cause’ such as parental lack of interest, lack of education, having a home language other than English or being

a single parent family (Hammer, 1998). In contrast, Hammer made the case for an ethnographic approach to elicit deep understanding and ‘thick description’ of the experiences of AAC families, noting that ethnographic methods are more consistent with the aspiration of providing truly family-centred services.

Since then, a modest number of studies have heeded Hammer’s call for rich, qualitative description of family AAC experiences. These studies point to the complexity of family experience and the potential reductionism of evaluating (non-)compliance. For example, parents are revealed to be juggling multiple competing roles ‘from loving caregivers to teachers, playmates, advocates, coordinators and [AAC device] programmers’ (Caron, 2015, p.8) as well as financial and health concerns, fatigue and stress (Mandak et al., 2017). Their responses to proposed interventions may be mediated by a range of emotions around their child’s diagnosis including sadness, fear, guilt, anger (Culp, 2003) as well as frustration and self-blame (Marshall and Goldbart, 2008). Additionally, family responses to a proposed intervention fluctuate according to what is currently happening within the family (Marshall and Goldbart, 2008). These findings point to a situation that is considerably more complex than a simple spectrum of (dis)engagement.

Qualitative studies also suggest that the home communicative environment differs from the educational or clinical setting in terms of privileged communicative modes, partners, topics and adult interpretative skill with idiosyncratic embodied communication (Caron, 2015; Goldbart and Marshall, 2004). The intersection of these complex axes of difference will inevitably compromise attempts to simply ‘export’ interventions from the clinical/educational setting to the family home. It is easy to dismiss parental skill in interpreting idiosyncratic behaviours as a *barrier* to AAC, claiming that families fail to understand that this approach will not serve their child well beyond the family home and in the future (Moorcroft et al., 2019b). However, for parents and AAC (non-)users, the rapid interpretation of idiosyncratic communication has affordances including speed and simplicity (Marshall and Goldbart, 2008) as well as emotional closeness:

*‘I see an AAC device as a bit impersonal like the Internet. If that were the goal, I would get one too and we could talk machine to machine. But without it we connect human to human’. (McCord and Soto, 2004, p.218).*

According to Marshall and Goldbart (2008), parents are fully aware that their choices diverge from professionally recommended practice: the ongoing interpretation of idiosyncratic behaviour instead of AAC use is a conscious choice based on the affordances outlined above. In a field of literature where the clinical voice predominates,

the affordances of interpreting idiosyncratic communication for families may risk being devalued by professionals (Moorcroft et al., 2019b).

### Theoretical framework

The theoretical framework underpinning this study draws from both ethnography and multimodality. Whilst not claiming to be a full immersive ‘ethnography’ (Green and Bloome, 2004), this study is *ethnographically informed* in its commitment to explore insider family perspectives and recognise families as ‘more like valuable experiential experts and less like objects of scrutiny’ (McCord and Soto, 2004, p.215). In this way, family communication practices are acknowledged as making sense to the family as a ‘speech community’ (Hymes, 1972) given their particular circumstances and social and cultural contexts. Ethnography further resists decontextualised analysis of children’s ‘communication disorders’, foregrounding instead the sociocultural settings of practices, roles, beliefs, institutions and knowledge where interactions occur (Solomon, 2008). This study, therefore, seeks to build a picture of the families’ everyday interactional practices and how parents understood and valued such practices.

The study also takes from ethnography the foregrounding of researcher positionality: we must be aware ‘of the conceptual shackles imposed by [our] own identities and experiences’ (Takacs, 2002, p.70) as well as the dynamics of power between researcher and participant. Few AAC studies are conducted by user-led or family-led research teams, and it is relatively unusual to find reflection on positionality and power between AAC researcher and participants. This has implications for the ‘the unequal hermeneutical participation’ (Tremain, 2017, p.4) of disabled people and their families in knowledge-generation; particularly since parents of disabled children feel subject to a high degree of scrutiny and judgement from professionals, friends, family and strangers (Ryan and Runswick-Cole, 2009) and may be highly sensitised to the positionality of the researcher. For this reason, the paper later undertakes explicit reflection on the author’s relatively unusual positionality as an AAC parent-turned-researcher and the decision to disclose this to participants.

Finally, ethnography foregrounds the power of the ‘micro’ to instantiate the ‘macro’ – that is, how everyday stories, anecdotes and recorded observations of seemingly trivial matters can display telling traces of legislation, policy and practice (Riitaoja et al., 2019). As Thomson et al., (2010) argue, policy ‘is articulated and re-written in a myriad of local settings all of which have their own ongoing tangle of histories, competing narratives, mores, teleologies and actors’ (p.639). In this study, the examples of everyday family interactions described by parents were inevitably located within and imbued with elements of the (inter)national context as follows: the autism diagnostic process, ‘deficit’ discourses of disability, early intervention in the preschool

years, Speech and Language Therapy provision, AAC and so-called ‘special’ education.

