

Title: 'Communication is everything I think'. Parenting a child who needs Augmentative and Alternative Communication

Running Head:

Parenting a child who needs AAC.

Key words:

Augmentative and Alternative Communication, parents, parents' experiences

Authors:

Julie Marshall

Senior Research Fellow, Research Institute of Health and Social Change
and

Senior Lecturer

Professional Registration Division, Faculty of Health Social Care and Education

Manchester Metropolitan University

Elizabeth Gaskell Site

Manchester

M13 OJA

UK.

Phone: (44) 0161 247 2581

Fax: (44) 0161 247 6364

Email: J.E.Marshall@mmu.ac.uk

Juliet Goldbart

Reader in Psychology

Continuing Professional Registration Division

Faculty of Health, Social Care and Education

Manchester Metropolitan University

Elizabeth Gaskell Site

Hathersage Rd

M13 OJA.

Structured abstract

Background: Anecdotal and research evidence suggest that professionals may not fully understand the perspectives of families of children who need or use AAC. This may impact on the provision of appropriate services.

Aims: The aim of this study was to explore the lived experience of parents of children in Britain who used AAC, with particular emphasis on the ways in which children's need for and use of AAC impacts on family life and communication.

Methods and procedures: The parents/carers of 11 children aged 3 to 10 years, who lived in Britain and who were in the early stages of using AAC, were recruited to take part in this study. Individual semi-structured interviews were carried out, in order to access rich descriptions of parents' experiences and views about having children who need to use AAC. The interviews were recorded, transcribed verbatim and analysed thematically to generate thematic networks.

Outcomes and Results: Analysis revealed three thematic networks. The three Global Themes represented by the networks were concerned with the following areas: the child's communication and interaction; wider societal issues; parents' views and experiences. Each Global Theme contained lower order Organisational Themes and these in turn were comprised of Basic Themes. Parents shared many common concerns but the data also revealed some diversity of views. The themes and sub-themes are described with illustrative and representative quotes.

Discussion, implications and conclusions: These parents are experts on their children and may also be experts on AAC. Many factors impact on parents and the level and type of involvement they have with their children and their upbringing. Speech and language therapists (SLTs) need to acknowledge parents' knowledge and expertise regarding their children. They need to recognise that there are

parent, child, family and external factors which impact on parents' ability and willingness to be involved in SLT provision and that these factors are not static in time. The use of ethnographic interviewing techniques should be considered a valuable aspect of SLT intervention.

What this paper adds:

What is already known:

AAC introduction is complex and family involvement in the process is increasingly considered to be vital. Data on parents' experiences of AAC and related SLT interventions is limited and mainly applies to populations outside Britain.

What this study adds:

This study gives a greater insight into the experiences of families in Britain having children in the early stages of using a formal AAC system. (The majority of recent research has taken place in the USA). It provides data on parents' perspectives on the process and suggestions about how to adapt current practice.

Background

Many children with complex communication needs may benefit from augmentative and alternative communication (AAC). AAC encompasses a wide range of high-tech, light-tech and unaided approaches. It is common for a number of different communication modes to be used by one person, dependant upon the context, communication partners, competence, the primary user's preferences (the person whose spoken communication is compromised) and over time. AAC modes may be introduced by external services, by families or by the primary user him- or herself. The introduction of AAC may be prompted by many circumstances and may happen gradually or more suddenly. For example, there may be a realisation

that the child's speech will be unintelligible to unfamiliar partners, for example at school, the child may be frustrated or the speech and language therapist (SLT) may recognise the need to extend the child's communication capabilities.

The choice of AAC system may be influenced by the child's characteristics such as motor abilities, cognitive levels and current communication skills, as well as by external factors, such as family attitudes, professionals' skills and knowledge, and the availability of funding and support. Parental involvement, which can take many forms, is increasingly considered to be vital, to both the introduction of AAC and to its successful implementation, although Parette and Hourcade (1997) suggest that family issues may be only partially considered in some situations.

Drawing on research from a diversity of cultures and settings Granlund, Bjorck-Akesson, Olsson and Rydeman (2001) and Granlund, Bjorck-Akesson and Alant (2005) have suggested that families may take on a number of roles during the process of communication intervention. They identify these roles as: family as decision maker; family as communication environment; family as consumers; family in crisis; and family as trainers. Whether and how these roles are adopted is likely to depend on many factors, including time and individual family and cultural differences.

Reports of parental involvement and experiences in the AAC literature are increasing but their findings are varied, despite the fact that a number of authors including Angelo, Jones and Kokoska (1995) and Cress (2004), have stressed their importance for successful AAC intervention. A number of studies have highlighted some negative parental experiences. In a small qualitative study of Mexican-American young people using AAC, McCord and Soto (2004) report on families' perspectives on AAC. They found that parents felt distanced from decision-making,

that they varied in the use of high-tech AAC at home and that the AAC devices often did not contain vocabulary relevant to the young people's home lives.

Allaire, Gressard, Blackman, and Hostler (1991) collected data from 110 caregivers (comprehensive data about their backgrounds was not given) of children who attended a rehabilitation centre in Virginia, USA. They asked about caregivers' perceptions of their children's use of AAC and found significant discrepancies between professionals' and caregivers' descriptions of the children's communication modes. These findings suggest the need for improved communication between parents/caregivers and professionals.

