Thesis

Title: Family perspectives on augmentative and alternative communication: a constructivist grounded theory

Creator: Pugh, D.

Example citation: Pugh, D. (2015) *Family perspectives on augmentative and alternative communication: a constructivist grounded theory.* Doctoral thesis. The University of Northampton.

Version: Accepted version

Family Perspectives on Augmentative and Alternative Communication.

A Constructivist Grounded Theory

Submitted for the Degree of
Doctor of Professional Practice
At the University of Northampton
Year 2015

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Family Perspectives on Augmentative and Alternative Communication.
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Abstract

This constructivist grounded theory explored the perspectives of twelve families of children who were using Augmentative and Alternative Communication Systems (AAC). There is a growing body of research literature concerning AAC but very little is focused on the perspectives of the 'whole' family and the use of AAC in the home environment. Twenty-five parents and children were interviewed using a variety of flexible qualitative methods including a 'draw and tell' approach for younger children and 'Talking Mats', a framework to support children with complex communication needs to express their views.

The core category, 'Finding a Voice', emerged from the analysis of the data as families expressed the desire for their child with complex communication needs to gain a voice through the use of AAC. A trajectory was identified which provides a framework underpinning the families' continuous progress towards 'Finding a Voice' for their child. The four phases in the trajectory: Loss of Voice, Prioritising a Voice, Gaining a Voice and Sustaining a Voice encapsulate the strategies parents used in implementing AAC in the home. Dynamic conditions associated with daily family life and routines resulted in parents redefining family roles and shifting priorities to allow the implementation of AAC. The findings show that although the use of AAC systems in the home can be challenging, parents in the study viewed successful communication as a high priority for their children.

These findings give a greater insight into the perspectives of families using AAC systems with implications for professional practice.

Acknowledgements

I would like to thank my supervisory team: Sarah Neill, Tracey Redwood and Jackie Campbell for their invaluable support and encouragement throughout my doctoral journey. Thanks to Sarah for steering and guiding me through the different forms of Grounded Theory and for our interesting discussions on the differences between a Glaserian and Charmazian approach. Thank you to Tracey who gave me the confidence to keep going when it all seemed insurmountable. Thanks also to Jackie for her expert guidance and organisation throughout the process.

I am hugely grateful to all the inspirational families who took part in the study, giving of their time in their busy family lives. Thank you to those families who agreed for me to use their children’s drawings and Talking Mats in this thesis and subsequent publications and presentations.

Sincere thanks to all my friends, particularly Rosaleen, who has always been there with a listening ear and encouragement to keep going.

I would not have completed this doctorate without the support of my husband, Anthony, who has read and ‘lived’ every page of this thesis and has always been there for me. I couldn’t have done it without you!

Finally thanks to my Mum and Dad for their unwavering belief in me and to Michael, Hannah, Grace and Tom for their support (and humour!) in my doctoral studies.

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Chapter 1 Introduction to the thesis

1.1 Introduction

This thesis reports the findings of a constructivist grounded theory study exploring families' experiences of using Augmentative and Alternative Communication (AAC) in the home. The research gained an understanding of the different perspectives of the 'whole' family including the parents, the child and young person with complex communication needs and their siblings. The provision of an appropriate communication system not only affects an individual's ability to make choices and their health and well-being (Bush and Scott, 2009; Hamm and Miranda, 2006) but it also affects the family's quality of life (Saito and Turnbull, 2007). The theory developed from this study has relevance for all those involved in supporting children and their families in using AAC systems in the home.

1.2 Background

Children with complex communication needs can benefit from the introduction of AAC systems which range from signing and symbols to high tech computer based technology with digitised or synthesised voice output. These different methods of communication are used alongside natural speech or used to replace speech.

AAC interventions can be used to augment natural speech (Hanline, Nunes and Worthy, 2007); develop autonomy (Romski and Sevcik, 2005); build language and literacy (Sturm and Clendon, 2004) and reduce challenging behaviours (Roberts, Chapman and Warren, 2008). Without a means of communication children are unable to develop social relationships (Blackstone et al., 2007); influence their environment (Beukelman and Mirenda, 2013) or attain their educational and personal goals (Lund and Light, 2007).

1.3 Definition of AAC

AAC includes two types of systems which are often differentiated by the terms 'aided' or 'unaided' communication. 'Unaided' communication refers to communication such as signing or gesture. Glennen and DeCoste (1997) described unaided communication as “*techniques that do not require the use of an external object”* (p.101). ‘Aided’ communication describes communication methods which require additional equipment. Aided communication can be low tech symbol books or communication charts to more high-tech communication systems such as voice output communication aids (VOCA) and computer based devices which involve “*the use of physical objects, typically referred to as aids or devices which are used to communicate messages*” (Glennen and DeCoste, 1997, p. 107).

1.4 Developing the Research Focus

The field of AAC is a relatively new area of clinical research and practice. The implementation of AAC for children has developed over the past few years from a focus solely on the child to a greater emphasis on the family (McNaughton et al., 2008) and the views of communication partners (Light, Beukelman and Reichle, 2003; Goldbart and Marshall, 2004). One of the underlying principles of AAC is that it should be conducted in natural environments (Beukelman and Mirenda, 2005) and yet very few studies are undertaken in the family home. AAC systems can have a significant impact on a child’s daily life with parents reporting that AAC supports their child’s independence and increases their number of communication partners (Bailey et al., 2006). Parents play an important role in providing social opportunities for their children and in facilitating their children's communication and social interaction skills (Dunst and Kassow, 2008; Huer and Lloyd, 1990). They are asked by professionals to share the responsibility for the introduction of AAC and the development of their child’s competence with their AAC system (Beukelman, 1991; Light, 1989). Parents are often responsible for selecting and updating vocabulary, programming an AAC device and for integrating it into their family routines (McNaughton et al., 2008). This can be extremely challenging when caring for a child with complex communication needs (Bailey et al., 2006; Angelo, Jones and Kokoska, 1995), consequently it is important for professionals to understand the concerns and views of both the AAC user and their families.

Previous studies in the UK have considered parents' perspectives on AAC (Goldbart and Marshall, 2004) and experiences of teenagers who use AAC (Wickenden, 2011) but there is a paucity of research on the experiences of the 'whole' family unit and their use of AAC in the home. This led to the research proposal aim:

> *To explore, from the perspective of the child and family, the use of different AAC systems in the home and the benefits and challenges faced by children and families in integrating these systems into their daily lives.*

1.5 Choice of Research Design

Research in AAC poses additional challenges due to the heterogeneity of the population of AAC users and the complexity of AAC systems. A qualitative research methodology was selected for this study to gain an in-depth understanding of the perspectives of families using AAC. Qualitative research encompasses a wide range of different philosophical traditions (Patton, 2002) which seek to understand the phenomena studied and enables the complexity of experiences to be studied. Grounded Theory (GT) was chosen as the overarching philosophical, theoretical and methodological framework as it moves beyond description to produce a theory grounded in the data (Charmaz, 2006). A constructivist approach assumes a relativist ontological position where the world consists of multiple individual realities. The use of a constructivist grounded theory (Charmaz, 2006) allowed the experiences of families to be explored and multiple views to be represented. It offered an interpretative analysis of their experiences and emphasised an 'understanding' rather than 'explanation' (Charmaz, 2006, p.126) of those experiences.

A constructivist grounded theory aims to demonstrate "*the complexities of particular worlds, views, and actions*" (Charmaz, 2006, p.132) with both parents and children as co-constructors within the research. The researcher is also a subjective member of the research process and part of the construction process. Adopting a constructivist grounded theory not only encouraged openness and an understanding of the participants' stories but had the potential to guide clinical practice (Charmaz, 2006).

1.6 Background of the Researcher

Interest in investigating this area emerged as a result of the researcher's role as a Speech and Language Therapist working within a multidisciplinary AAC team assessing children with complex communication needs. These experiences have highlighted the importance of involving parents in the AAC process and gaining an understanding of their expectations and experiences when adopting different communication systems. Seeking and understanding the voice of the child (United Nations Convention on the Rights of the Child, 1989; Department of Health, 2010) has been central to this role which has resulted in the use of a range of strategies to support children and young people with complex communication needs to give their views and opinions in a meaningful way.

1.7 Thesis Structure

The remaining thesis chapters have been organised as follows:

Chapter Two sets the scene through a review of AAC systems and the commissioning of AAC services in the UK. It presents an exploration of the social context in which AAC takes place and a review of current knowledge concerning family experiences of AAC.

Chapter Three describes the chosen methodology: grounded theory. It discusses the components of the method, its development and divergence and the rationale for the choice of a constructivist grounded theory for this study.

Chapter Four describes the data collection methods including the sampling processes, ethical considerations, data collection and analysis methods.

Chapter Five presents a review of the literature relevant to the emergent theory. They are considered in this chapter to prevent intrusion in the presentation of the findings.

Chapter Six and Chapter Seven present the grounded theory of 'Finding a Voice' which emerged from the analysis. Chapter Six considers the Trajectory identified and discusses the first two phases: ‘Loss of Voice’ and ‘Prioritising a Voice’. Chapter Seven explores the third and fourth phases of ‘Gaining a Voice’ and ‘Sustaining a Voice’.

Chapter Eight summarises the emergent theory and its contribution to knowledge. The implications for service delivery and practice are presented in this chapter.

Chapter 2 Augmentative and Alternative Communication: review of the context and existing knowledge

2.1 Introduction

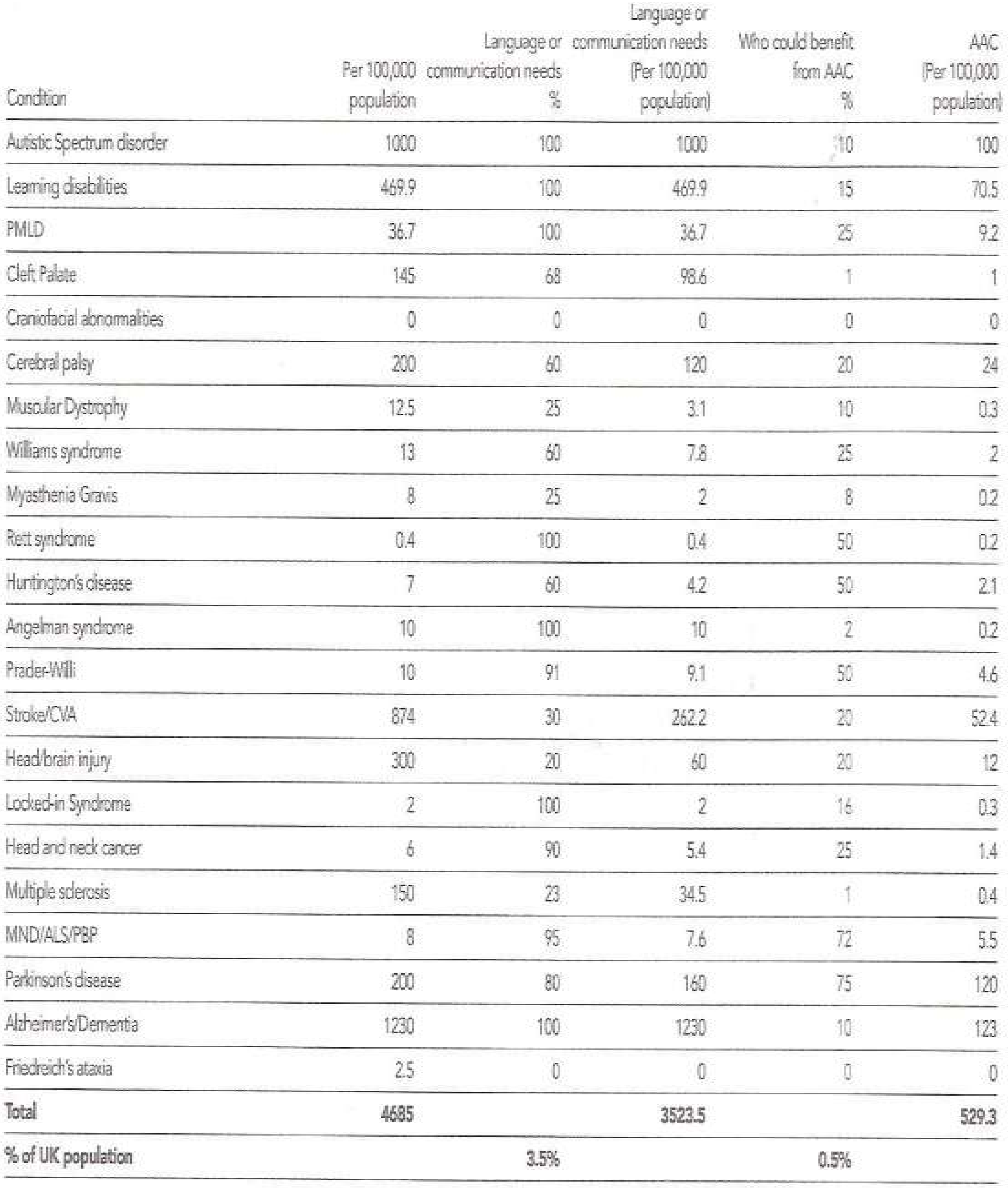
This chapter explores the need for AAC, provides a definition of AAC systems and describes the current context in terms of commissioning AAC services and equipment. A brief description is provided on some of the extensive literature on caring for children and the responsibilities for managing children in society which impacts family life and the use of AAC. Finally a review of the current literature exploring the experiences of children and families in their use of AAC is presented.

2.2 AAC: a review of the context

2.2.1 The need for AAC

The number of children in the UK who would benefit from AAC has yet to be accurately quantified. Scope (2007), a UK charity supporting people with disabilities, suggests that between 0.4% and 1% of the population could be supported by some form of AAC. The Royal College of Speech and Language Therapists (RCSLT, 2011) estimated that between 0.3% and 1.4% of the total population required the use of AAC systems. More recent data (Enderby et al., 2013) estimate that 0.5% of the UK population requires some type of AAC which equates to 529 people per hundred thousand of the population in the UK. In this group approximately 0.05% will require high tech AAC solutions (Enderby et al., 2013). This is considered to be a conservative estimate and it is anticipated that with the changing demographics and increased medical technology resulting in the survival of children with disabilities, this figure is much higher.

A range of individuals who have communication difficulties may benefit from the use of AAC systems. Table 1 shows the prevalence of conditions associated with the use of AAC (Enderby et al., 2013).



Condition	Per 100,000 population	Language or communication needs %	Language or communication needs (Per 100,000 population)	Who could benefit from AAC %	AAC (Per 100,000 population)
Autistic Spectrum disorder	1000	100	1000	10	100
Learning disabilities	469.9	100	469.9	15	70.5
PMLD	36.7	100	36.7	25	9.2
Cleft Palate	145	68	98.6	1	1
Craniofacial abnormalities	0	0	0	0	0
Cerebral palsy	200	60	120	20	24
Muscular Dystrophy	12.5	25	3.1	10	0.3
Williams syndrome	13	60	7.8	25	2
Myasthenia Gravis	8	25	2	8	0.2
Rett syndrome	0.4	100	0.4	50	0.2
Huntington's disease	7	60	4.2	50	2.1
Angelman syndrome	10	100	10	2	0.2
Prader-Willi	10	91	9.1	50	4.6
Stroke/CVA	874	30	262.2	20	52.4
Head/brain injury	300	20	60	20	12
Locked-in Syndrome	2	100	2	16	0.3
Head and neck cancer	6	90	5.4	25	1.4
Multiple sclerosis	150	23	34.5	1	0.4
MND/ALS/PBP	8	95	7.6	72	5.5
Parkinson's disease	200	80	160	75	120
Alzheimer's/Dementia	1230	100	1230	10	123
Friedreich's ataxia	2.5	0	0	0	0
Total	**4685**		**3523.5**		**529.3**
% of UK population		**3.5%**		**0.5%**	

Table 1: Prevalence of conditions associated with use of AAC (Source: Enderby et al., 2013)

Light and McNaughton (2012) suggest the recent changes in both the public and professional awareness of AAC will result in widening the range of client groups who would benefit from AAC systems. The increase in both AAC devices and more mobile technologies offer further benefits for children and families and may support and increase awareness of AAC.

2.2.2 Defining AAC systems

The term AAC (Alternative and Augmentative Communication) is used to describe a wide range of methods and strategies that can be used to help people communicate with others. Murray and Goldbart (2009) identified four components which are interconnected when reviewing AAC systems: the mode (the type of AAC equipment), the means (access to the system such as eye-pointing), the representational system used (symbols, photographs, the written word) and the interaction strategies (repairing conversational breakdown, initiating conversation).

Aided communication can be divided into two categories: ‘low tech’, which does not require an additional power source (e.g. books, charts and boards) or ‘high-tech’, all of which require a power source from a battery or mains. Low tech communication books are a way of representing vocabulary and are often organised into different categories (Latham, 2004) or according to communication function and conversation (Porter, 2007). The Picture Exchange Communication System (Frost and Bondy, 1994) is a low tech AAC system widely used in the UK for children with Autistic Spectrum Disorder (ASD). High tech systems can range from simple single message devices to more sophisticated equipment such as mobile devices, tablets and laptops (Communication Matters, 2015) which use digitised (recorded speech) or synthesized speech. In the UK high tech communication systems are often referred to as voice output communication aids (VOCAs).

The means of communication by which the child accesses the communication system is dependent on their level of physical limitations and motor skills. They may use direct selection involving pointing with either the finger, hand, eyes or any part of the body with reliable movement or indirect selection which often involves specialist software and hardware. Scanning is the most frequently used indirect system where the child will use one or two switches to operate the communication device. Scanning can provide the child with a number of options including an auto-scan, linear, row-column and encoding (Beukelman and Mirenda, 2005). The choice will depend on the requirements of the user and the complexity of the selection set. Colven and Judge

(2006) suggest AAC users move through a series of different control methods as they mature and develop.

A child can communicate using different representational systems on their AAC system which need to be organised for the most effective and efficient communication. These representational systems range from photographs/pictures to symbols and the written word. There are a number of symbol sets used in the UK including Widgit, Picture Communication Symbols (PCS) and Makaton. As the AAC user begins to develop their vocabulary the organisation of the representational system becomes more complex (Drager, Finke and Serpentine, 2010). For example, a normally developing three-year-old would require a vocabulary set of approximately 1000-1100 pictures or symbols (Harris, Ryder and Totten, 2010). The storage and retrieval of messages need to be carefully considered (Beukelman and Mirenda, 2005) for the child to be able to consistently find the vocabulary they need and to access it quickly.

Murray and Goldbart (2009) also consider interactional strategies such as repairing conversations, initiating conversations and turn-taking when using AAC. These can be difficult for AAC users as communication partners often adopt a dominant role and direct the conversational exchanges (Clark and Wilkinson, 2007; Pennington, Goldbart and Marshall, 2004). Romski and Sevcik (1996) observed that parents interacting with their child using AAC integrated spoken language and AAC use for only 10% of the time. The dominance of conversational partners can lead to passivity or “'learned helplessness”' (Basil, 1992) which can pose further challenges when using AAC systems.

2.2.3 Commissioning of AAC Provision

The commissioning of AAC services across the UK has led to different arrangements in different parts of the country resulting in a ‘postcode lottery’ (Communication Matters, 2011). In recent years there have been a number of significant changes in the provision of AAC. The Communication Aids Project (CAP) established in 2002 and managed by the British Educational and Communications Technology Agency (BECTA), gave support to children and young people with complex communication needs by assessing and providing high-tech communication aids. CAP represented a new development in the provision of communication aids but this government funding ceased in 2006.

The Bercow Report (2008) reviewed services for children and young people (0-19 years) with speech, language and communication needs and highlighted that children and young people requiring AAC struggle to have their needs met under the commissioning arrangements. The review found no consistent system for ensuring that those who needed communication aids received them. The report recommended the development of a ‘hub and spoke’ model to provide equitable provision of AAC with the establishment of regional ‘hubs’ to support local ‘spoke’ services. The lack of consistent and equitable services to meet the needs of AAC users was also highlighted in the report of the Office of the Communication Champion (2010). It was found that only one in ten regional commissioning teams were meeting the needs of adults and children requiring AAC.

The NHS White Paper ‘Equity and Excellence: Liberating the NHS’ (2010) proposed changes to the commissioning of all NHS services including commissioning arrangements for AAC in England. The proposed arrangements included Specialised AAC services providing assessments and communication aids for children and adults with complex communication needs, supported by local AAC services commissioned by Clinical Commissioning Groups (CCGs), education and social care commissioners in England. In April 2014, NHS England confirmed the allocation of monies for the development of specialised AAC Services in England. AAC provision at a local (‘spoke’) level is generally through local Speech and Language Therapy services but the development and commissioning of local AAC services is unclear with no specific guidance for CCGs on commissioning these services.

2.2.4 Defining Family

This study sought the perspectives of the ‘whole’ family on the use of AAC systems in the home. In the UK, many people no longer live in the traditional nuclear family model (ONS, 2010). The concept of a ‘family’ is explored extensively in sociology literature but as Bomar (2004) suggests the term ‘family’ can be defined differently by individuals, organisations, governments and researchers. In a review of the literature, the term ‘family’ includes significant diversity and a variation in definitions. Denham (2003) defines family as “*a collection of individuals with a general commitment to the well-being of one another and who label themselves as family*” (p.227). Different people are considered to be part of the family for different purposes (Allan, 2005). Carpenter and Carpenter (1997) view families as ‘contexts’ with an extended family support network reflecting the diversity in family life. The family can be seen as having its own culture with Winton (1990) describing family as having “*different values and unique ways of realising its dreams”* (p.4).

Therefore in this research it was important to have no assumptions about what the term ‘family’ constitutes and as a result parents and children and young people were asked to describe in their interviews their family and its composition.

2.2.5 Families with children

The social constructivist perspective of parenting is described by Arendell (1997) as follows:

> *“Parenting is situated in a place in time: it does not occur in a social vacuum, but rather is integrally interlinked with and shaped by demographic changes, historical events and patterns, cultural norms and values, systems of stratification, family developments and arrangements and shifts in societal organization and structure…Cultural meanings about parenting and parenthood are based on tradition, practice and ideology.”*
> *(p. 9)*

Parents will make decisions on different roles and responsibilities and these will be influenced by social, cultural and political contexts. A wide range of research consistently identifies it is women’s work to care for children (Cunningham-Burley et al., 2006; Gatrell, 2005, Hochschild and Machung, 2003; Ribbens, 1994). Ribbens (1994) reported mothers, in her feminist sociology of childrearing, as the social agents in the family and it is not only their role to create the family but also any connections with different social settings. Gatrell’s (2005) research in the UK also confirmed the stereotypical roles of parents, with mothers more likely to take on the caring role in the family.

In recent years the number of mothers in the workforce has increased but attitudes to work may be different between men and women. Bashir et al. (2011) interviewed 67 parents on their attitudes to work and reported all the women explained their relationship with work through reference to their role and responsibilities as a mother. Men made very few references to issues of childcare when discussing their work. Nangle et al. (2003) view is that the societal shift where more mothers are seeking employment has led to the increased societal expectations on fathers to be more involved with their children. Featherstone's (2009) "*Contemporary Fathering*" highlights that it is important to look at the mother and father in the context of their family, friends and society and the different roles they play. Featherstone suggests "*our increased understanding that 'fathers matter' must be located within an appreciation of how 'mothers matter' also*" (p.190). Allen and Hawkins (1999) identified that a father's involvement may be influenced by maternal gatekeeping where mothers retain control of activities and limit father's involvement. However, they also concluded that fathers may wish to support maternal gatekeeping as they do not want to take on more caring responsibilities.

There is a continued expectation in modern life that men's primary responsibility is the 'breadwinner' (Dermott, 2006), with a social expectation that they should be earning (Doucet and Merla, 2007). This could be as a result of gendered moral rationalities (Duncan and Phillips, 2008) or economic realities. Fagan (2010) reports the gender pay gap continues and this results in the higher earning man focusing on employment and the woman maintaining her primary caregiver role.

The impact of having a child with a disability has further effects on the family. Olssen and Hwang (2003) reported families have increased financial hardship, restricted social lives and modifications to family activities due to the time constraints caused by the additional care demands. Considerable evidence shows mothers take more responsibility for their disabled child than fathers (Lawler, 2000; Gray, 1997; Hays,

1996) and many mothers are the main carers of their child (Runswick-Cole, 2007; Traustadóttir, 1995). Two more recent studies have found fathers of children with disabilities look to their partners to take the main role in caring for their disabled child (Towers 2009; MacDonald et al., 2010).

There is evidence that families which include a child with disabilities are likely to be severely affected economically (Olssen and Hwang, 2003; Gordon et al., 2000). Contact a Family (2011) showed only 16% of mothers with disabled children work compared to 61% of other mothers which suggests that mothers are more likely to assume the main caring role for their disabled child.

2.2.6 Conclusions from commissioning and social context

Developments in low and high tech AAC systems in recent years offer new communication opportunities for children with complex communication needs. In the UK, the lack of an equitable provision has led to a 'postcode lottery' and the needs of children and young people requiring AAC have not been met under previous commissioning arrangements. New commissioning arrangements based on a 'hub' (Specialised services) and 'spoke' (Local services) model of AAC provision were recently implemented in 2014 to provide more equitable provision of AAC in England. In the changing social and political environment, the roles of mothers and fathers are continually being redefined to adapt to the new requirements of everyday life. Although there has been considerable social change in recent years, the gendered nature of parenting roles and responsibilities continues to persist and the use of AAC systems should be considered in light of these traditional models of parenting.

A concise review of the AAC literature is presented below to establish what is currently known about the use of AAC in families.

2.3 Family experiences of AAC: A literature review

The place and timing of a literature review is disputed in grounded theory and classic grounded theorists such as Glaser (1978) considered the inductive nature of the method requires the literature is reviewed only after the emerging theory has been constructed. The purpose of delaying a comprehensive literature review until after the analysis is to avoid the researcher being influenced by any *"received theories"* (Charmaz, 2006, p.165). However, theoretical sensitivity, one of the methods used in grounded theory, also supports the researcher to recognise and challenge their personal biases and diminishes the risk of foreclosure of the analysis in favour of these theories.

Charmaz (2014) acknowledges that researchers need to examine the literature to clarify and identify any knowledge gaps and enable the development of research questions. The initial literature review (see Appendix 2 for detail on search strategy) was completed in August 2012 to identify gaps in the research and provide a justification for the research proposal submitted to the Research Degrees Board and the NHS Research Ethics Committee.

The review question:

- What are the experiences and perspectives of children and young people and their families of using AAC?

The literature review identified four areas of existing knowledge around families' experiences of AAC:

- Parental expectations of AAC
- Families' use of AAC in the home
- Child/AAC user perspectives on AAC
- Societal views of AAC

2.3.1 Parental Perceptions of AAC

One of the major barriers to early AAC intervention identified in the literature focuses on parents' pre-conceptions and beliefs about AAC. Parents may believe an AAC system will hinder speech development (Beukelman and Mirenda, 2005; Romski and Sevcik, 2005) or the introduction of AAC signals to them that professionals involved do not believe their child will be able to speak (Iacono and Cameron, 2009). Early intervention relies on the acceptance of AAC but initially parents and professionals may adopt a ‘wait and see’ approach (Sevcik and Romski, 2002).

Angelo, Jones and Kokoska (1995) investigated priorities for AAC use with parents of children and young adults using AAC. They surveyed 91 parents (56 mothers and 35 fathers) reporting that increased knowledge of AAC devices and planning for the child’s future communication needs were priorities for both mothers and fathers. However, mothers and fathers differed in their priorities for AAC, with mothers focusing on the social opportunities and integrating AAC into the wider community while fathers’ priorities were funding, programming and maintaining AAC systems.

Parental involvement has been reported as vital in AAC decision-making (McNaughton et al., 2008; Granlund et al., 2008; Bailey et al., 2006). In a survey of 74 family members of AAC users in Israel, Hetzroni (2002) found that only 21% of families were involved in the development of the AAC system. As a result of this lack of involvement, McNaughton et al, (2008) reported parents were more likely to acquire AAC knowledge from friends than professionals. Goldbart and Marshall’s (2004) study of parents/carers of 11 children aged three to ten years who lived in the UK showed families varied in not only how much they wished to be involved, but also at which point/s they could prioritise AAC over other issues in the family.

Several studies report a lack of training and support for families (McDonald et al., 2007; Angelo, 2000). Bailey et al. (2006) interviewed six family members of seven children using AAC devices in school settings and reported AAC decisions were often made by professionals before involving parents and children. This study identified there was a need for increased collaboration between families and professionals with further training available for parents in using AAC. Hodge (2007) conducted semi-structured interviews with 31 AAC users (12 children, 19 adults) reporting that due to the heavy caseloads of Speech and Language Therapists, there were limits to the amount of support that could be given to AAC users and their families. Parents struggle to keep services involved with their child and they may support their child’s AAC system with limited professional input (Goldbart and Marshall, 2004).

McNaughton et al. (2008) found parents often had to learn to use their child's communication device by reading the manuals or gaining advice and information through searching websites. The lack of professional expertise in AAC is also highlighted in several studies (Crisp, Draucker and Ellett, 2014; McNaughton et al., 2008; Lund and Light, 2007; Goldbart and Marshall, 2004).

2.3.2 Families' use of AAC in the home

Jones, Angelo and Kokosa (1998), in their survey of 55 families with young children between the ages of three and twelve years who used different communication systems, reported AAC is challenging and families appear to be at risk of experiencing higher stress levels. The level of parental involvement needed to implement AAC may lead to greater stress for the parent and family (Marshall and Goldbart, 2008; McCord and Soto, 2004). AAC interventions and outcomes are frequently measured in different settings other than the home. Snell, Chen and Hoover (2006) reviewed 40 studies from 1997 and 2003 and the majority of interventions occurred in the school setting. However, Granlund et al. (2008) viewed that any AAC intervention will affect the child's interactions with parents and siblings within the family and their attitude to a communication system will be influential. Prior to the introduction of AAC, families will often have developed and established their own communication patterns with their child and understand their child's natural speech or non-verbal communication more quickly than they can using an AAC system (Rackensperger, 2012). Bailey et al. (2006) found participants in their study discussed not using the AAC device in the home as they relied on their child's effective "*nonsymbolic communication skills*" (p.57). McCord and Soto's (2004) small ethnographic study of four Mexican-American families, whose children were learning to use AAC systems, also reported devices may not be perceived as beneficial for interactions within the family and family members may not recognise any improvement in the child's communication by using AAC. McCord and Soto (2004) concluded this was primarily due to language barriers and cultural preferences for speed and spontaneity in communication. Judge and Townsend's (2013) survey of 43 parents, AAC users and professionals also reported that using a communication aid was a slower means of communication than naturalistic spoken language and this was often considered a barrier to using AAC.

The capacity and capabilities of family members impact on the successful use of AAC (Hodge, 2007). Due to the demands of parenting a child with a disability, feelings of guilt and frustration at not having enough time to spend with their child using AAC have been reported (Goldbart and Marshall, 2004; Schladant, 2011). Bailey et al. (2006) suggested much of the stress in implementing AAC was related to the amount of time required to programme devices. It was often mothers who were responsible for programming AAC devices and they often assumed the advocacy role on behalf of their child with complex communication needs (Angelo, 2000).

The vocabulary available on the AAC system is important for the functional use of AAC within the home but many systems give only limited access to effective communication or sufficient vocabulary (Ballin et al., 2011). This can be due to a restricted vocabulary available in the system (Hodge, 2007) and a lack of on-going support in learning strategies to increase communicative opportunities (Hetzroni, 2002; Hodge, 2007). Hetzroni (2002) reported 30% of families in her survey were unhappy with the content of the messages in their child's AAC systems which were restricted to mainly requests for food/drink, play choices and songs. There was an over-reliance on requesting rather than a range of communicative functions (e.g. commenting, describing, sharing information). Choosing vocabulary for AAC systems can be challenging and McNaughton et al. (2008) found parents lack skills in using AAC technology and selecting the right vocabulary for their child. Few studies consider how families develop their child's competencies in AAC and the strategies they employ but focus instead on the limited use of AAC in the home (Allaire et al., 1991; Angelo et al., 1996; Culp, 1987) and a need for further family support (Lund and Light, 2007; Rackensperger et al., 2005).

2.3.3 Child/AAC user Perspectives

AAC users give a wide range of reasons why they use AAC from making friends and socialising (Judge and Townsend, 2013) to participation in the community (Wickenden, 2011) and communicating with family (Valiquette, Sutton and Ska, 2010). Wickenden (2011) reported in her ethnographic study of nine teenagers using communication devices that they perceived AAC as essential for participation in school and they liked to talk about topics typical to teenagers such as shopping, sport, and romance. The teenagers in her study had positive self-identities and were more interested in similarities with others their own age rather than feeling they are ‘disabled’. Peer interaction is important for children using AAC but those using AAC are often perceived more negatively by their peers than children without communication difficulties (Beck and Dennis, 1996; Clarke and Kirton, 2003). Clarke and Kirton (2003) analysed the modes of communication used by 12 AAC user/peer dyads. This showed children with AAC systems preferred ‘natural’ channels of communication with gestures (46.4%) and vocalizations (35%) most commonly used resulting in infrequent use of their communication devices.

The limited use of high tech communication devices has been identified in several studies (Hodge, 2007; Judge and Townsend, 2013; Bailey et al., 2006) with the AAC user preferring to use other means of communication resulting in the device not being used to its full potential (Judge and Townsend, 2013; Hodge, 2007). The appearance of a device may also affect its acceptance to the AAC user and the participants in Clarke et al.’s (2001) study described their devices as “uncool” and “boring”. However 11/17 AAC users in this study described their communication devices as “useful”. Boggis (2012) sought the views of children and young adults who use AAC within the UK and found they had very limited involvement in decisions about the choice of AAC systems or the vocabulary available to them on their devices.

Device limitations are cited in many studies and these include poor voice quality (Baxter et al., 2012) and issues with portability (Judge and Townsend, 2013; Bailey et al., 2006). The unreliability of devices was reported by participants in Judge and Townsend’s study (2013) resulting in many AAC users left without their devices for considerable lengths of time. Other studies have also discussed the unreliability of devices which can affect AAC use (Lund and Light, 2013; McNaughton et al., 2008).

The personal characteristics of the AAC user and that of the family will affect AAC outcomes (Lund and Light, 2007). High expectations (Rackensperger, 2012), patience and hard work (Lund and Light, 2007) and self-determination (Light and Gullens, 2000) were all considered important characteristics in AAC. Light (2003) expanded her influential model on AAC communicative competence (operational, linguistic, social and strategic domains) to include psycho-social factors which impact on AAC including motivation and attitude (Light, 2003), confidence (Light and McNaughton, 2014) and resilience (Light and McNaughton, 2014).

2.3.4 Societal views

The number of AAC users remains quite low and different communication systems are not widely used in society (Hodge, 2007). In her ethnographic study Wickenden (2011) reported teenagers had received negative reactions from others in society particularly staring or assuming the AAC user was unable to do things for themselves. The stigma of using communication aids (Hodge, 2007; Parette and Scherer, 2004) and the reluctance of AAC users to use their systems could also be related to self-identity and self-image (Clarke et al., 2001). AAC can result in increased opportunities for children to communicate with wider communication partners (Bailey et al., 2007; Goldbart and Marshall, 2004). The use of different communication devices often requires the acknowledgement of these systems by others in the community. In some environments parents have acted as an 'interpreter' (Goldbart and Marshall, 2004) whereas other families have encouraged their children to introduce themselves using their communication system (McNaughton et al., 2008). The effective use of communication devices in wider society relies on both the skills of the AAC user and their communication partner. Unfamiliar communication partners often do not give the AAC user enough time to communicate (Wickenden, 2011) and may try to complete their sentences (McNaughton et al., 2008). Hodge (2007) suggested the lack of public awareness and information concerning different AAC systems marginalised AAC users in society.

2.3.5 Conclusions from the review of the literature

Findings from the review of the literature confirm families of children with complex communication needs are important stakeholders in AAC and their knowledge and experiences positively impact on AAC outcomes and practices. For children with complex communication needs, their family and home are important contexts for the development of their communication and the immediate family members are significant communication partners. Research findings have shown that families may face challenges in successfully implementing AAC due to limited access to available AAC systems and services. Several studies focus on the lack of support and training available for families in the use of AAC with decisions often made for them by professionals. However the underuse of AAC systems has also been reported in both the UK and USA suggesting AAC users and their families prefer more naturalistic methods of communication. More recent research has considered the psychosocial factors affecting AAC use including the motivation, confidence, attitude and resilience of both the AAC users and their families. Device limitations have also been cited as a major barrier to successful AAC use particularly the reliability of more high tech communication devices.

Baxter et al. (2012) highlighted the complexities of research in AAC and the difficulties in evaluating and comparing interventions. In practice AAC interventions for individuals are '*seldom exactly alike'* (Light, 1999, p. 16). The numbers of people who use AAC are also relatively small and currently the majority of AAC research evidence is based on small groups of research participants or case studies. Case studies have often been a focus of criticism (Hodkinson and Hodkinson, 2001) due to their limited generalisation. To overcome some of these difficulties, Murray et al. (2014) proposed a case study template to ensure consistency in ways in which communication intervention data was gathered. This will enable researchers to compare data across case studies in AAC which will contribute to developing research at a higher evidence level in the UK.

2.4 Conclusion

Studies in AAC are often undertaken in more controlled settings such as the school environment with little research focusing on the use of AAC within the context of the family. Baxter et al. (2012) in a systematic review of the AAC literature recommended AAC outcomes should be evaluated in “real-life settings” (p.17). Therefore it would seem appropriate to investigate family perspectives on AAC use in the home to provide a better understanding of their needs and how these can be met. This is a significant area of study in AAC, an understanding of which could support improvements in the provision and delivery of AAC services

The following chapters will focus on the research approach and process adopted for this study. Chapter 3 will provide an overview of the research approach and Chapter 4 presents an account of a constructivist grounded theory methodology to explore the perspectives of families in using AAC systems within the home.

Chapter 3 Methodology

3.1 Introduction

This chapter considers the chosen methodology: grounded theory. It outlines the development and divergence of grounded theory and considers its philosophical origins. An explanation is given of the different components in a grounded theory study with a focus on Charmaz's (2006, 2014) constructivist grounded theory.

3.2 Grounded Theory

Grounded theory is a methodological approach as well as a method of data analysis. It has distinctive features, which are explained later in this chapter, which distinguish it from other qualitative analysis (Wertz, 2011) and is an interpretive methodology (Lincoln and Guba, 1985). It provides the researcher with systematic tools for collecting and analysing processes, develops interpretations of the data through coding/categories resulting in a grounded theory. Schwandt (2001) defined grounded theory as "a *specific, highly developed, rigorous set of procedures for producing formal, substantive theory of social phenomena"*(p.110) The grounded theorist remains "*open to what is happening in the studied scenes and interview statements so that we can learn from our research participants' lives*" (Charmaz 2006, p.3). Grounded theory is considered suitable as a methodology where a phenomenon has not been adequately researched or explained (Henderson, 1995) and as a result was considered an appropriate methodology for this research.