The theoretical framework of this study also draws from the field of multimodality that is characterised by three core commitments (Jewitt et al., 2016). Firstly, human interaction is seen as involving wide range of semiotic resources – the voice, the body, material artefacts and so on – which offer different potentialities or ‘affordances’ for communication (Kress, 2010). Secondly, there is a broad consensus in multimodality that language should not be *a priori* privileged over other modes in analysis, nor should ‘non-verbal modes’ be presumed to play an orbital or supporting role to language. Thirdly, there is a commitment to analysis of how communicators select and orchestrate semiotic resources to produce a ‘multimodal whole’ (Jewitt et al., 2016).

The present study does not undertake direct fine-grained ‘multimodal analysis’ of video data relating to the children’s communication, as the author has done elsewhere (Doak 2018). Instead, the theoretical framework is infused with a broader *multimodal-informed understanding* of communication. The research, therefore, explores family perceptions of the relative affordances and constraints of communication modes used in the home.

### Methods

This paper draws on findings from a broader research project on communication with five minimally verbal children identified as having ‘Autism Spectrum Disorder’ and with their teachers and families (Doak 2018). They were recruited through a special school in the Midlands of England where the author spent six weeks undertaking ethnographic observation of classroom communication in one class which had five children, all of whom were project participants. The primary focus of the project was the children’s multimodal communication in the classroom, and it documented through video data how they combined embodied modes such as facial expression, vocalisation, gesture, posture and eye gaze with the manipulation of artefacts and some limited use of AAC. Whilst the main analytic focus of the project was on classroom communication, one single home visit was undertaken per child in order to discuss the children’s multimodal repertoires in the home environment and gain a multidimensional view of their communication. These visits yielded interesting data not only on home multimodal communication practices but specifically on the reasons why AAC practices from the classroom were not always transmigrating successfully to the home environment. This paper foregrounds this aspect of the data.

The first part of the interview was structured by the *Inventory of Potential Communicative Acts* or IPCA (Sigafos et al., 2000). In the IPCA, questions such as ‘How would your child communicate that they are happy about something?’ are then followed by an invitation to recount

anecdotal examples. This was followed by a semi-structured interview that invited parents to reflect critically on their child's existing and future communication practices. Two families had English as an additional language and this becomes evident in the syntax and vocabulary of quotations, although their spoken English was considered sufficient to obviate the need for an interpreter.

Data analysis drew upon Braun and Clarke's (2019) 'reflexive thematic analysis'. This approach to thematic analysis views themes as 'creative and interpretive stories about the data, produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data themselves' (Braun and Clarke, 2019, p.594). Rigour and quality are, therefore, demonstrated through a lengthy process of iterative engagement with the data and reflexivity on one's own theoretical assumptions and their influence upon theme generation, rather than through the 'neopositivist' approach of inter-rater reliability (Braun and Clarke, 2020). In this study, NVivo version 10 software (QSR International Pty Ltd. Version 10) was used to upload and collate the interview transcriptions and facilitated repeated re-readings and familiarisation. This was followed by identification of initial codes and subsequent collation into candidate themes. Inductive coding was undertaken manually within NVivo by ascribing nodes to segments of text, which could later be renamed, reallocated, further divided or merged as candidate themes were identified. Themes were then further refined and developed until they constituted 'a coherent and internally consistent account' (Braun and Clarke, 2006, p.22), which could be written up as a compelling narrative with vivid examples of participants' words (Table 2).

The study was carried out in accordance with the version of BERA's Ethical Guidelines for Educational Research, which was current at the time of fieldwork (BERA, 2011), and was approved by the author's University Research Ethics Committee. Written consent was obtained from the school headteacher, classroom staff and the children's parents/carers. All five families consented to interviews, and four out of five consented to audiorecording. Findings presented here are drawn primarily from the four audiorecorded interviews where participants' words can be directly quoted, although fieldnotes from the remaining interview (Luke) are paraphrased and discussed where relevant.

### Researcher reflexivity

As the researcher, I made a conscious decision to disclose to participants before interview that I was a parent of two AAC users. I was honest about my attempts to implement AAC at home and how they had not always been successful. This initial disclosure resulted in brief interspersed acknowledgements of shared parenting experiences throughout the interviews.

Thomas' Father: And, if I want to go in the room he will stand up, push me out and close the door.

Me: That happens in our house as well ((laughs)).

In general, parents did not ask about my family during recording, but some enquired more freely when audiorecording had finished. However, I recorded occasional references to our shared parenting experience within the interviews:

Anna's Mother: We are a mom so we always want to [do] more than, than we should I think.