Jones, Angelo and Kokoska (1998) studied the responses of families of children in Pennsylvania who used assistive speaking or writing devices. The 59 families predominantly described themselves as being middle-class, well-educated and married. Their responses about stress and support suggested that these families relied on professionals for support and so professionals in turn, need to understand families better although these findings may not apply to all families.

Starbie et al., (2005) reported positive results in using a family-centred approach to AAC implementation, with one educated, English-speaking North American family and their use of a satisfaction questionnaire to evaluate the family's views is to be welcomed.

Not all studies have reported negative experiences. For example, Angelo (2000) investigated 114, mainly Caucasian, middle-income parents of children in Pennsylvania, USA, about family experiences of acquiring an AAC device and these parents reported some positive experiences. They felt that their children's communication with parents, professionals and peers had improved, that their children were communicating more meanings than previously, and that their

devices were neither a stigma nor a burden. However, less positively, a majority of parents in her study felt that their roles and responsibilities had increased following the acquisition of an AAC device. Again, these results should not be over-generalised as the author admits that the sample was not very diverse.

Culture, particularly any differences between families' and professionals' cultures, may impact on AAC acquisition and implementation. A person's culture may be influenced by many factors, including ethnic origin, socio-economic status, religion, sexuality, age, disability status and language/s spoken. In turn culture may impact on successful AAC implementation in many ways, for example through family ideas about language learning, language socialisation, play, attitudes towards communication disability, epidemiology of communication disability and attitudes towards professionals (Marshall, 2000)

Huer (1997) has suggested that knowledge about linguistic and cultural factors may affect AAC intervention. Huer, Parette and Saenz (2001) and Huer and Saenz (2002) have written about adaptations and dialogue needed to encourage cross-cultural AAC and suggest a framework through which to research this. Parette, Huer and Wyatt (2002) provide guidance for working with families of African American children needing AAC. Bridges (2004) tracks the developments in cross-cultural AAC in the USA and gives guidance for future work. More generally, Hammer (1998) has argued persuasively that SLTs need much richer information about families and their lives in order to provide services that are congruent with those families' daily lives. She describes methods for obtaining such data, drawing upon Geertz's (1973) use of ethnographic methods.

Alant (1996), working in South Africa in schools with children from a range of cultural and linguistic backgrounds, described a school-based intervention

approach in which both school staff and families were involved in the technical and contextual aspects of AAC intervention. She considered that knowledge about family infrastructure and context, as well as the AAC device itself were important for success.

Parette, Huer and Brotherson (2001) examined the perceptions of 37 professionals, from across five states in the USA, of working with families on AAC provision. There are a number of useful findings, including that participants did not foreground cultural issues, perhaps suggesting a lack of awareness of their potential impact.

Huer's (2000) study of perceptions of graphic symbols by people in the USA, of different ethnic backgrounds, indicated that there is a need to be aware of possible cultural differences in this area. Parette, Brotherson and Huer (2000) carried out an exploratory study by interviewing families of Asian-American, Native American, Hispanic and European- American origin, from across five states in the USA, in order to understand what 'families from different ethnic backgrounds want professionals to know about AAC decision making'. The families wanted professionals to understand them better, including their ethnicity and values, and for there to be improved dialogue between professionals and families. The families wanted to know more about AAC and in their home language/s and to have contact with other families where AAC was used. Some families felt at a double disadvantage because they were both from a minority ethnic group and they also had a family member with a disability.

From the studies reported above (dominated by research in the USA) it is evident that the issue of parental perspectives and experiences with regard to AAC use, is likely to be important to successful service provision. Furthermore, our own clinical experience in the UK has suggested that communication is a matter of concern to

parents of children using AAC there. However, it seems that parental perspectives are often not fully accessible to professionals in formal intervention settings.

The aim of this study was thus to explore the lived experience of UK based parents¹ of children currently using, starting to use, or expected to need, AAC. Particular attention was paid to the ways in which children's current or future need for and use of an AAC system, impacted on family life and communication. This study aimed to extend the work of researchers such as those cited above, by examining these issues in the British context. As Angelo (2000: 46) has stated 'As long as professionals continue to prescribe AAC options and services, ongoing investigation of family impact and scrutiny of intervention outcomes is warranted.'

Method

In order to obtain rich data about the parents' views and experiences, it was felt that a qualitative approach was most appropriate. The aim of the research was to obtain an understanding of the lives and experiences of parents and so semi-structured interviews were used, followed by thematic analysis, leading to the development of thematic networks (Attride-Stirling, 2001).

Procedure

The researchers

The researchers were a SLT and a psychologist, both of whom work on the speech and language therapy programmes at a university in NW England. Both have experience of teaching about and working with children who use AAC and their families. The interviewer was a qualified school teacher with personal and professional experience of children with disabilities and their families. However she

¹ 'Parents' can include foster parents, grandparents and other primary caregivers of a child

did not know any of the participating families. It was felt that parents may feel more able to express their views freely about communication and perhaps speech and language therapy, if the interviewer was not a SLT.

Preparing for the interviews.

The initial proposal for the study arose from the researchers' and colleagues' clinical experiences and previous literature. The researchers wished to involve key stakeholders in the research design process. Indeed, Goldbart and Hustler (2005) state that attention is being given to how participants can be more fully involved in the research decision-making processes. Thus the ideas for the study were presented at a workshop at a Communication Matters (CM) conference. CM is the UK chapter of ISAAC (the International Society of Augmentative and Alternative Communication) which has a wide diversity of members, including AAC users, family members of people who use AAC, practitioners who work with AAC users, academics and researchers. Over 60 key stakeholders attended the session and as a result of the discussion a briefing guide for the interviewer was agreed. See table 1.