In this study grounded theory also allowed the researcher to consider the implicit meanings generated by the participants and to construct an understanding of the participants' perspectives of using AAC within the home.

3.3 Symbolic Interactionism: A theoretical Framework

Grounded theory has its origins in Symbolic Interactionism which has American philosophical roots and derives from the pragmatist tradition. Symbolic interactionism has influenced grounded theory with its emphasis on social processes and interactions (Glaser and Strauss 1967; Glaser, 1978). Symbolic interactionists consider the concept of 'self' as central and see the human being as having both a 'mind' and a 'self' which are constructed out of interactions with others in society (Blumer, 1986; Mead, 1934; Sandstrom et al., 2001). According to Blumer (1986), the three core principles are meaning, language and thought and these elements lead to conclusions about the concept of 'self' through interactions within society. The development of 'self' is through social interaction and is an ongoing process which is refined and is constantly changing. The interaction relies on communication and language and emphasizes the importance of what individuals know and how they view the world (Benzies and Allen 2001). Sandstrom, Martin and Fine (2001) consider that "*to understand people's social acts, we need to use methods that enable us to discern the meanings they attribute to these acts.*" (p.219).The researcher needs to look beyond the behaviour to find the underlying meaning and within grounded theory the researcher constructs a theory to understand or explain the actions and interactions of their participants. It aims to collect and analyse data to generate theory that furthers the understanding of the world of those under study (Chenitz and Swanson, 1986).

Charmaz (2006) summarises symbolic interactionism as a *"theoretical perspective derived from pragmatism which assumes that people construct selves, society and reality through interaction*" (p.189). Both constructivist grounded theory and symbolic interactionism assume there are multiple realities and focus on meaning, action and process (Charmaz, 2006). Within a family context where this study lies, parents will perform a range of different functions, differing roles, interactions and attitudes which may be affected by external events as well as interactions with wider society including health and social care. As a result symbolic interactionism cannot be viewed separately from grounded theory within this study as it is intrinsic to the overall process.

3.4 Grounded Theory: Development and Divergence

"The Discovery of Grounded Theory" (Glaser and Strauss, 1967) provided a qualitative methodological approach which challenged assumptions that quantitative research was more 'rigorous' and that qualitative methods were unsystematic. Glaser and

Strauss (1967) considered that the aim of grounded theory was '*The discovery of theory from data systematically obtained from social research'* (p.2). Grounded theory uses a combination of both inductive and deductive approaches (Heath and Cowley, 2004). The aim of the methodology is to discover theory by a primary approach of induction where the researcher is continually guided by the data. Deduction is later used to verify the codes and categories which have emerged during theory development. Classic grounded theory generates a conceptual understanding of social behavior from an objective stance. Strauss and Corbin (1990, 1998) later moved into a post positivist paradigm questioning the belief in objectivity although they retained much of the original grounded theory.

A further development in grounded theory is the constructivist approach (Charmaz, 2006) that results in an interpretive understanding of the participants experiences (Charmaz, 2006; 2014). Charmaz (2006) incorporates the multiple voices and views of participants in representing their lived experiences. A constructivist approach to research rejects any external, independent reality and considers that the social world is socially constructed (Green and Thorogood, 2004). The end product of a constructivist grounded theory is an interpretation; with the data and analyses being social constructions which are contextually situated. This contrasts to the original grounded theory where Charmaz (2014) contends the researcher is "*separate and distant from research participants and their realities*" (p.237). The data gathered is not independent of the researcher with the researcher's views and experiences taken into account (Charmaz, 2006). In her approach, Charmaz (2006) argues that the researcher's perspective is integral to the whole process and influences the final theory as "*neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect."* (p.10)

In a constructivist grounded theory the basic components of grounded theory such as sampling, coding and memo writing are still present but are re-examined through a '*methodological lens of the present century*' (Charmaz, 2006, pxii). She views that constructivist grounded theory aligns with 21st century methodologies and redirects grounded theory from its objectivist routes. Charmaz (2009) outlines how a constructivist approach *“sees knowledge as socially produced, acknowledges multiple standpoints of both the research participants and the grounded theorist, and takes a reflexive stance” (p. 129).*

Table 2 illustrates the differences between Glaser, Strauss and Charmaz on aspects of Grounded Theory Methodology.

Grounded Theory	Glaser (1992)	Strauss and Corbin (1990)	Charmaz (2006)
Research question/problem	The research problem is ‘discovered’ as coding begins. An area of inquiry is identified beforehand but not the research problem.	The research question is a statement that defines the phenomenon to be studied. The research question sets the boundaries around what is to be studied.	The initial question starts broadly and is narrowed down during the research process. The initial research aim or question is exploratory in nature.
Use of data	“All is data”.	Can use quantitative data but the analysis is qualitative.	Seeks ‘rich data’ depending on the topic and access to data.
Use of Literature	Should not read the literature in the substantive area until the core category is established.	Literature can produce sensitising concepts during the collection and analysis of the data.	An initial review of the literature at the beginning of the study can be helpful in narrowing down the topic of research and setting the stage for the study.
Verification	Grounded theory is not verified but modified to accommodate new data by integrating them into the existing theory.	Induction, deduction and verification are essential.	Emphasis on ‘induction’, and ‘abduction’.

	Emphasis on induction and theory emergence.		
Coding Types	Open coding and theoretical coding	Open coding, axial coding and selective coding	Initial, focussed and theoretical coding
Theory generation	Theory is grounded in the data and 'discovered'	The theory is interpreted by an observer	The theory is as a result of the co-construction between the participants and the researcher
Social Processes	A basic social process should be identified	Social processes need not be identified	Emphasis on what works in the context of the data and wider study.

Table 2: The differences between Glaser, Strauss and Charmaz on aspects of Grounded Theory Methodology.

3.5 Choosing a Constructivist Approach

Researchers beginning a grounded theory study will need to choose between the differing approaches as outlined above. A constructivist approach was chosen for this study and this decision was based on the researcher's philosophical position that meaning in the social world is socially constructed and there are multiple realities as opposed to one truth. This is supported by Crotty (1998) '*It is the view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context* (p.42).

Charmaz (2006) presents an emergent approach to grounded theory, providing practical and flexible guidelines to both data collection and analysis which felt comfortable to the researcher. A constructivist approach was also chosen as it places the emphasis on the voices of the participants and seeks to give a voice to participants and understand their experiences and actions. The analysis of the experiences of families using AAC offers an interpretative portrayal with an intent to represent their stories and to '*keep that life in the foreground*" (Charmaz, p. 526). As a practising

Speech and Language Therapist it was very important for the findings to keep the participant's voice and present them in the final writing of the grounded theory.

3.6 Grounded theory Methods

Grounded Theory has a number of distinct methods and strategies: open coding, constant comparative analysis, theoretical sampling, theoretical sensitivity, memo writing and theory generation (Charmaz, 2002). Each of these will now be discussed in more detail in the following sub-sections.

3.6.1 Sampling

Initial sampling in grounded theory is 'purposive' where participants are selected to explore a particular area of interest to the researcher. Charmaz (2006, p.101) views this as the beginning of the study where the researcher explores the phenomena. This is followed by theoretical sampling where the further selection of participants is based on the theoretical questions which have arisen during the analysis. Theoretical sampling can also occur within interviews with specific questions being asked of participants which allows for further elaboration of the emerging concepts. Through this process the researcher can question the concepts and their meaning for the developing theory and confirm or refute these categories (Charmaz, 2006). Conducting theoretical sampling allows the researcher to become more focussed with participants chosen on the basis of emerging categories. It develops and improves the researcher's understanding of the key properties.

3.6.2 Constant Comparative Method

Grounded theory uses constant comparative analysis which Glaser (1978, 1992) viewed as essential in any study using grounded theory. Constant comparative methods are used to establish distinctions in the analysis (Charmaz, 2014) and to find similarities and differences. From the initial interview, the researcher, where possible, is analysing data and comparing data to data (Charmaz, 2006) which leads to the generation of initial codes. Birks and Mills (2011) describe the constant comparative method as an "*iterative analytical method of constantly comparing and collecting or generating data that results in high level conceptually abstract categories rich with* *meaning"* (p. 94). Using the constant comparative method involves making comparisons during each stage of the analysis. In the initial stages of a study the analysis of the data involves coding line by line and coding each incident. Charmaz (2006) suggests this coding can help the researcher see processes which may be emerging from the data and encourages the researcher to question these processes and their consequences.

In grounded theory 'in vivo' coding refers to codes of the participants' comments which capture their experiences and meanings. Using 'in vivo' codes has the potential to keep the developing theory grounded in the data, however like any code they are subjected to the constant comparative method and need to be integrated into the theory (Charmaz, 2014). In focused coding the researcher seeks out relationships between categories and determines which codes have "*analytical power"* (Charmaz, 2014 p.140). Theoretical coding or advanced coding, described by Charmaz (2014) as a more "'*sophisticated"* level of coding (p. 150), which advances the "*analytic story in a theoretical direction*" (Charmaz, 2006, p.63).

The process of coding is not linear and the analytical stages overlap and even at the stage of theory building the researcher will return to theoretical sampling and coding activities (Mills and Birks, 2014).

3.6.3 Theoretical Sensitivity

Coding and theoretical sensitivity are influenced by each other. Charmaz (2014) describes theoretical sensitivity as "*the ability to understand and define phenomena in abstract terms and to demonstrate relationships between studied phenomena*" (p161). The purpose of theoretical sensitivity is to develop the researcher's codes to a more abstract and conceptual level. It requires the ability to conceptualise and allows the implicit meanings of participants to become more apparent. Birks and Mills (2012) suggest theoretical sensitivity is the culmination of the researcher's personal, professional and experiential learning which increases as the research progresses. In a constructivist approach theoretical sensitivity can also be developed through reflexivity (Charmaz, 2006). An important part of remaining open to the data is the capture of the researcher’s thoughts, feelings and ideas through the use of written memos. Writing memos also helps to refine theoretical sensitivity and the ability to view the data from multiple viewpoints

3.6.4 Memo Writing

Memo writing is a fundamental part of grounded theory. Charmaz (2006) recognises the importance of memo writing in capturing thoughts from the beginning of the research process but also she believes they can increase the productivity of the researcher. She describes memo writing as ‘*free and flowing*’ (p.80) and advocates that researchers include data in their memos to keep the participant’s voice and meaning present in the theoretical outcome (Charmaz, 2006; 2014). Wiener (2007) views memoing as occurring from data collection to the construction of theory. The use of analytic memos can also support the first drafts of chapters (Charmaz, 2014) and contribute to refining the emerging theory. The sorting of memos further defines the categories and the relationship between them.

3.6.5 Reflexivity

A constructivist approach proposed by Charmaz (2006), suggests that the researcher’s knowledge and understanding of the study is aided by the process of reflexivity. It allows the researcher to examine their decisions and as a result review how they have affected the research process and its findings. Finlay (2002) agrees that the researcher should examine their own impact on the study through reflexive analysis.

Charmaz (2006) views reflexivity as:

> *“the researchers scrutiny of his or her research experience, decisions and interpretations in ways that bring the researcher into the process and allow the reader to assess how and to what extent the researcher’s interest, position and assumptions influenced inquiry”* (2006, p188)

Reflexivity is an inherent part of a constructivist grounded theory and fosters an understanding of the researchers own interpretations and their implications on the research. Writing reflexive memos was important within the research process to both explore and acknowledge previous assumptions but also to identify gaps in the interviews where further questioning may elicit additional responses from participants. It was an opportunity to identify and explore specific areas in the data and collate thoughts on the implicit meaning of participants' experiences of using AAC.

3.6.6 Theory Generation

Theoretical coding is used to refine the categories and improve the clarity on the emerging theory. Although a fundamental component of grounded theory, theoretical coding is a procedure which is often not fully understood (Cutcliffe, 2000). Holton (2007) explains the purpose of theoretical coding is to develop a conceptual framework which explores the relationships between the core category and the related categories. Glaser (1978) highlights the importance of the generation of theory which occurs around a core category. However, Charmaz (2006) maintains a core category is not always necessary but places more emphasis on keeping the participants' words and their presence in the process of analysis. Following the conceptual analysis of the data, other materials are used as data for comparison such as previous literature and theoretical memos. Through sorting and integrating memos the researcher develops the relationship between categories and these can shape the writing of the theoretical framework. Sampling continues until 'theoretical saturation' where new data no longer- "*sparks new theoretical insights*" (Charmaz, 2006, p.113) or where no new categories emerge and the data are 'saturated' with the categories being well conceptualized. Dey (1999) suggests saturation occurs when there is sufficient data to support the claims being made. Theoretical saturation is a contentious issue with diverse opinions and disagreements concerning the meaning of saturation. Dey (1999) views saturation as 'imprecise' and suggests the term "*theoretical sufficiency"* (p.257) in grounded theory studies. Charmaz (2006) also cautions against claiming saturation which may be misleading and overstating the research findings. In this study the term 'theoretical sufficiency' was used where new data no longer revealed further properties of the core theoretical categories.

3.7 Conclusion

Grounded Theory was chosen for this research as it allowed the researcher to construct a theory which was grounded in the data collected. A constructivist grounded theory was adopted using an interpretivist stance focusing on how reality was constructed by participants. A constructivist grounded theory relies on many of the analytic tools which originated in classic grounded theory consequently it provided systematic guidelines for analysing and collecting data in order to develop a theoretical framework that explained the experiences of families using AAC in the home. A reflexive stance was taken through the use of memos and reflective writing to question both the interpretation of the participants and the researcher.

How data are collected and analysed will influence the development of the theory and the next chapter presents an account of the methods used in this grounded theory study.

Chapter 4 Research Processes: Using a constructivist grounded theory

4.1 Introduction

The previous chapter discussed the nature of grounded theory, its philosophical roots and divergence and the chosen methodology for this project: constructivist grounded theory. This chapter presents the data collection methods and the analytical processes employed in this research using constructivist grounded theory methods.

4.2 Sampling criteria

Purposeful sampling was used initially, because, as Coyne (1997) suggested, it is important to find 'information-rich' participants which fit the focus of the research. Families participating in the study met the following inclusion criteria:

- At least one child in the family was between the ages of 5-13 years with complex communication needs.
- The family were using aided communication systems within the home
- Speech was not the primary mode of communication for at least one child in the family.

Children on the researcher's caseload were excluded as the families' freedom to make decisions about their involvement in the study might have been affected by the therapeutic relationship.

4.3 Access to the sample

A favourable ethical opinion for the project was obtained from NHS Health Research Authority (NRES Committee East Midlands-Derby) in March 2013 (Appendix: 3) and from the local NHS Foundation Trust Research and Development in April 2013 (Appendix: 4) The research was registered with the Social Sciences Research Degrees Board at the University of Northampton in January 2013.

Data Collection: Phase 1

Initial access to families for the first set of data collection was through a NHS Trust Speech and Language Therapy Service. Speech and Language Therapists (SLTs) are specialists in communication difficulties and support AAC assessment, and provision (RCSLT, 2011) and are key professionals working with families with children with complex communication needs. Speech and Language Therapists were sent information about the study and those families on their caseload who met the inclusion criteria, were given a recruitment leaflet inviting them to take part in the research (Appendix: 5). Parents who expressed an interest by returning the reply slip were then telephoned to discuss the project further and a Participant Information Leaflet was sent to them (Appendix: 6). Four families were recruited to the project and all were interviewed in Phase 1 of the data collection.

This data set produced a sample of families who were in the early stages of using low tech AAC systems. The analysis of this data indicated the need to seek access to children and families who had been using AAC for a longer period of time and who were using high tech systems.

Data Collection Phase 2

The second data collection phase recruited families through Special Schools in the East Midlands. Powell and Smith (2009) indicate that researchers need to be sensitive to the hierarchy of gatekeepers in educational settings. As a result initial contact was made with Head Teachers by email or by telephone and then subsequent meetings were arranged to discuss the research in more detail. Twenty-five schools were approached and eight schools were willing to engage in the research and circulate information to families meeting the criteria. Five families were recruited and interviewed for the research.

This data set identified a gap in the sample of families and children who were using more high tech AAC systems and as a result the researcher contacted organisations involved in the assessment and provision of AAC systems for children.

Data Collection Phase 3

The third data set was through a local multi-agency AAC team and through two National Organisations supporting families with complex communication needs. A presentation about the research was made to the multi-agency AAC Team who agreed to send information to families meeting the inclusion criteria. The two National Organisations were initially contacted by telephone. Key staff identified by the organisations, were asked to circulate the project leaflet. Three families were recruited through Phase 3 of the data collection.

Further theoretical sampling took place at the end of the third data collection phase after analysis of the transcripts to explicate the emerging categories. Two families were re-interviewed before data collection was complete.

4.4 Sample Characteristics

Twelve families participated in the study with a total of 25 interviews conducted and analysed. Table 2 presents the characteristics of the sample interviewed, including the age of the child, age of siblings, the parents' occupation, ethnicity and the AAC system used. This was captured through the use of a questionnaire approved by the NHS Health Research Authority and completed by parents on the initial visit (Appendix: 7 and 8).

In the sample of 12 families, 11 parents were married and living in the same home and 1 parent was a single mother. All the fathers were employed full-time, one mother was employed full-time, five mothers were employed part-time and six mothers were unemployed. The families had been using AAC systems, both low and high tech, for periods of between one month and four years. Siblings were aged between 7-18 years. Nine children and young people using AAC were educated in a Special Provision, one child in a mainstream school and two children in a dual placement.

Participant names were replaced with code numbers and annotated as follows:
FxIx= Family number, interview number and Family member: Mother, Father, and Child.

Table 3: Sample Characteristics

Family Code	Family composition within household (Age Group)	Parent's Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
1	Mother (40-49) Father (40-49) Daughter (12) (AAC user) Son (8)	Mother: Teaching Assistant (F/T) Father: Self-employed Designer (F/T)	F1I1:Mother & Father F1I2: Daughter (Talking Mat) F1I3: Son (interview and drawing) F1I4: Mother	Communication book Makaton Voice Output Communication Aid	Two years Four years Two months	Severe Learning Disabilities	White British	Special School

Family Code	Family composition within household (Age Group)	Parent's Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
2	Mother (30-39) Father (30-39) Son (10) (AAC user) Son (7)	Mother: Nurse (P/T) Father : Accountant (F/T)	F2I1: Mother F2I2: Son (Talking Mat) F2I3: Son (interview and drawing) F2I4: Mother	Voice Output Communication Aid PECs book	One year Four years	Global developmental delay /Autistic Spectrum Disorder	M: White European D: White British	Designated Special Provision (DSP)

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
3	Mother (40-49)	Mother: Manual worker (P/T)	F3I1: Mother and Daughter (16)	Eye pointing (symbols/objects)	One Year	Quadriplegic cerebral palsy	White British	Special School
	Father (50+)	Father: Manual worker(F/T)						
	Son(13) (AAC user)							
	Daughter (16)							
	Daughter (11)							

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
4	Mother (50+) Father (50+) Daughter(13) (AAC user) (Daughter(19)- not living at home Daughter (22)- not living at home)	Mother: unemployed Father: Company Director (F/T)	F4I1: Mother	Voice Output Communication Aid Communication book Makaton	Two years Four years Six years	Chromosomal abnormality	White British	Special School

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
5	Mother (50+)	Mother: unemployed	F5I1: Mother and Father	Voice Output Communication Aid	Three months	Global Developmental delay	White British	Designated Special Provision
				Makaton				
	Father(50+)	Father: Sales Manager (F/T)		Communication book	One year			
	Son(10) (AAC user)		F5I2: Son (Talking Mat)					

Family Code	Family composition within household (Age Group)	Parent's Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
6	Mother (30-39)	Mother: Unemployed	F6I1: Mother and Daughter	Voice Output Communication Aid	Six months	Autistic Spectrum Disorder	White British	Special School
				PECs book	One year			
	Daughter (18)	Daughter: Student						
	Son (5)		F6I2: Son (Talking Mat)					
7	Mother (40-49)	Mother: Education (P/T)	F7I1: Mother	Voice Output Communication Aid	One year	Acquired brain injury	White British	Special School
	Father (40-49)	Father: Teacher (F/T)		Communication book	1 month			
	Daughter (9) (AAC user)							

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
8	Mother (30-39) Father (30-39) Son (13) Son (5) (AAC user)	Mother: Learning Support Assistant (F/T) Father: Engineer (F/T)	F8I1: Mother F8I2: Father and Mother F11I3: Son (interview only) F11I4: Son (Talking Mat)	PECs book	Two years	Autistic Spectrum Disorder	White British	Special School/ Mainstream School

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
9	Mother (30-39)	Mother: unemployed	F8I1: Mother	PECs book/symbols	Two years	Autistic Spectrum Disorder/ Severe Learning disabilities	White British	Special School
	Father (30-39)	Father: Medical services (F/T)		Voice Output Communication Aid	Six months			
	Son (6) (AAC user)							

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
10	Mother (30-39) Father (30-39) Son (5) (AAC user)	Mother: unemployed Father: IT Consultant (F/T)	F10I1: Mother and Father F10I2:Son (Talking Mat)	Communication book BSL Signing Voice Output Communication Aid	Three months Three years Two months	Chromosomal abnormality/Hearing Impairment	White British	Mainstream School

Family Code	Family composition within household (Age Group)	Parent’s Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
11	Mother(30-39)	Mother: unemployed	F11I1: Mother	Communication book	Two years	Acquired brain injury	White British	Special school/ mainstream school
	Father (30-39)	Father: Church worker		Voice Output Communication Aid	One year			
	Son (8) (AAC user)							
	Daughter (5)							
	Daughter (2)							

Family Code	Family composition within household (Age Group)	Parent's Occupation	Family members interviewed	AAC System Used	Duration of AAC use	Diagnosis of Child (given by parents)	Ethnicity	Education
12	Mother (30-39) Father (30-39) Son (11) Son (8) Daughter (5) AAC user)	Mother: Education (P/T) Father: unknown (F/T)	F12I1: Mother F12I2: Son (11) and Son (8)	Communication book Makaton	One year Two years	Severe Learning Disabilities/ Chromosomal Abnormality	British Asian	Special school

4.5 Informed consent

Adult participants were given verbal and written information outlining the purpose of the study and written consent regarding their participation was gained during the initial visit (Appendix: 9). All participants were assured the information they provided would remain anonymous, protected by a numerically assigned code for each family and pseudonyms would be used in the dissemination of findings. Confirming consent was an ongoing process and where second interviews took place, the participants were asked to re-sign the consent form.

Consent for the children's participation was initially obtained through the parents but it was important that the individual children were aware of what they were being asked to do and age appropriate information leaflets were given and discussed with the children (Appendix: 10 and 11). Consent for the child's participation was sought verbally at the beginning of the interview and assent was obtained in the most appropriate manner for the child including a visual format (Appendix 12 and 13). Neill (2007) considered the importance of respecting a child's privacy in the consent process as due to the power imbalance the child may have difficulties asking for time with the researcher without the parent or sibling present. Children were offered the opportunity to talk separately away from their parents and siblings if they wished. During this process children were monitored for any non-verbal signs that they may feel pressured to participate in the study by adults. Children were given the choice as to whether they wished their parents present throughout the interview. The majority of the children wanted their mother present particularly at the beginning of the interview. The parents' role was discussed prior to data collection and they were encouraged only to interpret the child's responses when requested to do so by the researcher. Shaw, Brady and Davey (1998) stressed the importance of parents and gatekeepers being briefed on their role and understand that they should not influence the responses of participants.

4.6 Researcher Positionality

In an interpretivist paradigm the beliefs and values of the researcher are recognised. Denzin and Lincoln (2005) acknowledge that research is shaped through the ways the researcher's own experiences entwine with those of their participants. Denzin (1986) considers "*interpretive research begins and ends with the biography and self of the researcher*" (p.12). The researcher, during the interviews, positioned herself as a Speech and Language Therapist and researcher with a particular interest in AAC. This shared interest in AAC with families allowed for more in-depth sensitive and empathetic questioning. Irvine, Roberts and Bradbury-Jones (2008) describe researchers as 'insiders' when they share a common language and culture with the participants. Although the researcher is a mother, she does not have a child with a disability and any interpretation will always be from a position of an 'outsider'. As a result it was important to examine and contextualise the researcher's position through reflexivity throughout the research process.

4.7 Data Sources

In depth interviewing was used to elicit each participant's experiences of using AAC. This type of data-gathering is considered to be similar to a '*directed conversation*' (Lofland and Lofland, 1995) where a topic can be explored with a participant who has experienced the phenomena being studied. Interviews were interactive (Morse, 1991) with the interviewer listening and encouraging the participant to respond whilst also allowing them to do the majority of the talking (Charmaz, 2006). The interviews were transcribed for analysis and field notes were written directly after each interview recording the researcher's thoughts on the interaction, the atmosphere during the interview and any non-verbal behaviour of the participants which may be relevant to the study..

4.7.1 Interviews with Adult Participants

Interviews were carried out in a location most appropriate for the family. Parents chose the date and time for the interviews and all the interviews took place in the family home. When making arrangements both parents were encouraged to be present during the interview but this proved more difficult than anticipated. Although the aim of the study was to explore the experiences of the 'whole' family this was not always possible. The reply slips returned to the researcher were all from mothers and the initial contact was made through them. In this study the mothers were the 'gatekeepers' to the rest of the family and were the ones who made decisions on their family's involvement in the research. Neill (2007) found that the researcher is dependent on *"prior conversations between the individual who was the first contact with the family and other adult family members"* (p. 440).

The following is an extract from a memo following a telephone conversation with a mother about the study

Memo 3/5/13

Following an explanation of the study the mother was very keen to be involved with the research as her daughter has used AAC for several years. When I invited both parents to take part she made it clear that any decisions on AAC were made by herself and her husband was not usually involved. I suggested it would be helpful to have the perspectives of both parents but she didn't feel this was possible due to his work commitments.

In line with grounded theory some broad open-ended questions were used to allow participants to respond and have more control over the conversation. The opening question 'Tell me about your family?' allowed the researcher to develop an initial rapport with the participants and develop a relaxed atmosphere. Throughout the interview priority was given to ensuring the participants felt relaxed by showing empathy and understanding as well as allowing participants to feel heard. Mills and Birks (2014) identify the importance of establishing a reciprocal relationship between the researcher and participant in a constructivist grounded theory. In the interviews the information obtained was produced by a process of giving and taking from each other and a shared relationship. This was achieved through a flexible approach to questioning so that participants had more power over the direction of the conversation. A reciprocal relationship was also achieved through a joint understanding of the issues which arose by creating an open and relaxed stance with the families. The direction of the interview was led by the parents who were encouraged to describe and reflect on their perspectives of using AAC within the home. When parents made comments which needed exploring a series of prompts and probes recommended by Rubin and Rubin (2011) were used to gather further data. These comments included "Tell me a little bit more about that" to expand participants ideas. Techniques of reflection were also used to clarify points and gain a clearer understanding of what the participants were saying. These techniques were used more frequently in later interviews as the researcher became more skilled in responding to participants' experiences. After each interview field notes were written. This excerpt from an initial field note was written after an interview with a mother who was describing her son and the effect of his complex communication needs on the family. All field notes were dated and the mother's words presented in quotation marks to distinguish them from the researcher.

Excerpt from Field notes: Family Code: 3 Date: 6/6/13

Shelley described her son's interests and favourite activities. Several times during the interview she expressed her wish that he could speak. His lack of speech causes considerable frustration for both him and the family resulting in behaviours everyone has to 'manage'. Matthew is very much the centre of the family with family members "*making the best of it and the most of him*".

Memoing was used throughout the process to question and analyse the time spent with families and to reflect on the data that was generated together. This involved consciously reflecting on the researcher's own beliefs, viewpoints and assumptions which may have influenced the grounded theory. It was also important to consistently include participants' voices when writing reflective memos. Charmaz (2006) recommends researchers keep the participants' voices in the foreground during the research process.

4.7.2 Interviews with children and young people

The researcher aimed to meet the children and young people on the initial visit to the home to develop a rapport and establish some familiarity and trust. This also gave the researcher the opportunity to gain as much information as possible on the child's development and communication. Taking time to get to know the child prior to the interview was important in addressing the power differential between the adult and child. Shaw et al (1998) recognise the importance of creating a relaxed atmosphere prior to embarking on the data collection.

Considerable time was taken prior to data collection to engage with the child in activities they enjoyed including games, stories and drawings.

Many of the children had learning disabilities and for this reason consent was an ongoing process, monitored by observing the children's non-verbal signals in particular signs of distress or lack of engagement. The researcher, due to her professional background, is skilled in listening and communicating with children with complex needs and this was beneficial during the interviews. Children were reminded they could 'stop' if they wanted the interview to pause or end and symbol cards for 'stop' and 'more' were used. Matthews and Tucker (2000) reported that care should be taken to guard against any psychological distress of the children. All the children were given the opportunity to take a break and re-engage at another time where appropriate although none of the children requested this during the interview process. The ethical considerations of involving children and young people were reviewed throughout. There is a need for researcher reflexivity during research with children and young people (Davis et al, 2000; Matthews, 2001) and as a result there were regular discussions with the supervisory team. The researcher kept a reflective diary to track reflections, thoughts and feelings related to the interviews.

It was important in the study to recognise the valuable contribution of all the children taking part, with each child's involvement being equally valued. The children involved in the study had a range of needs and abilities and different methods were used and adapted to suit the individual. Data were collected from six children who used AAC aged 5-13 years and seven siblings aged 5-18 years. Interviews were recorded and ranged from 8-40 minutes in duration.

Flexible methods of communication were used to increase the engagement with the children. A 'draw and tell' approach (Williams, Wetton and Moon, 1989; Driessnack, 2006; Holliday, Harrison and McLeod, 2009) was used with siblings in the 7-9 year age group to help them to express their views and tell their story. Visuals have been shown to be an appropriate way for children to express their views (Percy-Smith and Walsh, 2006) but it is important to recognise children have differing needs and there is no one 'voice' they present (Ritala-Kosinen, 1994). Those children who wished to use a 'draw and tell' approach were asked to draw themselves talking to their brother/sister who used AAC. The drawings were used to support the children in expressing their views and experiences of their sibling's use of AAC in the home.

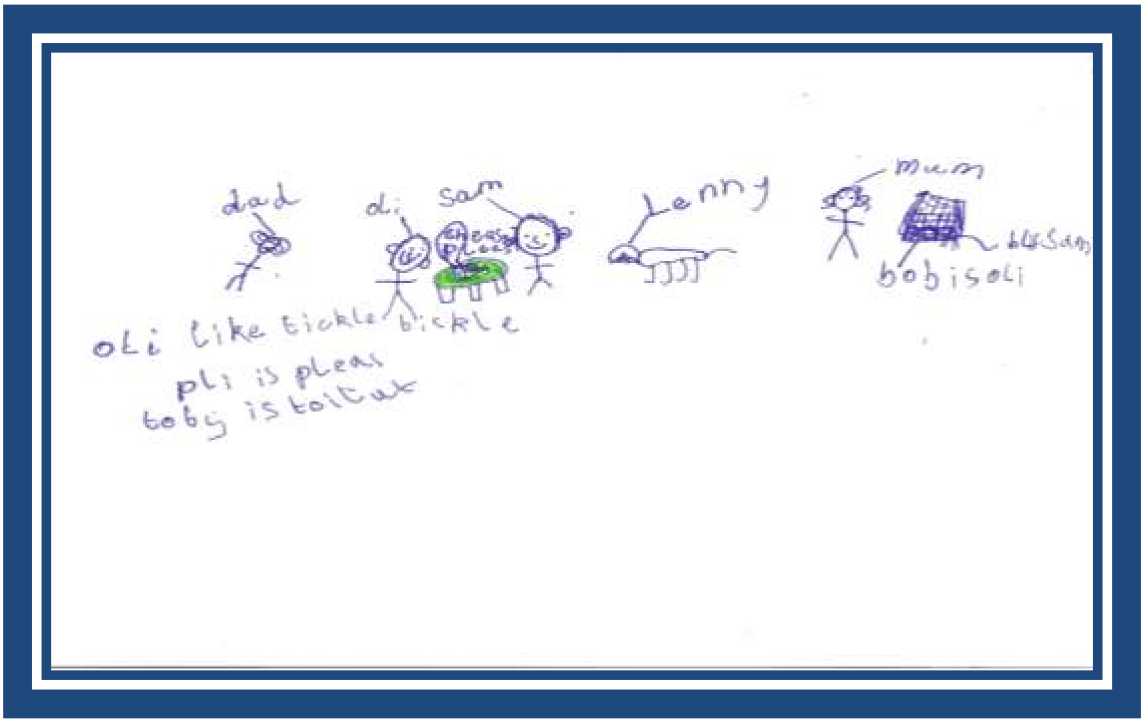


Figure 1: Drawing showing child communicating with his brother using a communication device

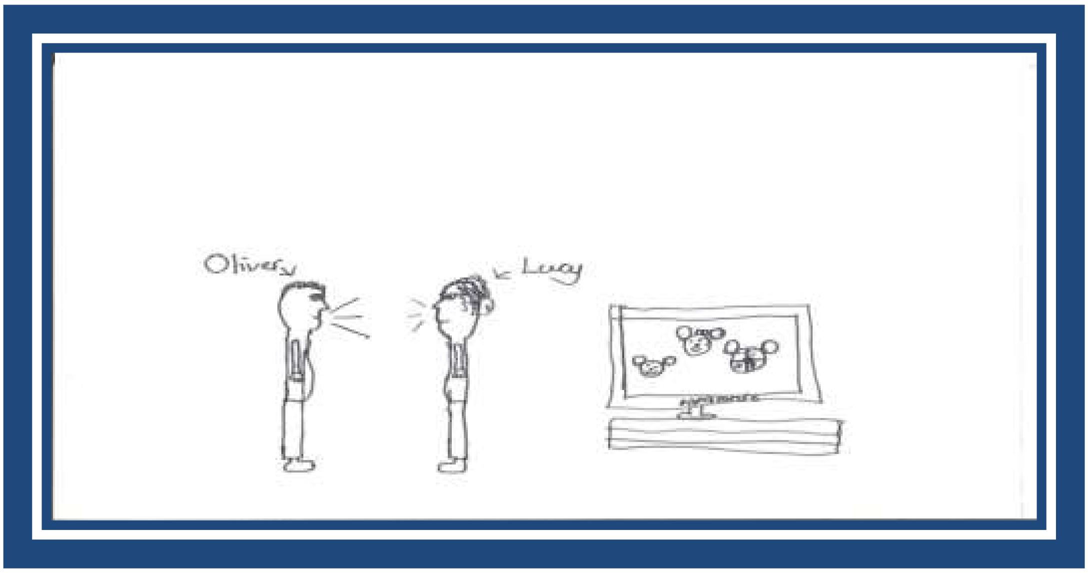


Figure 2: Drawing of siblings talking to each other

During the interviews an open atmosphere was created and it was stressed to the children there were no right or wrong answers thus allowing them to express their own views and feelings. The researcher endeavoured to work at the pace of the child, waiting for their responses and giving them plenty of time to respond to questions. Consideration was given to the child's age, general cognitive ability and attention span and for some children as suggested by Shaw et al, (1998), the researcher simplified the levels of language used during data collection. Prompts were necessary throughout the interviews with some direct questioning and the repetition and rephrasing of questions. On occasions the researcher used the pauses and silences in the conversation to wait for the child rather than asking a further direct question.

A Talking Mat approach was used with children with complex communication alongside their other forms of communication. The majority of the children in the study had learning and communication difficulties, therefore it was felt appropriate for parents to make the decision as to whether their child would be able to understand and participate in an interview. Goldbart and Marshall (2004) showed that parents of children who used AAC had a detailed knowledge of their children's communication skills. They believed parents would act in the best interests of their child.

In the interviews two main themes- activities and communication- were explored with the children (Appendix: 14)

Figure 3: An example of an initial Talking Mat on activities

Figure 4: An example of a sub-mat exploring features of the communication device

Child-specific symbols were prepared prior to the interviews and children were given access to a familiar symbol system. A set of blank cards were made available to draw any options the child wanted on the mat to ensure the researcher remained open to the views of the child as well as using the pre-selected vocabulary.

The symbols on the top scale of the mat allowed the children to indicate their feelings about their communication aid and included positive (like symbol), negative (dislike symbol) or neutral (unsure symbol). The number of symbols on the top scale varied depending on the information gathered about the child from the parents and as a result of the 'introductory' mats.

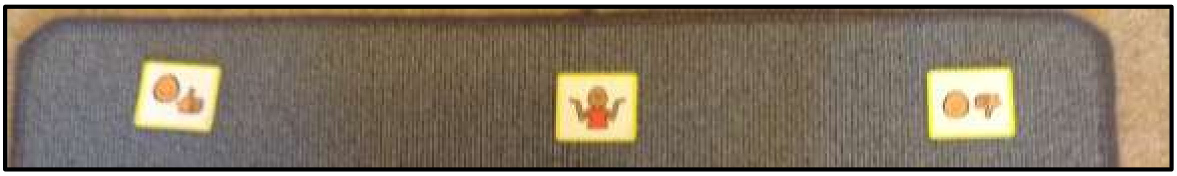


Figure 5: Example of a Top scale

Figure 6: Example of a simplified Top scale

Several 'introductory' mats were used to practise the concept and build the child's confidence.

Where possible the Talking Mats sessions were videoed and analysed using the Effectiveness Framework for Functional Communication (EFFC), a validated tool for using Talking Mats with a range of people with speech, language and communication needs (Cameron, 2010). This considers the effectiveness of the interaction based on the child's non-verbal and verbal (use of AAC) communication (Appendix 15). After each mat was completed a photograph of the mat was taken as a record of the conversation. Lewis (2002) argued authenticity requires the researcher to check the views expressed by the child with learning disabilities as fair and representative. Parents or a familiar adult (e.g. teaching assistant) were present during the interviews and gave valuable feedback on the Talking Mats process. All the children had additional learning difficulties and every effort was made to ensure that any questions asked were at the child's level of understanding. However Lewis and Porter (2004) state it is not only the style of questioning or the use of different communication methods which are important but the interviewer also needed to be proficient in the specific skills of interviewing people with learning disabilities

Four interviews took place in the family home and two interviews in the child's school. Five children were effective users of Talking Mats using the EFFC tool.