According to Wilkinson and Kitzinger (2013), feminist researchers typically manage their 'insider' status by *minimising it, utilising it, maximising it, or incorporating it*. Here I do not go as far as maximising (for instance, through an autoethnographic approach) or incorporating (by considering myself a research participant) but could be said to 'utilise' my insider status through disclosure and subsequent orientation to our shared experience (*'that happens in our house as well'*). The authors go on to argue that insider status can facilitate rich data collection by engendering trust and empathy, yet also caution against 'false assumptions of commonality, such that the researcher thinks her insider status entitles her to represent the voice of her participants in what is essentially her own' (Wilkinson and Kitzinger, 2013, p.254). Frost and Holt (2014) found that acknowledging a shared experience of motherhood 'enabled some mothers to voice the gap between expectations and reality with less fear of criticism and judgement' (p.6). In contrast, Scott (2013) cautions that such disclosure does not automatically result in participants viewing you as an 'insider' at all: a mother who is also a professional researcher in AAC/special education may be seen as a rather dubious 'insider'. Nevertheless, I would maintain overall that self-disclosure was beneficial in this study. Participants often visibly relaxed and showed interest when I explained my family circumstances during the pre-interview briefing. One mother, who was initially very apologetic about food being smeared on windows, appeared relieved to discover this was no surprise to me at all.

It is also useful to reflect on the impact of the researcher's positionality on data generation, interpretation and analysis. This paper takes a constructivist epistemological position that embraces the researcher's active influence in 'generating' (not neutrally 'collecting') data (Given, 2008). For this reason, the researcher's positionality as a fellow AAC parent was not a source of concern as a potential source of 'bias' or 'leading', as such concerns would be associated with the 'neopositivist' position outlined by Braun and Clarke (2019) above. Instead, it is acknowledged that positionality *inevitably* plays a role in data generation and interpretation. Nevertheless, qualitative research does have its own practices, which assure research rigour and trustworthiness. A reflexive research diary was maintained throughout fieldwork and analysis to facilitate reflection on researcher's positionality and

theoretical assumptions and their influence upon data generation (Ortlipp, 2008). Additionally, as Sandelowski (1993) argues, the validity of qualitative research may be enhanced by engagement with other researchers in the wider academic community about the interpretation of data. To this end, my initial themes and codes were presented with colleagues and at academic conferences in order to expose interpretative ‘blind spots’ or unwarranted interpretations arising from the researcher’s own parenting experiences. Finally, transcripts were sent to participants for validation (Long and Johnson, 2000).

### Participants

The five children were students in one class within the same special school in the Midlands of England, UK. Despite being classmates, they spanned the 6–8 age range: in UK, special schools students may be grouped on the basis of perceived similarity of special educational need rather than chronological age. All five had minimal or no spoken language. Two AAC strategies had featured in their education since their preschool years: *Picture Exchange Communication System* or PECS (Frost and Bondy, 2002) which involves the child’s learning to present adults with symbol cards, and Makaton, a simplified manual signing system (Grove and Walker, 1990). For further detail on either approach, see (Doak 2018). Table 1 presents background information on each child and their family, whilst Table 2 provides an overview of themes identified.

## Findings

### AAC in the family home

All families were aware that PECS was used in school with their child, and all reported professionals supplying laminated symbol cards for home use, typically food and drink items. In no household did the PECS cards feature extensively in the child’s communication, with families expressing doubts about their usefulness:

*I am sure he does brilliant at school with it, but he doesn’t do well at home with it. (Dominic’s Mother).*

In Dominic and Anna’s house, a symbol card for ‘drink’ was affixed to the fridge but was reported to be seldom used in either house as the children helped themselves. Similarly, Thomas’ father reported that ‘*he can grab everything at home.*’ He went on to explain:

*I think he just comes back home and thinks I am off I don’t have to use them anymore, I have free time, don’t bother me with pictures. (Thomas’ Father).*

Albert’s Mother reported that symbol cards had now been largely superseded by Makaton signing: it was now easier for Albert to sign ‘*toilet*’ instead of fetching the symbol card. In Luke’s house, the family had also been provided with some PECS cards from school and Luke would sometimes use the cards for *dinner*, *drink* or *toilet* to make a request. However, the family noted that sometimes Luke played with the cards rather than using them functionally.

All families were aware of Makaton signing and its use in school. However, unlike symbol cards with relatively transparent meaning, Makaton requires some prior knowledge to interpret a sign. Perhaps for this reason, Makaton appeared to play a negligible role in three households. The families of Anna and Dominic did not report any Makaton usage at all, whilst Thomas’ father did not recognise possible signing attempts:

*Just waving his hands around and sometimes making like it was a Makaton . . . But we cannot recognise that symbol. Just something exactly the same way every time, could not figure out what it is . . . (Thomas’ Father).*

**Table 1: Overview of children and participating families**

Participant pseudonym	Age	Diagnoses/labels	Family living situation
‘Albert’	8	Autism Spectrum Disorder (ASD)	Albert lives with his mother; whose first language is not English. The interview was conducted with his mother.
‘Anna’	7	Autism Spectrum Disorder (ASD)	Anna lives with her mother and father; both have a first language other than English. The interview was conducted with her mother.
‘Dominic’	8	Autism Spectrum Disorder (ASD)	Dominic lives with his mother and three older siblings. His mother, who is a native English speaker, took part in the interview.
‘Luke’	6	Autism Spectrum Disorder (ASD); Global Developmental Delay (GDD)	Luke lives with his mother, father and sibling. Both parents are native English speakers, and both took part in the interview along with Luke’s aunt who was visiting. The interview was not audiorecorded at the family’s request.
‘Thomas’	7	Autism Spectrum Disorder (ASD); Global Developmental Delay (GDD)	Thomas lives with his mother, father and sibling and some extended family members. Both parents have a first language other than English, his sibling is bilingual. Both parents took part in the interview.