[Insert table 1 about here]

Prior to the interviews the researchers discussed the briefing guide in detail with the interviewer in order to clarify its meaning. It was anticipated that the length of the discussion would vary amongst participants and so clarity about the priorities and purposes of the interviews was important, in order to maintain openness and to encourage discussion of issues that were of concern to the participants rather than topics being dictated by the researchers. Hence, the only elements of the interview that were kept consistent were obtaining some limited biographical data (which also served to relax participants) and an opening request to 'tell me about a typical day

with (child's name)'. Participants were encouraged to raise and discuss any and all issues that they considered to be relevant to the overall topic.

Recruiting participants.

Participants were recruited through three sources:

- schools in Greater Manchester where children likely to meet the inclusion criteria were being educated;
- Communication Matters;
- the UK parents' group, One Voice (<http://www.1voice.info>).

Where participants were recruited through schools, prior permission had been sought from head teachers for parents to be approached. Potential participants were approached with information about the study via an intermediary (e.g. their own SLT or the One Voice co-ordinator), in order to reduce direct pressure to participate. As potential participants expressed an interest in taking part in the study then the intermediary gave the researchers permission to contact them directly. All those who offered to participate were followed up. Once the participants had agreed verbally to take part, further information about the project and the interview procedure was provided and written consent was obtained.

The inclusion criteria for the study were:

a) participant had a child with the following characteristics:

- the child was aged 3-11 years old;
- speech was not the child's primary mode of communication;
- the child was already using or was expected to need to use a formal AAC system;
- the cause of the child's communication disability was congenital and non-progressive;

b) the intermediaries who first approached the potential participants considered that they would be able to cope with the potentially emotive topics addressed in the interviews;

c) all potential participants could speak and understand English at a sufficient level to take part in an interview without an interpreter being present.

Data Collection

Although Granlund et al. (2001) recommend videoing families, time constraints, practicalities, family sensitivities and the specific research questions being addressed, meant that this method of data collection was less appropriate than semi-structured interviews. These permitted the participants to raise issues that were felt by them to be relevant to the overall topic, whilst allowing the particular topics of interest to the researchers to be addressed through follow up questions.

Individual, rather than group interviews or focus groups, were chosen, despite the latter being more economical in terms of the interviewer's time. It was felt that group interviews were inappropriate, given that personal or sensitive issues may be raised, which could be difficult to explore in a group setting. Additionally, it was recognised that a families with disabled children may already be under significant pressures and asking them to travel away from home for an interview did not seem to be a reasonable request.

All interviews apart from one were conducted in the participants' home; the final one being conducted over the telephone, at the interviewee's request. The interviewer did not stipulate whether the child should be present for the interview. This was decided by the parents and, if their child was to be present, the child could be included in the discussion, if appropriate. Where the child was to be present but would be unable to contribute, care would be taken to ensure that discussions

would be sensitive and respectful to the child. Parents also decided if one or both parents would take part in the interview.

Each parent or couple was interviewed once and the interviews lasted between 45 and 120 minutes. They were recorded onto minidisk and then transcribed verbatim. Copies of transcripts were sent to interviewees for their verification and comments.

Data Analysis

Our aim was to generate 'a rich conceptual analysis of lived experience' (Chamatz 1995) rather than a substantive grounded theory. Thus thematic analysis was used in order to organise and make sense of the data, leading to the development of thematic networks. Attride-Stirling (2001) describes a six stage process of thematic analysis. The process is described briefly below but more detail about its use in this study may be found in Goldbart and Marshall (2004) or more generally in Attride-Stirling (2001). In stage one the transcripts were entered into the qualitative data analysis software package Atlas.ti (1997) and were then read and reread to identify recurrent or salient issues. The transcripts were coded (i.e. meaningful segments of the transcripts were marked according to the issues/s they addressed) using this list, adding to it if necessary. The coded pieces of text were referred to as 'quotes'. In the second stage the quotes for each code were re-read to identify recurrent themes and the codes and quotes amended or reassigned, if necessary. In the third stage the thematic networks were developed. The structure consisted of Basic Themes which were grouped into more abstract Organising Themes. In turn the Organising Themes were grouped together to reflect super-ordinate Global Themes, each of which reflected a major issue in the transcripts.

In the fourth stage each network was described with illustrative quotes. At this stage the networks were presented at a workshop at a subsequent Communication

Matters conference. This aimed to establish *credibility* (that the findings were believable from the perspective of participants) and invited the audience to consider alternative explanations of the data (suggested by Miles and Huberman 1994). It also aimed to some extent to establish *transferability* (Lincoln and Guba 1985), by sharing the results with people other than the research participants. In stage five each network was summarized to identify the main issues. Stage six involved using the significant themes to address the research questions.

All three Global Themes and the thematic networks developed to represent them are presented here, in brief. Detailed examination of specific Organising (OT) and Basic Themes (BT) have been published and presented elsewhere e.g. (Goldbart and Marshall 2004) or are under review elsewhere.