4.8 Communication systems used by Families

Most children who use AAC have multiple modes of communication (Binger et al 2008; Light, Collier and Barnes, 1985) including informal and formal methods. The participating children used a variety of informal ways of communicating including body movement, eye and hand pointing, facial expression and vocalisations. The children also used a range of low and high tech communication systems. The low tech systems included Picture Exchange Communication System (PECs) and communication books. Sign language, both Makaton[1] and British Sign Language[2] (BSL) were used by some of the children in the study as another mode of communication.

A range of high tech communication aids or voice output communication aids (VOCAs) were used and these varied in design with a number of different 'voice' options including American or British accents. Children accessed their devices directly by finger pointing at the cells or icons on the screen or through eye-gaze[3].

The size and weight of the VOCA's varied. Some of the children had their communication devices mounted on their wheelchairs whereas other children were able to position them on tables or hold them while moving around.

The children had access to different software on their devices but predominantly 'The Grid 2' software was used. Children using iPads for communication had a range of communication apps available to them including My Choice Pad, Prologuo2go and Sounding Board. Further information on the hardware and software is shown in Appendix: 16.

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1 Makaton sign language is often used with children with learning and/or communication difficulties and it uses signs in spoken word order.

[2] BSL is the language commonly used by the deaf population in the UK and has its own grammar, word order and regional variations.

[3] Eye gaze systems allow children with severe physical disabilities to access a computer as the technology tracks where their eyes are looking, enabling them to move the mouse pointer around the screen and to select a symbol by dwelling or blinking.

Table 4: Different AAC systems used by the children

Family Code 1	Mode of Communication	Means of Communication	Representational system
1	Communication book Makaton Voice Output Communication Aid (VOCA) with the Grid 2 software	Direct access with finger	Symbols (Widgit)
2	Picture Exchange Communication book (PECs) VOCA (Proxtalker)	Direct access with finger	Combination of symbols (Widgit) and photographs
3	A range of photographs/symbols	Eye-pointing	Combination of symbols (Widgit) and photographs
4	Communication book Makaton VOCA: iPad with apps Sounding board/My choicepad	Direct access with finger	Symbols (PCS)
5	Communication book Makaton VOCA with Grid 2 software	Direct access with finger	Symbols (Widgit)
6	PECs book VOCA: iPad with Prologuo2go software	Direct access with finger	Symbols (PCS)
7	Communication book (PODD) VOCA with Grid 2 software	Eye-pointing	Symbols (PCS)
8	PECs book	Direct access with finger	Symbols (PCS)

9	PECs book VOCA: iPad with Prologuo2go software	Direct access with finger	Symbols (PCS)
10	Communication book British Sign Language VOCA with Grid 2 software	Direct access with finger	Symbols (PCS)
11	Communication book (PODD) VOCA with Grid 2software	Eye-pointing	Symbols (PCS)
12	Communication book Makaton	Direct access with finger	Combination of symbols (Widgit) and photographs

4.9 Data Management

QSR NVivo 10 was used to support the researcher in collecting, organising and coding the data. NVivo allowed the researcher to create codes to data which can be viewed at any point during the analysis. The coding stripes function on NVivo allowed the researcher to view segments of text and to see which nodes were coded to it. Each node could also be colour coded and this gave a visual overview of how the nodes were created and the coding density.

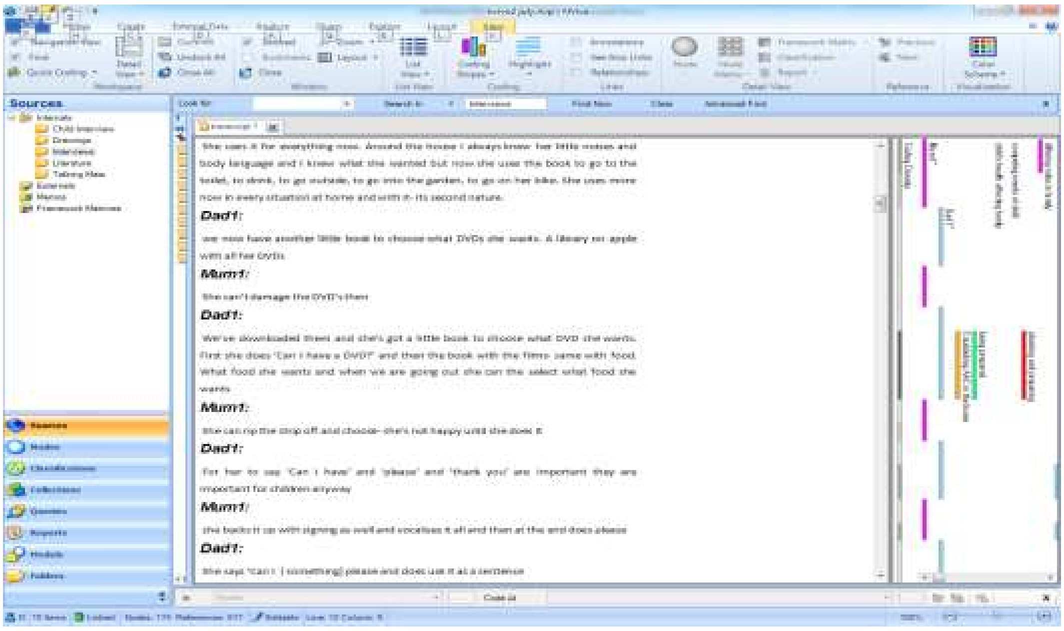
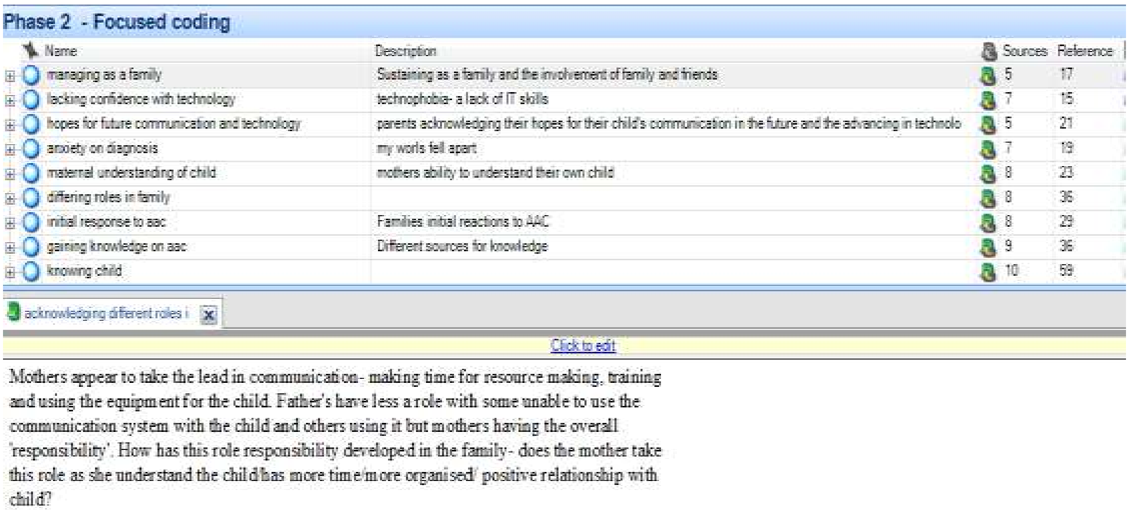


Figure 7: Coding strips and coding density

During coding memos were written and linked to nodes when they were created. Each node was also given a description.



Phase 2 - Focused coding

Name	Description	Sources	Reference
managing as a family	Sustaining as a family and the involvement of family and friends	5	17
lacking confidence with technology	technophobia- a lack of IT skills	7	15
hopes for future communication and technology	parents acknowledging their hopes for their child's communication in the future and the advancing in technolo	5	21
anxiety on diagnosis	my worls fell apart	7	19
maternal understanding of child	mothers ability to understand their own child	8	23
differing roles in family		8	36
initial response to aac	Families initial reactions to AAC	8	29
gaining knowledge on aac	Different sources for knowledge	9	36
knowing child		10	59

Mothers appear to take the lead in communication- making time for resource making, training and using the equipment for the child. Father's have less a role with some unable to use the communication system with the child and others using it but mothers having the overall 'responsibility'. How has this role responsibility developed in the family- does the mother take this role as she understand the child/has more time/more organised/ positive relationship with child?

Figure 8: Linking memos to nodes in NVivo 10

As analysis progressed the number of nodes and memos increased and NVivo was particularly useful in identifying where specific concepts were coded and where they were linked to more than one category. Following the initial analysis codes were moved, merged and relabelled during more focused coding. Folders for each phase of coding supported the managing and organising of all the data.

Although NVivo supported the exploration of the data, transcripts were re-read on numerous occasions to ensure the participants' voices were not lost during analysis. Constant comparative analysis occurred throughout the coding process where nodes, categories, incidents were compared with each other and the properties for each category were developed through comparative analysis. As the analysis progressed the researcher returned to more manual methods of sorting memos, field notes and coding notes to identify relationships between concepts and categories in the emerging theory. This supported the identification of the core category.

4.10 Analysis of data

The analysis of the data followed the constructivist grounded theory guidelines proposed by Charmaz (2006):

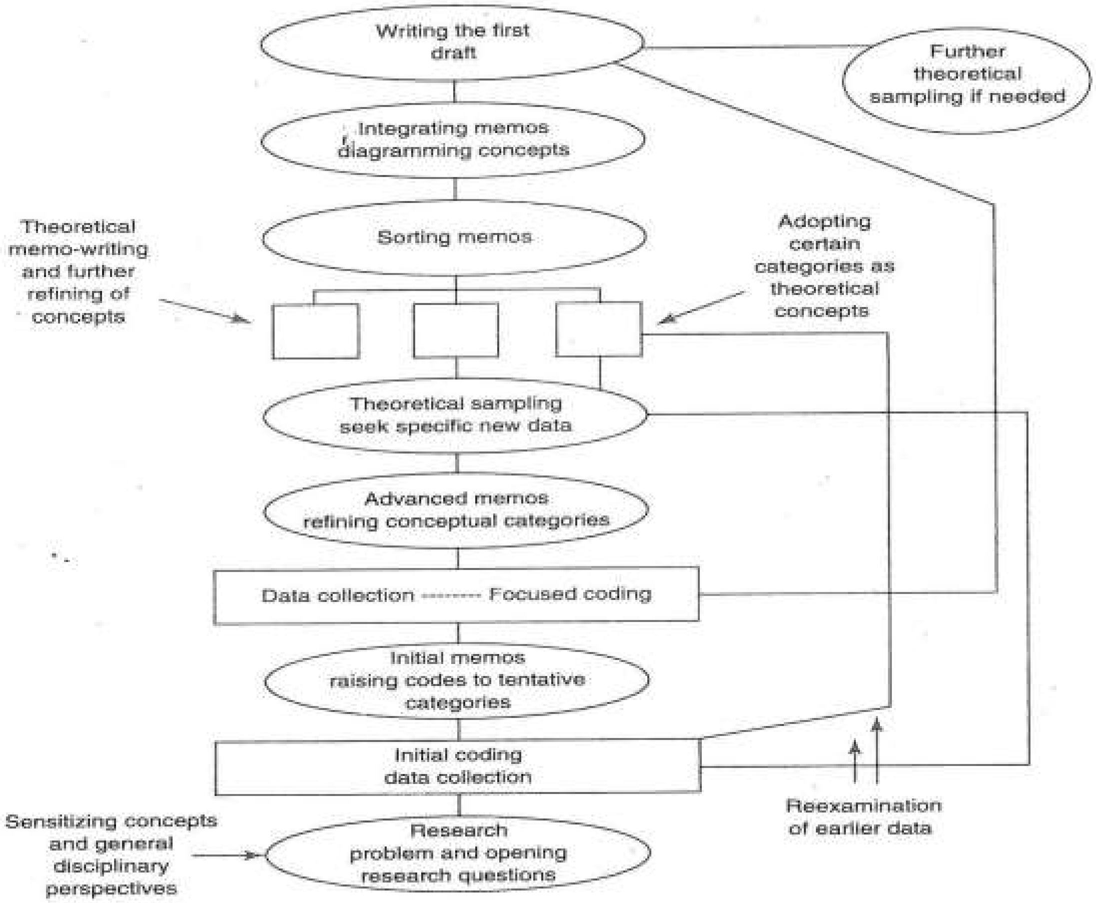


Figure 9: The Constructivist Process (Charmaz, 2006, p11)

4.10.1 Initial and Focused coding

Data from each interview was analysed line by line and they were assigned initial short codes which were then coded within NVivo. The initial phase of coding produced over 500 ‘nodes’ or codes representing ideas and concepts in the data.

Data was further broken down into distinct ideas and events during focused coding. Through focused coding the words used by participants were examined and this led to recoding based on the researcher’s interpretation of their experiences and the meanings they attached to those experiences. Action codes were used to keep the coding closer to the participants experiences. In vivo codes were also used to reflect the wording used by the participants in the interview which the researcher felt were important. Even at the initial coding stages the influence of the researcher was evident as Charmaz (2006) views that “*we choose the words that constitute our codes*” (p. 47). The words used to construct the codes and categories (except ‘in vivo’ coding) were chosen by the researcher based on the interpretation of the data.

The initial stages of coding generated early maps which were created through using models in NVivo10 and these reflected the codes created describing the data rather than the conceptual framework. Figure 10 shows an early map with initial coding.

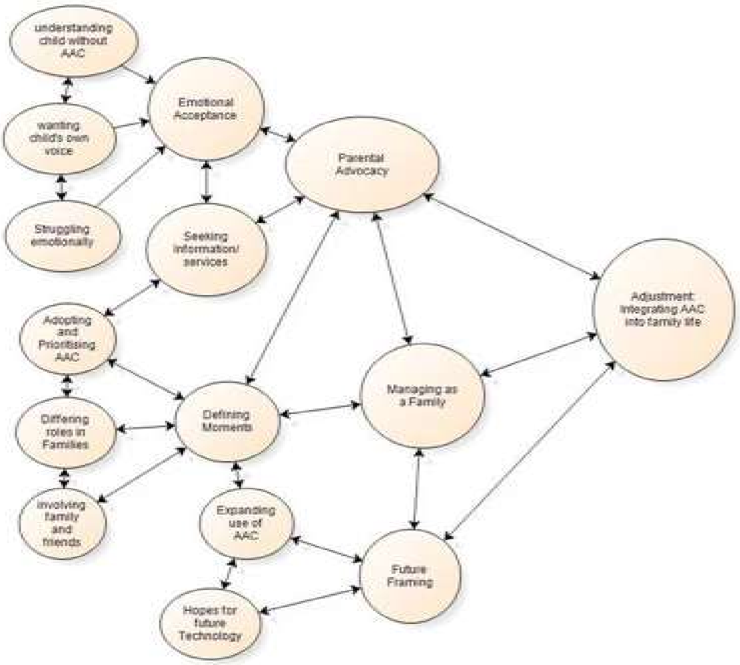


Figure 10: Early mapping of Categories

In the analysis of subsequent data more abstract coding occurred. In the following extract the code 'maintaining a balance' alerted the researcher to consider the interactions within the family and a desire to balance the needs of the child with those of other family members. This allowed the researcher to look for data expressing similar concerns.

The following extract from an interview [Family 1] shows the initial and more focused codes used by the researcher to capture the participant's meanings and actions:

Family Code 1	Transcript	Initial Coding	Focused Coding
Father	Time! Taking it out and taking it to that environment	Finding the time Taking the system out	Allocating time Extending use
Mother	Yes for her clubs. She has weekend clubs and drama club. I have to get all the symbols ready and I put them all in the activities file. You	Using communication outside home Preparing the system Feeling pressured	Extending use Planning ahead Time pressures

	have to race around for them. Same for the weekend news for school. They need a photograph of news from the weekend. I don't do anything at the weekends, we only	Finding time Having other tasks Wanting time off Not being pressured	Valuing communication
	use the [communication] books, we don't do all the homework and then Monday morning is a dash because we haven't done anything but we have to have a weekend off!	Having time off	Maintaining a balance
Father	Some weekends you don't want to do anything. We just want to chill	Having time off	Maintaining a balance

Table 5: Initial Coding and Focused Coding

The constant comparison method required the researcher to return to the data to compare incident to other incidents in the data and was also used to compare emerging concepts.

A reflective approach was also maintained throughout the study and memo writing was used to enable the capturing of thoughts and reasoning behind emerging categories and their interrelationships. Initially this process was very difficult and as a result the memos were very descriptive and short. As analysis progressed and potential categories were established, memos became more developed and theoretical in nature. The example below is an earlier memo which considers the parents need to seek and gain information in the early stages following diagnosis:

Example of an early Memo 4/5/13

Seeking information and gaining information is important for families in the early stages post-diagnosis. Is this seeking information about possible ways forward and the available resources as well as the rights for their child? Is gaining information an important aspect of gaining control following the uncertainty of a diagnosis? What are the consequences of information gathering? How does this relate to using AAC and gaining access to services for a family?

The later memo considers the assumptions and beliefs associated with seeking and gaining information:

Example of memo during later analysis 2/5/14

Seeking Information: information underpins the development of the families understanding of AAC either though access to information being denied or through parents being creative and resourceful in identifying appropriate information. Information is obtained through a variety of sources including books, the internet, attending training courses and through the experiences of other families. Parents often seek knowledge of both rights and available resources locally. Is having information key to the ability to access services or “fight” (‘in vivo’ coding) for appropriate resources and services. Is “fighting” for services a part of everyday life with a disabled child- is the system a barrier for families in accessing services? Is fighting’ part of a grieving process or an element of advocacy and “doing the right thing” (in vivo coding) for your child.

4.10.2 Theoretical Sampling

During focused coding several concepts such as ‘managing as a family’, ‘uncertainty’, ‘shifting priorities’ and ‘maternal advocacy’ were examined. These were presented at the Communication Matters Conference in 2014 to professionals and families of children using AAC and their feedback provided further confirmation of these categories. Theoretical sampling occurred during data collection and became more important in determining the content of later interviews where additional questions were asked based on emerging categories. Some of the earlier concepts were explored following interview 4 by presenting additional focussed questions: “Some families have said…..”, “How do you feel about……”. This allowed refining of specific categories developed from the data.

4.10.3 Theoretical Coding

Theoretical coding was used to integrate and refine the developing theory. This process seemed to be the most time consuming and challenging for the researcher as a novice grounded theorist. During this time there was a marked increase in both the use of memos and the development of conceptual maps to increase the researcher's understanding of the families' use of AAC within the home. The writing and reflecting on memos was vital in the development of the final theory.

A trajectory was identified through further analysis and the processes in each phase conceptualised. The phases changed over time and it was clear it was not a linear process but families moved between the phases at different points in their AAC journey. The core category was established through diagramming, creating and sorting memos and questioning the relationship between the categories. At this point in the research the transcripts for each participant were reviewed again to ensure the storyline represented the data and the voices of the participants. This part of the process also involved returning to two families (Family code 1 and 2) and each identified their own experiences within the trajectory. This new data supported the existing data and provided further confirmation of the core category. Once the core was established, relevant areas of the literature were reviewed and the constant comparative method established their fit with the emergent theory. In writing the theory it was important to keep the experiences of the participants at the forefront as well as presenting the analytic framework. Charmaz (2006) stated within a constructivist grounded theory the writing needs to maintain the participants' presence and emphasise how they construct their experiences.

4.11 Conclusion

This chapter has described the application of a constructivist grounded theory (CGT). Within CGT the theory established is co-constructed between the researcher and participants and offers an interpretation of the studied phenomena. Coding allowed the researcher to develop from an initial description of the participants' experiences to more theoretical interpretations. Through ongoing analysis and engaging in theoretical sampling, memo writing, sorting and diagramming, a core category was established. This was then considered in relation to wider theoretical concepts and each relevant area of the literature was subjected to the constant comparative process in relation to the emergent theory. Prior to the findings chapters, a review of the areas of literature relevant to the emerging theory is presented in Chapter Five.

Chapter 5 Review of theoretical areas relevant to emergent theory

5.1 Introduction

In this chapter a concise review is presented of the theoretical areas which emerged from the analysis as relevant to the grounded theory in this thesis. Following the establishment of the core category, pertinent areas of literature were reviewed and compared with the emerging theory. The areas reviewed were scrutinised by using a constant comparative process to further establish relationships between concepts and their relevance to the emerging theory. These are presented in this chapter to prevent intrusion into the presentation of the grounded theory in Chapters Six and Seven. The theoretical areas are presented in the trajectory identified through the analytic process and linked to the phases of the grounded theory presented later in this thesis.

5.2 Uncertainty

In the first phase of the trajectory a high level of uncertainty was experienced by parents regarding their child's diagnosis, prognosis and day to day life. Uncertainty has been described in several studies with parents of children with serious illness (Bailey et al, 2009; Mishel, 1997; Stewart and Mishel, 2000). Mishel's Theory of Uncertainty (1997) suggests that when an event is perceived as uncertain it is as a result of the person being unable to determine the meaning of the illness-related events. Families facing uncertainty are described as having to deal with 'multiple unknowns' (Eggenberger et al., 2011, p.287). Williams (2003) identified the different types of uncertainty: diagnostic, symptomatic and trajectory uncertainty in people with chronic illness. Stewart and Mishel (2000) also described uncertainty in illness theory with parents of children with serious illnesses. They identified the time from the first signs that something was wrong with their child to the confirmation of a diagnosis was characterized by heightened stress for parents. Diagnosis is often not a single process and Clavering, Goodley and McLaughlin (2007) described diagnosis as a continuous process with parental experiences of uncertainty remaining over the long term. An uncertain prognosis for the child may also result in parents feeling out of control which contributes to their emotional distress (Mishel, 1983; Cohen, 1995). Those families receiving a delayed diagnosis may also experience a greater degree of uncertainty (Goodley and Tregaskis, 2006) than those with an earlier diagnosis which allows access to early professional support and services (Smith and Daughtrey, 2000, Strehle and Middlemiss, 2007). Uncertainty can also remain after a diagnosis and is often linked to the future and what it will hold for their child with disabilities (Fisher and Goodley, 2007; McLaughlin, 2006). For some families this may result in them living in the present and adopting a strategy of living one day at a time (Cohen, 1995; Beresford, 1995; Redmond and Richardson 2003). Stewart and Mishel (2000) question whether uncertainty is ever resolved for families of children will chronic illnesses.

Several studies have reported personal growth of parents can be a positive outcome of uncertainty and extends the possibilities for a positive outcome for their child (Cohen, 1995; Clarke-Steffen, 1993; Rosenthal et al., 2001).

5.3 Loss and grief

Theories of grief are helpful in understanding the experiences of parents who have children with disabilities. Parents will respond in different ways to a diagnosis and Kearney and Griffin (2001) describe experiences of shock, numbness, sorrow and denial when parents realise there is something wrong with their child. Kingston (2007) also found that, on receiving a diagnosis, some parents experienced a profound sense of emptiness. Families of children with disabilities may also go through a cycle of grief as reported by Kubler-Ross (1975) who identified five stages of grief: denial, anger, bargaining, depression and acceptance. Worden (1995) views the experience of grief as unique to the individual and states that it should not be considered a linear process. Turnbull and Turnbull (2001) suggest that feelings of denial and grief are emotions that may disappear and reappear in all families. Barnett et al. (2003) uses the term 'grief adaptation' to describe the normal process where parents of children with disabilities need to cognitively gain and assimilate information about their child's impairment and emotionally express their feelings of having a child with a serious disability. This does not happen just at the point of diagnosis but as a result of '*the unfolding nature of parents' knowledge of their child's prognosis'* (p190).

5.4 Personal Control

Perceived personal control was important for parents in this study for managing their uncertainty. Lipinski et al. (2006) investigated the relationship between perceived control and uncertainty among parents of children with rare chromosomal abnormalities. They found that parents who felt greater uncertainty perceived that they had less control over their situation. Perceived personal control is defined by Thompson (1981) as ''*the belief that one has at one's disposal a response that can influence the aversiveness of an event*'' (p 89). Clavering et al. (2007) reported parents may engage in problem solving behaviours such as information seeking as a result of their uncertainty and develop their own knowledge of their child's disability. Parents are reported to seek information from a number of sources (Beresford, 1995; Sloper, 1999) which they then use for problem solving (Beresford, 1994) and empowerment (Gibson, 1995). Understanding their child's diagnosis may give parents more personal control. Locus of control was first defined by Rotter (1966) as an individual's perception of where the underlying responsibilities for events reside. A person with an internal locus of control believes that an outcome is contingent on their own behaviour whereas a person with an external locus of control believes that the outcome is not as a result of their own actions. An external locus of control has been associated with parental distress (Dunn et al., 2001; Friedrich, Wilturner and Cohen, 1985; Hassall, Rose and McDonald, 2005). Lloyd and Hastings (2009) reported that external locus of control in parents of children with a learning disability was found to be significantly associated with stress and depression. Information seeking is viewed as a positive strategy to support parents to take control of events and is shown to be related to decreased levels of stress (Friedrich Wilturner and Cohen, 1985; Frey, Fewell and Vadasy, 1989).

5.5 Advocacy and Mothering

Mothers in the study identified their advocacy as something they 'should do' and as their responsibility within the family. This was also found by Wang et al. (2004) who identified in their study of ninety-six parents that advocacy was often considered a moral obligation and as a means to improve services. Many families in Wang et al. (2014) study described their advocacy activities as a '*life-long battle*' (p. 148) which had a negative impact on their family life. Advocacy can also be defined as enabling a person to have a 'voice' (Oliver and Dairymple, 2008) and throughout the trajectory the mothers in the study sought a 'voice' for their child. Two types of parental advocacy were proposed by Nachshen and Jamieson (2000): empowered and unempowered. Empowered advocacy is where parents perceive advocacy as a way to improve their child's quality of life and achieve positive outcomes.

Unempowered advocacy is where parents find advocacy a challenge resulting in a detrimental effect on family functioning. This can lead to negative outcomes contributing to depression, guilt, and anxiety. Empowered advocacy is the most relevant for families with a child with a disability as it enables them to use advocacy as a coping strategy with decreased feelings of stress (Nachshen and Jamieson, 2000). All parents act as advocates for their child at certain times but mothers of children with a disability develop this role more than other parents (Traustadottir, 1991). Landsman (1998) interviewed 60 mothers of children with disabilities who identified advocacy as important in obtaining services and ensuring their child was not '*written off'* (p. 127). Ryan and Runswick-Cole (2008) reported that mothers of children with disabilities advocate at a more complex level than other parents, identifying both the '*mother advocate'* and the '*mother activist'* (p. 44) roles. In their study most mothers adopted an enhanced advocacy role and some mothers demonstrated an activist role extending their efforts to campaigning for change for other families. They suggest that 'fighting' on behalf of their children is more than advocacy. Poston et al. (2003) found mothers with children with disabilities often described their advocacy in terms of anger and frustration whereas mothers of normally developing children discussed advocacy in terms of opportunities for their child. As a result mothers of children with disabilities have been described as vigilantes (Blum, 2007) and warrior-heroes (Sousa, 2011) as they battle to gain services and support for their children. Blum (2007) explored how mothers of children with invisible disabilities (e.g. ASD, dyslexia) evaluate themselves as caregivers and found that they acted as a vigilante advocate for their invisibly disabled child particularly in terms of their education and medical needs.

McKeever and Miller (2004) also found mothers viewed advocacy as adopting 'good' mothering by ensuring everything possible is done to benefit their child. 'Good' mothers are obligated to parent with "intensity" (Hays, 1996), accessing professional advice and services to develop their child's development. Mothers often have to assert their own identities as 'good' mothers within a society which undervalues mothers of a child with a disability (Skinner and Weisner, 2007; Landsman, 2003). When McKeever and Miller (2004) looked at mother's accounts of caring for a child they found women were often conforming to the rules associated with a 'good mother' in "*which mothers devote themselves selflessly to the welfare of their children*" (p. 1181). Social discourse concerning good mothering is that mothers will always put their child's needs above everything else which results in them not discussing their own problems as this could be viewed as competing with the needs of their child (Blum, 2007; Todd and Jones, 2003).

5.6 Family Functioning

In an ecological model, it is argued that behaviour cannot be understood independently of the social context in which it occurs. Bronfenbrenner (1979) describes the influences of the social environment on the behaviour of parents caring for a child with disabilities. His ecological theory is comprised of different systems which are all related and nested within each other. Bronfenbrenner’s perspective reflects the works of Bandura (1977) and Vygotsky (1978) in that environment is considered as a primary mechanism in a children’s development. In Bronfenbrenner’s model a child’s development is shaped by the varied systems of the child’s environment and also by the interrelationships between the systems. Within a family the child is at the heart of the ecological systems’ model and each child is recognised as an individual with their own uniqueness and developmental level which is influenced by his/her interface with the environment (Bronfenbrenner, 1979). The child’s development occurs within a social and cultural context with the most important influences being their interactions and relationship with their family (Hook and Paolucci, 1970). Within the ecological model different systems of influences occur at distinct levels. The child’s micro-system includes the immediate relationships within the family where the parents’ beliefs will affect the child and the child’s behaviour may also have an impact on the parent’s responses. The meso-system focuses on the connection between two or more systems for a child with a disability (e.g. communication between professionals and parents). The exo-system denotes settings that may affect the child indirectly (e.g. parents’ workplace) and the policies and decisions that are made at a wider level. Finally the macro-system comprises of the different cultural values, customs, and laws and represents the ways social structure can influence the child and family.

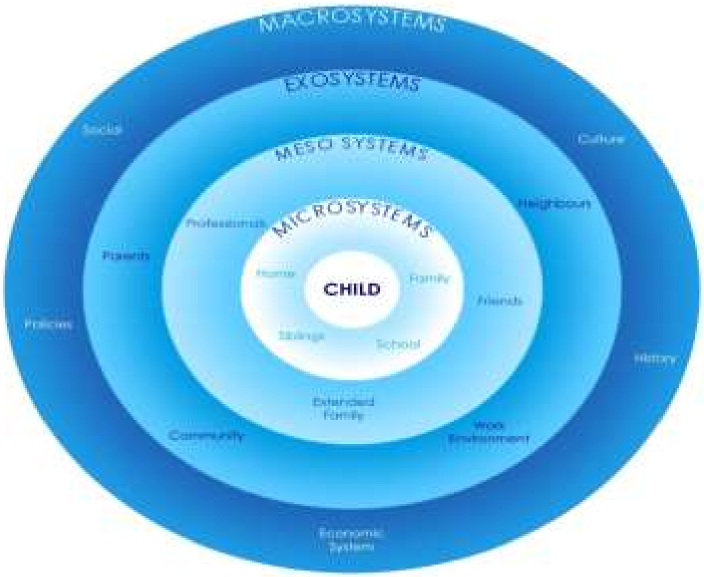


Figure 11: Bronfenbrenner's ecological model

Closs (1998) used Bronfenbrenner’s (1979) model in discussing the quality of life of children with life-threatening conditions and found the inner circle of close family members are particularly influential, whereas the mesosystem of more distant friends, relative, neighbours is reduced. Bronfenbrenner’s model (1979) highlights the interactions between systems which surround the family which are influential in the development of the child.

5.7 Family Adaptation and Resilience

Family adaptation to a child with a disability includes a series of adaptation-oriented components and resiliency processes (McCubbin et al., 1996). Throughout the trajectory families adapted their daily lives to facilitate the use of AAC in the home by developing strategies, problem-solving and accessing resources for their child and family. Resilience studies have been based on the ecological model which identifies resilience as a combination of factors including the individual characteristics of the person as well as the family, community and access to services and support (Schoon, 2006; Ungar, 2011; Lerner, 2005). McCubbin et al. (1996) referred to resilience as the ability to ‘*bounce back and to adapt to the situation by changing their patterns of functioning’* (p.6). Muir et al. (2008) described three interrelated steps that form the basis of resilience in families with a child with a disability. The first step is the family’s experiences of one or multiple adverse situations which may relate to having a child with a disability. Secondly the family draws on their resources and strengths from within and outside the family to try to maintain their functioning. The final step is for families to adapt the way their family functions so that it balances the needs of the other family members with the needs of the child with the disability. Muir et al (2008) concludes that how the family adapts is an important part of resilience. Resilience is not a static concept but is a continuous process (De Haan et al., 2002) dependent on numerous factors at different levels.

McCubbin et al. (1996) viewed the key to understanding family resilience is the identification of their protective factors and processes. The concept of family resilience extends beyond individual members to focus on risk and resilience in the family as a unit. Walsh (2003) considered that these protective and risk factors will change in relation to the contexts in which the family is exposed and will lead to different outcomes. Benzies and Mychasiuk (2008) reported family resilience is optimised when protective factors are strengthened across all the levels of Bronfenbrenner's ecological model. Muir (2008) identified family functioning as playing an integral part in family resilience. McCubbin et al (1996) described the key protective factors that protect families and help them experience resilience. These were adapted by Muir (2008) for families with a child with a disability. Muir identified four important factors for families with a child with a disability: the ability to solve problems and balance relationships within the family, family hardiness, social support and routines. Gardner and Harmon (2002), McCubbin et al. (1997) and Patterson (2002) reported other important resources and strengths for families to draw from are hope and flexibility, truthfulness, empowerment and spirituality.

Ungar (2005) takes a constructionist approach and locates resilience in a network of resources such as materials resources, relationships, community cohesion and social justice which are available to the individual (or family). A constructionist approach defines resilience as '*the outcome from negotiations between individuals and their environments for the resources to define themselves as healthy amidst conditions viewed as adverse'* (Ungar, 2005, p 242). This definition is supported by Runswick-Cole and Goodley (2013) who propose '*networks of resilience'* (p.12) where resources are inter-connected with each other. They acknowledge that underpinning these networks are local, nation social policies and legislative practices

5.8 Stigmatisation

Erving Goffman (1963) in his research conceptualised and created a framework for studying stigma. Goffman defined stigma as an "*attribute that is deeply discrediting*" (1963, p.3) which reduces the bearer "*from a whole and usual person to a tainted, discounted one*" (1963, p.3). Link and Phelan (2001) identified different components of stigma including the labelling of difference, applying negative stereotypes, separation, status loss and discrimination. Families in the study experienced different forms of stigmatisation which affected all the family members.

Goffman (1963) first used the term 'courtesy' stigma to describe stigma which spreads from the *"stigmatised individual to his close connections"* (p 43). In a family with a child with a disability it will be family members and close friends who experience 'courtesy stigma'. Goffman (1972) identified visibility as a factor in experiencing stigma and made a distinction between visible (discredited) and not visible (discreditable) attributes. Gray (2002) in his work with children with ASD and Turner et al. (2007) study with children with Proteus syndrome reported that parents of children with visible (discredited) disabilities suffered more stigmatisation. Scambler and Hopkins (1986) described the difference between two forms of stigma: felt and enacted. 'Felt' stigma refers to the fear of enacted stigma but also includes the shame and expectation of discrimination. 'Enacted' stigma refers to instances of discrimination which are experienced. Gray (2002) reported that parent's mainly experienced 'felt' stigma and embarrassment was the most likely expression of this type of stigma. Mothers will often feel more stigmatised than fathers as they may have greater public exposure (Gray, 1993; 2002). Gray (2002) suggests parent's experiences of felt and enacted stigma cannot be viewed separately as they result in the same negative experience for the families. Parents may employ coping strategies to control the effect of stigmatisation including concealing, limiting disclosure, covering and withdrawing from social situations (Scambler and Hopkins, 1986). The experience of stigmatisation can affect both parental identity and enhance stress (Beresford, 1994) when families are already experiencing feelings of uncertainty. Several studies have found families who feel stigmatised experience social isolation (Blum, 1991; Gray, 1993; Green, 2001; Birenbaum, 1992).

5.9 Impression Management

Selective self-presentation, or impression management, means "*accentuating certain facts and concealing others*" (Goffman 1959, p.65). In families with young children, parents are concerned with the impressions they create and their child's appearance (Cahill, 1990; Collett, 2005) or behaviour (Voysey, 1972) will reflect on their capacity as parents. Todd and Jones's (2003) study with parents of children with learning disabilities found that they monitor their relationships with professionals as they felt their worth as mothers were being continually scrutinized. Impression management gives mothers an opportunity to demonstrate their capabilities as good mothers (Goffman 1963; McKillop, Berzonsky, and Schlenker, 1992) and is a reflection of their moral worth (Cahill, 1987). Children's behaviour in public places will also reflect on the perceived competence of their parents. Gray (2003) described parents of children with ASD being embarrassed in public places due to their child's behaviour. As a result Ryan (2008) found mothers often demonstrating their moral responsibility through apologising to others present or by explaining their child's behaviour. Information control is one of the ways stigmatised individuals control the effect of stigmatisation (Goffman, 1963; Scambler and Hopkins, 1986). Gray (2002) reported a frequent coping strategy employed by families was to restrict information to give the impression of being a 'normal family'. This may result in families limiting their interactions to those who are more understanding of their child (Birenbaun, 1992; Green, 2001).

5.10 Conclusion

Research suggests families of children with disabilities may experience ongoing uncertainty following a diagnosis regarding the prognosis of their child and their future. Families may adopt a strategy of information seeking to support them in problem-solving in order to manage this uncertainty. Parents may also develop their advocacy on behalf of their children and research has found mothers of children with disabilities may extend this role to a more complex level than other parents. In an ecological model the child's development is shaped by the different systems and the interactions within and outside of the family. The literature on stigmatisation suggests that families will be affected by how others see and respond to them which will also impact on their family functioning and social interactions. Families often adapt the way their family functions to balance the needs of the family members with the needs of the child with the disability. How the family adjusts and adapts is an important part of the resilience process.

This chapter has presented concise reviews of the theoretical areas which emerged during the analysis. It provides some extant theory which contributes to the emerging theory presented in the following chapters.

Chapter 6 Finding a Voice: Part 1

6.1 Introduction

This is the first of two chapters presenting the grounded theory and introduces the core category of 'Finding a Voice'. Data analysis elicited the participants' experiences of using AAC in the home and 'Finding a Voice' is the conceptualisation of these experiences. A trajectory was identified in the core category of 'Finding a Voice' with four phases: *Loss of Voice*, *Prioritising a Voice*, *Gaining a Voice* and *Sustaining a Voice*. This first chapter considers the initial two phases within the process: '*Loss of Voice'* where families face uncertainties and the potential loss of their child's voice and *'Prioritising a voice'* during which families seek alternative and augmentative ways for their child to communicate and prioritise different communication systems. Chapter Seven explores the phases of '*Gaining a Voice'* and '*Sustaining a Voice'* during which families learn to manage AAC in the home and extend its use in different social networks. Figure 12 shows the different phases within the core category of 'Finding a Voice'

Figure 12: Finding a Voice and its associated phases

Progress through each of these phases is not a one way process and families can move back and forth between the phases over considerable periods of time. At any time families may revert back to a previous stage. This can occur particularly when there is further communication breakdown with their child or as a result of continually seeking new technologies and information which leads to the process starting again. The trajectory provides the framework within which the theoretical concepts are located and the sense of movement towards the process of 'Finding a voice'. Each phase is associated with a number of sub- categories which are discussed in detail. Figure 13 shows the sub-categories within the first phase of *Loss of Voice*.