**Table 2: Themes and illustrative quotations**

Theme	Sub-theme	Example quotations
AAC in the family home	Sometimes useful	'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 ...' (Albert's Mother).
	Food requesting symbol cards sent home	'I have a jug in the fridge, jug of orange, once the orange has gone, he will sometimes take the thing [symbol card] off and show it to me'. (Dominic's Mother).
	Desire for more training	'At school I am asking or Googling [an unfamiliar Makaton sign] ... I don't know what it means but yes I would like to have some lessons myself, so I could use it at home ...' (Albert's mother).
	Independence versus communication	'He is smart, it is easier for him to get a chair and climb up and grab whatever he wants than to show us'. (Thomas' Father).
	AAC perceived as belonging in school	'We try to do it with the PECS and everything but it will seem like, use them at school, we cannot make this transition with home'. (Thomas' Father).
	Extended family role	'His dad, he has got a new partner now and she, because she knows some of the [Makaton] signs so I know she is teaching Albert's dad ...' (Albert's Mother).
Embodied idiosyncratic communication	Fetching/pointing to items to indicate request	'He will give me bread to make him a sandwich. If he wants to play game he will give me a joystick ...' (Thomas' Father).
	Furniture as referent	'I know if he sits at the table he wants something to eat'. (Dominic's Mother).
	Zones of house as referents	'If he is tired and he wants bedtime ... he will take me upstairs to put him to bed'. (Albert's Mother).
	Proxemics (use of space)	'He will grunt or put his hands up and move away, or he will sit in another chair'. (Dominic's Mother).
	Positioning of others	'He will come and hold my hand, or he will lift my face up to look at him. And then hold my hand and take me either in the kitchen, or to the door'. (Dominic's Mother).
	Touch	'He does that all the time, bumps his head into me, and I am expected to chase him ... he just bumps and I am supposed to chase him. If I don't, he will just bump harder'. (Thomas' Father).
	Vocalisation	'I have to stop him there, no, no ice cream ... he will jump up and down and scream and shout'. (Dominic's Mother).
	Facial expression	'[When she is happy] she is smiling, she is laughing, you can see on her face, eyes you know'. (Anna's Mother).
	Eye gaze	'If she wants some movie, I know which one she likes now ... if she wants [movie] she looks longer [at it] then I say ok? and she says ok ...' (Anna's Mother).
	Gesture	'When I put him on a swing, and I am swinging him, and maybe it is too much he will just clap his chest and I know it is too much I have to stop'. (Thomas' Father).
	Self-injury	'He has a tendency now to bite his thumb or his finger when he is angry'. (Dominic's Mother).
	Echolalia	'He will just yank my hand, and I say 'no, this way'. Then he repeats 'no, this way'. And there is a few times he has said it without me saying it ...' (Dominic's Mother).
	Silence	'If I turn it back to Sponge Bob, he is quiet and I know I will leave this on for a bit ...' (Dominic's Mother).
	Parental confidence in interpreting	'I don't need to use [symbol cards] as much because I know what he wants and he knows how to ask me, in a way ...' (Albert's Mother).
Recognising limitations	'Whenever he is ill we don't exactly know what it is wrong with him ... he doesn't want to drink, or eat so we know sore throat, we can see runny nose, other than that we just are guessing ...' (Thomas' Father).	