Results

Participants

Eleven interviews were carried out. Nine of these were with mothers only, one with two long-term foster carers and one with a mother and father together. Interviewees were all Caucasian, English-speaking, primary carers of 11 children who were using or starting to use an AAC system. Three of the families were single parent families and eight were two parent families, with two of these having an additional adult living in the house.

The children had nought to five siblings. The children ranged from three to ten years old and there were six girls and five boys. Nine children were described as having cerebral palsy, six had intellectual disabilities, two had impaired hearing and one had epilepsy. Educationally, six children attended special schools, three

attended inclusive (mainstream) schools or nurseries and two spent time in both special and mainstream schools. All of these schools were state funded.

All background information, including medical, educational and speech and language therapy data were obtained from the parents/carers, as the researchers did not have access to medical, SLT or school case notes/records

Parents/carers reported that the children used a minimum of two and a maximum of five modes of communication. The most commonly reported mode of communication was signing (e.g., British Sign Language or Signalong) which was used by nine children. Six of the children had a high-tech communication aid with one other child having some access to a high-tech aid. Five children used a communication book or board (referred to as 'symbols' in Table 2) and three children were learning the Picture Exchange Communication System (PECS).

Within the UK the number of potential participants for this study was relatively small. Some of the family and child characteristics were unique and thus provision of more data may have enabled them to be identified. Protection of privacy outweighed the desirability of providing further rich individual contextualising data. Thus, data on many other factors which might influence their cultural identity, for example, religion, sexuality, socio-economic status, disability status of the parents, were not collected. At a macro level (Goldbart and Marshall, 2006) the participants were relatively culturally homogeneous. Table 2 contains limited biographical and background data about the interviewees and the children. All parents approved the transcripts that had been sent to them.

[Insert table 2 about here]

Thematic Analysis

Three Global Themes emerged from the data as follows:

- The child's communication and interaction
- Wider societal issues
- Parents' views and experiences

and were represented by three thematic networks (see figures 1, 2 and 3).

When these three networks were presented and discussed at CM conference, the audience of approximately 100 AAC users, family members, practitioners and researchers supported the overall findings. The discussion focused particularly on one Organising Theme, Demands on Parents and this Organising Theme was explored in detail in a separate paper (Goldbart and Marshall, 2004).

Each of the three Global Themes identified above were made up of a number of Organising Themes which themselves consisted of Basic Themes. The three Global Themes and their constituent Organising Themes are described in turn, although there is inevitable overlap. The Basic Themes will be mentioned only briefly. Following the description of the themes, illustrative quotes, from a range of participants are given. The origins of the participants' quotes are not identified, in order to protect anonymity, but the researchers did ensure that they were representative of all participants.

Network 1- Global Theme: The Child's Communication and Interaction

[Insert figure 1 about here]

The Global Theme for this network is made up of six Organising Themes (see Figure 1). Overall this theme is concerned with the parents' ideas and experiences of their children's communication. It encompasses how the parents communicate with their children and factors which impact on or are in turn impacted on themselves, by the children's communication.

(i) How and about what do the parents communicate with their children?

There was considerable discussion about this topic, which was expected given the scope of the study. Analysis of parents' quotes about this topic revealed that this Organising Theme could be divided into four Basic Themes:

- Input and output modes
- Communication topics
- Communication strategies
- Interaction

Parents' descriptions of their children's input and output modes demonstrated that many were aware that their children used multiple modes to communicate and that AAC systems were being used at home and at school. The data revealed that some parents had taken considerable responsibility in setting up and developing systems. This quote is representative:

I taught Hannah to sign and myself to sign from the book she signs at school she speaks we also use pecs

Parents described common communication topics in the home. Wants and needs in terms of everyday items were most common. Some parents raised the difficulty of talking about things that happened outside the home. Some parents described their more able children's abilities to talk about complex, abstract issues whilst others were aware that this was a problem for their children, for example:

That is really hard 'what have you done today'...if I think 'what else have you done' she won't be able to answer me

You never know whether you are suggesting it to her or whether she truly feels it herself

Parents' descriptions of the communication strategies that they used with their children gave insights into their knowledge about their children and about

communication itself. Some parents were aware that the strategies they used at home for speed and simplicity may not be what would be recommended by professionals. One said:

We constantly ask closed questions which is what you're not supposed to do

In describing their interactions with their children parents showed that they had thought about communication, how to include their children in family conversations in a manageable way and that they empathised with their children, as this quote illustrates:

I've realised that when I feed Andrew I'm... sometimes I don't talk to him at all and other times I do talk

Often their solutions were unique and based on their intimate knowledge of their children:

Always letting her know what's happening to her so if we were going to wash her and dress her and let's brush her teeth now and let's do this we don't just suddenly come at her with a toothbrush

(ii) The child's level of communication

Parents' descriptions of their children's communication fell into three Basic Themes:

- Describing their current skills
- Current difficulties
- Commenting on their skills

In describing their children's current skills parents were able to comment on both receptive and expressive language and included comments on semantics, pragmatics and age equivalence. Whilst the researchers were not in a position to verify the accuracy of the parents' comments, they suggested a level of knowledge

about communication development and shared concerns with SLTs, as shown below:

His comprehension is excellent and his memory is excellent

There's quite a range of sounds that aren't there yet

In commenting on their children's current difficulties parents contrasted positive and negative aspects.