Throughout the findings quotations from participants are used and annotated as follows:
FxIx= Family number, interview number followed by family member Mother, Father, Child

6.2 Phase 1: Loss of Voice

The first phase in this theory is *loss of voice* which begins with the realisation '*something is wrong'* (F7I1: Mother). Central to this phase is the parents' feelings of 'uncertainty'. Parents can experience grief over the loss of the child they had hoped for and struggle to understand the way forward in terms of their child's communication. There is often a slow realisation that their children may not be able to use speech as their main form of communication which leads them to experience a range of emotions and a grieving process. This sense of loss is on-going and parents will continue to feel a form of grief for the loss of their child's voice at different points throughout their child's development. During this phase parents are unclear about the best way to support their child and they begin to seek information and help from a range of sources. This acquisition of knowledge develops their confidence regarding their child's communication and the way forward for their child's communication.

Table 6 shows the major coding nodes associated with the first phase.

Sub-categories	**Coding Nodes**
Uncertainty	Unexplained differences Waiting for diagnosis Seeking support
Experiencing grief and loss	Struggling On-going loss Maternal isolation
Uncertainty (speech development)	Waiting for answers Hopes for speech development ‘Waiting to see’/’stepping stone’
Personal control	‘Educating ourselves’ Emotional readiness Gaining information Seeking support
Fighting/battling (for services)	Battling / fighting Mismatch in expectations Lack of services/knowledge ‘Doing it ourselves’
“Doing all we can”	Gendered roles Maternal Advocacy
Hopes for AAC	Future independence Social development Attaining full ‘potential’
Seeking a voice	Identity and personality (of the child) Acceptability for the family

Table 6: Category: Loss of Voice (Phase 1)

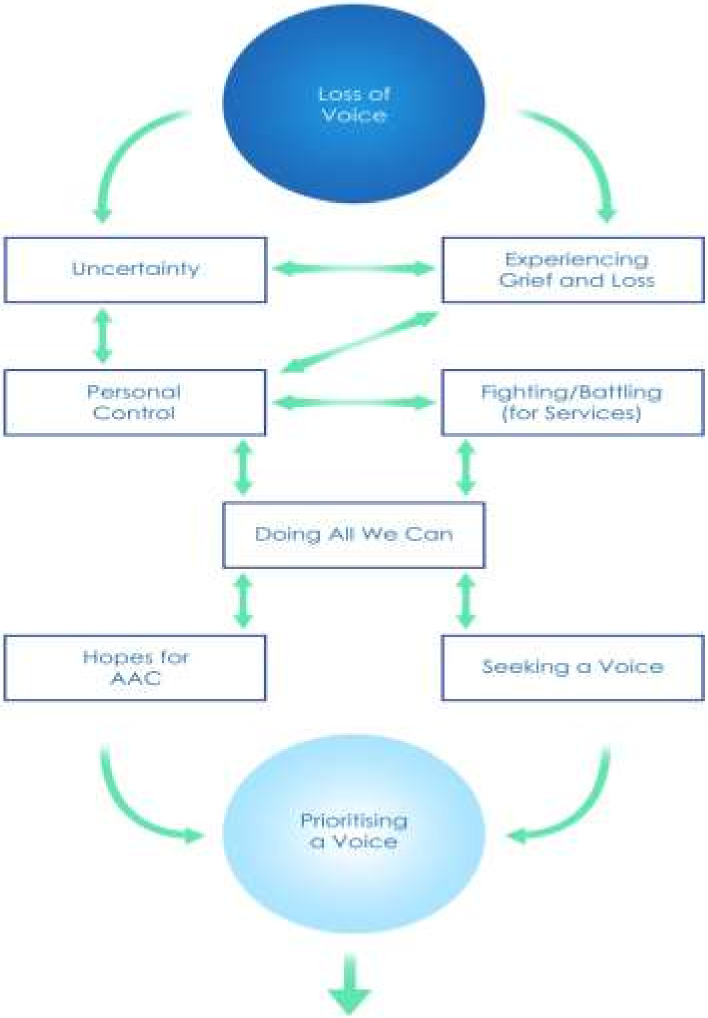


Figure 13: Loss of Voice

6.2.1 Uncertainty

This study found all parents experienced different degrees of uncertainty prior to their child's diagnosis, on receiving a diagnosis and over time through the different phases of the trajectory.

Parents, particularly mothers, described how they perceived very early signs in their child's development which differed from what they expected. Several mothers commented on their child failing to reach milestones or developing speech as they had hoped and expected.

For some mothers there was a more traumatic realisation that there was something wrong. In Family 9 the mother described how her child's development regressed '*overnight*'

> "*Basically his eye-contact went, he didn't want to be touched and he just completely zoned out. To be honest it was horrendous*" *(F9I1: Mother)*

Mothers felt their closeness and proximity to their child and their perceived maternal instinct made them more receptive to any problems and inconsistencies with their child's development. These early signs raised enough concerns for them to seek professional opinion. In the first instance mothers approached either the health visitor or General Practitioner (GP) about their concerns. The mother in Family 3 described her experiences of knowing there was something wrong with her child and although she could not fully identify his problems, she did believe in her maternal instinct. Mothers reported they `instinctively knew' there was something wrong with their child. When this was explored further with participants they felt it was a part of the bond between mother and child.

> *"I knew there was something wrong with him but the doctor said there wasn't. I can remember his words even now. I got to see another doctor on the Tuesday and he was diagnosed with cerebral palsy by the Thursday" (F3I1: Mother)*

Although maternal instinct is disputed (Hay, 1996) these mothers suggested that they followed their instinct because they had an increased awareness of their child's difficulties. Prussing et al (2005) obtained similar findings in their study which suggested maternal intuition was an important source of knowledge.

In the study reported here, mothers identified their child's difficulties rather than fathers. Mothers discussed their concerns with professionals and other family members including their husbands but often their knowledge that something was wrong with their child was not acted upon or listened to. The mother's perception of difference led them on a quest for an understanding and explanation of the problem and this reinforced their fears and apprehensions regarding their child and their child's future.

> *"I was really concerned and thought it was autism but she [health visitor] said 'definitely not' as he doesn't line his toys up and that was it, she dismissed it. So even professionals have got this stereotypical idea of what autism is. I said this to my husband and family, they said I was comparing him to other children but I was the only one really that knew what was going on" (F8I1: Mother)*

This lack of sensitivity or belief in the mothers' instinctive knowledge by others led mothers to begin their battle with health professionals. This is discussed later in the trajectory. Parents, who were not given a specific diagnosis at birth or in the first few months, experienced frustration and further feelings of uncertainty due to the delayed diagnosis.

Uncertainty can also affect families where a problem has been acknowledged but they are not given a specific diagnosis. In these situations they are unable to attribute their child's difficulties to a specific label or cause and the child may have an unclear developmental progression.

> *"Often people ask 'What is his diagnosis?' and it's very difficult. His statement has various statements on it but his sister is the same and she struggled but she progressed very quickly" (F5I1: Father)*

Parents viewed a label as a way to help them understand their child's difficulties. The families in the study wanted a diagnosis for their child as they believed this would provide them with some control over the future for their child and family.

6.2.2 Experiencing Grief and Loss

Parents commented that receiving a diagnosis was one of the most difficult times of their lives. The mother in Family 2 described her feelings following her child's diagnosis of ASD. Even though she had already identified some of her child's difficulties she still experienced immense sadness and struggled to come to terms with the diagnosis.

> *"My whole world fell apart. I think I kind of knew before because I remember ringing the National Autistic Society. It turns your life*

> *upside down, inside out but you know you have to get your head around it" (F2I4: Mother)*

Although mothers knew instinctively there was a problem with their child, the diagnosis was still a shock and mothers reported a grieving process.

> *"They call it a grieving process and it really is. You think oh my gosh my child is not going to grow up into the child I had hoped for, it's very strange." (F8I2: Mother)*

Mothers acknowledged their love for their child but they also expressed concerns regarding the future for their child which led to more uncertainty. In Family 6 the mother recognised the challenges ahead for her child and the need for extra help and support.

> *"You love that little person and wouldn't want them to be any different but at the same time you don't want them to have all those struggles and it's a very peculiar set of emotions" (F6I1: Mother)*

For some parents grieving was an ongoing issue over time and remained unresolved. Parents in the study with older children who had used AAC for several years were still coming to terms with their child not being able to use speech as their main form of communication. Although they valued alternative communication systems, there was still a sense of loss for their child's voice as they slowly discovered the full extent of their child's communication difficulties. Turnbull and Turnbull (2001) found in their study that feelings of grief in families with children with disabilities may reappear at different stages particularly in periods of transition. The realisation that a child may never speak affects all members of the family differently. In Family 4 the mother had accepted her daughter would not speak but other family members were still waiting for the time when their daughter/sister would talk.

> *"I have come to terms with the fact she won't speak but I'm not sure about the rest of the family" (F4I1: Mother)*

This caused isolation for the mother and an unwillingness of other family members to come to terms with the extent of the child's communication difficulties.

6.2.3 Uncertainty (speech development)

Parents were not only uncertain about their child's diagnosis but unsure whether their child will gain (or regain) speech and anxieties were reported about their child's lack of speech development. Parents were still coming to terms with their child's diagnosis as well as being unsure as to whether their child would ever use speech as their main form of communication. Parents expressed the hope their child would ultimately be able to speak.

> *"We would like him to talk as much as any other person" (F10I1: Father)*

In Family 9, the mother described the loss of her child's voice and the 'waiting' to hear it again.

> *"Four years may not seem a long time but when you are a parent and haven't heard your child's voice for four years, it's really hard" (F9I1: Mother)*

Parents looked to professionals to give them answers as to whether their child would ever acquire speech and if so, when this would happen. They expect and wait for professionals to give them a definitive answer but this is not always possible as in many cases even professionals are unable to predict how a child will develop.

Parents want their child to speak but as a result of the uncertainty about whether their child would develop their expressive language, there was often a delay in the implementation of AAC. In Family 1, the Father reported that if he had known his child was not going to develop speech, they would have considered AAC at a much earlier age.

> *"We didn't realise she wouldn't speak and I think in hindsight we should have focused on AAC much earlier but it's hard as I didn't think she wouldn't be able to talk" (F1I1: Father)*

There was a relationship in this study between the parents' decision to introduce AAC and the children's diagnoses. Those families with a diagnosis of cerebral palsy or serious brain injury were often more open to using AAC at an earlier stage than those with a diagnosis of ‘developmental delay’ which contributed to adopting an approach of ‘wait and see’ if speech develops. This diagnosis of ambiguity led to a delayed acceptance of the need for any intervention. For some families the use of AAC was only viewed as a ‘stepping stone’ for speech production.

> *“I am hoping she will talk at some point and we think it [AAC] will help her and move her along more” (F12I1: Mother)*

Families often need to balance their child’s additional physical, medical and behavioural needs but the ability to ‘speak’ was considered to be the most important skill for their child to acquire. The mother in Family 11 expressed her desire for her child to speak above everything else.

> *“I suppose if I had a wish list then the absolute ideal would be for something to unlock his body so he could actually speak. I know he has all the cognition there and everything in there except the ability to do it” (F11I1: Mother)*

6.2.4 Personal Control

Parents following their child’s diagnosis and uncertain prognosis concerning their child’s speech development, often felt a loss of control. Both mothers and fathers looked to reduce their uncertainty surrounding their child’s communication by seeking information. This took the form of learning everything they could by obtaining information from a wide variety of sources including the internet, books, professionals and advice from other parents. The increase in access to the internet and specific websites in recent years has supported families need for information (Howard et al, 2001; Gundersen, 2011; Neill, 2014).

> *“I’m a geeky sort of person and I had researched it” (F10I1: Father)*
>
> *“But at night I chose to sit and read books on autism and PECs” (F8I1: Mother)*

It was through the process of seeking information and gaining knowledge some parents increased their control and managed their feelings of ‘uncertainty’. However, for other parents the amount of information on AAC acted as a barrier to early AAC intervention. Mothers in particular discussed a sense of being ‘overwhelmed’ by the volume of information they obtained, or were given, and the different ‘language’ and terms used in AAC.

> *“It was so different, so much information and I only heard about using symbols and I didn’t know anything about them. I was overwhelmed and I wasn’t ready to deal with this” (F1I1: Mother)*

Being ‘overwhelmed’ led to a sense of helplessness and stress resulting in some parents not being able to focus on AAC at that particular time. They felt they had to be ‘ready’ to accept AAC for their child.

Parents viewed gaining knowledge about AAC as a steep learning curve and a gradual process of *“getting our head around it”* (F8I1). They often needed time to reflect on the relevance and usefulness of the information for their circumstances. Families 2 and 7 discussed the importance of educating themselves and independently seeking information.

> *“Most of it is educating ourselves” (F7I1: Mother)*

> *“But actually being open, there is so much out there and you need to be educated by” (F8I2: Mother)*

Parents also sought information from other families of children with disabilities and they shared information and knowledge amongst themselves in as many ways as possible e.g. formal support groups, online Parent Forums and Conferences.

> *“Then I asked other families about communication aids they used and you gather all the information you can” (F2I4: Mother)*

Mothers often used their personal knowledge of their child gained through their daily interactions against the advice and information they had gained.

> *“It’s been a real learning curve but children are different and one autistic child is not the same as another so we’ve had to learn from him as we have gone along and we are absolutely happy to do that” (F9I1:Mother)*

Parents looked for information at different stages particularly following diagnosis and at transition stages for their child. In this study they not only gained information on AAC but on all aspects of their children's lives which led to an increase in their personal control.

> *"We are actually at the stage when we are trying to gather information on what might happen when she is nineteen but she is only thirteen but there will come a point when we need to think about what will be next" (F4I1:Mother)*

Families spend considerable time searching for comprehensive information regarding their child's diagnosis and the different approaches available to support their child's communication. This search for information is on-going and helped them to overcome some of their feelings of 'uncertainty'.

Parents felt they needed to seek information and extend their knowledge as it was their personal responsibility to support their child. This internal locus of control enabled them to feel more empowered, consequently the information and knowledge they acquired lead directly to more control and choice. They became more aware of their rights and entitlements and the availability of local services. For some parents information led to fighting for services for their child. Battling and fighting were often strong elements in their engagement with professionals with whom they and their child were involved.

6.2.5 Fighting and battling (for services)

Parents highlighted difficulties in obtaining services through the NHS and education system. They consistently spoke of the need to 'fight' and 'battle' for services for their children.

> *"It's a constant battle to get services involved with us" (F11I1: Mother)*
>
> *"We have to fight for everything with X (name of child)" (F3I1: Mother)*

This was also reported by Paradice and Adewusi (2002) who found parents of children with speech, language and communication difficulties had to fight for services to be involved. In

Goldbart and Marshall (2004) study parents expressed concern they had to be 'pushy' (p 206) to access services.

Mothers in particular, reported '*being let down*' (F10I1) by organisations and systems, consequently this strengthened their efforts to fight for their child and obtain services they perceived would support their child. Continuity of services was important for parents as they benefitted from a more supportive relationship with professionals who had gained an understanding of their child and also the family.

> *"There's a lack of therapists, they are all or nothing. Most of them are locums and then they go and you are back to square one" (F3I1: Mother)*

Feeling 'let down' by services had a profound impact on some parents causing additional stress. The experiences of fighting for services and their subsequent disappointment often increased their reliance on the knowledge obtained through the different sources and their maternal instinct. This led some families to implement different communication strategies and systems with limited professional input. Family 8 implemented PECs (Picture Exchange Communication) within the home, obtaining and purchasing using their own resources.

> *"I had researched it and I thought in the end you know what I am going to get on the website, order some things and just get started myself" (F8I1:Mother)*

Family 10 learned and implemented signing with their child without initial professional support.

> *"At that time we learned sign language and we taught him that as much as we could" (F10I1: Father)*

Other families were unsure of the most appropriate therapy strategies to introduce and their search for information only reinforced their uncertainty. They wanted services to be involved and professionals to support them in the best way forward. However they were often disappointed in services in terms of both their frequency of input and professionals limited knowledge resulting in a lack of trust by parents in the services provided.

Parents reported frustrations particularly in terms of Speech and Language Therapy services in relation to the amount of time allocated to their child and the expertise of the Speech and Language Therapist. They were continually frustrated by professionals' limited knowledge of AAC and consequently the support they received from them.

> *"You have to have someone experienced. So often they don't know anything about the technology and it's really frustrating" (F7I1: Mother)*

Families also discussed additional barriers of long waiting lists, difficulties in sustaining input from services and being declined for more Specialist AAC services due to their child's level of functioning.

Whilst many families were fighting for access to services, some reported very positive support and good parent-professional relationships. In Family 2 the mother was concerned her child would not meet Specialist AAC services criteria for support and he would not receive the support she felt he needed.

> *"It was a brilliant experience dealing with our AAC team but the lady that referred us said it was quite complex and said it might not happen and that worried us as he might not get a communication aid" (F2I4: Mother)*

Families' primary motivation for information seeking and their efforts to access services was to ensure their children had the best outcomes possible. It also allowed them to plan for both their child and family, reducing some of the uncertainty around their child's communication. Limited access to services resulted in parents having a continual 'fight' to access appropriate services for their child.

6.2.6 "Doing all we can"

Families referred to "doing all we can" in various ways including decision making, implementing interventions and accessing services to support their child. Mothers in particular referred to becoming 'the voice' of their child, speaking on their behalf and adopting the role as the child's advocate as they felt nobody else could fulfil this role.

Mothers believed they were the best advocates for their children particularly in the early years following diagnosis.

> *"You need to go for it! As a parent you are emotionally involved but you have to be the voice for your child if you like. If you think it's the right thing, just go for it." (F2I1: Mother)*
>
> *"I really believe I am the best advocate for my child, if I don't fight his corner nobody else will" (F8I1: Mother)*

Mothers discussed the importance of their advocacy and the expectation that they *should be (F10I1: Mother)* their child's advocate. Wang et al (2004) also found that advocacy was perceived as a moral obligation. Social expectations of being a good mother may reinforce the ideology that good mothers do all they can for their child (McKeever and Miller, 2004; Todd and Jones, 2003).

Mothers focused on the needs of their child and developed knowledge of their own child which they perceived was greater than anyone else. This increased their self-esteem and their perception that they were the best advocate for their child. They used this knowledge to make decisions they felt were 'right' for their child.

> *"By my own experience I know this is the right way" (F4I1: Mother)*
>
> *"When you do know your child's ability you watch and you know what is right" (F2I1: Mother)*

In Family 9 the mother expressed her desire to do everything to help her child.

> *"I never want to not do as much as I could for him" (F8I1: Mother)*

Mothers spoke of wanting to have '*no regrets*' (F8I1: Mother) when they looked back at what they had achieved for their child. They made decisions they thought were 'right' for both their child and their family at that time.

Mothers overcame some of their feelings of disempowerment as a result of their interactions with professionals by becoming more assertive. In Family 8 the mother felt she had to act as an advocate for her child at both an individual and organisational level.

Mothers often became more confident by taking control and were persistent in their endeavours to obtaining services or resources they felt their child needed.

> *"I really have to stamp my feet and not just with the school but with other professionals, psychologists, the local authority. I write letters and state if he doesn't receive this there will be a detrimental effect on his development" (F4I5: Mother)*

Todd and Jones' (2003) reported how mothers in their study moved from a position of passivity in which they felt threatened to a position in which they challenged professionals.

Mothers extended their advocacy role by becoming involved with parent support groups. In Family 10 the mother felt she had gained a greater understanding of herself through the experience of having a child with a disability and wanted to support other families. Becoming an advocate allowed her to share her experiences and developed her self-esteem in being able to offer support to other families.

> *"I am now taking a course to be able to support other families to be a kind of advocate" (F10I1: Mother)*

Mothers by becoming advocates for their child became more self-confident and this led them to taking more personal control over decision-making for their child.

The overriding motivation to act as an advocate was to provide the child with the best opportunities available with regards to therapy, support and services. It also enables them to speak on their behalf if there are any injustices or lack of provision. For the mothers in the study advocacy was a clear role they felt they had to adopt and was a major part in developing their child's use of AAC systems.

6.2.7 Hopes for AAC

Finding the 'right' communication system for their child was a high priority for parents.

> *"For her to directly communicate with us is the next best thing to talking" (F4I1: Mother)*
>
> *"It far outweighs anything else" (F1I1: Father)*

Parents perceived AAC as a way of promoting their child's independence. They were unsure about how their child would develop but having a voice through AAC was viewed as giving their child the best opportunities to develop their future independence. AAC was also seen as a tool to support them in making friends and developing relationships.

> *"It would be nice if he could talk to his peers, for me that is where the eye-gaze can take us" (F11I1: Mother)*

Parents wanted their children to be able to communicate with other children and have their own friends. AAC was seen as the way forward to ensure their child was not isolated in the future.

Families 7 and 11 felt their children needed access to technology due to their children's severe physical disabilities and this would allow their child to reach their full potential. Mothers were aware their child may be stereotyped and AAC was also seen as a way to demonstrate the abilities of their child to others.

> *"She can't speak she can't do anything with intention she can't walk she's got very limited or any independent movement…. but she is cognitively fine and I hope ultimately she will use AAC at a sophisticated level" (F7I1: Mother)*

The parents expressed their hope that AAC could develop their child's communication abilities and prepare them for the future. Hope is one of the protective factors identified by McCubbin et al. (1997) to building and strengthening family resilience.

6.2.8 Seeking a Voice (for the child)

Although parents acknowledged the importance of AAC and their future hopes for their child's independence and social development, some viewed AAC as a very 'atypical' means of communication which prevented their initial acceptance. In Family 9 the mother expressed her anxiety about the introduction of symbols.

> *"In the beginning I was so sceptical about it because I was going through all these emotions myself and I felt slightly resentful and*

> *upset...I kinda felt how frustrating you need these to communicate with your own child" (F9I1: Mother)*

The introduction of AAC can undermine parents' abilities as they have already developed their own communication with their child. Parents may not be able to adapt to taking on a different form of communication and may perceive AAC as interfering in their relationship and bond with their child.

However following their initial anxieties parents were generally accepting of the support AAC would give their child.

> *"If your child does not have the language you are going to have to try to reduce the frustration for him not being able to vocalise his needs" (F2I4: Mother)*

In families 1 and 5 the Fathers were very clear that families should explore AAC and look positively at opportunities available for their children in terms of technology.

> *"It doesn't matter what it is, you shouldn't have any pre-conceptions. 'I don't want this! I don't want that!' You're narrow-minded. You've just got to try it and look at the positives as they far outweigh the negatives" (F1I1: Father)*

Parents also considered the individuality of the voice for their child and the importance of finding a 'suitable' voice. A person's 'voice' is often seen as unique and part of our identity. Identity is often expressed by voice quality and intonation (Collins and Markova 1999). For some parents the perceived quality of the voices on high tech electronic aids was viewed negatively. In Family 1 AAC was associated with a 'robotic' voice which the mother felt would not reflect her own child's identity. Synthetic voices were often seen by parents as a loss of their child's uniqueness and lacking in any emotion.

> *"I didn't want a robot talking for her" (F12I1: Mother)*

IPad's with different communication apps were used by several families with their children. Parents often wanted a 'voice' which was acceptable to all the family but only a limited number of voices were available on some of the iPad apps.

> *"I thought it would be nice to get a young voice on it but the only young girls on it are American so it's not something that's easy" (F4I1: Mother)*

In a Talking Mat with Tom[4] (F1012), a child who uses a tablet computer with symbol communication software, the characteristics of the communication device were discussed. He indicated that he did not like the quality of the voice on his communication device. He placed it on the negative side of his mat and used his communication device to indicate he thought the voice on his device was 'funny'.

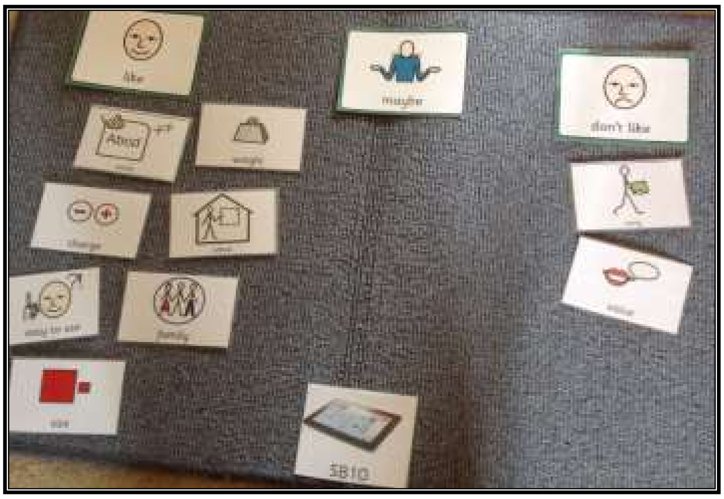


Figure 14: Talking Mat (F1012)

In Family 1 the mother's desire for their child's 'own voice' was further emphasised when her daughter used a communication device to play the role of Mary in the school play. She did not want her child to be given another 'voice' and one she did not recognise as her daughters.

> *"Yes the first I heard it she had to press it and it said 'Come in' or something. She was Mary and I sat and burst into tears" (F1I1: Mother)*

One Father with a son with some vocal communication (Family 5) considered the ideal communication aid would adopt his own son's voice as he was concerned his child's identity could be lost.

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[4] Pseudonyms are used throughout the presentation of results in this thesis

> *"At the moment it's great for him but in the future I would like his voice and phrases on it. I'm not sure whether it is possible but technology is changing so much" (F5I1: Father)*

The parents in this study not only considered the perceived quality of the voices but also a voice which was fitting for their child's identity.

Families expressed the desire for the child to develop a voice through using AAC but, for them, it was important that their child's voice was acknowledged by others in the child's environment and their social networks.

> *"I think for her to be able to communicate and have her voice heard and acknowledged is the main thing and to be able to communicate as well as she can and to the best of her ability" (F12I1: Mother)*

6.3 Summary

Mothers in the study identified early signs their child was not developing as they hoped for. In this phase on the trajectory they believed in their 'intuitive knowing' and 'maternal instinct' that something was wrong and often had to convince professionals and other family members these problems existed before gaining a diagnosis. Parents were not only uncertain about their child's diagnosis but unsure whether their child would gain (or regain) speech. During the 'loss of voice' phase parents not only seek information regarding their child's diagnosis but also strategies to support their child which includes the use of AAC. Families were often frustrated with the services they obtained, the infrequency of any interventions and the limited expertise of professionals. This resulted in mothers in particular having to 'fight' and 'battle' on behalf of their child to give them the best opportunities they could. The theme of voice is important within Phase 1 as mothers not only seek an acceptable 'voice' for their child but begin to find their own voice through a process of advocacy for their child.

6.4 Phase 2: Prioritising a Voice

The second phase is ‘**Prioritising a Voice’** which is a continuous process where parents review, evaluate and shift existing priorities with the aim of being able to introduce AAC within the home. A redefining of priorities occurs throughout the AAC process where the child’s needs shift the emphasis of the family to the management of AAC. For those families who have made the decision to accommodate AAC, their child’s ability to communicate is foremost in their priorities. This has many implications not only for the child but also the family. Figure 15 shows the different subcategories in ‘Prioritising a Voice’.

Table 7 below lists the major coding nodes for the second phase ‘Prioritising a Voice’

Sub-categories	**Coding Nodes**
Redefining Family roles	Roles and responsibilities Mother/Father role in family Mother’s role in AAC Sole responsibility
Shifting Priorities	Shifting and reviewing child/family needs Time and organisation Maintaining a balance
Maternal understanding	Hindering AAC “Knowing your child”
Defining Moments	‘Trial and error’ Redirecting expectations Celebrating success Ownership

Table 7: Category: Prioritising a Voice (Phase 2)

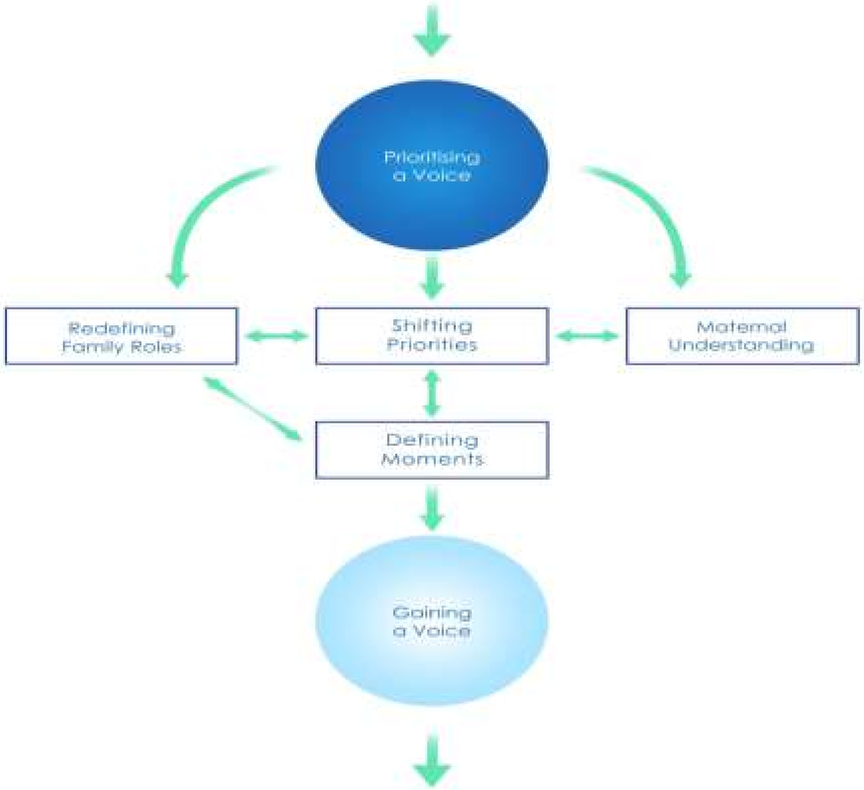

Figure 15: Prioritising a Voice

6.4.1 Redefining Family Roles

All parents reported there was a re-organisation of family priorities in response to their child using AAC. Families often make many decisions on roles and responsibilities and who will take particular responsibility for tasks within the family. Mothers in the study assumed additional roles on a daily basis in terms of AAC: taking the lead at all stages of the AAC process including setting up the system, ensuring its use, developing the system and liaising with professionals.

In Family 2 although the Father used the AAC system with the child, it was the mother who was responsible for ensuring it was available.

> *"My husband, well, to be fair it's mainly me. He does know but I have to get everything ready" (F2I1: Mother)*

Mothers in the study adopted this role as they wanted to be the advocate for their child and for some families the mothers acknowledged they had more time or flexibility in their employment to fulfil this responsibility. Mothers reported having given up work as a result of having a child with disabilities or choosing to work part-time.
In Family 7 the mother had given up a high profile position to care for their child.

> *"bang goes your career as you have a new career as a professional parent of a child with a disability" (F7I1: Mother)*

The mother in Family 4 perceived she was the only one in the family who could care for her child and had sole responsibility for ensuring the best outcomes for her. This led to considerable maternal worry and uncertainty around the child and the family's future.

> *"My husband wouldn't cope as he's never got involved with the nitty gritty or anything" (F4I1: Mother)*

In terms of AAC, mothers felt their husbands provided them with emotional support with regards to their child's communication but attending training, appointments, and assessments was mainly regarded as their role as a mother.

In Family 1 and Family 8 the mothers acknowledged their role in the implementation of AAC but also the role their husbands played in terms of emotional support and reassurance.

> *"He is very grounded, gosh he is straight thinking and sensible whereas I wear my heart on my sleeve" (F8I1: Mother)*
>
> *"but I am also more emotional and you're the calmer one. I come away, I take all the information away with me but he says 'why are you freaking out?' All the way along I have attended all the courses because [name of husband] has his own business, that's how it should be" (F1I1: Mother)*

Societal influences and personal beliefs about parental roles are an important influence on the implementation of AAC. Mothers in the study talked about their responsibilities, both practical and emotional in caring for their children. The continued social construction of motherhood includes responsibility for both the caring and welfare of children in families (Ehrenreich and English, 2005; Wall and Arnold, 2007).

6.4.2 Shifting Priorities

Shifting priorities is a continuous process where AAC as well is prioritised which results in a reviewing and revising of existing priorities to accommodate AAC. Parents shift and modify their family's priorities and make changes to their daily lives to enable them to support their child's communication. Management of AAC systems changes over time and there is a continual rebalancing of the child's and family needs. Challenges to time management created additional pressure particularly for mothers in the early stages of adopting AAC.

Parents reported that the initial setting up of the system was very time consuming as they often needed to attend training, programme devices, prepare symbols and liaise with professionals. In Family 8 the mother commented on the amount of time she spent on preparing her child's communication book.

> *"It is so time consuming and really you can spend an entire weekend just making a handful of symbols because you are printing, collecting them first from the PECs CD [Picture Communication System] or the internet, finding the right ones, printing them, laminating them, velcroing the back of them. One night my hands were throbbing after doing all these symbols. So yeah very time* consuming *just getting it set up without even using it with your child"* (F8I1: Mother)

This resulted in a shifting of priorities and the re-prioritising of time to enable the introduction of AAC.

> *"How am I going to get my ironing done and sit down and do all this programming. When am I going to find the time? Once I thought about it I am going to have to leave the ironing and the house cleaning and just sit down and do it!" (F1I1: Mother)*

Some families had the benefit of support from AAC teams or Speech and Language Therapists who set up the initial communication system in the home but families still had to alter their priorities to become familiar with the system and to begin to use it with their child.

Parents often found the amount of additional paperwork generated through AAC (e.g. filling in forms, applying for funding etc.) was also extremely time-consuming. Many felt the paperwork involved when applying for funding for a communication device was too onerous and some families had a continual struggle to obtain funding.

> *"I think I need a PA or administrator to manage it all as it generates so much paperwork" (F7I1: Mother)*

Parents also often had to redefine their priorities according to their child's needs. Many of the children had significant health and behavioural needs which affected the family and their priorities. In Family 10 the mother commented at one stage her child's medical needs needed to take priority over the communication system.

> *"For a long time he was so poorly I couldn't think of anything else" (F10I1: Mother)*

The prioritisation of AAC may vary over time as mothers parents are challenged when meeting the everyday needs of their children in terms of their physical, social and emotional needs.

All the parents expressed their desire to use the systems within the home whilst also acknowledging the huge commitment families must undertake when implementing AAC which subsequently impacts on family organisation and time. In Family 1 the Father commented that although they were willing to spend the time on their child's communication system he doubted how many families would have the time or 'commitment' to the process. The time commitment and the organisation and prioritisation of communication also hindered the family's enjoyment and spontaneity.

> *"Sometimes it would be good to go out and not worry about it, otherwise you have to spend the whole time having to assess and*

> *evaluate everything and we have to pre-empt things which can take the fun out of things" (F1I1: Father)*

Although families wanted to prioritise their child's communication there was a continual reviewing and re-prioritising dependent on the needs of not only the child who used AAC but the family's needs in response to different situations. Their family functioning needed to be adapted not only according to the needs of the child but also the rest of the family. Muir (2008) also found in her study that families negotiated the resilience process by changing their family functioning to adapt to all the needs of the family.

6.4.3 Maternal Understanding

Mothers, in particular, acknowledged they were able to understand their child without any formal means of communication as they understood their child's non-verbal behaviours and vocalisations.

> *"Around the house I always knew her little noises and body language and I knew what she wanted" (F4I1: Mother)*

In Family 5 the Mother and Father discussed their intuitive understanding of their child. The mother felt she needed to provide further opportunities for their child to use his communication system but this was often difficult as she understood him without the use of AAC.

> ***Mother:*** *"Yes I understand everything and I suppose because I understand him I keep forgetting to do it so I need to say 'What do you want for lunch?' or something like that. That's the kind of thing I need to do so in September I need to ask him what he wants in his packed lunch."*
>
> ***Father:*** *"You see sometimes he will say something but you cut it short and he might want to say something else."*
>
> ***Mother:*** *"I am the worst and I think I mustn't do that but you know it's often something I know and people say 'how did you understand that?' but I just do." (F5I1: Mother and Father)*

Mothers considered their understanding of their child was often a hindrance in their use of AAC and they had to ensure they gave their child the opportunity to use the communication system. They often had to make a conscious effort to encourage their child to use the device/system rather than relying on what they perceived was more 'natural' communication (e.g. non-verbal behaviours) as part of the mother-child bond. As a result communication using AAC was initially viewed as stilted and enforced. For many mothers the use of AAC resulted in a change in their previous communication behaviours with their child and was also more time-consuming.

> *"That's the tricky bit because you can anticipate what she wants and I do it constantly. She goes a a a and so one tends to shortcut that and one has to be really conscious and say no! She has to tell me what she wants" (F12I1: Mother)*

In a Talking Mat with Ethan (F5I2) who uses an iPad with communication software, he placed the symbol of 'home' on the negative side of his mat when asked by the researcher 'how do you feel about using your iPad at home?' His mother reported she understood his vocalisations at home whereas in school staff were unable to understand him verbally.

Figure 16 shows Ethan's sub-mat on his views and use of his communication device.

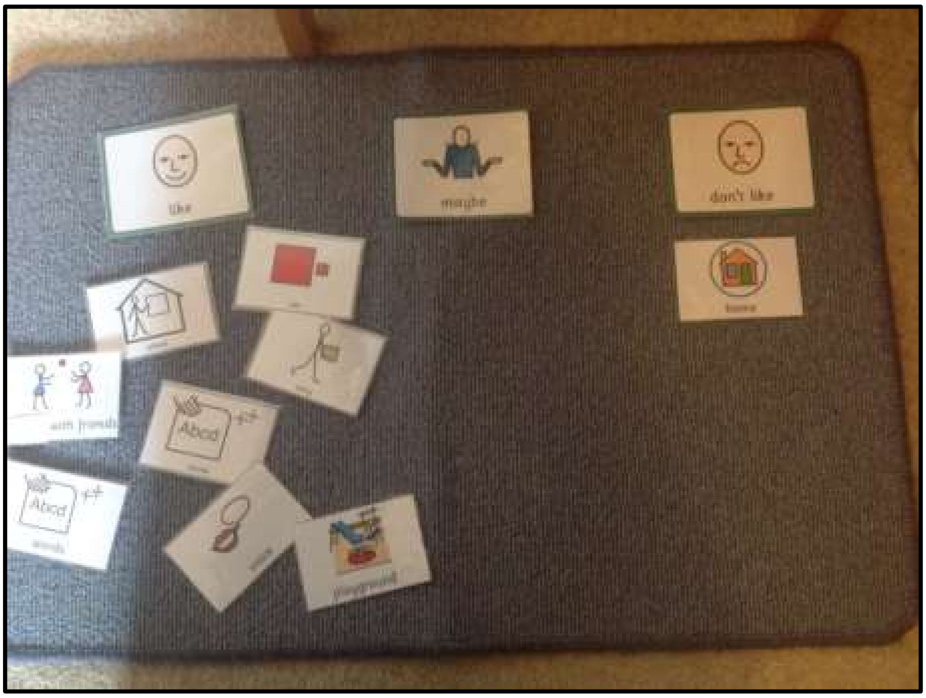

Figure 16: Ethan's Talking Mat (F512)

Parents acknowledged that as their children grew older and extended their social networks, they may not know all the things their children wanted to talk about.