*(Continued)*

**Table 2:** (Continued)

Theme	Sub-theme	Example quotations
Competing household priorities	Challenging behaviour	'He will try and come towards your face, angry with fingers like that, he might scratch, he might pinch, he might slap or he would simply kick the wall, or the door or try to bite the handles. . . ' (Albert's Mother).
	Keeping child safe	'And it is not always safe, if it is a dangerous situation and there is a road nearby . . . as soon as I just let go of his hand he will run straight away'. (Thomas' Father).
	Anticipating needs before they are expressed	'Normally I have [a drink] waiting for him when he comes in because it is a long journey ride on the bus.' (Dominic's Mother).
	Routine & structure	'If that gets too long and he is already in his [school] shirt and jacket and the bus still hasn't come he will get upset because, where is that bus. . . should be here some time ago'. (Thomas' Father).
	Balancing siblings' needs	'He wants to watch Sponge Bob all the time. Well he can't, because there is 3 other kids here . . . ' (Dominic's Mother).
	Pressure of work outside the home	'I am realistic so I know that I don't work with her how I should I would like to, like sit with her and work, but then I started to think ok, you are working full time . . . ' (Anna's Mother).
	Bilingual household	'I can speak to [my daughter] in Polish, and she can speak both languages, with [Thomas] I can't do that . . . not everybody in my household can talk in English but at least we are both trying . . . ' (Thomas' Father).
Parent emotions	Pleased with progress	'[His communication] is a lot better than it was . . . he is not obviously doing what he should for his age, but I think he has become more aware'. (Dominic's Mother).
	Hopefulness for future	'I would like for him to just develop some kind of language whether it is spoken, whether it is sign language whether it is picture language whatever, but something that I can have a conversation with him'. (Thomas' Father).
	Guilt	'If I try to sit at the table with her and show her, she doesn't want to work like that, that was our big problem always for me because I thought that I am bad mom, bad teacher or something like that'. (Anna's Mother).
	Longing for closeness	'The worst time for our relation[ship] was when she started to be autistic . . . she was very small still and she completely closed in her world and I couldn't go there and it was difficult'. (Anna's Mother).
	Upset by 'deficit' discourse	'There was a lot of . . . expressing that he is not doing this, he is not doing that, and it depressed me when I went in [to school]. So I didn't go in so much'. (Dominic's Mother).

Only two families reported spontaneous Makaton signing in the home environment. Luke's family reported that he signed *more*, *please*, *thank you*, *stop* and *no*, and these signs were known and responded to by his relatives. Albert's mother noted her son's performance of the signs *sleep*, *more*, *again*, *drink*, *please*, *thank you*, *toilet* and *horse*. She noted:

*It is simple things like, showing he needs toilet, which is such a massive [thing] . . . when he is out and about and he needs toilet that is when I feel proud when he is asking me. (Albert's Mother).*

Two parents (Thomas' Father and Albert's Mother) expressed a desire for more training in Makaton so they would be able to better support their child.

In summary, neither PECS nor Makaton occupied a prominent role in any household. There was generally low enthusiasm for food/drink PECS cards as these requests were already occurring through object manipulation or alternatively were unnecessary due to the child's independence. Makaton played a useful but limited role for two students out of five who had learned some signs to the point of spontaneous production and were able to reproduce them at home.

*Embodied idiosyncratic communication*

At home, children have access to multiple rooms that are imbued with associations such as sleeping, eating, bathing and entertainment. This means that taking oneself to a particular room (or leading the adult in that direction) assumes a communicative significance that may not be apparent in educational or clinical settings:

*I know if he sits at the [kitchen] table he wants something to eat. (Dominic's Mother).*

*If he knows there is bag of sweets or biscuits and he can't go in [to the cupboard], that is when he would take me constantly until I give in. (Albert's Mother).*

*If she is tired . . . she take my hand and she says [word in home language] it means come, come and then we will go to upstairs . . . and it means that she wants to go to bed. (Anna's Mother).*

The children also drew extensively on the artefacts available within each room to convey meaning. Commonly reported objects appropriated for communication purposes included shoes and coats (as a request to go out), TV remote controls, DVDs, food items, cutlery and crockery and games console joysticks.

*. . . getting the frying pan out . . . a plate out, with a knife and fork and he will get the bacon and eggs out and put them at the side of the cooker, which is what I do when I am preparing it so everything is on show and he is sitting down at the table looking at me. (Dominic's Mother).*

Luke's family described the process of selecting a TV programme as a process of elimination involving object manipulation and non-verbal vocalisation: they would scroll through the on-screen previews of available options using the remote control, and Luke would say 'uh' when they reached his desired programme.

However, families also demonstrated critical awareness of the limitations of everyday artefact manipulation as a communication strategy:

*But I am not sure if I have made the right decision for him, because he can't tell me to leave Sponge Bob on, and it is, if I put Peppa Pig on, and he don't like Peppa Pig, he will just go and get the [remote] control again. (Dominic's Mother).*

*He wants to go out, he will bring me his own shoes for example but I don't think he express exactly where he wants to go. (Thomas' Father).*

Children also communicated with family through embodied idiosyncratic communication including non-verbal vocalisation, gesture, eye gaze and facial expression. In some

instances, families expressed confidence in their interpretative abilities:

*When I put him on a swing, and I am swinging him, and maybe it is too much he will just clap his chest and I know it is too much, I have to stop. (Thomas' Father).*

*You know as a parent . . . I think you know to certain degrees if it is a hurtful cry, they are in pain, kind of cry. If it is a frightened cry, you know. (Dominic's Mother).*

However, families demonstrated critical awareness of their interpretative limitations: identifying the precise nature of the child's illness was a prominent shared concern.