She can't ask it is just one or two words... she can't ask questions

He doesn't seem to understand sentences but he would understand a

key word

(iii) Comprehension and intelligibility difficulties

Parents expressed concern that other factors, apart from their children's own abilities, may act as barriers to communication. For example some parents felt that their inability to understand their children was at fault. One parent said:

It doesn't come out very clearly and I am guessing and getting it

wrong

(iv) How the child communicates choices

Almost all of the parents described systems to enable choice-making, which they regarded as important. Choices were often made through a closed set, using a mode such as eye pointing, as these quotes illustrate.

I take out every cereal box and I say which do you want

She will use colours quite a lot so she will point to the red and I will

know that she wants to wear red trousers

(v) Impact of the child's personality

All of the parents talked about their children's personalities and the impact on communication, whether facilitating or inhibiting.

if you don't understand you have got to be very careful you have got to try to cool him down so he doesn't blow his top

she's very persistent she never gives up easily so if people don't understand her straight away she will keep making the same gestures

(vi) Child's social inclusion or exclusion

Communication skills were seen to impact on levels of social inclusion, whether at home, school or in other contexts. These two quotes are typical

It is so very very hard...that stops children like Hannah having friends

When they play 'school' she misses out physically ...she is part of it but she does miss out on the banter

Network 2: Global Theme - Wider Societal Issues

Insert figure 2 about here

This Global Theme for this network was concerned with parents' ideas about the wider societal issues that impacted on them. This Global Theme is divided into two Organising Themes (see Figure 2).

(i) Societal attitudes towards AAC

Within this Organising Theme parents' comments fell into two Basic Themes regarding others' communication with their children:

- Communication with familiar people
- Communication with unfamiliar people

Familiar adults were generally considered to respond positively and were seen as willing to attempt interaction, particularly where the children used a Voice Output Communication Aid/Speech Generating Device (VOCA/SGD), for example:

We find a big difference between the children she's with at school who are used to her and are able to get through

However when the interaction was with unfamiliar people it was often less positive and they often had to be encouraged by the AAC user's parents.

I think for people who don't know him well he cannot communicate direct with them

Sometimes parents recounted negative experiences, as this parent reports:

I have had numerous arguments with people in the street I really have...he is fascinated by cars he might touch them and someone might shout at him you know

The effects of societal attitudes are also expressed in the third Global Theme in 'parents' feelings and emotional responses' (see below).

(ii) Financing of AAC

Parents' comments on issues related to a range of financial issues. This included communication aids, equipment to facilitate AAC use (e.g. a mounting system for a VOCA) and funding for services such as SLT. The limitations imposed by lack of money were mentioned by several parents, as these quotes illustrate.

It is a total nightmare so my dream...have a lovely electric wheelchair and I have got no mounting system for that because nobody will pay for it and it is £800

Yes we bought it for him...if the school buys it he can only use it at school

I haven't got the stuff to do that or the finances to do it

During the time when these parents were being interviewed the funding system for communication aids in England was undergoing significant alterations, as it has again, more recently.

Network 3: Global Theme - Parents' Views and Experiences

(Insert Figure 3 about here)

The Global Theme for this network (see Figure 3) represents parents' views and experiences of parenting children who use or need AAC. It encompasses both external and internal pressures and includes both practical and emotional issues. These ideas and experiences made up six Organising Themes.

(i) Parent as expert

Parents described number of ways in which they felt they were or were expected to be an expert in relation to their children and their abilities and needs and these emerged into a number of Basic Themes:

- Special knowledge of their child
- Seeking or acquiring specialist knowledge
- The effect of parental expertise on professionals
- Parents acting as interpreters for their child
- Not wanting to be an expert
- Supporting and informing other parents.

They described having a very close relationship with their children, and had high levels of knowledge about the children's medical condition, communication or equipment. One parent said:

It is amazing how you can learn to communicate with a child in your own special way

For some parents this knowledge had been sought out by them as this parent described

I bought three Mayer-Johnson books...with all the pictorial symbols....I spent a lot of time getting them out photocopying them cutting them out putting the pages back

but for others training and guidance had been offered.

Their views about how professionals responded to parental expertise and if they, as parents, wished to be viewed as experts on their children or on AAC, were varied as these parents' quotes show:.

In a way I think professionals are often quite scared it is like they don't want to give you too much information because you can't cope

I feel that they (SLTs) are the ones...that should be doing the introduction to appliances

Support from other parents was important to some participants.

Speaking to other parents as well who want to be contacted is incredibly useful because the best people for information are other parents who have been through it

(ii) Decision making in AAC

Parents varied in both the *extent* to which they were involved in making decisions about their children's communication and in how much they *wanted* to be involved.

As one parent said:

I think we should be very involved...he needs to communicate with us and we need to communicate with him

They also varied in their views about how much and when they were given information.

I think professionals make a big mistake in hiding they don't deliberately hide but look at your child's diagnosis of cerebral palsy but we will give you a book in a year's time when you have come to terms with it but you don't come to terms with it unless you have read

(iii) Parents' views on services

Parents' views of services comprised four Basic Themes:

- Parents' experiences of professionals
- Parents' views of school
- The sufficiency of services
- Parents' opinions of how SLTs see parental roles.

Parents' experiences of help from schools and other professionals were varied.