> *"I intuitively know what he wants to say. He's eight now and he is bound to come out with things that I don't know. Even with his eye-gaze he is quite funny as he comes out with things that are off the wall but I think great!" (F11I1: Mother)*

Mothers in the study also expressed guilt they were not using the system as much as they perceived they should with their child and their maternal understanding was "*holding her back*" (F12I1: Mother). Mother's self-blame was often linked to their expectations of a 'good' mother and societal discourses of maternal culpability.

6.4.4 Defining Moments

During the early stages of AAC, mothers often dominated the interaction with their child and needed to structure opportunities for the child to use their communication system. They employed different strategies to encourage their child to use the system in the home. In Family 7 the mother commented on the importance of 'modelling' and using the communication system on a daily basis.

> *"Make sure you use the system as well because the child won't use it unless you are day to day. You have to put the effort in as six months down the line and if you haven't the child won't use it [the system]" (F8I1: Mother)*

Often parents had to interpret and reinforce their child's choices when at times it was difficult to ascertain whether they were actively communicating a choice.

> *"It's quite difficult to interpret what he does want and you have to go with it and say 'Oh you smiled, you want the toy" (F11I1: Mother)*

Parental recognition of their child's early communications is important in AAC and the interpretation of these behaviours may develop more complex communication skills (Cress, 2002). For children using AAC the development of language is complex and there is insufficient research regarding which methods and strategies are effective in supporting language development of young children who require AAC (Beukelman & Mirenda, 2005).

The use of AAC systems was described as challenging by parents in the study as they needed to learn the system and acquire new skills to communicate with their child. This was often through a ‘trial and error’ process with continual problem-solving which challenged family time management and prioritisation.

> *“You can go for several days without using it and I have to stop and refocus and make sure we all use it with him” (F8I1: Mother)*

In this phase of prioritising AAC there are high levels of parental directness and limited agency of the child. There was often little feedback from the child in terms of their independent use of the communication system.

Parents often had to change their focus from ‘normal development’ and ‘developmental milestones’ to consider their own child’s gains. In Family 2 the mother commented on her shift in thinking by recognising her own child’s development rather than societal ‘norms’.

> *“You go down to your child’s level because in society we live in, everyone has to do certain things by a certain age and you have to fill in the red book but you have to not worry about that and just go down to what he can do” (F2I4: Mother)*

Parents had to redirect their expectations in terms of their child’s development and celebrate their child’s own successes. They identified significant ‘defining moment(s)’ where the child used their communication system unexpectedly and independently. These defining moments supported their belief in AAC and their child’s potential to use it. These moments also provided justification for the parents belief they were ‘right’ to prioritise communication. It also helped them gain ‘ownership’ of the device or communication system. The following are examples of the defining moments experienced by the families.

> *“That particular night she had her iPad and went through and found the one she wanted. I thought yes, she is getting the hang of this” (F4I1: Mother)*

> *"I knew he wanted to go outside but then he went to his book and found trampoline and gave it to me" (F6I1: Mother)*

> *"He was feeling really tired so he wanted to go in the car so he got the tiles 'tired go car' which I thought was really brilliant" (F2I1:Mother)*

> *"He went from one category and picked something and then to another category. He surprises us every day" (F5I1: Father)*

The 'defining moments' were very different for each family and for some families the defining moment(s) took a considerable amount of time to achieve.

> *"I got to the point where I thought this was a waste of time" (F4I1: Mother)*

Several families had been using AAC for 12-18 months before their child independently used the system. All the children were using different symbols on their communication systems and learning the representational code of AAC may take considerable time. The readiness of their child to use AAC was discussed by several families.

> *"When she was ready to have that sort of information, it came slowly but once she started and got the hang of what it was all about, she went with it and she rocketed with it and hasn't looked back" (F1I1: Mother)*

The children had varied diagnoses and were at different levels in terms of their receptive and expressive language and their social skills. As a result the methods, objectives and time taken to facilitate the child's use of AAC varied from family to family.

The 'defining moment' was often as a result of the families' determination and persistence in adopting the communication system. During this phase families need to adapt their communication behaviours to be able to accommodate using a different communication system.

6.5 Summary

The second phase, ‘prioritising a voice’, is the phase in which families decide to prioritise AAC and during the process, mothers find it necessary to shift and adjust their priorities to accommodate a different form of communication. Parents view communication for their child as a high priority as they consider it could enable their child to increase their future independence, to make friends and to fulfil their potential. The adoption of AAC systems requires a huge commitment from families and impacts on their time and organisation. Mothers adopt multiple roles in the family and are continually balancing the needs of the child and the needs of other family members. Mothers often expressed guilt and frustration at not being able to find the time to do as much as they had hoped in terms of implementing AAC. They felt their understanding of their child’s non-verbal behaviours and vocalisations was a barrier to their use of AAC. The ‘defining moments’, where their child uses their system independently, confirmed their belief they were ‘right’ to prioritise AAC. With this increased confidence in the use of AAC, families progress to the next phase of ‘Gaining a Voice’.

Chapter 7 Findings: Gaining and Sustaining a Voice

7.1 Introduction

Chapter Seven considers the third and fourth phase of ‘Finding a Voice’: ‘*Gaining a Voice*’ and ‘*Sustaining a Voice’*. It considers how families gain confidence in using AAC and how they sustain the use of AAC by developing their child’s voice in different social networks and society in general.

7.2 Phase 3: Gaining a Voice

The third phase ‘Gaining a Voice’, follows the initial success of AAC observed in the second phase and is where families continue to develop their child’s use of the communication system. During this phase families discussed their desire to manage as a family in terms of AAC. The focus is on the families’ aspiration to increase their child’s confidence in ‘Gaining a Voice’ within the home. The concept of ‘Gaining a Voice’ is a continuous process where families evaluate and develop AAC. During this phase the support and availability of resources are significant factors which allow families to manage AAC and provide opportunities for their child to continue to develop their communicative independence. Figure 17 shows the sub-categories associated with ‘Gaining a Voice’.

Table 8 below lists the major coding nodes for the second phase ‘Gaining a Voice’

Sub-categories	Coding Nodes
Managing as a family	Flexibility Self sufficiency ‘Normal’ family Living one day at a time Managing resources
Adapting (to AAC)	Competing time pressures Continual problem solving Hopes for future Ease of programming Determination
Becoming an expert	Maternal Knowledge Increased confidence Maternal Knowledge of child
Being a ‘family team’	Positive relationships (with siblings) ‘Interpreter’ ‘Protector’
“Just don’t quite get it”	Lack of understanding by family members Being ‘scared’ Isolation

Table 8: Category: Gaining a Voice (Phase 3)

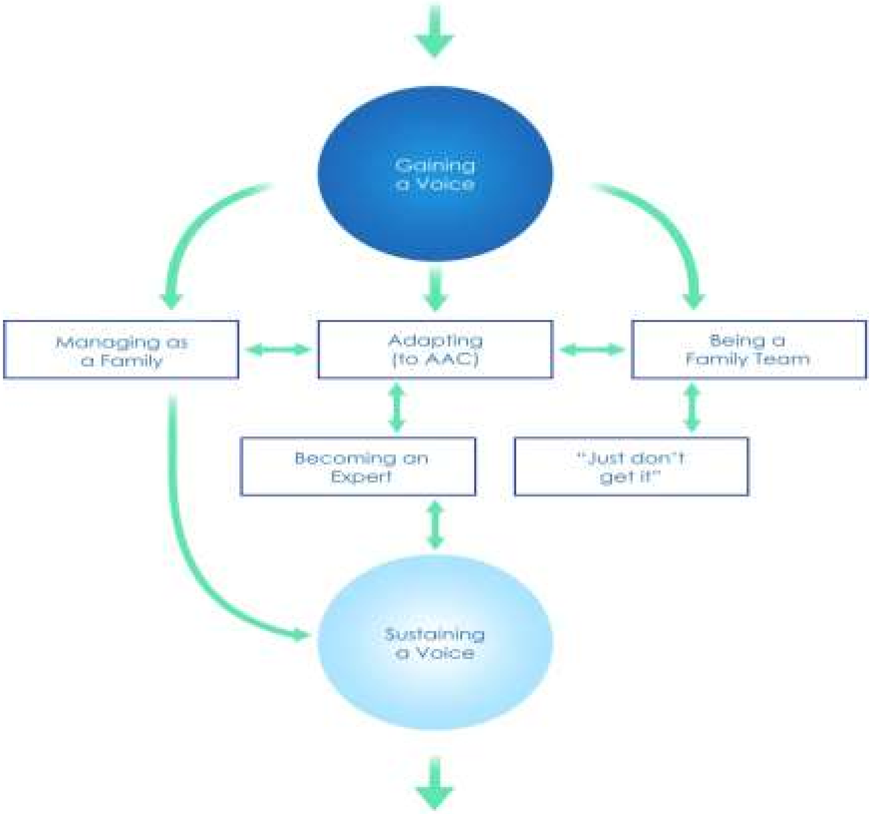

Figure 17: **Gaining a Voice**

7.2.1 Managing as a Family

The term 'family' can be defined in many different ways (Bomar 2004) but parents in their interviews defined 'family' as consisting of their children and themselves. This was also found by Neill (2006) where families defined themselves in the same way when their children were acutely ill, even when there were extended families locally.

The preservation of family life was important and parents worked towards establishing normality for their child and family. They discussed the need to 'manage' as a family and to be 'self-sufficient'. Mothers in particular were determined to make family life as normal as possible and maintain the quality of life for all family members by managing the day to day routines of the family. Parents often felt they just '*got on with it'* (F9I1) and coped on a day by day basis. Studies (McCubbin et al., 1997; Muir, 2008; Walsh, 2003; Breitkreuz et al.,

2014) have identified an important factor to resilience in families was their ability to maintain a 'normal' routine of family life which balanced the needs of all the family members.

Flexibility was also identified as an important strategy used by parents to enable them to manage as a family.

> *"We are very flexible, we unusually manage everything ourselves with her" (F1I1: Father)*

Flexibility was generally related to employment, taking time off work and adjusting family priorities to provide for the needs of the child using AAC. Flexibility was also referred to in terms of AAC where strategies were applied on a daily basis and plans continually modified depending on the changing needs of their child and family. McCubbin et al. (1997) identified flexibility as a protective factor which assists families to adapt and change their functioning and routines accordingly. In Family 3 the importance of the family unit was highlighted to such an extent the mother did not want other people outside the family or professionals involved. She felt she did not want to be 'judged' by others. This mother also felt the family was the best environment for the child and they were the only people who could cater for his needs.

> *"But as parents we can't let him go. I don't want the interference. We do things as a family" (F3I1: Mother)*

Neill (2011) reported in her study that parents' desire to avoid criticism of their moral status as 'good' parents affects when they involve professionals due to significant hidden anxiety. Todd and Jones (2003) also found that mothers felt they were scrutinised by professionals in terms of their worth and character as mothers. Parents as a result may limit the number of people involved by isolating themselves as a family unit limiting their exposure to scrutiny.

Parents described themselves as '*living one day at a time*' (F1I1: Father) as a consequence of their uncertainty about the child's future. Beresford (1994) also found that families with children with disabilities adopt a strategy of living day by day due to the uncertainty of the future for their child and family. Some of these concerns not only focused on uncertainty about their child's future communication but also their wider caring role. Older parents avoided or minimised thinking about what would happen if they were no longer able to care for their child. The mother in Family 4 describes her feelings of isolation and doubts on the capacity of others to care for her daughter.

> *"I worry about the future; it's a black cloud really. You take everything day to day but there is always that niggly thing what if something happens to me and I end up [pause] whatever, you know there is nobody else that could take over" (F4I1: Mother)*

Uncertainty about the future makes any planning difficult for parents and this may result in them living in the present and managing on a day to day basis.

> ***Mother:*** *We don't think too much about the future*
> ***Father:*** *Maybe we should, I don't know*
> ***Mother****: I can't*
> ***Father:*** *We take one day, week, month at a time to be fair*
> ***Mother****: It's a big worry but we just don't know, don't know*
> *(F1I1: Mother and Father)*

Uncertainty also related to AAC in terms of the lengthy 'journey' which the child and family had ahead and the feelings of uncertainty in terms of the outcomes of AAC. It was often difficult for them to imagine the outcome of AAC but they hoped that it would increase their child and family's quality of life. The use of emotional coping strategies of retaining 'hope' and a positive future image for their child helped lead to successful implementation of AAC systems. For some parents AAC provided hope their child would continue to develop their communication which in turn could lead to further independence.

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

The perceived benefits of using AAC also reduced the uncertainty about the child's future communication.

> *"I have found a method that will help him hopefully and one to build on it doesn't have to be just about requesting food. We can use it for a whole host of communication needs and things so it was really exciting when he cracked it- we thought oh yes! we have found something we can really utilise here" (F8I1: Mother)*

The term 'managing' also referred to how the communication system was used in the home and the appropriate resources and opportunities for their child to use AAC in the home. Mothers often regarded managing AAC within the family unit as something they should 'do' as a 'good' parent. The mother in Family 7 commented:

> *"It's a tricky situation as parents we should be doing it ourselves. I do feel for those parents who are perhaps not as knowledgeable as we are or not willing to be knowledgeable as that has a real effect on their children" (F8I1: Mother)*

Managing AAC in the home involved the purchase of appropriate resources i.e. symbol software which enabled them to increase the vocabulary in the child's communication system rather than relying on the school or Speech and Language Therapist to provide these. Families wanted to access resources and financial support that would allow them to be more self-sufficient with AAC in the home, however, the financial burden of using AAC for some families was significant and on-going.

> *"We got one of the Boardmaker DVD so we could use it at home and that was very good so we could make our own symbols to use" (F2I4: Mother)*
>
> *"There should be more financial support for parents if they want to go out and buy these things to try and help their children, they should have these things available" (F8I1: Mother)*

7.2.2 Adapting (to AAC)

Throughout the trajectory parents sought effective strategies to support not only their child using AAC but all the members of the family unit. These strategies were interwoven with in the context of the family and the constantly changing conditions within which the family operated. Parents were able to give detailed accounts of their child's use of different communication systems in the home. As with other studies (Loncke et al., 2006; Light, Collier and Barnes, 1985) the children in this study used multimodal communication with a combination of low and high tech AAC.

Parents acknowledged that using AAC in the early stages was '*not easy'* (*F7I1: Mother*) and a '*struggle'* (*F8I1: Mother*) but they persisted with its use and developed strategies to support them on a daily basis.

> *"Communication has been like a dark tunnel but I can now see light at the end of it" (F8I1: Mother)*

One of the most consistent areas of parental concern was in relation to the additional time demands which arose as a result of integrating AAC into the family. In Family 12 two children in the family had disabilities and the mother found it difficult to find time to learn the AAC system.

> *"It's time to sit down and do it. I just find with children with complex needs, they take up more time than other children. That's why I struggle with doing it" (F12I1: Mother)*

The need to '*juggle*' (F4I1: Mother), '*balance*' (F1I1: Mother) and '*plan*' (F12I1: Mother) describes the complexities of integrating AAC in the home. Mothers developed schedules to allow them to fit everything in to the child and family's daily routine. However mothers also experienced guilt and frustration as they were unable to achieve as much as they had wanted for their child. They acknowledged this was mainly due to a lack of time compounded by the multiple roles they had to fulfil at home. Some of these multiple roles were specifically related to the child's disability but also the challenges of meeting the needs of their other children and the demands of family life. Feelings of guilt were also associated with their perceived responsibility for their children and not meeting their expectations of themselves as 'good' mothers. Mothers worked towards a healthy balance where the focus on the children's communication was balanced with their other needs and the families' daily lives. Being able to respond and balance the needs of the whole family was identified in other studies (Gardner and Harmon, 2002; Patterson, 2002) and is reported to play an integral role in family resilience (McCubbin et al., 1997; Muir et al., 2008).

Competing time pressures resulted in mothers linking the use of the communication system into set family and daily routines. This relied on considerable organisation and the ability to plan ahead. In Family 11 the mother reported using the communication system required continual problem solving to integrate the system into their daily lives.

> *"Yes I think we need to be a bit more organised … but on a day to day basis we definitely have set times we get it out" (F1I2:Mother)*

Pennington and McConachie (1999) found that children often do not have opportunities to express novel ideas due to the restrictions imposed by communication partners. In this study parents linked AAC to typical daily routines. They also engaged in problem-solving to find ways to develop increased AAC participation in the home. They described a process of continuous evaluation, prioritisation and management of the needs of their child using AAC in the context of all the other challenges of family life. Parents wanted professionals to be more actively involved in supporting them with extending the use of AAC in relation to their family, their routines and daily lives. They believed this input would have helped them to plan further AAC interventions through joint problem-solving. The mother in Family 11 reported an example of such professional support from her Speech and Language Therapist in helping her to develop her son's use of a communication book.

> *"We are looking at how we can extend the use of his book and we think it would be good to use it for more games and then his sister can join in as well. Yes I think that's what we will do next" (F11I1: Mother)*

Most parents were continually modifying their strategies based on their understanding of their child and their experiences of using AAC. As families integrated systems into family life some of the children became increasingly motivated in conversations and were more spontaneous in their use of their AAC system.

In this phase parents needed to allow time for their child to construct messages using their communication system and to learn to wait and listen to them. In some situations parents described this as 'frustrating' due to the other demands on their time.

One father discussed the challenges of having a conversation using AAC.

> *"He is quite calm but he can spend five minutes trying to tell you what he wants [on his communication device] and if you don't wait, he gets really upset" (F5I1:Father)*

The child's speed of communication using a device is often slower than non-verbal communication and families had to consider whether to choose speed over the complexity of the communication. Parents often did not have the time to wait for their child to use the communication device and instead relied on non-verbal communication which they were able to quickly interpret.

Parents described their children becoming more determined and independent in their use of their different communication systems. Consequently children persevered in giving information to them.

> *"If he can't find a way he will keep trying. He did it the other day - I can't remember what it was now- oh it was about he saw a grey digger. I was saying I don't know what you are trying to say and then he went to the internet and found a digger and then went to a page [on his communication device] to say 'grey' but he persevered and when we got it right you would think he'd won the lottery!" (F5I1: Father)*

This determination was also seen in children who were using low tech AAC for requesting their wants and needs. In Family 4 the mother reported how her daughter was now persistent in her attempts to show her a photograph of what she wanted.

> *"She gets quite stroppy if you don't take note of what she wants" (F4I1: Mother)*

This resulted in parents feeling great pride in their child becoming increasingly more assertive and independent in their interactions with them. Parents recognised that the individual characteristics and personality of their child could help support the use of AAC. They described their children as 'clever', 'funny', 'persistent', 'motivated' which all contributed to the continued development of the communication system.

In their Talking Mats interviews all the children viewed their communication systems positively by placing the symbol on the left hand side of the mat. Figure 18 shows Ben's (F212) Talking Mat where he placed his Proxtalker communication device on the positive side of the mat.

Figure 18: Talking Mat showing Ben's preferences in terms of activities

Some families described AAC as '*part of our lives'* (F1I2) where they had adapted and integrated communication systems into the home. This required a considerable investment in terms of time and energy and resulted in increased self-confidence for all the family members. One of the main barriers for parents in integrating AAC systems was their ability to add new vocabulary quickly to their child's system. For the majority of families this was not possible as it required considerable time, technical knowledge and organisation. The mothers in the study often described themselves as "technophobic" or "not computer-minded". They identified the complexity of programming communication devices as a major barrier in using AAC. Although mothers did not explicitly talk about the stress this caused, it was referred to as '*another thing to do'* (*F5I1 M*) and perceived as a burden. The mother in Family 4 had spent considerable time programming an app for her daughter's iPad.

> *"I am not very technical but time is a big factor. Certainly setting up the app took me days and days as I had awful problems with it and I had to keep phoning them up. I am sure they got really fed up with me. I still haven't completely got to grips with it." (F4I1: Mother)*

Mothers felt they invested significant time and energy learning AAC and were frustrated when they had to change software or adopt a different approach. Continual changes in software or communication systems were seen as demotivating and presented further challenges to families when using AAC. They wanted communication devices which could ‘grow’ with their child rather than having to continually learn new systems.

Families 7 and 11 commented on the unreliability of their children’s eye-gaze devices and the need for frequent repair resulting in them being without any device for a considerable length of time.

> *“It doesn’t always work and we couldn’t get it to work at all for quite a while” (F11I1: Mother)*
>
> *“The problem is that as its new technology I get quite cross with it and you spend ten minutes putting it on and then it won’t open and then you think maybe it has too many pictures on it and you think that can’t be slowing it down.” (F7I1: Mother)*

This led to considerable frustration and resulted in parents relying more on their child’s non-verbal communication.

7.2.3 Becoming an expert

Parents provided many examples of the new skills, knowledge and language they had learned specifically related to their child’s use of AAC. This expertise was gained through experience as well as receiving information from different sources e.g. professionals, internet, and parent groups. Mothers in particular, relied on their own knowledge of what was best for their child and then used the information given to them and adapted it to help their child on a daily basis. In this way they managed AAC and integrated it into their daily lives.

> *“There is a lot of professional pressure at times but you know your own child. When he was two it was a nightmare with professionals but you have to get the information and research it and I like to focus*

> *on the practical day to day use. That's how we help him" (F10I1: Mother)*

Throughout the trajectory mothers accumulated knowledge about AAC and developed their self-trust and confidence resulting in them assimilating the information given by professionals and deciding whether it was right for their child and family. This led them to become very knowledgeable and skilled in their child's communication. They were able to observe, plan and had an understanding of the right thing for their child.

Mothers showed an increased reliance on their own knowledge, becoming more confident in using the different communication systems as they developed the use of AAC. Mother's, who had advocated for their child over many years, learned to use these experiences and their own knowledge of their child to develop further AAC strategies. They also became more aware of their child's learning style and rate of progression focusing on their child and their needs.

> *"We will just have to see. He does move on but it is very slow progress and we have to go with him and I think the Proxtalker is sufficient enough for him and his needs" (F2I4: Mother)*

7.2.4 Being a 'Family Team'

The importance of including siblings was described by parents in the use of different communication systems and the development of the 'family team'. They were able to give many examples of family teamwork where siblings were involved with the practical aspects of AAC such as cutting out symbols for a communication book and recording their voice on to the aid.

Siblings were included in the use of AAC much earlier than other family members.

> *"It's me that mainly uses it and definitely [name of sibling]. It was important to make him part of it. It was a new thing and the fact that he records the voices on there, he feels quite important that he is helping his brother to talk. Yes very definitely he feels part of the team and he's helping his brother." (F2I1: Mother)*

Mothers were particularly anxious that siblings felt included and were involved with supporting AAC. Mothers perceived this as a way of supporting and strengthening the family unit.

One sibling (Family 1) was very involved with the technical aspect of his sister's iPad taking on responsibility for trouble-shooting any difficulties:

> *"…sorting out the iPad if something goes wrong. I help her as mum hasn't a clue so I just figure it out." (F1I3: Child)*

The use of mainstream technologies such as the iPad with communication grids can both support the involvement of siblings and support parents with the challenges of technology.

Families stressed the importance of involving siblings by using the communication system in different play activities. This has the dual benefit of promoting positive relationships between siblings and involving all the children in the implementation of AAC.

> *"They all hang off the back of his chair and are playing with something on his computer and they seem to be having a good time" (F11I1: Mother)*

The continual advocacy on behalf of their child using AAC resulted in a perceived imbalance with regard to addressing the needs of other family members. This resulted in anxieties about the limited amount of time spent with their non-disabled children who they felt had 'missed out' on their attention.

> *"Children with special needs take up so much more time and I worry about the effect on [name of child]" (F12I1: Mother)*

Mothers described struggling with dividing time between the children. However they believed their children had benefitted from having a sibling with a disability resulting in a special relationship and an understanding of each other.

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

During the interviews with siblings they described their relationship with their brother or sister in positive terms.

> *"He's really fun to be around when he comes in from school. He's just really a nice little brother." (F8I3: Child)*

> *"She likes playing with me and is pleased to see me" (F1I3: Child)*

Siblings described their brother or sister as '*clever*', '*good around the house*', '*funny*', '*alright*' and '*polite*'. In their descriptions they focused on their brother/sister's strengths rather than their disability. They gave examples of the things their siblings were able to do such as riding a bike, playing football rather than things they could not do.

> *"She has a wheelchair and she knows how to use it really well" (F12I2: Child)*

There were many examples given of shared activities and things they liked to do together particularly where there were younger siblings with disabilities.

> *"Play fights. He's got a room upstairs and we play in there and we've got a little basketball hoop." (F8I3: Child)*

Many of the activities described were physical activities e.g. play fighting, tickling, cuddling. There were also examples where younger siblings had progressed beyond their brother/sister's developmental level and were taking a more dominant role in the interactions.

> *"I like to play with her. I push her in our buggy even though she is quite big for it. She still fits in it though. She doesn't know how to use like a computer. Sometimes on my computer I let her watch Mickey Mouse in the morning while I get ready. She likes coming into my bedroom like every morning if I leave the door open" (F1I3: Child)*

Older siblings were involved with caring tasks e.g. helping their sibling to eat or baby-sitting on an ad hoc basis. These activities were viewed as part of their family routines and 'normal' in their family.

Siblings were able to describe their sibling's communication skills and gave in depth accounts of their different communication systems. They were able to name the AAC system used by their brother/sister and how they used it with them. The following sibling describes how he responds to his brother using PECs and also understands his brother's speech.

> *"He sometimes says a word and I say do you mean this and he says yeah. I just help him a bit with his words sometimes. He sometimes uses symbols to show what he wants- he's got like a strip and he's got I want this please and he's got the symbols of what he needs and he will give it to like me, mum or dad and we will get it for him and he will say thank you at the end. He is quite polite" (F8I: Child)*

Other siblings were involved in using high tech communication devices with their brother/sister. They had considerable knowledge of the communication needs of their sibling and how to support them.

> *"He says some words and goes to the Proxtalker [communication device] sometimes I do his schedules so he doesn't get annoyed. He gets annoyed if he doesn't know where he's going" (F2I3: Child)*

Younger siblings (7-11 years) referred to talking their sibling's 'language' and suggested they were able to interpret and understand their sibling's vocalisations and verbal attempts.

> *"I talk in his language. Totee means toilet and ple means please and tic tic means tickle tickle. I do [name of child] language" (F2I3:Child)*

> *"She goes blblblay like that and it means I am happy and she said peepe for ipad . She has her own language" (F1I3: Child)*

This resulted in siblings often acting as 'interpreters' for close family members particularly grandparents. The role of 'interpreter' also increased the siblings' self-esteem and they were often praised for developing a special knowledge of their brother/sister's communication. Barr et al's (2008) study with siblings of children with speech impairments also identified the role of 'interpreter' in relationships between siblings.

Figure 19 shows two siblings in conversation.

Figure 19: A drawing of two siblings communicating

The negative consequences of having a sibling with a disability focused more on worries about the safety of their brother or sister with a disability. Two children were upset and worried that their sibling with a disability was being bullied at school.

> *"I am a bit worried when he's in class because there's a boy who hasn't been very nice to him and use to bite and scratch him in the playground" (F2I3:Child)*

One sibling expressed some concerns about his sisters behaviour and he used several strategies to manage the situation including ignoring the behaviour or removing themselves from the situation.

> *"She slaps me all the time, I always just ignore it as I do get on with her a lot" (F1I2: Child)*

Two older siblings in the study (Family 3 and Family 8) discussed societal views in relation to their sibling and the perception of others and the effect on them. 'Staring' and 'being treated like a baby' were the most difficult aspects of being in public places. Their responses of frustration and anger about other people's attitudes to their brothers resulted in them often explaining their sibling's difficulties or making others aware of their behaviour.

> *"Sometimes he can be a bit like [pause] People say 'What is he doing?' and things like that because he can be a bit like[pause] different and I say he has autism." (F8I3: Child)*

> *"He doesn't like being talked to like a baby. He hates people patronizing him. I get really cross and often stare at them to get them to realize what they are doing" (F1I1: Child)*

These two older siblings found themselves protecting their brothers from the negative reactions of others and appeared to act as a 'protector' outside the home. Older siblings maintained their sibling's identity by often deliberately mediating on their sibling's behalf. Donnelly et al. (2000) in their study with siblings with ASD reported they often mediated on their brother/sister's behalf.

7.2.5 "Just don't quite get it"

Parents were able to identify key people in their lives who supported them as a family and provided social and emotional support. However, they also discussed family members and friends who "Just don't quite get it" (in vivo coding). This lack of understanding resulted in families only including friends and family members who were more receptive to their child's difficulties. This has been shown in other studies where stigmatisation of the whole family is reported (Gray, 2002). As a consequence some parents reported to restrict public encounters, only socialising with friends and family who are sympathetic to their child's difficulties. Mothers also felt that as a result of their child's communication difficulties, it was difficult for them to leave their child with anyone else particularly outside the family.

Parents expressed the need to be confident in using the communication system themselves before extending its use with other family members.

> *"I need to get my head around it first. It's all consuming and I need to know it and she needs to be using it before I show anyone else." (F12I1: Mother)*

Families commented on the lack of understanding of family members and friends. Some of these were related to understanding the child's diagnosis and the long term difficulties the child may experience.

> *"…but the extended family they just don't quite get it and don't understand as much as you would like them to. They say 'oh he'll get*

> *better'. My dad has a classic line 'give him another year, he's getting there' but you think he's getting where! I am quite a realist and I don't protect myself from what is happening or question it but I think this is what is happening and we have to deal with it as best we can but it has been a struggle." (F9I1: Mother)*

Grandparents were, however, often a source of support for the families and were actively involved and positively contributed to the functioning of the family. They provided respite, emotional support and financial support for the families. Often family members, particularly grandparents, thought that their child would "*grow out of it*" (F8I1).

Grandparents received information about their grandchild second hand from their son or daughter and as a result the benefits and reasons for adopting AAC may not have been fully explained. They were often perceived by parents as being uncertain of how to communicate with their grandchild. Families described grandparents as being 'scared' of communicating with their child with a disability.

> ***Father*** *We knew there was a chance of communication problems*
>
> ***Mother:*** *Part the problem was getting others to accept it.*
>
> ***Father:*** *That was the hardest thing really getting them to communicate with him*
>
> ***Mother:*** *They were scared to talk to him (F10I1: Mother and Father)*

This resulted in some parents taking considerable time encouraging grandparents to communicate with their child. For others this lack of understanding caused them to disconnect from grandparents and friends. Previous research has shown that families with children with disabilities may feel isolated because of the negative responses from family and friends (McLaughlin, 2006; Kearney and Griffin, 2001).

Grandparents were reported to have particular difficulties using both low tech and high tech AAC. Some of the grandparents were perceived as not making an effort to understand their grandchild's difficulties. This was partly due to a lack of understanding about how the communication system worked but also the perception that they knew 'best' which often left parents feeling frustrated.

> *"Even if you left the book there she wouldn't use it. She thinks she knows her grandchild even though she sees her infrequently. That's my mother. I'm taking her tomorrow but she won't get it out the bag." (F1I1: Father)*

In some cases learning to use the communication system was too difficult for grandparents and resulted in them withdrawing from the family.

> *"Dad will play with him and chat away to him now but he is traditional old school and finds it hard. He doesn't really see him much" (F9I1: Father)*

Some grandparents offered considerable help to families in terms of caring for their grandchildren but discussed their difficulties in communicating at an appropriate level.

> *"He is becoming a little bit more independent. Mum is great, don't get me wrong. I talk a lot but she talks more but uses a lot of language with him. She puts him in the bath and talks all the time, let's get the shampoo, let's do this let's do that and there is too much for him. I think he just switches off" (F7I1: Mother)*

Although parents appreciated the support grandparents gave to the family in terms of caring for the children and providing respite support, they were often frustrated that they did not value their child's communication system or acknowledge the communication system used by their grandchild.

Families acknowledged time was again a factor in becoming familiar with a device or communication system. Family members needed to gain confidence with using the communication system with the child.

> "*My brother doesn't really understand what we are trying to do but its time. You need to get use to these things."* (F5I1: *Mother)*

7.3 Summary

In Phase 3, ‘Gaining a Voice’, families strive to manage AAC as a family and adopt strategies to support the use of AAC in the home and integrate it into their daily routines. Mothers, in particular, provide opportunities for their child to use their system, continually problem-solving ways they can extend their child’s use in the home. Many parents adopt a strategy of living one day at a time due to the uncertainty about their child and their family’s future. Parents initially ‘struggled’ with AAC but as they developed their child’s communication system they began to make their own decisions based on their growing confidence in knowing what was right for their child. Siblings play an important role in promoting AAC but also act as an interpreter of their sibling’s vocalisations particularly with grandparents. Older siblings also adopted the role of protector for their sibling. Grandparents are often actively involved, contributing to the positive functioning of families. However they are reported to find it difficult to use AAC systems with their grandchildren. In this phase both the child and family grow in confidence in using AAC in the home and consider different ways to extend their child’s communication.

7.4 Sustaining a Voice

The fourth phase is '*Sustaining a Voice'* during which the child and family become more confident in the use of AAC, integrating communication systems into the home and wider social networks outside of the family. Some of the families in the study had yet to reach the 'Sustaining a Voice' phase as a result of their age and the family's competency in using the communication system. As the children moved into their teenage years the use of communication systems outside of the family unit was reported to become more important. Figure 20 shows the sub-categories related to the final phase 'Sustaining a Voice'.

Table 9 below lists the major coding nodes for the second phase 'Sustaining a Voice'

Sub-categories	**Coding Nodes**
Involving others	Increasing opportunities Social networks Paid workers
Living with criticism	Stigmatisation Mother's advocacy Counteracting negativity
Hopes for technology	Hopes for future technology Access to funding Increased autonomy

Table 9 Category: Sustaining a Voice (Phase 4)

Figure 20: Sustaining a Voice

7.4.1 Involving Others

As their children grew older, parents planned ways in which their child's communication could be extended by involving different communication partners and increasing their child's social network. This was perceived by parents as being very difficult due to a wide range of factors including time, suitable activities and appropriate communication partners. The lack of social opportunities and relationships affected many aspects of the family and child's social functioning.

Parents often relied on their own network of family friends and found it difficult to find appropriate opportunities outside this network to support their children's communication.

> *"…because she goes to very few people when she goes to our best friends who she calls Auntie Kathy and Uncle Andrew they use it with her all the time [communication system]. It's only more recently that we've got more people involved outside the family. I suppose it's*

> *because we want to extend her communication skills, her outlook and social skills." (F1I1 M)*

In Family 1 both parents discussed their change of focus as their child grew older with their emphasis shifting from communication within the family to an increased concern about participation in wider environments and the ability to 'fit in' and become more independent..

> *"It's all very safe, too safe to keep her with friends and family. They do exactly the same as us so they know her so well so that's why we decided to do the family link thing…with the family link they are actually an older couple with grandchildren who have been in this line of work for about 15 years. They do completely different things so she will have to be more self-reliant. She will have to fit in with everyone else which is what we want for her" (F1I1: Father)*

Over time families came to rely on more formal services to support them and to take on roles previously performed by family members or friends. Paid workers in this study were often linked to the child's school and parents reported more confidence with sessional workers[5] who had experience of children with complex communication needs. Some of the sessional workers also had prior knowledge of the child's communication system and the way it worked which was considered a great advantage by parents. Several studies have found (Birenbaum, 1992; Green, 2001b; Seligman & Darling, 1997) that individuals and in this case families, may prefer to limit their interactions to members of the 'wise' category, those who are familiar with disability.

In order to benefit from respite opportunities, the mothers in the study, needed to be assured their child was able to communicate and that they were happy. Mother's again took a leadership role in describing their child's communication system to others and for making the system available to use in different settings.

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[5] sessional workers care for a child or young person with disabilities on a one to one basis

The mother in Family 4 experienced feeling ‘loss of control’ over the development of her child’s communication. She hoped her child was given access to her communication system but she was anxious her daughter would have difficulties communicating without her present. The bond between mother and child was very strong and this mother found it difficult to ‘let go’ and establish trust with her daughter’s respite carer.

> *“At respite she has her communication book and I know the lady who looks after her also has a file which is a bit bigger with photographs in but how much she uses it, I just don’t know” (F4I1:Mother)*

7.4.2 Living with criticism

The attitudes and responses of the public were important issues for all the families as these could cause distress, concern and, at times, anger. Families described experiencing social disapproval when out with their children which mainly took the form of staring.

> *“He attracts everybody and he doesn’t like that and I can be quite outspoken and say rude words if people look for too long. People stare particularly if I ask a simple question ‘What yoghurt do you want?’ He loves yoghurt but I can’t stand them looking for so long but then I find them quite rude and I make remarks” (F3I1 M)*

The mother in Family 11 stated that she believed that in many situations it was easier for her son to be accepted as he had a more visible disability.

> *“We are very lucky and we have been blessed a bit by how disabled he is. A terrible thing to say but one of his friends had been in a local school and they wrote to his mother and said they didn’t want him anymore but he’s autistic and was disruptive in class whereas [name of child] can only sit so the amount of disruption isn’t huge” (F11I1 M)*

The mother in Family 7 described situations where her child would act in non-socially acceptable ways but because he did not appear disabled, she felt she was blamed for her poor parenting skills. These encounters reduced her self-esteem and increased her feelings of being a ‘bad mother’.

> *"You shouldn't judge a book by its cover because he looks perfectly normal doesn't mean he hasn't got problems and issues. If he had Down syndrome probably they would have more compassion. They just all looked at me as if to say useless parent who can't control their child" (F7I1: Mother)*

Goffman (1963) identified visibility as a factor in experiencing stigma and made a distinction between visible (discredited) and not visible (discreditable) attributes. Ryan (2010) identified the lack of outward signs of ASD results in disapproval from the public based on inappropriate judgements about the children (and parents). Gray (2008) also reported parents experienced difficult encounters with other people resulting in their abilities as a parent being questioned. Although most mothers did not provide explanations of their child's behaviour, they did adopt a range of coping strategies in response to perceived stigmatisation. These included ignoring, returning the stares or resorting to commenting on the inappropriateness of the person's behaviour.