*If he is feeling unwell, you are second guessing constantly why is he crying, he is not usually like that, why is he crying that is when you are a bit 'oh I don't know what to do'. (Albert's Mother).*

*She had a problem with urine infection and of course you know she couldn't tell me that she feel pain . . . so I am scared that kind of situation because that really I can't be sure because she can't tell me. (Anna's Mother).*

In summary, family communication patterns are strongly linked to the materiality of a family home: the meaning-making deeply imbued into rooms, furniture and a multitude of readily available artefacts, combined with parents' finely honed ability to interpret idiosyncratic communicative moves based on years of experience. This may reduce enthusiasm for AAC, particularly where it is seen to duplicate existing communication strategies. However, parents demonstrated critical awareness of the strengths and limitations of their approach, and this awareness will be later explored as fertile ground for useful AAC at home.

*Competing household priorities*

All the five families faced a multitude of challenges in daily family life. Some of these were the usual demands many families facing, such as strained co-parenting arrangements, balancing the needs of siblings and juggling family and employment commitments. However, some challenges were specifically associated with the child's disability. These issues included managing physical aggression, property damage, incontinence, lack of sleep and anxiety about keeping their child safe.

*He will try and come towards your face, angry with fingers like that, he might scratch, he might pinch, he might slap or he would simply kick the wall, or the door or try to bite the handles. (Albert's Mother).*

*And it is not always safe, if it is a dangerous situation and there is a road nearby . . . as soon as I just let go*



*of his hand he will run straight away.* (Thomas' Father).

Some families reported that their anxieties about managing behaviour outdoors led them to plan cautiously with a limited range of familiar destinations, thus obviating the need for communication and choice.

I would just choose for him because I know which places would be the calmest ... (Albert's Mother).

*It is a rarity we go out you see which is my fault completely ... we go to the park round the corner ...* (Dominic's Mother).

Families also reported that quickly anticipating their child's needs before any communication was needed.

*Normally I have [a drink] waiting for him when he comes in because it is a long journey ride on the bus.* (Dominic's Mother).

These findings point to the need for professional understanding of the challenges faced by parents of disabled children: in addition to the everyday stressors shared by all families, they face additional layers of challenge associated with their child's disability. These stressors provide powerful explanations for decisions, which professionals might regard as a sub-optimal communication environment, such as anticipating needs without discussion or withholding choice to ensure an outing will be manageable and calm.

#### Parent emotions

Parents reported that their child's communication had a much deeper significance than a purely transactional or functional skill. Rather, communication was deeply intertwined with many competing emotions around parents' hopes and fears for their disabled child's future, their own self-concept as parents, and the desire to enjoy close and loving relationships.

*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 ...* (Albert's Mother).

*The worst time, our time, for our relation was when she started to be autistic and she had almost 2 years and that year ... was very difficult because I think she was very small still and she completely closed in her world and I couldn't go there ...* (Anna's Mother).

Several parents expressed feelings of self-doubt in the face of their child's ongoing communication challenges:

*Sometimes I feel we are not trying hard enough ...* (Thomas' Father).

*If I try to sit at the table with her and show her she doesn't want to work like that, that was our big problem always for me because I thought that I am bad mom, bad teacher or something like that ...* (Anna's Mother).

For Dominic's Mother, contact with school had become associated with a deficit discourse, which she found increasingly difficult:

*I used to go up to the school for meetings, I don't go up so much now ... there was a lot of ... not putting him down but you know, expressing that he is not doing this, he is not doing that, and it depressed me when I went in. So I didn't go in so much ... there is only so much of that you can take* (Dominic's Mother).

Emotions were also located within a temporal dimension, which extended back to the moment of diagnosis: Anna's mother reflects on the time when 'she started to be autistic' as 'a difficult time'. This temporal dimension also extended forwards to fears about the future when the parent is no longer there to advocate for the child:

*I can't stop to think what will do with her when missing me.* (Anna's Mother).

#### Discussion

The findings of this study point firstly to the need for deep understanding of the affective dimensions of communication for families with a disabled child. It may be difficult for a professional who enters and leaves the child's life at designated times to truly appreciate the longitudinal affective dimension of the child's posited communication 'deficit' for parents. It may also be difficult to appreciate how inseparable communication is from the perceived closeness of the parent-child relationship: 'I want him to say Mamma so badly'. Transactional AAC vocabulary such as the food/drink requesting symbols sent home, which in turn possibly reflect the performativity of the classroom, may fail to address this dimension of communication as a builder of emotional bonds. It is argued here that the data point to complex entanglements between communication, emotion and relationships for parents. It is, therefore, important to reflect on whether the practical, transactional and advocacy-based benefits of 'communication' advanced by professionals may misalign with parental perspectives, which are more akin to the etymological roots of 'communication' as 'communion' (Malinowski, 1936).