If she thinks we're wrong about something she can just tell us that but we want to be involved and be active

A frequent, but by no means universal concern, was about the adequacy of SLT, in both quality and quantity, although some parents recognised the limits on professionals, as can be seen below:

She was sent there because she had severe communication needs and she didn't see a speech therapist

The teachers in his school have been the best teachers he could ever have had

I think they would all say that they all would want to do a lot more but you know their caseloads are huge

Some parents felt that professionals needed greater insight into the burden parents carried.

(iv) Parents' reflections on communication

This Organising Theme was made up of three Basic Themes:

- Reflecting on the nature of the child's communication history
- Reflections on AAC and its strengths and limitations
- Reflecting back on the nature of communication and communication impairment.

Parents' accounts about communication went beyond description, revealing reflective consideration of issues relating to communication and communication impairment. None of them expressed concern over the introduction of AAC and some wished for it to have been available earlier. Two parents said:

I wish I would have thought about that when she was young

I think it's helped Rhiannon's self esteem more than anything

Parents of children using high-tech communication aids often experienced difficulties with the system and recognised that AAC implementation is effortful. Conversely, they were also positive about the increased opportunities that AAC brought.

We know how much language we want our son to have access to so the only way he can have access to that is if we keyboard it in...it's very time consuming

In reflecting on communication impairment the parents tried to understand how their children might feel about their communication impairment, as this quote demonstrates:

He won't ask, he can't ask, so that's the hardest thing ...he could be wondering and thinking one thing and I'm standing there wittering on

(v) Parents' feelings and emotional responses

Four Basic Themes emerged in this area:

- Social isolation and exhaustion
- Discovering the extent of the children's communication difficulties
- Parental feelings of guilt
- The importance of communication

The parents expressed strong feelings about their responses to having children with disabilities. The feelings of isolation and having to devote a lot of time and energy to their children's special needs were particularly evident. One parent said:

When you have got a disabled child everybody...you don't see...they just totally disappear

Guilt and frustration at the limitations of time were also features and for some they were overwhelming.

I think families should realize that it is time consuming

Their feelings were broader than just the communication difficulties and put communication needs into some kind of context. However, communication occupied high priority and some parents movingly reflected on how their children's lives may have been if they were able to speak, as these two quote show:

I think it's about first of all accepting the truth that the child will probably never speak.

*Like most parents I think they would say yes the wheelchair fine but give me the voice it is far worse than not walking not speaking is the worst....
Nina's biggest disability*

(vi) Demands on parents

This Organising Theme incorporates four Basic Themes:

- Having sufficient information for collaboration,
- The initiation and implementation of AAC
- Communicating with their child or enabling others to do so
- Being 'pushy'

Parents often felt that they were expected to develop their own knowledge and that the importance of communication and AAC intervention was not made explicit. One parent reported:

Even when it was introduced nobody sat down and said this is why we use AAC and this is what it is going to mean in the future

The amount, type and level of parental involvement in AAC acquisition and implementation were variable. Learning to communicate with a child who uses AAC and facilitating others to do so often involved considerable effort for the parents, as this quote reveals:

I went to school for three weeks running to pick up some ideas what his signs (were)

Some parents felt that they had to be what they described as 'pushy' (a term which has pejorative connotations in British English) in order to access services and equipment for their children. Other parents who did not see themselves as being pushy appeared to feel distanced from involvement. These two quotes indicate contrasting experiences:

There are not many kids...who would have got where she is if I hadn't have been a pushy parent

I wish there was more I could do I don't know see how the speech and language thing works

These Global, Organisational and Basic Themes give structure to the abundance of rich data provided by this group of parents. The discussion will consider how these findings relate to previous literature and also the implications of the data for speech and language therapy services for children who use AAC and their families.

Discussion

The parents in this study discussed their experiences of living with children who use or need AAC. The wealth of data, much of which went beyond simply describing their children and their lives, to include reflections and hypothesising, increase practitioners' understanding of British parents' perspectives and priorities.

It is clear from the data that these parents have extensive knowledge and understanding of their children, their communication in the home environment, (including their modes, topics and levels), their abilities and limitations with different types of communication partners, their individual personalities and the factors that restrict their communication. The parents in Parette, Brotherson and Huer's (2000) study wanted better understanding from professionals and this study contributes to improved understanding.

Increased knowledge may also facilitate compromise, for example, where parents knowingly choose speed and simplicity over advice from SLTs or where SLTs want to select vocabulary that is not seen by families to be relevant, as found also by McCord and Soto (2004).

These data also allow practitioners access to perspectives that are not always considered, for example, the importance that parents attach to the impact of an individual child's personality. This issue was also identified in a recent UK-based study by Marshall, Goldbart and Phillips (in press) of parents' explanatory models about language development, delay and remediation`.

There are many factors impacting upon parents' engagement with professionals and on parents' involvement with their children's communication development. These factors include the heavy burden that parents face in living with and

supporting children who have limited communication and, typically, additional disabilities. Parents often feel isolated and exhausted from the experience and there is often an additional communicative responsibility involved in acting as an interpreter when their children communicate with other, less familiar, people. These findings bear some similarities to the findings of Angelo (2000), that parents had increased roles and responsibilities following AAC device acquisition.

Parents vary in how much and at what point/s they prioritise communication over other issues, how involved and how 'expert' they want to be. They experience the insufficiency of time which makes it difficult to achieve all that they would like to and they may feel frustrated and guilty about their children's difficulties and what they are able to offer them. They sometimes see themselves to blame if they cannot understand their child.