A mother's response to stigmatisation may change depending on the situation and the frequency of the child's negative behaviour. In Family 7 the mother experienced different emotions and levels of coping. At one point she considered overtly describing the extent of her child's disability.

> *"I thought shall I get a T-shirt for him to wear so that people know. 'Please be kind to me and my mummy!' It's an invisible condition that people don't see. This little boy who looks normal and his gross motor skills are good and he climbs and physically he is fine. It's been hard work" (F7I1: Mother)*

The feeling of being stigmatised affected mother's self-esteem and their confidence in dealing with the behaviour of their children in public places. The child's use of the communication system also heightened the levels of attention from the public.

> *"We walk around Tesco's but because it's not her favourite thing she has three grids with six items on there [communication system] and we go around trying to use it and that brings a lot of stares but she is totally oblivious to staring but other days I think can't I just do this*

> *without people staring at us but half the time I don't mind because we haven't got a choice and it's much better than her stripping off and keeps her calm." (F1I4: Mother)*

Families adapt to these challenges and manage situations to the best of their ability. Parents were aware some of the responses from the public were due to the technology used and people's curiosity. Mothers in their advocacy role often explained to staff how their child communicated and actively encouraged them to engage with their child particularly in ordering food in restaurants.

> *"We tend to go to the same places so they are used to her. They say "Hello [name of child]. Have you got your book?" She makes a choice for her meal and they are very patient" (F1I1: Mother)*

At other times mothers reported the heightened attention was intrusive and they often avoided this by returning to familiar shops, restaurants and venues where they had received positive feedback. Green (2003) also reported mothers who had found positive ways of coping with the stigmatizing reactions of others, may feel burdened by the constant need to use these coping strategies.

Some parents tried to 'normalise' the communication system and this was supported by the use of mainstream technologies and the visual appearance of the device. The father in Family 5 viewed his son's iPad as an acceptable device due to its mainstream use and it was a device which could be carried in different social settings.

> *"He loves his iPad, we take it out and he shows people and goes from page to page and he loves all that" (F5I1: Father)*

Parents actively promoted their child's communication system to redress the misapprehension of others and to counteract the negative perceptions of their child. This resulted in positive outcomes both in terms of impressing people with the technology and also showing their child as an effective communicator increasing the self-esteem of the child and parents. The need to develop positive identities appears to be one of the key motivators for impression management (Goffman, 1959; Leary and Kowalski, 1990). Other studies have also found parents are concerned with the impressions they create (Cahill, 1990; Collett, 2005).

Parents commented on the bulkiness, size and weight of high tech communication devices which made them difficult to use in many situations outside the home. For some families taking the communication system into the community was perceived as a burden and "*yet another bit of kit*" (F7I1) they were responsible for and its lack of portability affected its use.

7.4.3 Hopes for Technology

Families stressed the important role technology can play in developing their child's communication and enhancing the quality of their lives. At the beginning of the AAC journey they expressed the hope their child would be able to speak. Later this changed to an acceptance that their child's ability to communicate was vital to support them in developing friendships, giving information and encouraging their later independence in society. The gradual realisation, for some families, that their child will not be able to live an independent life changed their perspectives and goals for their child. Despite these changes they still viewed AAC as a means for their child to make choices at whatever level was possible for them. They expected that the growth and development in technology would provide further tools for their child to increase their communication skills.

> *"We are trying just different things at the moment. We don't know what is happening in two, three and fifteen years from now in terms of technology and what she could do" (F1I1:Father)*

They were able to describe the types of technology they would like for their child in the future both in terms of the software and hardware their child may require. Through their experiences of using AAC and their knowledge of their child, families had clear ideas on the systems they required.

> *"The ideal would be to have his voice on it. How it would do it is beyond me. As he gets older he can have it set up with an icon with a sentence in it rather than a word. Even now he has some of them and then it makes it quicker for him to tell people something" (F5I1: Father)*

> *"I would like it to be all magnetic and bespoke for use but again it's having the tools to do it. We have to beg, steal and borrow them. If we have to, we will do it" (F3I1: Mother)*

There was an acknowledgement of the difficulties families experienced in accessing funding and the need for more professional support for families requiring AAC. Parents had hopes for future AAC technology but expressed concerns about the funding and services that may be available for them.

Eye gaze technology was considered the way forward for children with severe physical difficulties. Parents viewed this technology as vital to allow their child to access a wide range of different communication methods including online access and environmental control to support their future independence.

> *"I hope ultimately it will be her communication tool, to be used at quite a sophisticated level and I think her teacher agrees that is the way she should be going. She will be able to use it for text based and to write things herself and go online to talk to people whatever and in the right home environment use it to open doors, to choose TV channels and have some level of autonomy because that is hugely absent really and that's really difficult. That's where I hope to go and I think potentially we can get there" (F11I1: Mother)*

The ability to communicate and to become an effective AAC user was fundamental for families when thinking about the future. Parents had hopes their child would be able to have a 'voice' and stressed the importance of their child's ability to communicate.

> "*We don't know what there will be out there but we want whatever works for him. I know it is long term but whatever as long as he can communicate with others" (F3I1: Mother)*

7.5 Summary

In the final phase in this trajectory, '*Sustaining a Voice*' parents attempted to extend their child's use of their communication system into the community and differing social networks. However they found these opportunities were limited and their child's interactions were predominantly restricted to paid workers. Families, particularly mothers, describe experiencing social disapproval when out with their children. This, mainly, took the form of starring and blame for their poor parenting skills particularly if their child behaved in a non-socially acceptable way. The child's use of their communication system also heightened public attention but these responses were often due to curiosity particularly with high tech devices. Mothers often restricted the places they visited by returning to places where they had received positive public feedback. In their advocacy role mothers explained to others how their child communicated and encouraged others to communicate with their child.

Parents viewed technology as playing an important role in developing their child's communication and enhancing the quality of their lives. They had hopes that future technology would continue to support their child's communication and described specific features and characteristics of communication systems they perceived as important in future designs and specification.

Chapter 8 Discussion and Conclusion

8.1 Introduction

The final chapter considers the emergent theory of 'Finding a Voice' and presents a summary of the trajectory within it to explain the perceptions of families using AAC systems in the home. This chapter brings together the literature presented in Chapter Two and Chapter Five and considers the implications for AAC service delivery and practice. The research aim was to explore the perspectives of the 'whole' family in the use of AAC in the home. The grounded theory presented offers a new way to look at family views and experiences of AAC and augments existing knowledge.

8.2 The grounded theory: Finding a voice

In this grounded theory the core category 'Finding a Voice', emerged from the analysis of the data as families expressed the desire for their child to gain a voice through the use of AAC. The trajectory pathway was different for each family and their progression from one phase to another was unique to them. For some families 'Finding a Voice' could take a considerable amount of time and was not only affected by the child's response and development in AAC, but also the situation and challenges encountered by families and their response to them (e.g. when child is ill, managing multiple roles in family, needs of other family members). Throughout the phases there was a continuous process of problem solving, adjusting and balancing the needs of the child and those of other family members. Dynamic conditions associated with daily family life meant as they progressed along the trajectory parents implemented, reviewed and reprioritised AAC in the home.

Figure 21 shows the different phases of the trajectory and factors associated with the use of AAC in the home.

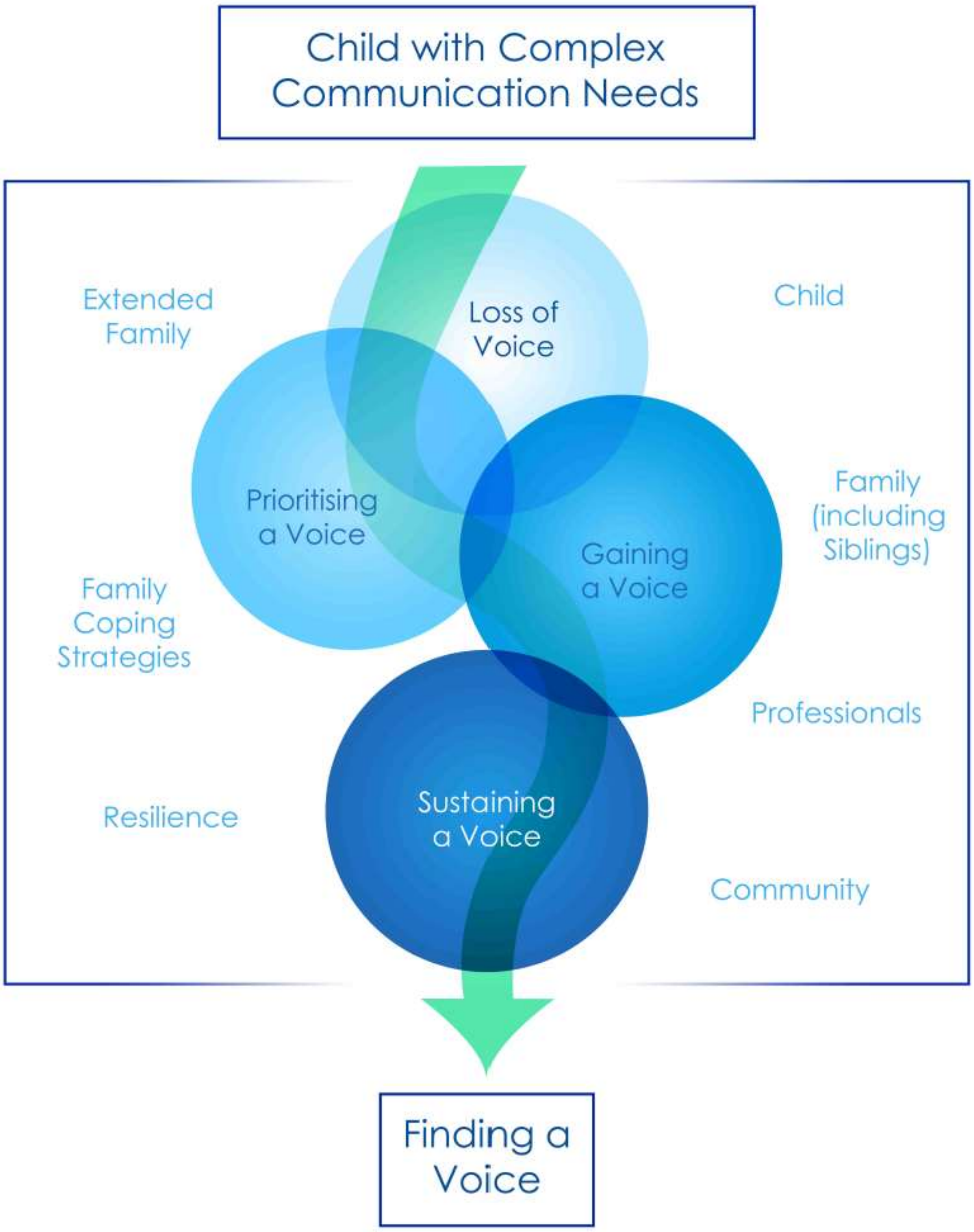

Figure 21: Finding a Voice

8.2.1 Loss of Voice

The intense feelings of uncertainty surrounding their child's diagnosis and whether their child would gain speech are associated with the first phase on this trajectory: 'Loss of Voice'. Mothers in this study had often recognised unexplained differences in their child in these early stages. Baxter (1986) in a survey of 131 families with children with learning disabilities found parents had identified their child's difficulties before a diagnosis. It is now recognised that mothers of children with disabilities do not have the same trajectory as other mothers owing to the uncertainty of having a child with disabilities (Ryan and Runswick-Cole, 2008; Graungaard and Skov, 2007; Kearney and Griffin 2001). Families experienced differing degrees of uncertainty throughout the trajectory. Even though parents had often identified that something was wrong in terms of their child's development, the diagnosis was still a shock and parents experienced a grief-like reaction for the loss of a healthy child (Foley, 2006; Olshansky, 1962). Parents in the study who had used AAC for several years were still coming to terms with their child not being able to use speech as their main form of communication. Although they valued augmentative and alternative communication systems, there was still a sense of loss for their child's own voice.

All the families in the study wanted their children to use speech as their main form of communication and the acceptance of AAC as an alternative to natural speech was often a difficulty. The findings support Murray and Goldbart (2009) where parents may not be ready for atypical communication systems and families may need time and support to adjust and accept these alternatives. The importance of gaining speech also resulted in some families adopting a 'wait and see' approach described by Sevcik and Romski (2002) or viewing AAC as a 'stepping stone' to support their child's speech acquisition. Families were also concerned an alternative 'voice' for their child should reflect their child's personality and identity and for many parents the synthetic voices used on communication devices were not an acceptable alternative. Several papers have described the limitations of AAC in terms of the appropriateness of the voice but this was often a cultural issue where English was a second language (McCord and Soto, 2004; Lund and Light, 2007). Crisp et al. (2014) reported in her study that parents expressed dissatisfaction with the quality of the voices on communication devices particularly in relation to their children expressing emotions. The parents in this study not only considered the quality of the voices on devices but also wanted a voice which was appropriate for their child's identity.

Families, as a result of uncertainty regarding their child's development of natural speech, were often unsure of the direction in which they should proceed and this motivated them to seek information and services to support their child. Beresford, Rabiee and Sloper (2007) reported families in their study sought information from a number of sources which helped them to feel informed. Finding resources and seeking information was a strategy parents used throughout the trajectory particularly following a diagnosis and as a result of their child’s lack of speech development. In the study parents described their information seeking as a positive strategy to support them in understanding the different communication systems which may help their child. Mothers in particular needed to possess information and understand their child’s disability in order for them to be a good advocate for their child. They were motivated to learn and to gain new skills which increased their self-confidence and supported them in their ‘battles’ with professionals. Mothers used the terms ‘fight’ and battle’ to describe their experiences of accessing professional support. There is often a mismatch between parental expectations of what services should be provided compared with the actual levels of therapy available for their child. This led some families in the study to implement AAC systems with little or no professional support. This research supported previous studies (Hodge, 2007; Wormnaes and Malek, 2004; Goldbart and Marshall, 2004; Crisp et al., 2014; McNaughton et al, 2008) describing the lack of AAC competencies in Speech and Language Therapy (SALT) services and the limited amount of SALT support given to AAC users and their families.

8.2.2 Prioritising a Voice

Mothers play an integral role throughout the AAC process both in accessing appropriate services and also in supporting the integration of AAC in the home. This resulted in mothers having further roles and responsibilities in terms of AAC as well as the adoption of more traditional roles and expectations within the family unit. In Angelo’s (2000) study mothers were more likely to take greater responsibilities with AAC. Angelo’s study was conducted in Pennsylvania, USA with predominantly middle-class families but the results are reflected in this study where mothers perceived an increase in their personal investment in time and energy associated with AAC. Mothers caring for a child with a disability often conform to the rules associated with being a ‘good mother’ where they ensure everything is done for the benefit of their child. Many mothers also carry the emotional burden of AAC which can result in them feeling guilty and frustrated that they had let their child down by not having been able to do enough in terms of using and programming AAC systems. These feelings of guilt and frustration were related to their perceptions of the role of a ‘good mother’.

Mother’s acknowledged they were often able to understand their child without the use of AAC systems and their maternal understanding of their child was considered by them as a barrier to AAC use. Other studies (Rackensperger, 2012; Bailey et al., 2006) demonstrate parents often establish their own communication with their child and may not see AAC as beneficial for interactions within the family. However all the parents in this study viewed their child’s communication as a high priority and they valued AAC as a means of communication. Valuing the system and support from family members were reported as important factors in Johnson et al. (2006) study. Mothers expressed the importance of their child being able to communicate with others in the future and to gain their independence. They expressed a strong belief in AAC and in the child’s future use of AAC systems. This was also reported by Bailey et al. (2006) and they also identified increased independence for the child as an expectation of AAC device use. For some families, as they progressed through the trajectory, there was a change in their expectations in terms of their child’s future independence. They became more aware of their child’s complex needs, however, having a voice through AAC was still considered important as it would allow their child to achieve certain levels of independence.

8.2.3 Gaining a Voice

The family unit is an important aspect of this study as at the micro level the family is most influential in developing AAC. Competing time pressures within the family often affected the use of AAC with mothers juggling priorities for all family members and the child. A wide range of research consistently identifies it is women’s work to care for children (Cunningham-Burley et al, 2006; Gatrell, 2005; Hochschild and Machung, 2003; Ribbens, 1994) and several studies suggest that as well as caring for their child with disabilities, mothers still felt responsible for meeting the needs of all family members (Ribbens, 1994; McKeever 1991). Time restrictions and competing time pressures were discussed by mothers affecting their implementation of AAC systems. Curran et al (2001) reported the time demands required to meet the personal care needs of a sample of 16 children with a range of disabilities compared to a sample of 31 non-disabled children. They found the number of items required of parents to meet the child’s personal care needs per waking hour was significantly higher amongst the disabled children group**.** The amount of time needed to implement AAC was considered a barrier to AAC particularly the initial setting up of the communication system. Some mothers described themselves as 'technophobic' and as a result of competing time pressures and the multiple roles they adopted in the family; they often lacked confidence in adapting and programming devices. The ease of use of devices has been identified as important for successful AAC outcomes in other studies (Bailey et al, 2006; Marshall and Goldbart, 2008; Crisp et al, 2014). Time was a recurring theme in terms of programming devices and integrating communication systems into the home. Time also related to the child's use of the system and the time they needed to be given to generate a message using AAC. The speed of interaction using a communication system or device can be much slower than speech or unaided communication. This resulted in times when they had to make compromises in terms of speed versus complexity of communication. This is also reflected in other studies (Hodge, 2007; Dattilo et al.,(2007); McCord and Soto, 2004) and is a challenge for both families and AAC users. Parents wanted communication systems which could be developed with their child rather than having to learn new systems or different software. The challenge of learning communication systems and implementing them into family life is immense and frequent changes in approaches may leave families feeling disempowered.

Mothers were responsible for creating opportunities for their child to use AAC in the home and they discussed the importance of integrating communication systems into their daily lives. They identified daily routines where the device was used and where the active participation of the child in these routines was encouraged. Many of the families described predictable and stable routines in their family. Although parents in the study encouraged communication linked to daily routines, they were also problem-solving and developing the use of the communication system in the home. This was dependent on the competing needs of the family and they often had to reconcile family demands versus their child's use of the communication system. Parents discussed the need to 'manage' as a family and to be 'self-sufficient'. This also has wider societal implications in the ways families are expected to manage independently and conform to social expectations. In terms of AAC parents wanted to be able to develop AAC systems without always relying on professionals to provide them with symbols and resources. For many families there was a financial burden in developing AAC and they wanted access to resources and financial support that would allow them to be more self-sufficient in the home.

In an ecological model maintaining relationships within and outside the family is important with the development of a network of people to support the family. Grandparents are often an important source of support for families with children with disabilities (Seligman and Darling, 2007; Mitchell, 2007). The influence of grandparents and their role in AAC is little researched. In this study grandparents of children using AAC were perceived to have considerable difficulties in accepting or understanding their grandchild's diagnosis as well the complexities of their communication needs. As a result they rarely used the communication system with their grandchild and often relied on siblings to act as an 'interpreter'. This is also reflected in other studies where grandparents have great difficulties in accepting their grandchild with disabilities (Hornby and Ashworth, 1994; Hastings, 2000) and receive little information on their grandchild's disability (Schilmoeller and Baranowski, 1998).

8.2.4 Sustaining a voice

In the final phase on the trajectory, 'Sustaining a Voice', families wanted to develop the use of AAC into community settings and extend their child's social networks. Mothers described experiences of both 'enacted' and 'felt' stigma which impacted on their self-confidence and contributed to a negative image reinforcing a 'bad' mother identity. A number of other studies have considered the effects of stigmatisation on families with children with disabilities (Birenbaum, 1970; Landsman, 1999; Green, 2003, 2007; Gray, 1993, 2002; Lalvani, 2011). Families commented on the 'visibility' of the communication system and the feeling of being noticed. In community settings the families reported heightened levels of attention received from the public when their child was using their communication device. To avoid continually having to explain their child's communication system, families limited the number of places they visited and returned to places where they had received positive feedback. Parette and Scherer (2004) also reported the visibility of the communication system may leave the child and family feeling stigmatised and unwilling to use AAC in the community. Families in the study identified the development of mainstream mobile technologies offered an increased social acceptance for the child and family. The size and visibility of AAC systems was identified as a barrier to 'Sustaining a Voice' indicating a need to consider more advanced technological platforms to be developed.

8.3 Evaluating a Constructivist Grounded Theory

Charmaz (2006) identified four criteria to use to evaluate a constructivist grounded theory: credibility, originality, resonance and usefulness. Ultimately she states that it is the reader who judges the quality of the work (Charmaz, 2006).

Charmaz (2006) states credibility can be achieved through '*intimate familiarity'* (p. 182) with the research area. As a Speech and Language Therapist, working in the field of AAC, the researcher has gained considerable understanding of the impact of AAC systems on the daily lives of families. Within a constructivist grounded theory the processes outlined in Chapters Three and Four, provide a detailed account of the robustness of the study. The researcher remained open to the data by continually returning to the transcript interviews to ensure, in separating the data into categories, the process for each family was not lost to the analysis. Reflexivity throughout the process also enhanced credibility by the researcher acknowledging her own thoughts and assumptions which could influence and impact on the study.

Charmaz (2006) judges the originality of a constructivist grounded theory on its ability to bring new insights to a field of study. As demonstrated in the literature review in Chapter Two no studies have taken place in the UK focusing on the perspectives of the 'whole' family in the use of AAC. The categories developed offer a deeper understanding of families' use of AAC and builds upon existing work to provide a new conceptual framework. The study also acknowledges the importance of involving children as active participants in research. The use of flexible interviewing techniques provided opportunities for the children to contribute to the study and allowed the researcher to gain the perspectives of all the family members.

Resonance described by Charmaz (2006), is the ability to capture the fullness of the studied experience. Through the research process regular supervision meetings and attendance at a Grounded Theory Forum supported the researcher during analysis to identify more abstract concepts and develop theoretical coding. This allowed the researcher to develop the analysis from a descriptive level to an analytic level. The quotations in the writing of the theory were carefully chosen to keep the participant’s voice and meaning present in the final outcome.

The usefulness of a theory relates to the ability for the interpretations to be used. The social and theoretical significance of the study is also its potential practical use in therapy and for informing practice. The categories explored and the trajectory identified offers an interpretation of family perspectives of AAC in the home, which may help professionals working in the field of AAC understand family processes in the prioritisation and implementation of AAC. The theory produced is of a substantive type of grounded theory and its scope is therefore restricted to the context within which the research was conducted.

8.4 The contribution of the grounded theory to existing knowledge

The following components of the grounded theory presented in this thesis offer the most significant contributions to knowledge in three key areas: uncertainty, mothers’ advocacy, the centrality of the family in using AAC.

Uncertainty has been reported in parents of children with a wide variety of chronic health conditions (Mullins et al., 2007; Maikranz et al., 2007; Stewart and Mishel, 2000) and was identified throughout the trajectory in this study. This was seen in terms of the child’s diagnosis, their prognosis in terms of speech development and management uncertainty. Uncertainty also involved broader aspects of the family’s life (e.g. home, work) and influenced daily routines and activities. For some families the uncertainty concerning their child’s speech development led them to adopt a strategy of ‘wait and see’, delaying the use of AAC systems. Following a decision to prioritise AAC, families reviewed and shifted existing priorities to allow them to accommodate a different communication system. Parents were uncertain as to whether AAC would offer any more for their child and family as they had often already established their own communication within the family. The ‘defining moments’ identified by the families, where their child used the communication system independently, affirmed their decision to adopt AAC. These defining moments resulted in increased ownership of the communication system and reduced parental uncertainty about their child’s use of AAC and their future communication. The emergent theory extends thinking regarding the different forms of uncertainty in families who use AAC.

The theme of voice is particularly important in this study as it not only applies to finding a suitable voice for the child but also relates to mothers finding their own voice during the process. Mothers act as their child’s 'voice' by speaking for them and representing them through a process of advocacy. In the early stages of the trajectory decisions are based on their ‘maternal instincts’ and ‘intuitive knowing’ but they accumulate skills and knowledge as they progress through the phases and acquire new skills and competencies throughout the trajectory. As part of the development, mother’s gained increased confidence in using AAC and a sense of knowing what was ‘right’ for their child. Mothers in this study acted as advocates for their child developing adversarial skills as they progressed through the trajectory. This resulted in mothers gaining increased self-confidence in decision-making on behalf of both their child and their family. Mothers viewed advocacy as ‘something they had to do’, a moral obligation, and they considered they were the only person who could fulfil this role. Advocacy was a necessity and perceived as an essential part of their role as a ‘good mother’. The mothers in this study did not adopt an 'activist' (Ryan and Runswick-Cole, 2008) or ‘crusadership’ role (Seligman and Darling, 2007) but their advocacy played a major part in 'Finding a Voice'.

The centrality of the family in the implementation of AAC was also highlighted in the study where mothers, in particular, balanced the needs and interests of all family members. In this study siblings of children using AAC played an important role in supporting their development. The views of siblings are rarely sought in studies in AAC but offer an important ‘voice’ within the family. In this study siblings adopted the different roles of ‘interpreter’ and ‘protector’ for the child using AAC. Families showed how through the trajectory they were able to build their resilience in using AAC. Strategies were continually tailored to the child and family’s needs and their flexibility allowed them to balance the needs of the child using AAC and the rest of the family. The use of emotional coping strategies of retaining ‘hope’ and a positive future image for their child also helped lead to successful implementation of AAC systems. Families were able to draw on resources and strengths from within and outside the family. Many of the families were able to solve problems, balance relationships within the family, adapt family functioning and establish 'normal' routines, all important factors identified by Muir (2008) in building resilience. Resilience is a complex process and families will not do well in all circumstances (Masten and Powell, 2003). The lack of availability of services, resources and the effects of societal stigmatisation found in this study will affect the families' use of AAC systems.

8.5 Implications for Practice

In recent years there have been several changes in policy impacting on families with children with disabilities. The White Paper 'Equity and Excellence: Liberating the NHS' (2010) focused on the importance of listening to families and having shared decision making-"*no decision about me without me*". The Code of Practice (2014) in Education (Special Educational Needs) also stresses the participation of children and young people and parents in decision-making at individual and strategic levels. Consequently the current health and education agenda places considerable emphasis on listening to families and children. The results of this grounded theory support a family-centred, collaborative approach to developing AAC and recognise the fundamental role of family members in successful AAC interventions. When considering the complex processes involved with 'Finding a Voice' for their child, there is a clear need for parents to have access to appropriate resources and support.

In the early stages of AAC implementation, professionals may need to be particularly sensitive to the needs of individual families by providing them with timely information about AAC and its benefits for their child. Parents may not be at the stage when they are emotionally ready for AAC but still require access to information to augment their understanding of AAC systems. Some families' may need additional support and time in these early stages from professionals before they can accept AAC. Their preconceptions and expectations of AAC will need to be sensitively explored. Mothers spend considerable time developing their understanding of their child's non-verbal communication and professionals should be careful to not undermine these abilities. Parents would benefit from access to information to assist their understanding on how AAC can impact on their child's future communication. This study has demonstrated the tensions which also arise when parental expectations of AAC services do not match the reality of services provided or where families consider the advice and knowledge of professionals insufficient. Clear AAC pathways and referral criteria would support families in accessing both ‘hub’ (specialist) and ‘spoke’ (local) AAC services in the new commissioning arrangements (2014).

Professionals should be conscious of the many roles and responsibilities individual family members adopt when they have a child with complex communication needs. The amount of responsibility parents wish to have will vary throughout the trajectory and will depend on the competing needs of both their child and other family members. Mothers took the leadership role for AAC and were responsible for its implementation within the home but professionals need to work more collaboratively to ensure support is available and a personalised approach is adopted regarding families’ routines and values. The multi-modal nature of communication was evident in this study where children used both unaided and aided communication systems in the home but all the families viewed AAC as a high priority. However the implementation of AAC was often described as a ‘struggle’ and families required more professional support to be able to integrate systems successfully and to support them in problem-solving and extending AAC opportunities for their child. This requires professionals to be involved long-term and funding available at a ‘spoke’ (local) level. Without sufficient support, families may be forced to seek their own solutions or they may even reject AAC as an option for their child.

The focus of any AAC intervention should not be based purely on assessing and providing equipment but on improving the families’ confidence and self-esteem in both programming devices and helping them to implement and develop AAC systems in the family. The study highlighted the importance of increasing the awareness of AAC and providing training for the families support networks such as grandparents, school, community groups which will lessen the ‘burden’ on mothers and widen the understanding of AAC systems. Professionals will need to explore the priorities and daily management strategies parents employ when implementing AAC and any advice given should be congruent with their existing circumstances and routines. Mothers have considerable knowledge about their child and gain understanding of different AAC systems which should be acknowledged by professionals if they are to develop collaborative AAC outcomes.

One of the major barriers to successful AAC outcomes identified both in the literature (Goldbart and Marshall, 2004, Angelo 2000) and in this study is time. The implementation of AAC requires families to give considerable amount of time and energy to AAC. Professionals also need to be aware of the potential feelings of guilt and frustration experienced by mothers as a result of them believing they are not doing as much as they should for their child and not conforming to the stereotypical view of a ‘good’ mother. There will be times when parents are unable to act on professional advice due to the competing needs of the child or other family members. At other times families may listen to advice but prioritise their decisions based on what they believe will work best for their child and their family. In order to achieve supportive and collaborative parent-professional relationships, parents must feel ‘safe’ to discuss the difficulties with AAC without feeling they have failed in some way. Professionals can support and develop parental involvement in AAC by giving encouragement and having a non-judgemental attitude when interacting with parents. This will allow professionals and families to set joint realistic targets which take into consideration the time pressures and other commitments of the family which impact upon their level of AAC involvement. The families’ prioritisation of AAC may also change over time and services will need to be flexible in terms of the services they provide.

For families, their child’s autonomous communication may take a considerable amount of time and parental input. Professionals can highlight progress and celebrate the small steps achieved by the child and their families as this will promote confidence which will have the potential to develop further AAC integration in the home.

For families, the availability and cost of AAC resources can be an additional challenge. Many families found it difficult to obtain the software to support their child in the home and the on-going costs of AAC had considerable financial implications for them. Families would benefit from information and signposting to available resources or sources of funding to allow them to access further AAC equipment. Families also identified technological barriers when using AAC including device reliability, complexity of programming, appearance and portability of communication systems. The voice quality and the need for more personalised voices were also considered an obstacle to successful AAC outcomes particularly where the family perceived them as an unacceptable alternative for their child. This has implications for the design of communication systems and it is important to involve children and their families in influencing the design of future communication devices and systems. Table 10 considers some examples of professional support which could be offered to families using AAC based on the findings presented in this thesis.

Factors to consider in developing AAC based on the grounded theory presented.	**Examples of professional support in developing AAC**
AAC (introduction of AAC systems)	• Explore pre-conceptions of AAC with family • Professionals to support families understanding of the aims of introducing AAC • Discuss the family's short term and long term goals and outcome for AAC
Family problem-solving	• Professional awareness of the family structure/roles/responsibilities • Problem-solve with family's the 'right time' for them emotionally and practically • Support the family in problem-solving ways AAC can be introduced in the home • Sibling involvement-specific resources/support to play an active role in AAC • Training in AAC to assist family problem-solving with AAC • On-going involvement with families to develop and maintain AAC • Open communication with family and understanding 'shifting' priorities dependent on family needs and circumstances
Building ownership of AAC	• Empower parents to feel in control of the use of AAC

	• Help families to maintain their confidence in AAC (e.g. celebrating successes and defining moments) • Provide support when family are struggling with AAC and encourage joint problem solving • Build confidence in their abilities in using AAC
Developing understanding of AAC within the families support networks	• Understand the family's social networks and involve family/friends in support network (e.g. grandparents and family friends) • Provide information on support networks • Flexibility in service delivery and appointments to allow for both parents, extended family to attend (e.g. home visits) • Provide support through contact with other families using AAC • Train other service providers (e.g. respite care) on AAC
Integrating AAC into family routines	• Assist families by reviewing routines and how to integrate AAC • Support family in realistic goal setting through an understanding of the family routines and rituals • Understand family functioning and differences in terms of culture, responsibilities and expectations • Acknowledge the investment of time and energy to adopt AAC
Hope	• Understand the family's hopes for AAC • Focus on child/family AAC successes • Assist family's to develop and maintain positive and realistic outcomes

	• Support families in any change in these hopes as situations emerge
Flexibility	• Assist families to adapt to new roles as a result of AAC • Provide resources to allow families to develop AAC
Communication (professionals and family)	• Encourage information sharing between AAC providers and family • Encourage the sharing of AAC with all family members/social networks • Provide age appropriate information to siblings to encourage AAC involvement • Provide timely and relevant information on AAC • Support families in accessing recommended websites/ literature on AAC • Provide information on services available and pathways of support • Acknowledge parents as experts of their child • Support parental advocacy for their child • Actively involve parents in decision-making

Table 10: Examples of professional support in developing AAC

8.6 Training for Parents and Educational Staff

The major categories from the emergent theory have been developed into the revised '*You Matter'* (2015) training course to support and empower families and educational staff of children who are using or considering AAC (Appendix 17). This two day training course acknowledges the important role parents play in AAC and recognizes that each parent, child and family is unique. The course has eight sessions which focus on the parents' concerns, hopes and expectations as well as the development of AAC with practical ideas to incorporate different communication systems into families' daily lives. Parents are invited to bring other key family members to the course to support their understanding and use of the communication system. '*You Matter*' considers how the child currently communicates and the communication skills that families hope will be achievable in the future.

The '*You Matter*' training course for educational staff emphasises both the development of AAC and the importance of involving parents in setting collaborative goals for school and home. The training considers how to support children using AAC in the curriculum, the role of the communication partner and the importance of developing interactions between peers and children using AAC. The short term evaluations of this training are positive but further long term follow up of the families is needed to assess the outcomes achieved.

8.7 Limitations of the Study

The sample for this qualitative grounded theory study was small and from a relatively homogenous group of parents in England. The majority of participants were mothers even though initial invitations were extended to both parents in the study. Although some fathers were interviewed it was the mother's voice that was at the forefront of the study and this may reflect the imbalance in care-giving (Cunningham-Burley et al, 2006, Gatrell 2005, Hochschild and Machung, 2003; Ribbens, 1994) and the advocacy role adopted by mothers when implementing AAC systems (Goldbart and Marshall 2004; Angelo, 2000).

The study involved only a small number of children and did not represent culturally diverse experiences. Families recruited were using AAC systems in the home and the study focused on their perspectives on implementing AAC. It is not clear whether those parents who had 'abandoned' AAC would have had the same challenges and experiences as those that were successfully using AAC systems in the home. The trajectory identified relates to families with children using AAC aged 5-13 years and future research of families with older children and young people using AAC would be beneficial.

A limitation of the study is that data were collected at only one point in the families' lives and yet AAC is often a life-long journey for many families. Family perspectives may also change over time and more longitudinal studies would be beneficial in identifying the range of factors which impact on successful AAC outcomes for children and families.

8.8 Research Implications

This study has resulted in a grounded theory with implications for both professional practice and future research. Studies with further cohorts of families would contribute to the breadth and depth of the theoretical categories identified. An additional area to extend the theory is to explore families' perspectives of AAC in more longitudinal studies, identifying the changes in families that occur as they accumulate more knowledge and experience over time.

This study showed the importance of involving all family members in the implementation of AAC in the home. Grandparents were important sources of support for families with children with complex communication needs but there is very little published research concerning the roles and experiences of grandparents in relation to AAC and this is an important area for future research. Further studies should include multiple family members to capture the perspectives of the 'whole' family.

Research involving children and young people is challenging particularly for those with a learning disability (Lewis and Porter, 2004) however, the perspectives of children using AAC systems is fundamental and further research should maximise opportunities to allow them to communicate their knowledge and explore strategies to enable them to become co-constructors within research.

A Constructivist Grounded Theory approach can provide further understanding of different perspectives of AAC and offer an interpretative analysis of these experiences.

8.9 Conclusion

The twelve families involved in this study have contributed to our understanding of the perspectives of families implementing different AAC systems in the home. The study adds to existing knowledge about families using AAC as it identifies a trajectory which provides the framework within which the theoretical concepts are located and underpins the families' continuous progress towards the purpose of ‘Finding a Voice’ for their child. The dynamic nature of the trajectory illustrates the shifts and changes families experience in adopting AAC in the home and the challenges they face as they develop and extend the use of AAC**.** The research demonstrates the complexities in adopting AAC and the commitment and time needed by parents to find a suitable ‘voice’ for their child. Through listening to families, interventions can be meaningful and based on their priorities and concerns. ‘Finding a Voice’ has a range of applications for service development and for designers of AAC system.

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Family Perspectives on Augmentative and Alternative Communication.

A Constructivist Grounded Theory

Deborah Pugh

Appendices

Appendix 1

Presentations:

September 2013: East Midlands Research Forum(Leicester)
Title: Developing the use of Augmentative and Alternative Communication Systems in the home: A research project

December 2013: Grounded Theory Forum (University of Northampton)
Title: Developing insight: Neophyte Journeying into Chamazian Grounded Theory

March 2014: **Images of Research exhibition (University of Northampton)**
Title: I can speak

June 2014: Postgraduate Conference (University of Northampton)
Title: Exploring the different voices in Families using Augmentative and Alternative Communication systems

September 2015: Communication Matters (National Conference: Leeds)
Title: Listening to different voices in families

September 2015: Title: 'You Matter' (revised edition) (available through the ACE Centre)

November 2015 (in print) Communication Matters Journal
Title: Listening to different voices in families

November 2015 (in print) 'You Matter': a one day course for educational staff supporting children using AAC (available through the ACE Centre)

Appendix 2 : Literature Review and Search Strategy

Inclusion Criteria

- Published research reports available in electronic databases to present (2015)
- Articles published in the English Language
- Parental perspectives of the use of AAC systems (including low and high technology)
- Experiences of the AAC user (developmental conditions)
- Family influences on AAC

Exclusion Criteria

- AAC with adult acquired conditions
- Curriculum Technology providing access to computers/switches in education
- Communication difficulties resulting from a primary hearing or visual loss

Relevant published literature was identified via electronic database searching using AMED, ASSIA, CINAHL, Cochrane library, MEDLINE, British Education Index, Child Development and Adolescent Studies, Education Research Complete, ERIC, PSYCHNET, Science Direct, Web of Science, Wiley.