Discussions of parental guilt and self-blame for failure to implement AAC resonated with me on a visceral level. Children were positioned as 'deficient' communicators from the point of diagnosis, and Dominic's mother eventually protected herself from this deficit narrative by

minimising contact with professionals: *'there's only so much of that you can take'*. There then follows early intervention – all parents reported being introduced to PECS and Makaton by Early Years Practitioners and/or SLTs before their child reached school age – which appeared to position parents as key players in their child's acquisition of AAC. This may reflect what Broomhead (2013) terms 'parental determinism': that is, a UK governmental focus on policies and interventions, which foreground parental responsibility as the cornerstone of child development outcomes. However, Goldbart and Marshall (2004) make the important point that the foregrounding of parental responsibility may 'serve to mask a lack of services' in education, health and social care (p.207). None of the families reported regular ongoing visits from a SLT after the preschool years who could troubleshoot the specific implementation problems they had encountered. Moorcroft et al., (2019a) stress the importance of setting children and families up to succeed in the early days of AAC to secure ongoing motivation, but acknowledge that professionals may not have 'the required time, knowledge or resources' (p.199) to provide the necessary support for families.

This paper contends that parental attitudes towards AAC implementation need to be viewed systemically in the context of the (lack of) support network around the family. This means not only SLT support to address AAC issues but also support from other professionals relating to the myriad challenges described such as challenging behaviour and safeguarding. Findings suggested that participating families juggled a range of competing concerns relating to their children, which understandably compromised their ability to prioritise AAC: coping strategies included becoming risk-averse and reducing outings, making unilateral decisions about outings and anticipating needs before they are voiced. From an AAC perspective, these strategies create a sub-optimal communication environment as the child is not required to make choices or advocate for their own needs. However, for these families, daily family life requires an extensive level of advance planning to ensure the safety and wellbeing of everyone. Understood in this way, AAC avoidance may be seen as an understandable act of self-preservation in a situation where demands are many, support is minimal, and physical and mental reserves of energy must be rationed.

Findings also suggest that we cannot graft AAC on top of existing family communication practice without significant understanding of the existing modal and functional features of home communication. Data suggested that parents were natural multimodalists who recognised facial expression, vocalisation, object manipulation, proxemics, haptics and posture as well as (limited) traces of AAC in their children's multimodal repertoires. For instance, requesting food and drink was already happening in Dominic's house through sitting at the kitchen table (proxemics) or arranging objects such as crockery and

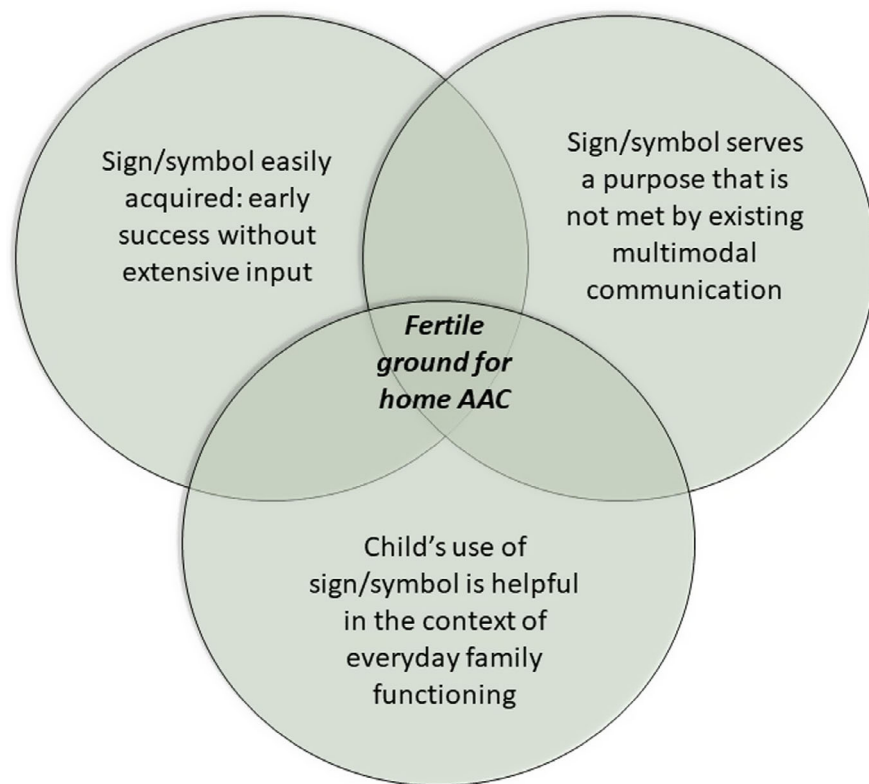
cutlery (object manipulation). From a clinical perspective, introducing food and drink AAC remains important for Dominic for him to communicate in other settings and also to support a range of other speech functions such as expressing opinions about food. However, in households which are under considerable pressure to balance a range of health, education and social care needs of their disabled child, parental motivation to expend energy on recasting the message through AAC are likely to be low when the immediate gains in terms of family functioning seem negligible.