These variations may reflect cultural variations in parents' views of their roles compared to those of professionals. Parents are also affected by external factors that impact on their families, such as an insufficiency of speech and language therapy and other services, and financial pressures. It is important for practitioners to be aware of these factors and to demonstrate their awareness to parents, because as Jones, Angelo and Kokoska (1998) point out, these pressures may result in parents giving up on AAC devices.

Parents' levels of knowledge and their assertiveness or 'pushiness' in trying to obtain what their children needs is variable, as is their desire to change in these respects. Paradice and Adewusi's (2002) study of parents of children with speech, language and communication difficulties in the UK also found that the parents felt that the services they received were mainly due to them fighting on behalf of themselves and their child, suggesting that that these findings are not unique.

Conclusions and recommendations

Varied views were expressed by this small and relatively homogenous group of parents from one part of the Britain, whose views were sought over a short period of time. These data suggest that their knowledge, abilities, feelings and desire for involvement in provision of services were variable, but there are similarities with prior research in the USA. The similarities with some of the studies in the USA suggest that there may be a specific 'community of practice' (groups of people who share ways of thinking believing, valuing and behaving, Erickson, 2002) of parents of children using or needing AAC. Considering these parents in this way may help to understand those who are not 'pushy', because perhaps they are peripheral participants in this community of practice. These data further support previous studies in recommending individualised assessment and intervention. To this end, ethnographic interviewing approaches, such as those suggested by Westby (1990), or semi-structured interviews, perhaps replicating the methods used here, would enhance collaboration with families.

Parents need to hear explicit acknowledgement of the burden they are under and an understanding that their engagement with and prioritisation of communication issues may vary over time. Parents need to have their views about their child's personality and its impact taken into account. Information about the nature of communication, AAC and its implementation should be available to parents at various stages and repeatedly, as families may differ in when, how much and what type of information they want or are able to absorb. For those who feel that school should play a significant role in AAC implementation, Alant's (1996) dialogical model may be appropriate.

Practitioners should also acknowledge and negotiate with parents the levels of expertise that parents wish to develop and the amount of responsibility they want to have. Professionals need to learn more positive strategies for responding to parents who are 'pushy' and also need to consider how best to understand and support those who currently feel more distanced from involvement in their child's communication development, as they may not be content with this situation (as these data suggest) and may receive poorer services.

Practitioners are rarely in a position to alleviate the financial pressures resulting from a child using or needing AAC, but they should be aware of the impact on families, acknowledge their concerns and, wherever possible, use their influence to improve the availability of communication aids.

Many of these issues will be influenced by cultural factors which may vary from family to family and so it is important to increase understanding of parents' views, for example by gathering further data on cultural background in all studies, as well studying parents from a wider range of geographical and cultural backgrounds. As family perspectives are unlikely to be static, research needs to be repeated over time, as the contexts in which parents are raising children are constantly changing.

Parents may arrive at SLT with a complex matrix of experiences and opinions, including prior experience of health/education professionals, differing levels of knowledge, family support and structures, reflective abilities and socio-economic status, all of which contribute to their outlook. These data have identified some common concerns but have also revealed diversity even within this relatively homogenous group. In short, each family is unique and this must be acknowledged in our practice.

Acknowledgments

This project was partly supported by a British Telecom Bursary. With thanks to parent participants, participants at the Communication Matters workshops, other parents and SLTs who supported the project, Debbie Burton for interviewing, and Louise Atherton for transcription. We are grateful to the reviewers for their helpful comments on this paper.

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Table 1

Briefing guide for the interviewer.

Main question:	Describe a typical non-school day (i.e. weekend or school holiday time)
Supplementary questions:	How you and other people communicate with your child? How does your child communicate with other people in your family (including modes and functions)? Easy and difficult things for you/other people in the family and your child to communicate about. Things that need 'fixing' in terms of your child's communication. Describe the importance of communication for you and your child. What factors affect your child's ability to learn to speak? What are your views on your role in your child learning to communicate/use AAC? What are your views on what you consider SLTs think your role should be? What do you think are the effects of AAC (now and in the future)? Can you tell me anything that might enhance SLTs' knowledge about parents/carers in your situation?

Table 2

Participant and child data

Child's gender	M	F	M	F	M	F	M	F	M	F	M	F
Child's age (years)	8	10	8		3	6	8	7	8	8	4	6
Schooling *	S	MS and S	S	MS and S	MS nursery	S	MS and S	S	MS	MS	S nursery	S
Modes of AAC reported by parents/carers **	Sign VOCA Speech Gesture	Sign VOCA	Sign Speech PECS	Sign VOCA Symbols	Sign VOCA Symbols	Sign PECS Gesture Objects of Reference Vocalises	Sign VOCA Symbols Speech	Sign VOCA Symbols PECS	Sign VOCA Symbols Speech	Sign VOCA Symbols Gesture	Sign VOCA Symbols Speech	Sign Symbols
Interviewee/s relationship to child	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Mother	Foster parents (Male and Female)	Mother and Father
Household members	Mother + 2 children	Parents and 3 children	Mother and 1 child	Parents and 2 children	Parents and 3 children	Mother and 3 children	Parents and 1 child	Parents and 1 child	Parents, au pair, 6 children	Parents and 1 child	Parents, 1 other adult and 1 child	Parents and 2 children
Is/are interviewee/s working outside the home?	No	Yes	No	No	No	Yes	No	No	Yes	No	No	No
Main carers of child	Mother	Parents	Mother	Parents and paid carers	Parents and sisters	Mother + sisters	Mother, Father, Grand-parent	Mother	Parents school helpers, LSAs	Parents	Foster mother (+ father)	Parents