Grey literature was accessed through organisations (The Royal College of Speech and Language Therapists (RCSLT), The Office of the Communication Champion, The National Institute for Health and Clinical Effectiveness), Communication Matters and ISAAC conference Abstracts and hand searching through the International Journal of Language and Communication Disorders. Thesis and dissertations were searched using the database EThOS and through University repositories.

Search terms were selected through discussions with colleagues, other AAC professionals and support from Supervisors and Librarians at The University of Northampton.

Appendix 3: NHS Health Research Authority Ethical Approval

NHS
Health Research Authority
NRES Committee East Midlands - Derby
Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839440

20 March 2013

Mrs Deborah Pugh
Speech and Language Therapist
Northamptonshire Healthcare Foundation Trust
Speech and Language Therapy Dept
Highfield Clinical Care Centre
Northampton
NN1 5BD

Dear Mrs Pugh

Study title:	**Listening to different voices in families using Alternative Communication systems within the home.**
REC reference:	**13/EM/0070**
Protocol number:	**not available**
IRAS project ID:	**103932**

Thank you for your letter of 26 February 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Vice-Chair.

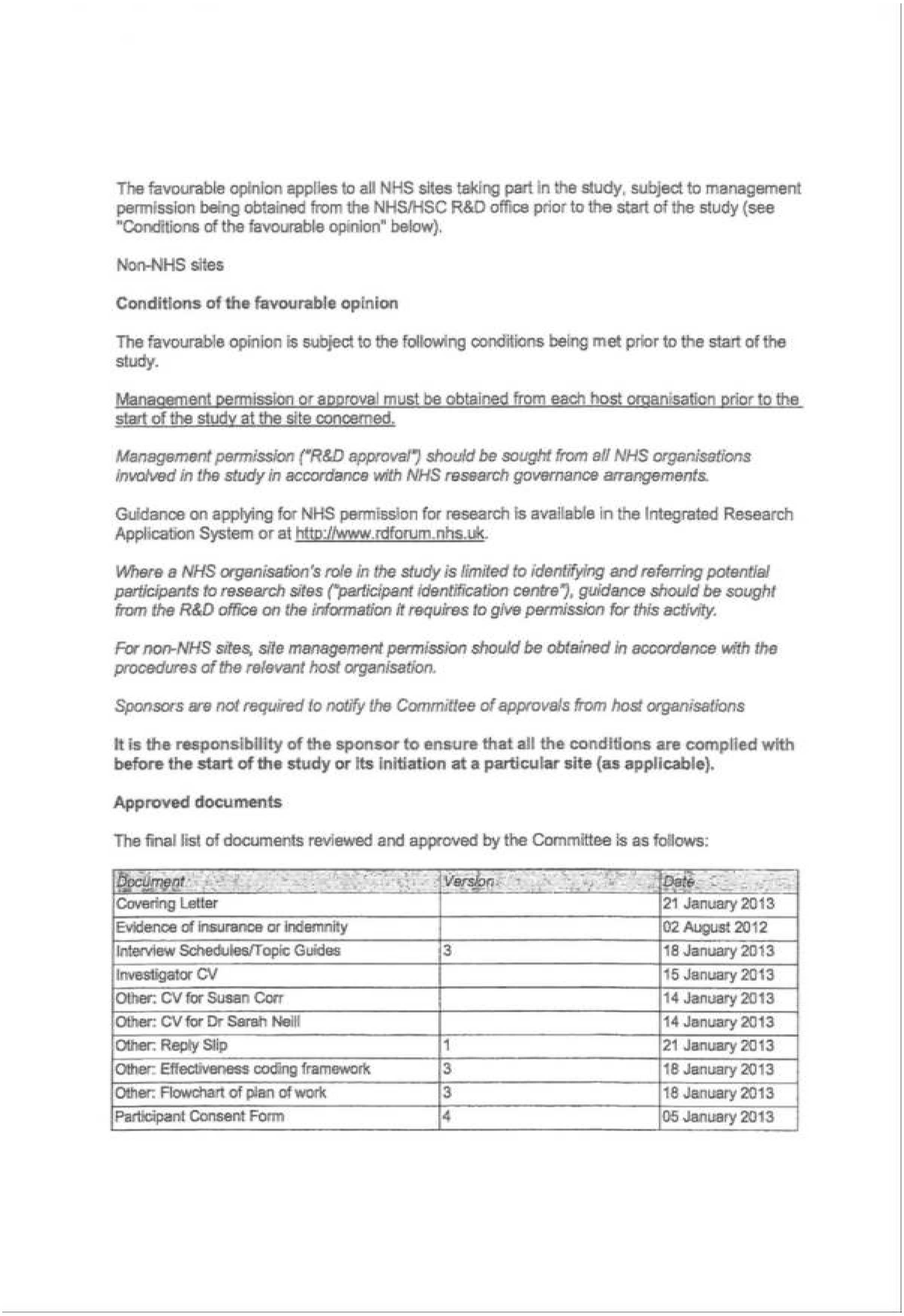
We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Tracy Leavesley, NRESCommittee.EastMidlands-Derby@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites



The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

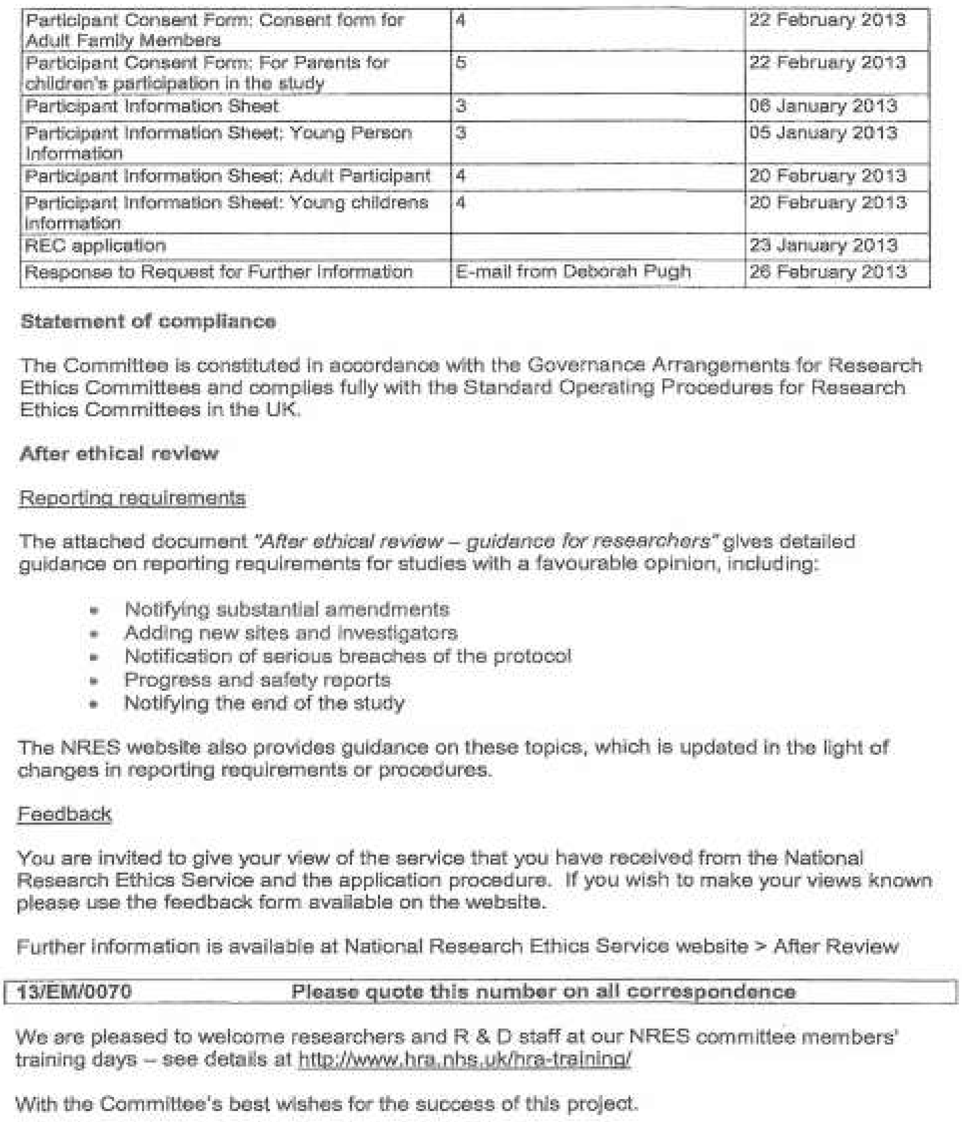
Sponsors are not required to notify the Committee of approvals from host organisations

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering Letter		21 January 2013
Evidence of insurance or indemnity		02 August 2012
Interview Schedules/Topic Guides	3	18 January 2013
Investigator CV		15 January 2013
Other: CV for Susan Corr		14 January 2013
Other: CV for Dr Sarah Neill		14 January 2013
Other: Reply Slip	1	21 January 2013
Other: Effectiveness coding framework	3	18 January 2013
Other: Flowchart of plan of work	3	18 January 2013
Participant Consent Form	4	05 January 2013



Participant Consent Form: Consent form for Adult Family Members	4	22 February 2013
Participant Consent Form: For Parents for children's participation in the study	5	22 February 2013
Participant Information Sheet	3	06 January 2013
Participant Information Sheet: Young Person Information	3	05 January 2013
Participant Information Sheet: Adult Participant	4	20 February 2013
Participant Information Sheet: Young childrens information	4	20 February 2013
REC application		23 January 2013
Response to Request for Further Information	E-mail from Deborah Pugh	26 February 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

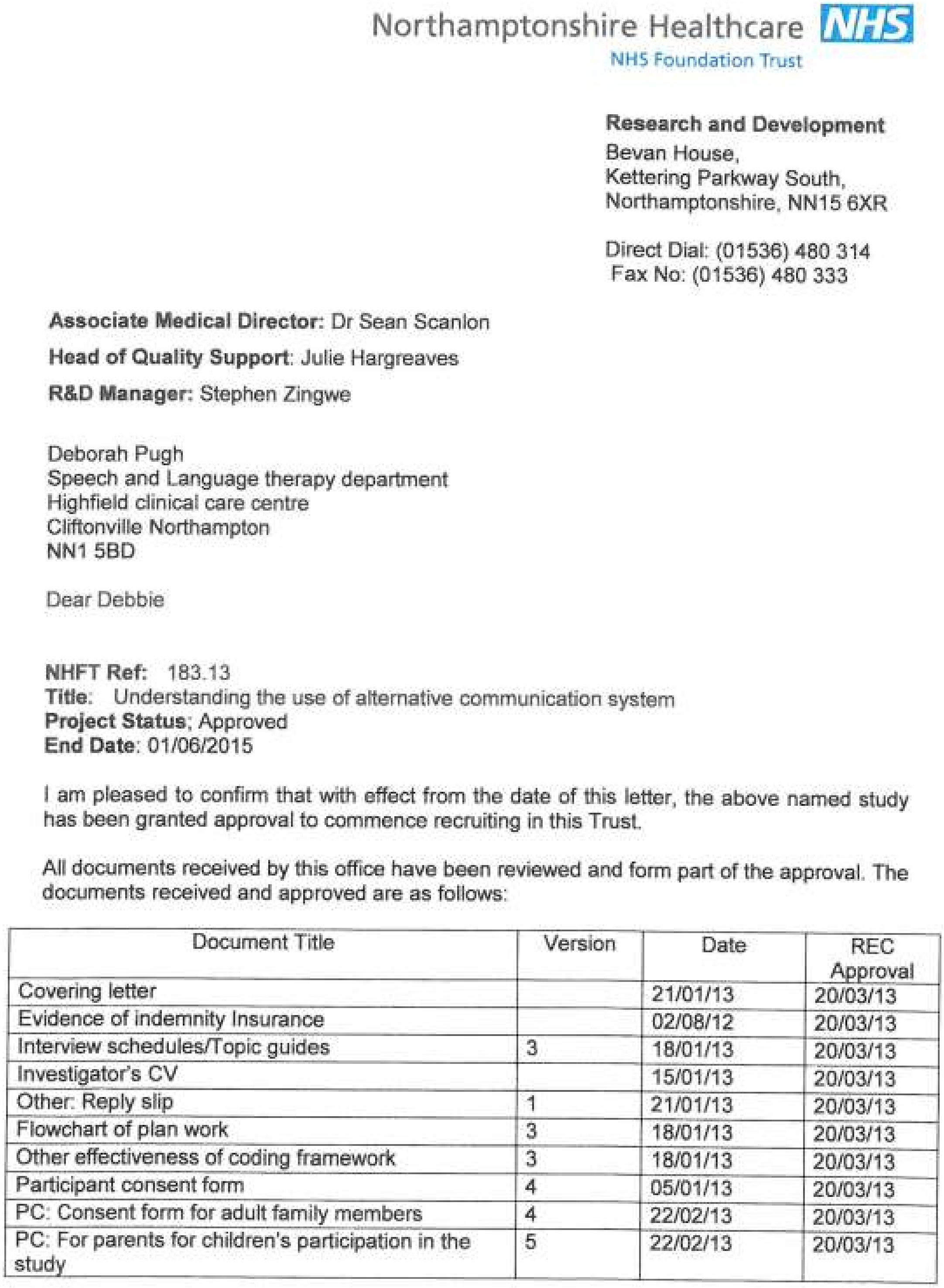
Further information is available at National Research Ethics Service website > After Review

13/EM/0070	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Appendix 4: NHS Foundation Trust Research and Development Ethical Approval



Northamptonshire Healthcare NHS
NHS Foundation Trust

Research and Development
Bevan House,
Kettering Parkway South,
Northamptonshire, NN15 6XR

Direct Dial: (01536) 480 314
Fax No: (01536) 480 333

Associate Medical Director: Dr Sean Scanlon
Head of Quality Support: Julie Hargreaves
R&D Manager: Stephen Zingwe

Deborah Pugh
Speech and Language therapy department
Highfield clinical care centre
Cliftonville Northampton
NN1 5BD

Dear Debbie

NHFT Ref: 183.13
Title: Understanding the use of alternative communication system
Project Status; Approved
End Date: 01/06/2015

I am pleased to confirm that with effect from the date of this letter, the above named study has been granted approval to commence recruiting in this Trust.

All documents received by this office have been reviewed and form part of the approval. The documents received and approved are as follows:

Document Title	Version	Date	REC Approval
Covering letter		21/01/13	20/03/13
Evidence of indemnity Insurance		02/08/12	20/03/13
Interview schedules/Topic guides	3	18/01/13	20/03/13
Investigator's CV		15/01/13	20/03/13
Other: Reply slip	1	21/01/13	20/03/13
Flowchart of plan work	3	18/01/13	20/03/13
Other effectiveness of coding framework	3	18/01/13	20/03/13
Participant consent form	4	05/01/13	20/03/13
PC: Consent form for adult family members	4	22/02/13	20/03/13
PC: For parents for children's participation in the study	5	22/02/13	20/03/13

Participant Information sheet	3	05/01/13	20/03/13
PIS: Young person information	3	05/01/13	20/03/13
PIS: Adult participant	4	20/02/13	20/03/13
PIS: Young children's information	4	20/02/13	20/03/13
REC Application		23/01/13	20/03/13
Response to request for further information	E-mail from Debbie Pugh	26/02/13	20/03/13

Please be aware that any changes to these documents after approval may constitute an amendment. The process of approval for amendments should be followed. Failure to do so may invalidate the approval of the study at this trust.

We are aware that undertaking research in the NHS comes with a range of regulatory responsibilities. Attached to this letter is a reminder of your responsibilities during the course of the research. Please ensure that you and the research team are familiar with and understand the roles and responsibilities both collectively and individually.

You are required to submit an annual progress report to the R&D Office and to the Research Ethics Committee.

The R&D Office is keen to support research, researchers and to facilitate approval. If you have any questions regarding this, or other research you wish to undertake in the Trust, please contact this office.

We wish you every success with your research.

Yours sincerely

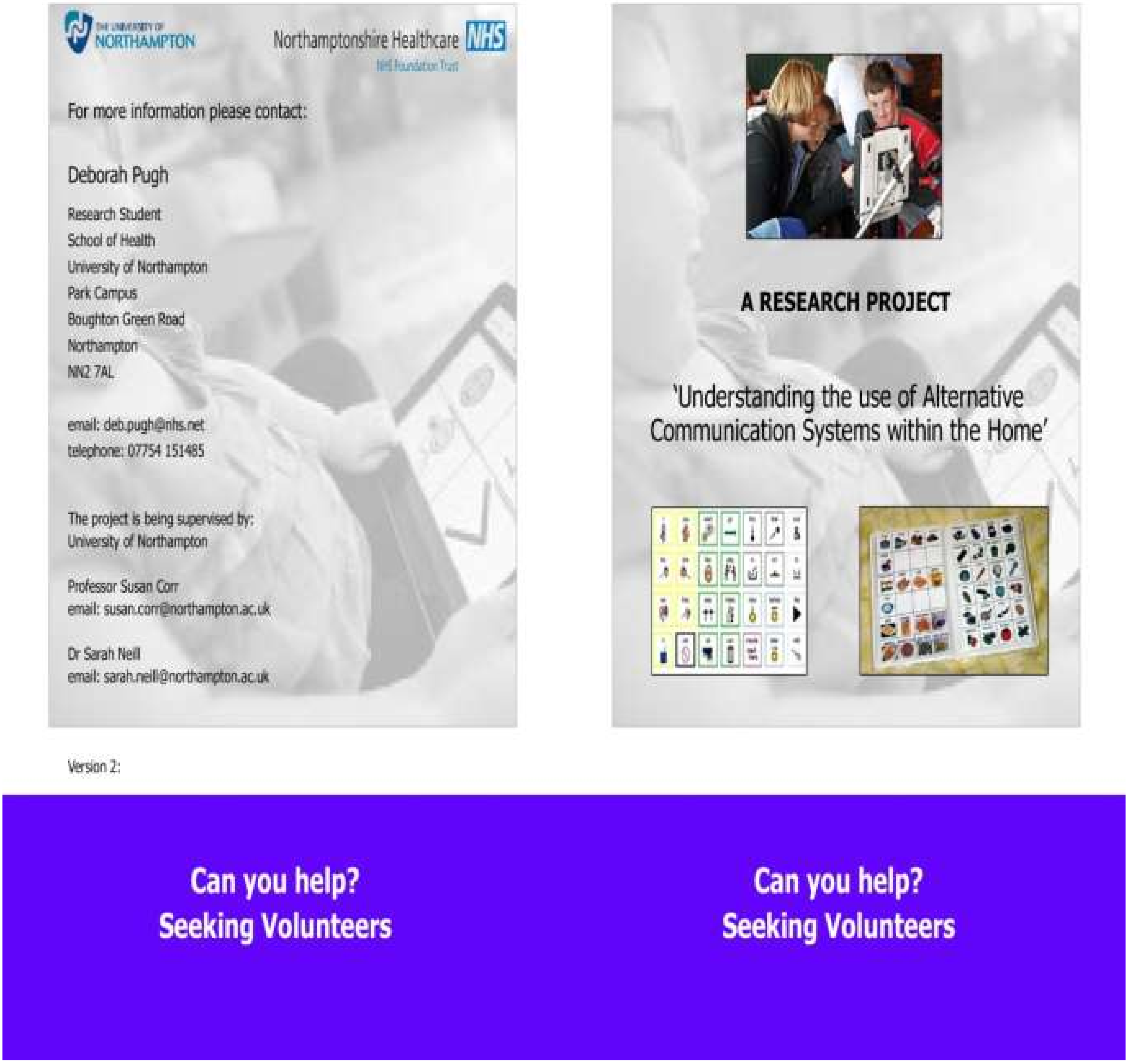
Stephen Zingwe
Research and Development Manager

CC:

Encs: Researcher Information Sheet

Please note that some of the documents may not apply to your study.

Appendix 5: Recruitment Leaflet



THE UNIVERSITY OF NORTHAMPTON

Northamptonshire Healthcare NHS
NHS Foundation Trust

For more information please contact:

Deborah Pugh

Research Student
School of Health
University of Northampton
Park Campus
Boughton Green Road
Northampton
NN2 7AL

email: deb.pugh@nhs.net
telephone: 07754 151485

The project is being supervised by:
University of Northampton

Professor Susan Corr
email: susan.corr@northampton.ac.uk

Dr Sarah Neill
email: sarah.neill@northampton.ac.uk

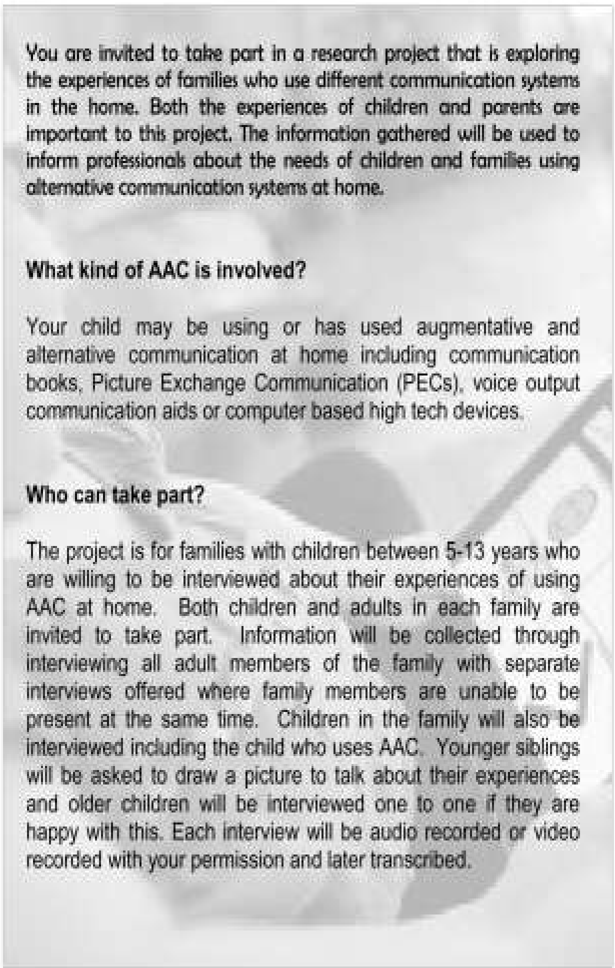
Version 2:

Can you help?
Seeking Volunteers

A RESEARCH PROJECT

'Understanding the use of Alternative Communication Systems within the Home'

Can you help?
Seeking Volunteers



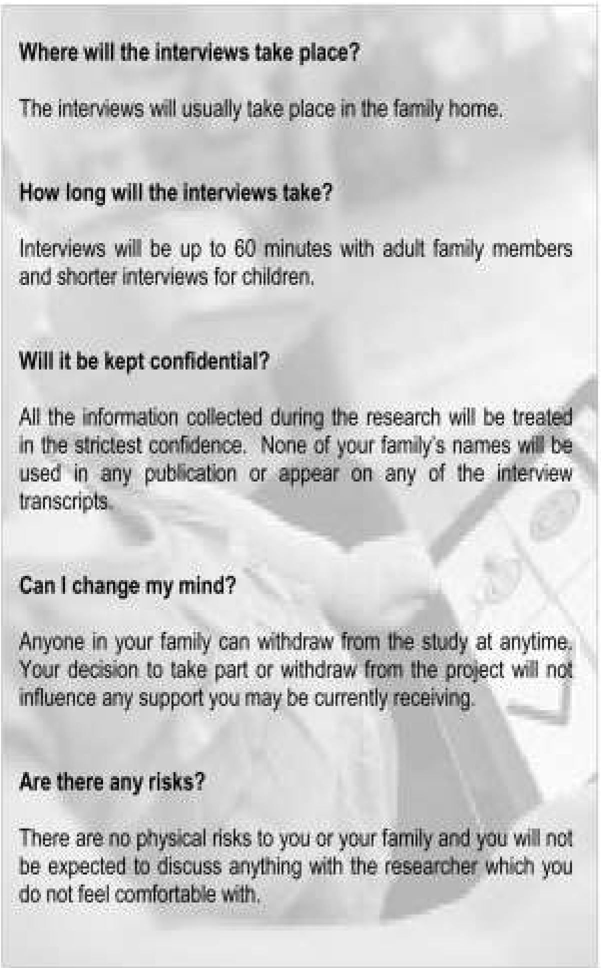
You are invited to take part in a research project that is exploring the experiences of families who use different communication systems in the home. Both the experiences of children and parents are important to this project. The information gathered will be used to inform professionals about the needs of children and families using alternative communication systems at home.

What kind of AAC is involved?

Your child may be using or has used augmentative and alternative communication at home including communication books, Picture Exchange Communication (PECs), voice output communication aids or computer based high tech devices.

Who can take part?

The project is for families with children between 5-13 years who are willing to be interviewed about their experiences of using AAC at home. Both children and adults in each family are invited to take part. Information will be collected through interviewing all adult members of the family with separate interviews offered where family members are unable to be present at the same time. Children in the family will also be interviewed including the child who uses AAC. Younger siblings will be asked to draw a picture to talk about their experiences and older children will be interviewed one to one if they are happy with this. Each interview will be audio recorded or video recorded with your permission and later transcribed.



Where will the interviews take place?

The interviews will usually take place in the family home.

How long will the interviews take?

Interviews will be up to 60 minutes with adult family members and shorter interviews for children.

Will it be kept confidential?

All the information collected during the research will be treated in the strictest confidence. None of your family's names will be used in any publication or appear on any of the interview transcripts.

Can I change my mind?

Anyone in your family can withdraw from the study at anytime. Your decision to take part or withdraw from the project will not influence any support you may be currently receiving.

Are there any risks?

There are no physical risks to you or your family and you will not be expected to discuss anything with the researcher which you do not feel comfortable with.

Appendix 6: Participant Information Leaflet (adult)

Northamptonshire Healthcare NHS
NHS Foundation Trust

THE UNIVERSITY OF NORTHAMPTON

INFORMATION FOR PARTICIPANTS

A RESEARCH PROJECT

Research Project Title: 'Listening to different voices in families'. The use of alternative communication systems within the home.

Thank you for expressing an interest in the research project on the use of alternative communication systems within the home. Before you decide to take part, it is important that you understand why this research is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If you require further information or are unclear about any aspect related to this study please feel free to speak directly to the named researcher.

Why is the study being carried out?

Some children may have difficulties acquiring speech, it may be slow to develop or it may be impaired and professionals may suggest supporting or replacing spoken words with pictures, symbols, signing or communication devices. Your family has been identified by professionals as using, or having previously used alternative communication systems with your child within the home. This may be a communication book, communication boards, PECs, a voice output communication aid or a computer based communication device.

This study is exploring the experiences of families who use different communication systems in the home. Both the experiences of children and parents are important to the study. The information gathered will be used to inform professionals about the needs of children and families using alternative communication systems.

This research is in part fulfilment of a Doctorate in Professional Practice at The University of Northampton.

What will I be asked to do if I agree to take part?

If you agree to take part the researcher will explain more about the project and will go through this information sheet and answer any questions you may have. If you feel happy to proceed you be asked to sign a participant consent form giving your consent and consent for your children to take part in this study.

The researcher will visit you at home on two or three occasions during a three month period. Information will be collected through interviews with both children and adults within the family. Session lengths will vary but usually interviews with adult family members will last up to 60 minutes and will be shorter for children. However you and your child can choose to end the session at any point.

The young person with communication difficulties will, where possible, take part in face to face interviews using their current communication systems. For some young people their communication may be supplemented using visual tools such as photographs, symbols or a Talking Mat, a communication framework which supports children and young people to express their views.

Younger siblings will be asked to draw a picture to talk about their experiences and older siblings will be interviewed on a one to one basis if they are happy to do this.

For accuracy of reporting, it would be most beneficial to record your interviews but in order to use such equipment, we must be certain that you are happy to have your experiences recorded in this way. Interviews for adults and siblings within the family will be audio recorded but for the young person with communication difficulties, it would be beneficial to video record the interview. The video recording will only be used for the purposes of this study. All recordings and data collected will be anonymised (no names will be recorded; only an ID number will be used). Notes (typed transcripts) will be made of your interview and returned to you for checking.

Do I have to take part?

No, it is up to you to decide whether or not to take part. Your decision to take part, or not to take part, will not influence any treatment/therapy you are receiving from anyone.

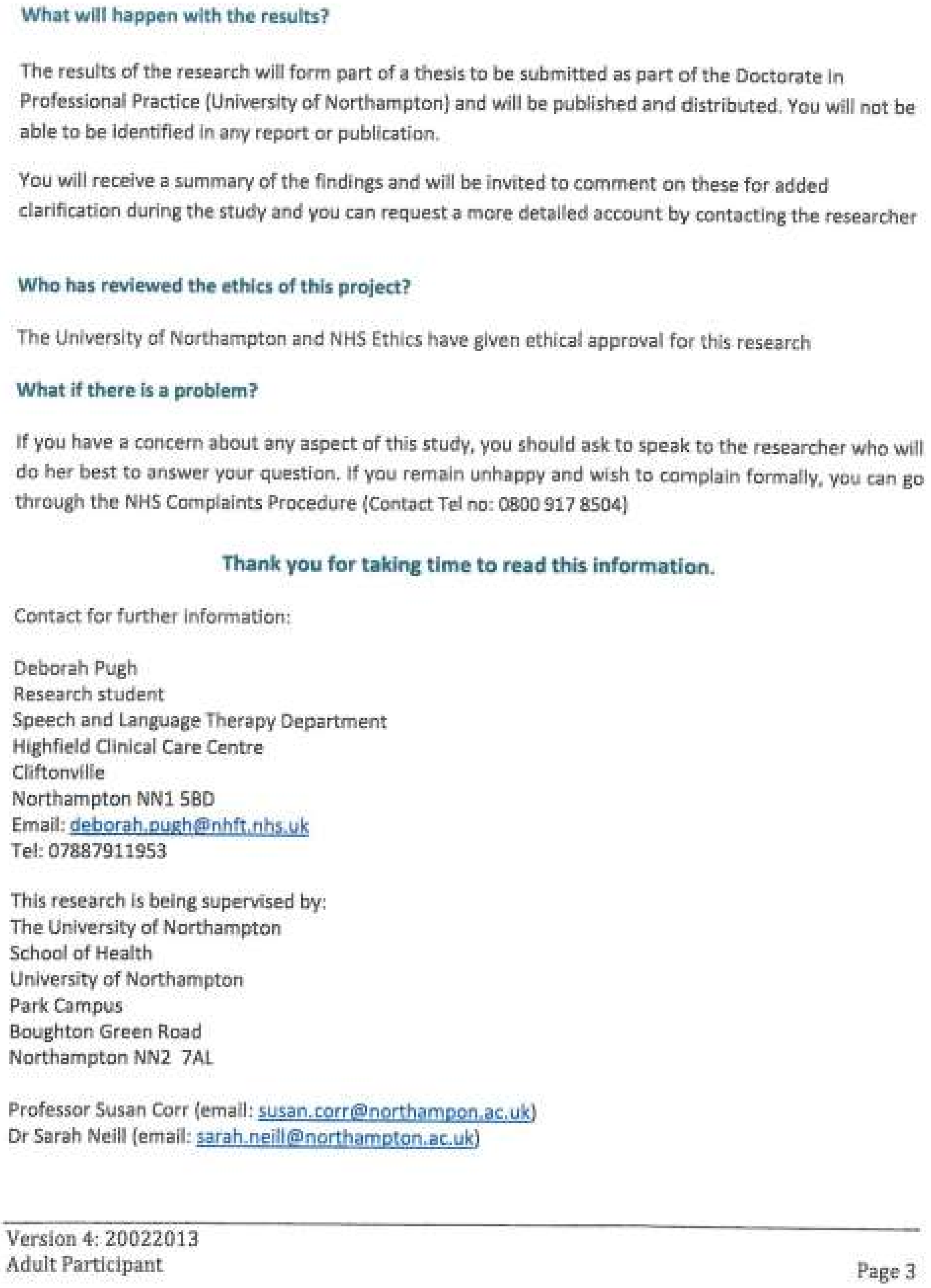
Are there any possible disadvantages and risks of taking part?

There are no physical risks to you as a person and you will not be expected to discuss anything with the researcher, which you do not feel comfortable with or would you be expected to justify your withdrawal from the study.

Will the information collected about me be kept confidential?

All interviews will be treated as strictly confidential and information collected from you during the course of this research will be entirely anonymous. It will be stored in a secure place and will be protected by a password if saved on a computer.

In certain circumstances it may not be possible for the researcher to guarantee confidentiality where a child or others are at risk of harm and the researcher has duty of care to contact the appropriate authorities.



What will happen with the results?

The results of the research will form part of a thesis to be submitted as part of the Doctorate in Professional Practice (University of Northampton) and will be published and distributed. You will not be able to be identified in any report or publication.

You will receive a summary of the findings and will be invited to comment on these for added clarification during the study and you can request a more detailed account by contacting the researcher

Who has reviewed the ethics of this project?

The University of Northampton and NHS Ethics have given ethical approval for this research

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your question. If you remain unhappy and wish to complain formally, you can go through the NHS Complaints Procedure (Contact Tel no: 0800 917 8504)

Thank you for taking time to read this information.

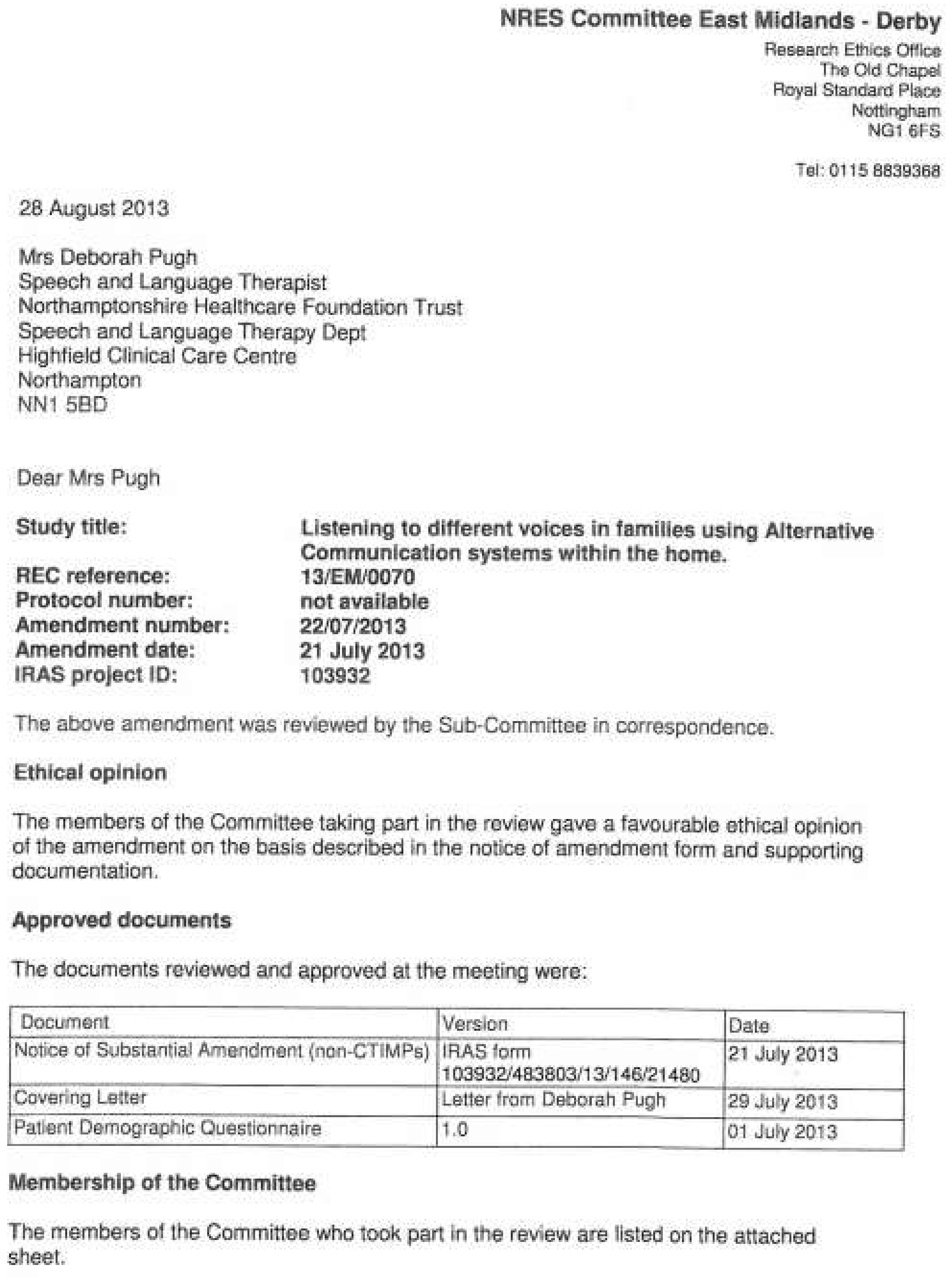
Contact for further information:

Deborah Pugh
Research student
Speech and Language Therapy Department
Highfield Clinical Care Centre
Cliftonville
Northampton NN1 5BD
Email: deborah.pugh@nhft.nhs.uk
Tel: 07887911953

This research is being supervised by:
The University of Northampton
School of Health
University of Northampton
Park Campus
Boughton Green Road
Northampton NN2 7AL

Professor Susan Corr (email: susan.corr@northampon.ac.uk)
Dr Sarah Neill (email: sarah.neill@northampton.ac.uk)

Appendix 7: NHS Health Research Authority (amendment)



NRES Committee East Midlands - Derby
Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 8839368

28 August 2013

Mrs Deborah Pugh
Speech and Language Therapist
Northamptonshire Healthcare Foundation Trust
Speech and Language Therapy Dept
Highfield Clinical Care Centre
Northampton
NN1 5BD

Dear Mrs Pugh

Study title: **Listening to different voices in families using Alternative Communication systems within the home.**
REC reference: **13/EM/0070**
Protocol number: **not available**
Amendment number: **22/07/2013**
Amendment date: **21 July 2013**
IRAS project ID: **103932**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

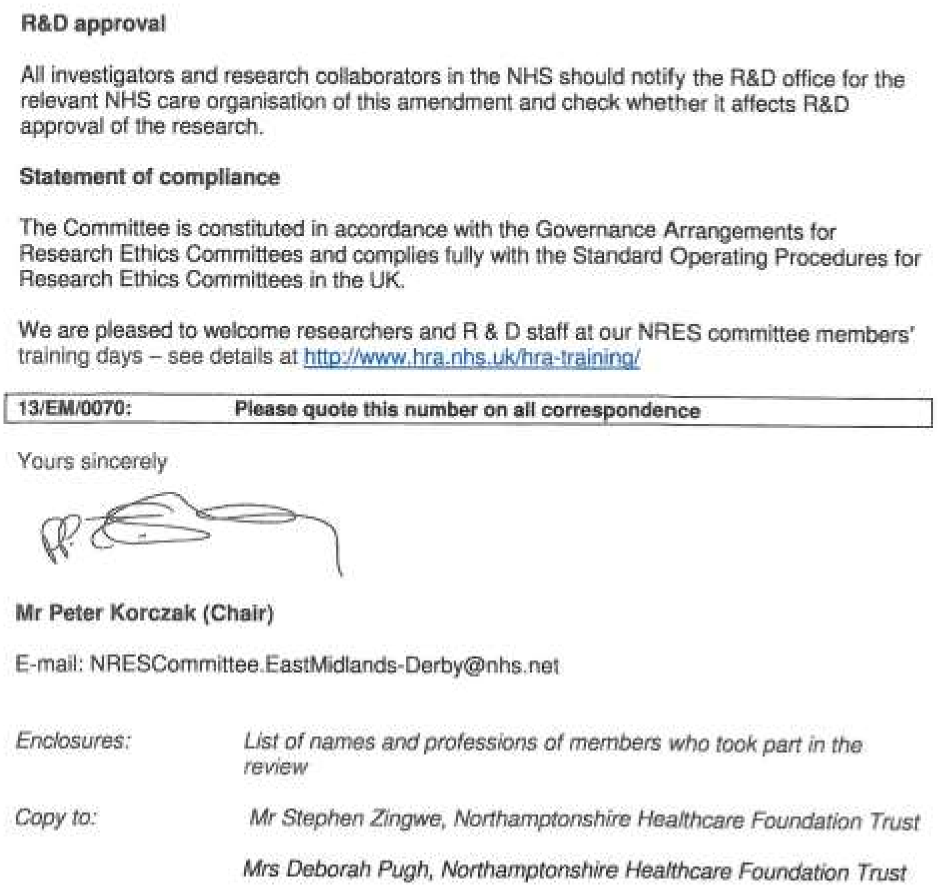
Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	IRAS form 103932/483803/13/146/21480	21 July 2013
Covering Letter	Letter from Deborah Pugh	29 July 2013
Patient Demographic Questionnaire	1.0	01 July 2013

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.