#### *Implications for AAC family engagement*

Having noted a generally low level of AAC at home, it is useful to reflect on what can be learned by practitioners from the 'outlying' instances where a sign or symbol *was* in frequent use. One salient example here is Albert's use of the Makaton sign for *toilet*, and it is useful to explore the reasons for this by locating the use of the sign within the themes identified through Thematic Analysis above. Firstly, in terms of embodied idiosyncratic communication, *toilet* is not an easy concept to convey when out and about: in the family home, leading an adult to the bathroom is feasible but not in an unfamiliar space, and there is no obvious artefact that might be presented to the adult as an object of reference. This meant that the Makaton sign for *toilet* played a distinctive role in Albert's multimodal repertoire and was not duplicated by any existing form of communication. Secondly, with regard to competing household priorities, Albert's use of the *toilet* sign was instrumental in making family outings easier and less stressful and was, therefore, welcomed by his mother. Thirdly, relating to the emotional dimensions of communication for families, the use of the sign in Albert's preferred AAC modality (Makaton) was easily acquired and Albert's success with the sign led to positive effect in his mother's reaction: *'I feel proud when he is asking me'*. This echoes the findings of Moorcroft et al., (2019a) that early instances of AAC success are important emotionally to secure ongoing family participation. A diagram illustrating how the identified themes relate to the identification of an AAC 'entry point' is displayed below (Figure 1):

Another possible 'entry point' to family AAC engagement suggested by the data might be the provision of signs/symbols to facilitate the selection of a specific television programme, since several families noted the presentation of a remote control as a non-specific object of reference. The provision of such symbols would, therefore, not duplicate the multimodal communication (presentation of the remote control) but rather build upon it, and could potentially make family life simpler by enabling the programme selection process without 'trial and error' for both the child and their caregivers.

It is important here to offer the caveat that these suggestions are intended for beginning AAC with families who



**Figure 1: Identifying early entry points for AAC at home**

do not initially perceive it as a valuable addition to their busy household life, rather than a universal guide to AAC vocabulary selection. Indeed, the author has argued elsewhere that the overall goals of AAC vocabulary should be primarily child-centred and should enable agency, self-advocacy and personalisation for the AAC user (Doak 2018). However, there may be value in the early days of home AAC implementation of 'widening the lens' and also considering holistic family functioning including the emotions, stresses, strains and competing demands placed on families of disabled children. This may support the identification of early AAC 'entry points', which will be perceived as genuinely supportive of everyday family life.

### Conclusion

This study set out to explore family perspectives on communication, including but not limited to AAC. The ethnographic and multimodal theoretical framework foregrounded the perspective of families and the meaning and value they attached to the diverse modes mobilised by their children and themselves to make meaning. Findings suggested that communication has a strong affective/relationship-building dimension for families, and that parents experience a range of competing emotions including self-blame and guilt when reflecting on their child's communication. It was also found that AAC played relatively little role in any household, but a wide range of multimodal communication strategies including eye gaze, facial expression, vocalisation, posture, proxemics and object manipulation were orchestrated to make meaning by children and their families. It was suggested that apparent

lack of enthusiasm for AAC may be an understandable act of self-preservation in the face of considerable demands and few supports, with families learning to quickly anticipate their child's needs in order to prevent problems before they occur. Additionally, as a rare example of an AAC study led by an AAC parent/researcher, the study reflected on the importance of positionality and power in AAC research and the need for more research led and designed by AAC users as well as AAC families.

A limitation of this study is that it did not include any children with a speech-generating device as their AAC modality; as these can present additional device programming challenges for families (Pugh, 2015). Secondly, it is possible that the low level of contact between families and SLTs described here may be reflective of the UK model of delivery where SLT services are funded by the National Health Service (NHS), caseloads are large, and direct contact between families and SLTs is relatively infrequent. Thirdly, it is acknowledged that the small sample size (five families) can offer only preliminary insights into the insider's perspectives of AAC families, and more extensive research is warranted to investigate whether these findings are generalisable on a larger scale. Finally, the interviews were drawn from a study that focused primarily on observation of classroom communication practices and therefore did not include direct observations of home communication. It would be useful to conduct further research undertaking comparative multimodal analysis of children's communication practices in the home and school environments.

The study also has implications for SLTs and classroom practitioners who can imbue their practice with ethnographic and multimodal-informed insights. From ethnography, practitioners can distinguish between their own professional perspective, which may privilege linear, measurable communication progress, and the parental perspective, which may instead privilege relationships, emotional closeness and managing the multiple competing demands of everyday life. From multimodality, professionals can take the insight that *all* communicative modes have affordances and constraints (including AAC), which professionals and families may weigh differently: for instance, the emotional closeness of interpreting embodied multimodal communication versus the perceived interpersonal barrier of an AAC device. By acknowledging that family perspectives and existing interactional practices have value, it is hoped that fruitful dialogue can occur about whether and how AAC might be genuinely supportive in the context of the family home.

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### Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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