VOCA =
MS =
S =
PECS =

Voice Output Communication Aid
Mainstream primary school
Special educational provision
Picture Exchange Communication System (2004) <http://www.pecs.com/>

Figure 1

Thematic network 1: The child's communication and interaction

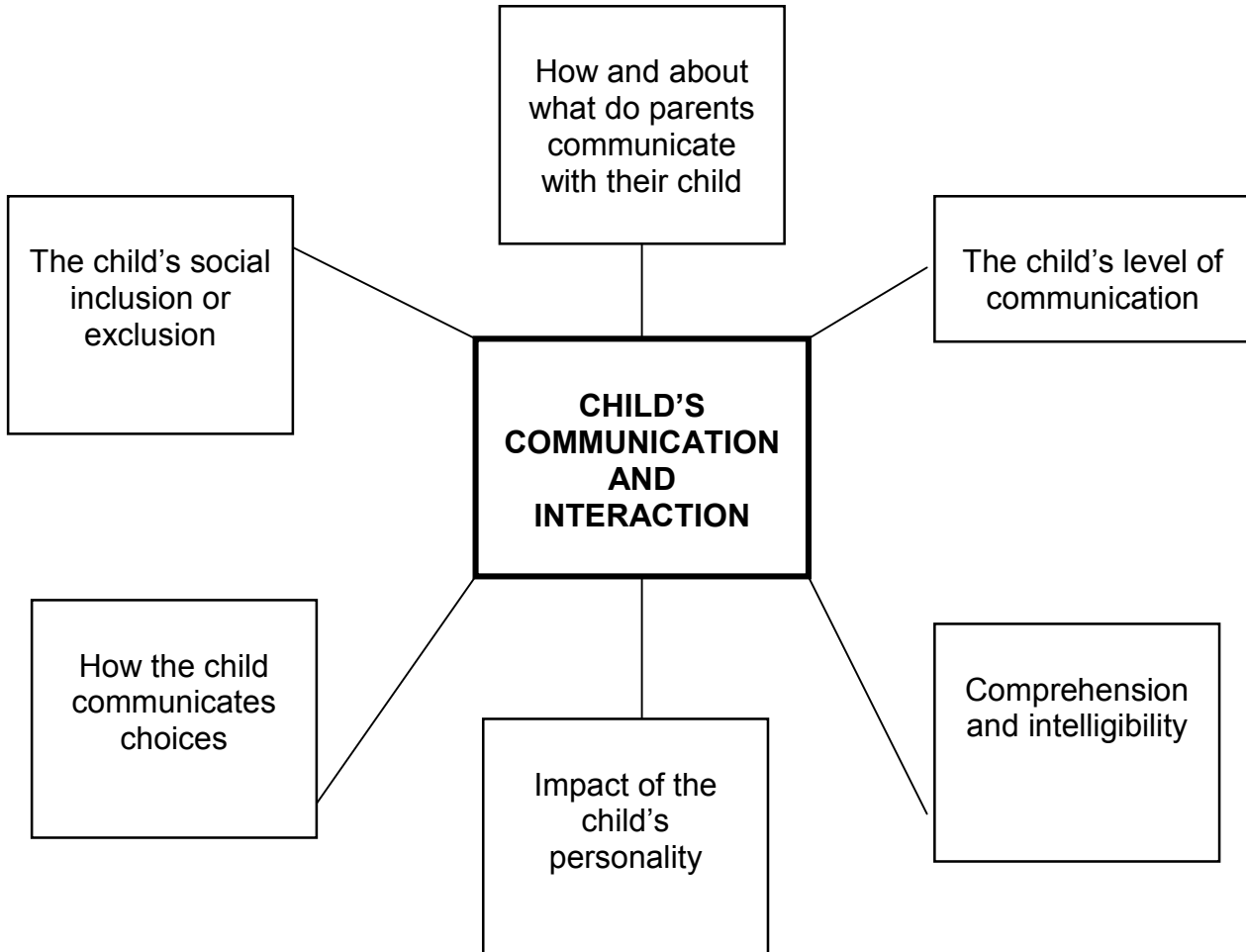


Figure 2

Thematic network 2: Wider societal issues

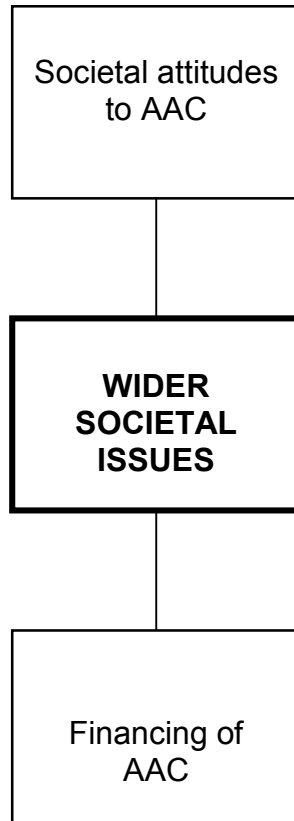


Figure 3

Thematic network 3: Parents' views and experiences