R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

13/EM/0070:	**Please quote this number on all correspondence**

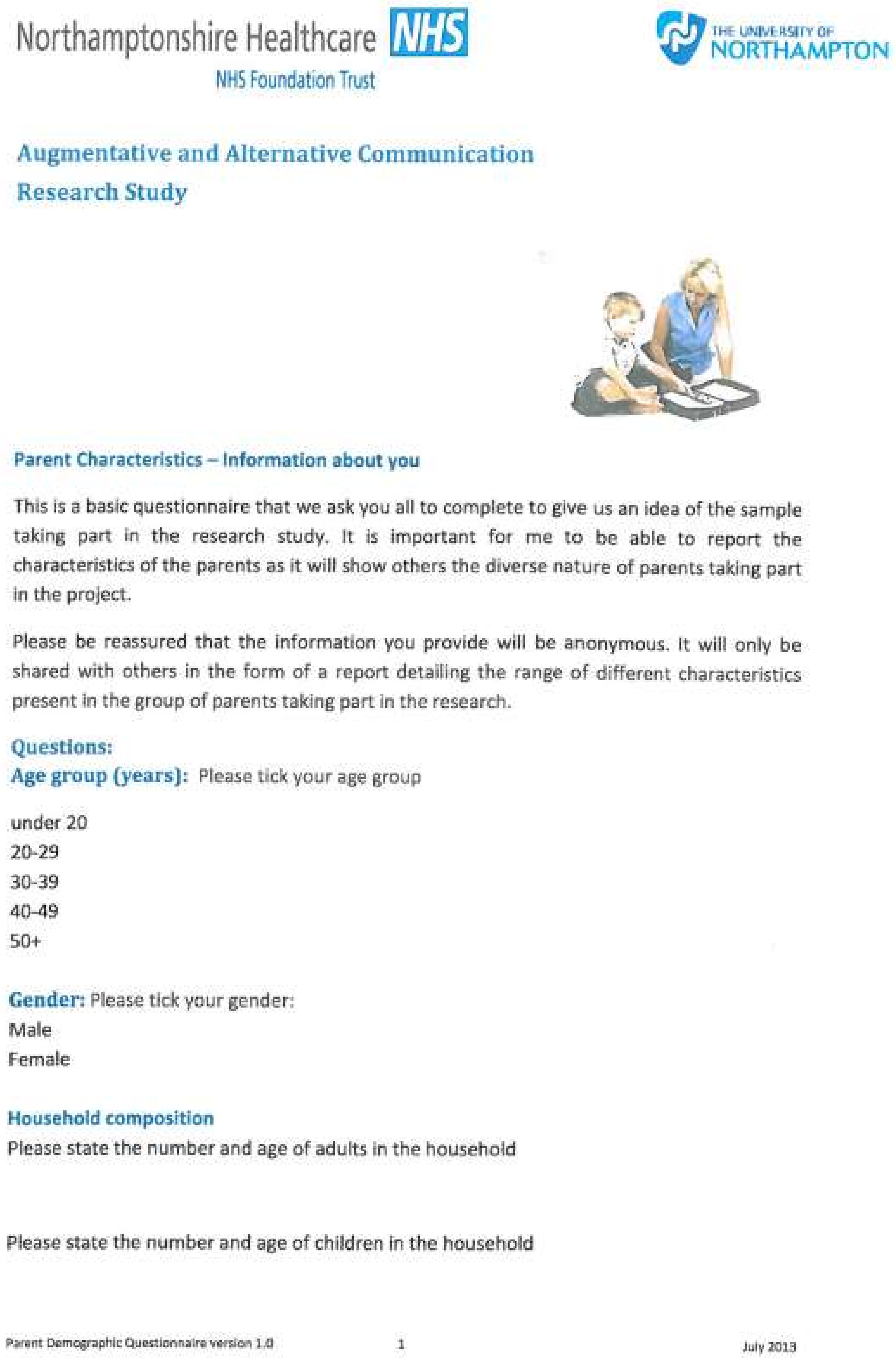
Yours sincerely

Mr Peter Korczak (Chair)

E-mail: NRESCommittee.EastMidlands-Derby@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
Copy to:	*Mr Stephen Zingwe, Northamptonshire Healthcare Foundation Trust*
	Mrs Deborah Pugh, Northamptonshire Healthcare Foundation Trust

Appendix 8: Demographic Questionnaire



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Augmentative and Alternative Communication Research Study

Parent Characteristics – Information about you

This is a basic questionnaire that we ask you all to complete to give us an idea of the sample taking part in the research study. It is important for me to be able to report the characteristics of the parents as it will show others the diverse nature of parents taking part in the project.

Please be reassured that the information you provide will be anonymous. It will only be shared with others in the form of a report detailing the range of different characteristics present in the group of parents taking part in the research.

Questions:

Age group (years): Please tick your age group

under 20
20-29
30-39
40-49
50+

Gender: Please tick your gender:
Male
Female

Household composition

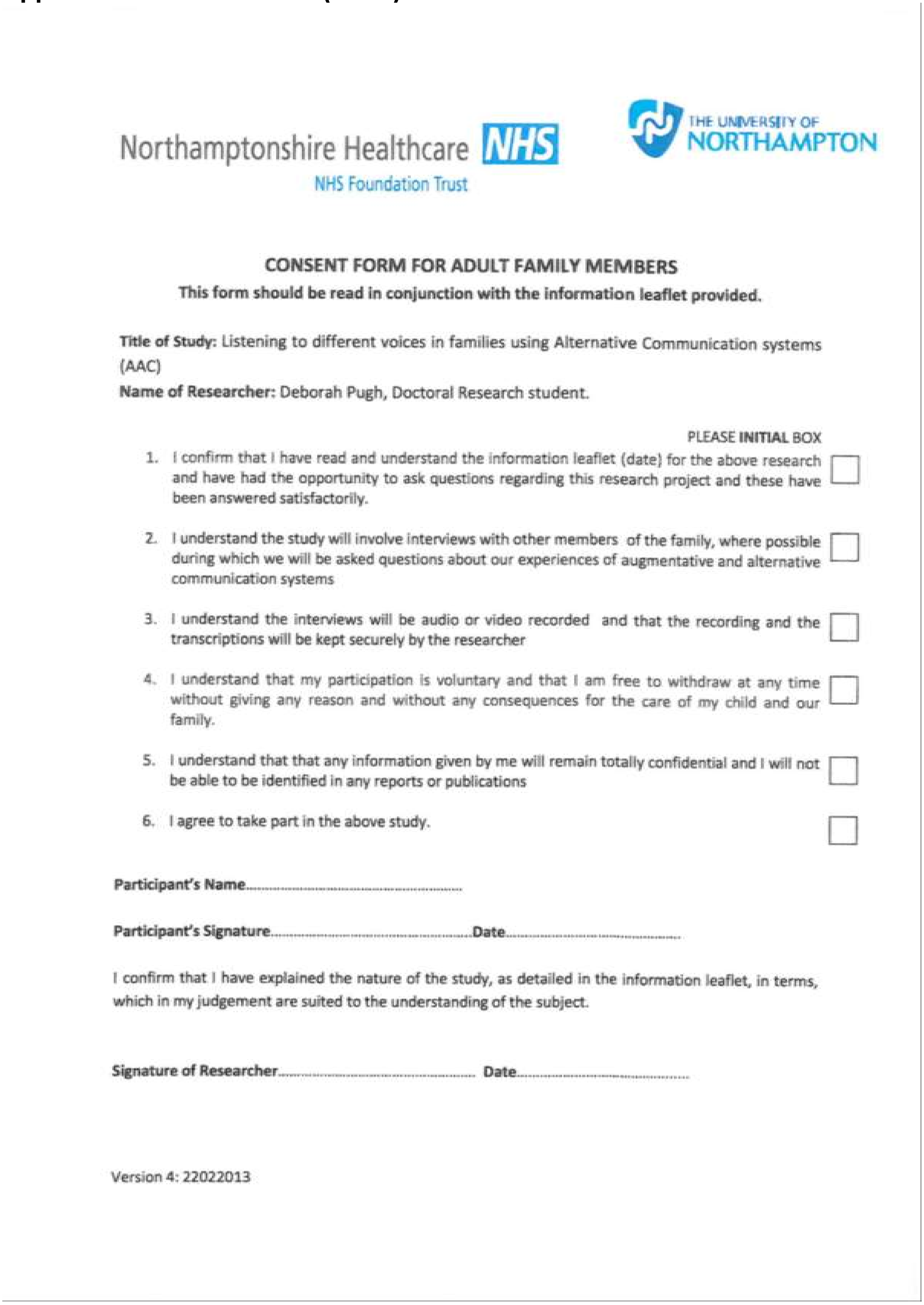
Please state the number and age of adults in the household

Please state the number and age of children in the household

Do you have a mobile phone which supports 'Apps'? Yes No

Thank you for completing this questionnaire. The results will be collated to give a picture of the composition of the group of parents taking part in the research. This will be presented as the number of people in any one group. This will enable us to identify where we may need to seek additional parents for the research and to demonstrate to others the diversity of the parents involved.

Appendix 9: Consent Form (adult)



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CONSENT FORM FOR ADULT FAMILY MEMBERS

This form should be read in conjunction with the information leaflet provided.

Title of Study: Listening to different voices in families using Alternative Communication systems (AAC)

Name of Researcher: Deborah Pugh, Doctoral Research student.

PLEASE **INITIAL** BOX

1. I confirm that I have read and understand the information leaflet (date) for the above research and have had the opportunity to ask questions regarding this research project and these have been answered satisfactorily. ☐
2. I understand the study will involve interviews with other members of the family, where possible during which we will be asked questions about our experiences of augmentative and alternative communication systems ☐
3. I understand the interviews will be audio or video recorded and that the recording and the transcriptions will be kept securely by the researcher ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without any consequences for the care of my child and our family. ☐
5. I understand that that any information given by me will remain totally confidential and I will not be able to be identified in any reports or publications ☐
6. I agree to take part in the above study. ☐

Participant's Name...

Participant's Signature...**Date**...

I confirm that I have explained the nature of the study, as detailed in the information leaflet, in terms, which in my judgement are suited to the understanding of the subject.

Signature of Researcher... **Date**..

Version 4: 22022013

Appendix 10: Participant Information Leaflet (young person)

Northamptonshire Healthcare NHS
NHS Foundation Trust

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INFORMATION FOR PARTICIPANTS

A RESEARCH PROJECT

Research Project Title: 'Listening to different voices in families'. The use of alternative communication systems within the home.

We are asking if you would take part in a research project to find out about your families experiences on the use of alternative communication systems within the home. Before you decide if you want to join in, it is important to understand why the research is being done and what it will involve for you. Please take time to read the leaflet carefully and discuss it with your family and friends if you want to. If you want any more information or are unclear about the study please feel free to speak directly to the researcher.

Why is the study being carried out?

Some children may have difficulties learning to speak and professionals may suggest supporting them by using pictures, symbols, signing or communication devices. Your family has been identified by professionals as having a child who is using, or has previously used different communication systems within your home. This may be a communication book, communication boards or a voice output communication aid or a computer based communication device.

This study is exploring the experiences of families who use different communication systems in the home. Both the experiences of children and parents are important to the study and this is why you have been invited to take part. The information will be used to help professionals learn about the needs of children and families who use different communication systems.

This research is part of a Doctorate in Professional Practice at The University of Northampton.

Do I have to take part?

No, it is up to you to decide whether or not to take part.

What will I be asked to do if I agree to take part?

If you agree to take part the researcher will explain more about the project and will go through this information sheet and answer any questions you may have. If you feel happy to proceed you be asked to sign a form giving your consent or assent. You will be given a copy of this information sheet and your signed form to keep.

Version 3: 05012013
Young Person Information
Page 1

The researcher will visit you at home on one or two occasions during a three month period. Information will be collected through an interview will you which will last up to 45 minutes.
For some young people their communication may be helped by using visual tools such as photographs, symbols or a Talking Mat to help them express their views and younger children may be asked to draw a picture.

It would be helpful to record your interviews with an audio or video recorder but it is important that you are happy to have your experiences recorded in this way.

Is there anything else to be worried about if I take part?

You will not be expected to discuss anything you are not comfortable with and you are free to stop taking part at any time during the research without giving a reason.

Will anyone else know I am doing this?

We will keep your information in confidence. This means we will only tell those who have a need to know and anything you say will not be identifiable in any report.

What will happen with the results?

The results of the research will form part of the Doctorate in Professional Practice (University of Northampton) and will be published and distributed.

You will receive a summary of the findings and will be invited to comment on them and you can request a full report by contacting the researcher.

Who has reviewed the study?

Before any research goes ahead it has to be checked by a Research Ethics Committee who make sure that the research is fair. This study has been checked by them.

What if there is a problem?

If you have a concern or any further questions about the study, you can ask to speak to the researcher who will do her best to answer your question. You can also talk to your family who will be able to contact a Complaints Procedure. (Contact Tel no: 0800 917 8504)

Thank you for taking time to read this information.

Contact for further information:

Deborah Pugh
Research student
Speech and Language Therapy Department
Highfield Clinical Care Centre
Cliftonville
Northampton
NN1 5BD

Email: deborah.pugh@nhft.nhs.uk
Tel: 07887911953

This research is being supervised by:

The University of Northampton
School of Health
University of Northampton
Park Campus
Boughton Green Road
Northampton
NN2 7AL

Professor Susan Corr (email: susan.corr@northampon.ac.uk)
Dr Sarah Neill (email: sarah.neill@northampton.ac.uk)

Appendix 11: Participant Information Leaflet (Child)

Northamptonshire Healthcare NHS
NHS Foundation Trust

THE UNIVERSITY OF NORTHAMPTON

INFORMATION SHEET

A RESEARCH PROJECT

Study Title: Different ways of talking

Research is a way to find out answers and we want to find out about your feelings on using different ways of talking within your home.

Why is the study being carried out?

Some children may find learning to talk quite hard and they may use different ways of talking such as using pictures, symbols, signing or communication devices. In your family a child is using a different way of talking and this is why you have been invited to take part. We want to hear what everyone in your family feels about different ways of talking including your Mum, Dad, brothers and sisters.

What you say to me will be used to help other people know more about children and families who use different ways of talking.

Do I have to take part?

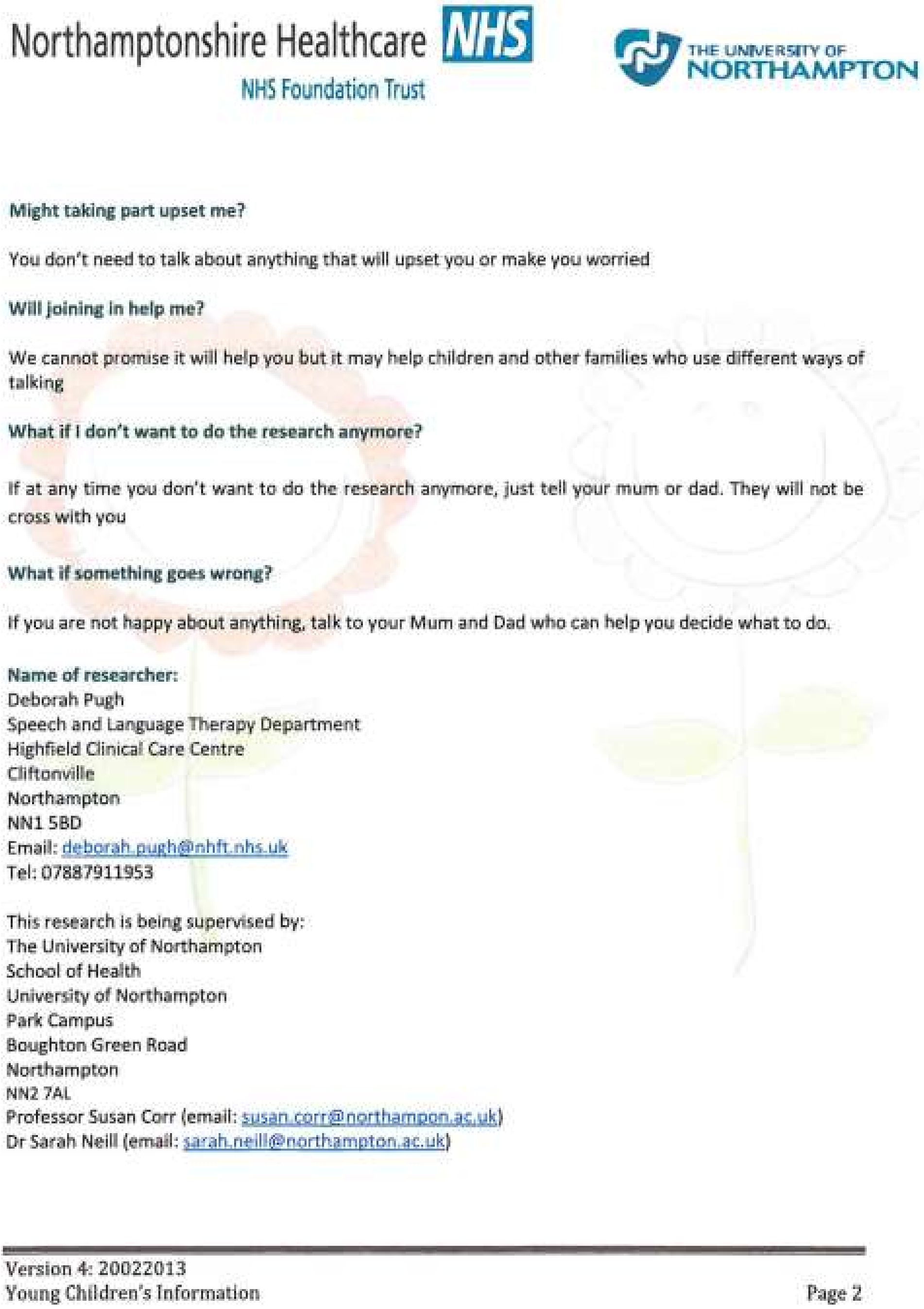
No, it is up to you.

What will I be asked to do?

If you would like to take part I will talk to you more about the study and I will go through this information sheet and answer any questions you have. If you feel happy to take part, your mum and dad will be asked if you can talk to me. You can choose to talk on your own with me or you can ask your mum or dad to be there as well. I may ask you to draw a picture or use pictures and photos to help us talk about your feelings.

I would also like to record our talk by using a video recorder or tape recorder but it is important that you are happy with this. I will have a 'stop card' and a 'go card' and if you are sad or want to stop talking with me, you can show me the card and we will finish. You can decide if you want to carry on later or whether you want to stop and not take part anymore.

Version 4: 20022013
Young Children's Information
Page 1



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Might taking part upset me?

You don't need to talk about anything that will upset you or make you worried

Will joining in help me?

We cannot promise it will help you but it may help children and other families who use different ways of talking

What if I don't want to do the research anymore?

If at any time you don't want to do the research anymore, just tell your mum or dad. They will not be cross with you

What if something goes wrong?

If you are not happy about anything, talk to your Mum and Dad who can help you decide what to do.

Name of researcher:
Deborah Pugh
Speech and Language Therapy Department
Highfield Clinical Care Centre
Cliftonville
Northampton
NN1 5BD
Email: deborah.pugh@nhft.nhs.uk
Tel: 07887911953

This research is being supervised by:
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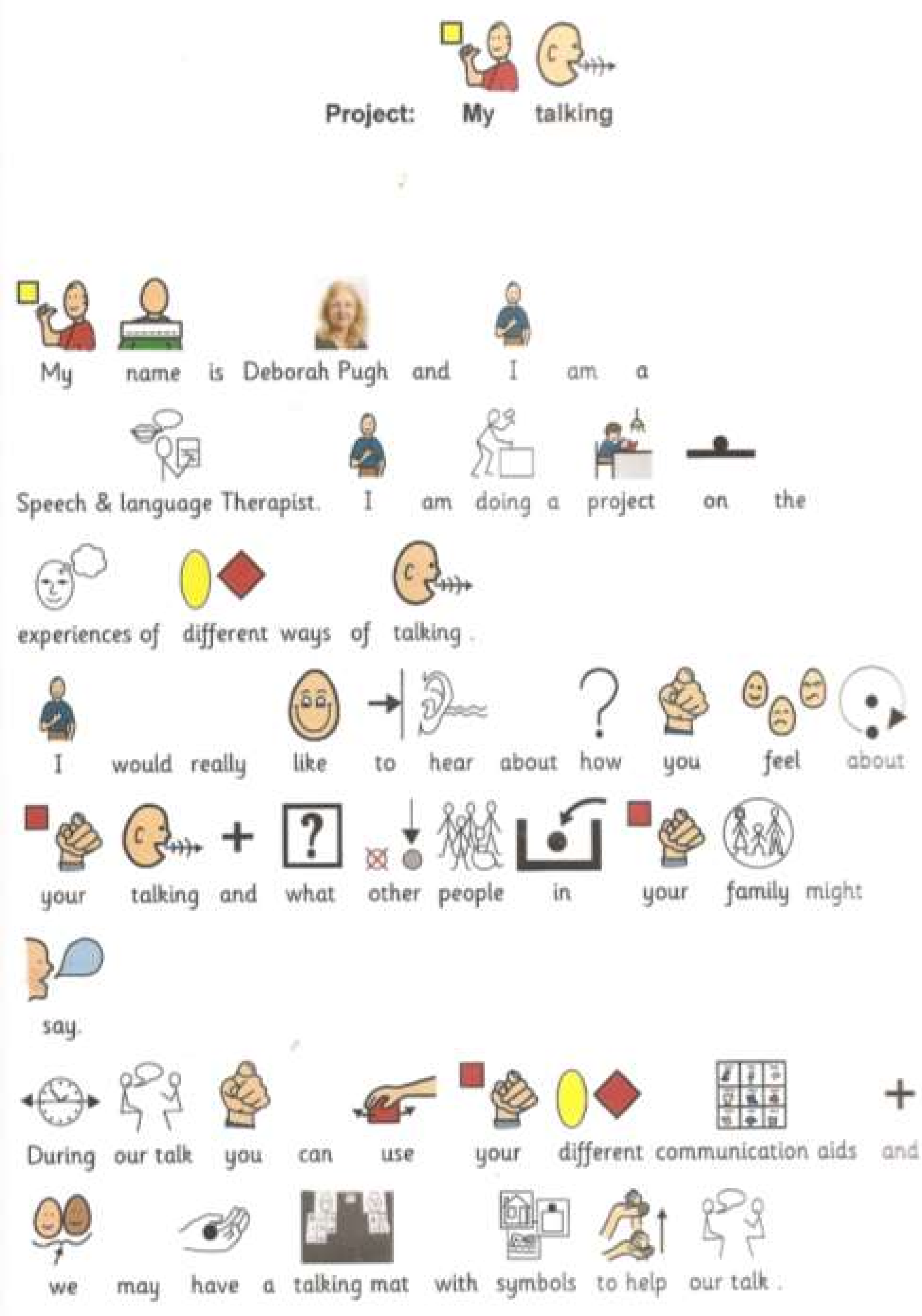
School of Health
University of Northampton
Park Campus
Boughton Green Road
Northampton
NN2 7AL
Professor Susan Corr (email: susan.corr@northampon.ac.uk)
Dr Sarah Neill (email: sarah.neill@northampton.ac.uk)

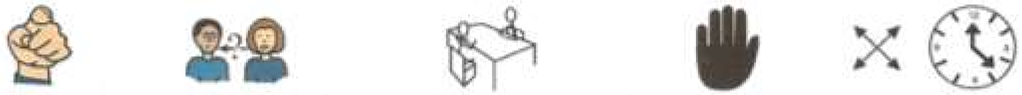
Appendix 12: Visual consent form



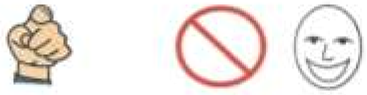
Project: My talking

My name is Deborah Pugh and I am a
Speech & language Therapist. I am doing a project on the
experiences of different ways of talking.
I would really like to hear about how you feel about
your talking and what other people in your family might
say.
During our talk you can use your different communication aids and
we may have a talking mat with symbols to help our talk.

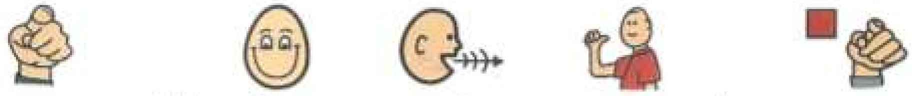
The interview will be recorded. What you say will be private.



You can ask for the interview to be stopped at any time if



you are not happy.

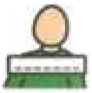


... If you would like to talk to me about your

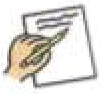
communication, please let me know.

☐ yes ☐ no

yes no

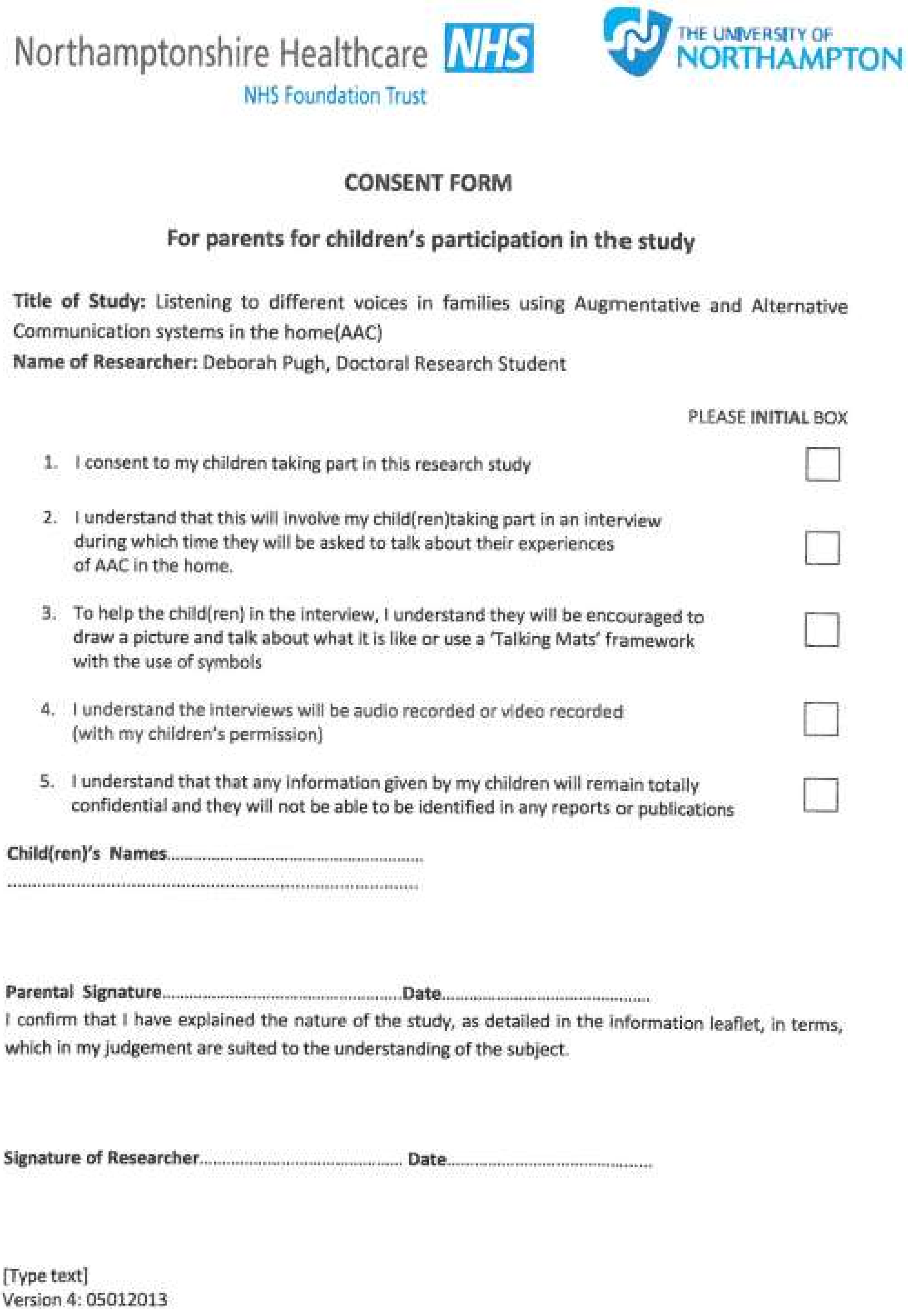


name . ...



sign ....

Appendix 13: Consent for children's participation



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CONSENT FORM

For parents for children's participation in the study

Title of Study: Listening to different voices in families using Augmentative and Alternative Communication systems in the home(AAC)
Name of Researcher: Deborah Pugh, Doctoral Research Student

PLEASE **INITIAL** BOX

1. I consent to my children taking part in this research study ☐
2. I understand that this will involve my child(ren)taking part in an interview during which time they will be asked to talk about their experiences of AAC in the home. ☐
3. To help the child(ren) in the interview, I understand they will be encouraged to draw a picture and talk about what it is like or use a 'Talking Mats' framework with the use of symbols ☐
4. I understand the interviews will be audio recorded or video recorded (with my children's permission) ☐
5. I understand that that any information given by my children will remain totally confidential and they will not be able to be identified in any reports or publications ☐

Child(ren)'s Names...
....

Parental Signature..**Date**..

I confirm that I have explained the nature of the study, as detailed in the information leaflet, in terms, which in my judgement are suited to the understanding of the subject.

Signature of Researcher.. **Date**...

[Type text]
Version 4: 05012013

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ASSENT FORM FOR CHILDREN

(To be completed by the child and their parent/guardian)

Title of Study: Listening to different voices in families using Alternative Communication systems in the home

Child/ young person (or if unable parent on their behalf) to circle all they agree with

Have you read (or had read to you) about this project?	Yes/No
Has anyone else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy to take part?	Yes/No

If any answers are 'no' or you don't want to take part don't sign your name

If you do want to take part, you can write your name below or ask your parent to do it for you

Your name...

Date:..............................

The researcher who explained this project to you needs to sign too

Name...

Date:..................................

Version 2: 06012013

Appendix 14: Talking Mats

Talking Mats can be used as a clinical tool and as a research method for children with communication difficulties. The researcher is an accredited trainer in Talking Mats and has extensive experience of using them in her work with children with complex communication needs.

Talking Mats Research

Talking Mats are grounded in research and used to determine the views of children and young people who use AAC (Clarke et al., 2001). Cameron and Murphy (2002) evaluated the effectiveness of Talking Mats as a communication resource to enable people with a learning disability to express their views on life planning. They interviewed 48 participants on four separate occasions over a four month period. Their findings identified Talking Mats improves the quality of an interaction with people with a learning disability but their effectiveness directly relates to the participant's level of understanding. They determined adults and children who can only understand at a one word comprehension level are unable to use Talking Mats reliably. During a 3 year research study into multi-agency services for children with complex healthcare needs, Watson et al (2006) used a variety of innovative methods including Talking Mats to engage children in the research. In their study over half the children had no verbal communication and for the majority of children their parents acted as advocates. Although the researchers reported challenges, the parents and children valued being listened to and the research provided insight into the lives of the families.

The research of McKay and Murphy (2012) supported the use of Talking Mats as a more effective framework than interviewing alone. More recently Talking Mats were used to enable AAC users in Scotland to give their views on services which can be used to inform service delivery. Children with profound and complex learning difficulties have also used Talking Mats and Whitehurst (2006) researched the perspectives of 6 young people to elicit the children's views on inclusion.

Brewster (2004) used Talking Mats with two people with learning disabilities and reported there was a danger of '*putting words into their mouths'* (p.169). When interviewing people with complex communication difficulties, the vocabulary has to be selected for them and Grove et al. (1999) argue that authenticity, credibility and trustworthiness of the researcher are paramount when interviewing people who use AAC. Brewster (2004) reported the use of video may help monitor the interviewer's influences and ensure a shared responsibility of the Talking Mat.

The children's use of Talking Mats: engagement with the researcher

The children demonstrated both their ability to take control during the interview and assertiveness during the process. This was shown in interview F2I2 where the child terminated the interaction by selecting the 'stop' card and in interview F5I2 where the child on seeing a symbol of a 'digger' navigated through his pages to show the researcher different transport symbols he was interested in. Sharing power with the children and young people in the interviews was a positive experience which enabled the completion of a Talking Mat which both the child and parent valued. Some of the children used single words and vocalisations to communicate alongside the use of Talking Mats and they were able to use a verbal or nonverbal response for 'yes' and 'no' to confirm their choices. Five of the six children interviewed were able to reliably express their preferences but the scores of one child were unreliable on analysis using the Effectiveness Framework For Functional Communication (EFFC) and subsequently were not used in the findings.

Acquiescence is often seen as a particular difficulty when interviewing people with a learning disability (Sigelman et al, 1981) where there is a potential for biased information in terms of participants choosing the 'right' answer. This did not seem to be a problem as the children were often very clear in their likes and their dislikes. Cameron and Murphy (2000) considered the use of Talking Mats may reduce acquiescence. For some children further sub-mats were explored which considered the positive and negative aspects of their communication systems.

Participants

Six children who used different communication systems were interviewed using a Talking Mat framework. Four of the children were educated in a Special school, one child in a Designated Special Provision (DSP) attached to a Primary school and one in a mainstream Primary school.

Sally: Talking Mat: F112

Sally[6] is twelve years of age and uses a combination of vocalisations, signing, an iPad with the gridplayer app and a low tech symbol book to communicate and the same communication systems are used both at home and school. Sally placed each of the symbols carefully on the Mat and spent time looking at the symbol prior to placing it. During the interview she placed the iPad and PECs book on the positive side of her mat.

Positive	Negative
Mirror	Shopping
Feeding ducks	books
PECs book	Lorries (traffic)
Disco	
iPad (communication device)	
Playground	
Trampoline	

---

[6] Names have been changed to protect the identity of the participants

Jack: Talking Mat: F8I4

Jack is 6 years of age and uses a range of different communication systems including symbol boards, a symbol schedule and an iPad with a communication app. During the Mat he used a clear 'yes' and 'no' verbal response to confirm his choices. He used some speech during the interview mainly single words which were unclear. He used his communication device during the session to find a photograph of his school. He placed the symbol of his communication device on the positive side of the mat

Positive	Unsure	Negative
ipad (communication device)		Cinema
School		Swimming
Pub		Shopping
Television		
Park		
Party		
Music		

Ben: Talking Mat: F2I2

Ben is 10 years of age. He communicates at home through the use of symbols, vocalisations and a communication device. He uses his communication device predominantly with his mother and younger brother at home and with his teaching assistant in school. He completed the Talking Mat quickly with the support of his brother. He placed the symbols on the mat and was clear with his responses and these were affirmed by his younger brother during the interview. He used the /stop/ symbol at the end of the interview to indicate he had finished. He viewed his communication aid positively.

Positive	Negative
Seaside	Singing
Park	Shopping
Horse riding	Computer/laptop
Bike	Bowling
Dancing	
Birthdays	
Proxtalker (Communication device)	

Ethan: Talking Mat: F5I2

Ethan was 10 years of age and an enthusiastic communicator using a combination of signs, speech and his iPad with gridplayer app. He uses his iPad in a range of different situations. The initial mat showed he was positive about many topics and placed his communication device on the positive side of his mat.

Positive	Unsure	Negative
Bike riding		Showers
Diggers		
Dinosaurs		
Drawing		
Computer		
iPad (communication device)		
Restaurants/Pub		
Speech		

A sub-mat was used to elicit his further views on his communication device, both in terms of its appearance, voice, vocabulary and its use with others in his environment.

The sub-mat showed he was positive about his communication device and used it at school with both his teacher and friends. When given the symbol of home and asked ‘How do you feel about using it at home?’ he placed the symbol on the negative side of the mat. On discussion with his mother, she felt it maybe as a result of him using more speech at home as they were able to understand his vocalisations whereas outside the family he was very difficult to understand.

Positive	Unsure	Negative
Size		Using at home
With Friends		
Using at school		
Using with teacher		
Voice		
Words		
Using it outside (playground)		
Carrying it		
Appearance (‘look’)		

Tom: Talking Mat: F10I2

Tom was five years of age in a mainstream school. He used signing, a symbol based communication book and a Tablet SB10 communication device with The Grid 2 software and speech to communicate.

Positive	Unsure	Negative
Computer		Soft play
Playing with Friends		Noisy places
Books		
Cartoons		
Trains		
Fire engines		
Television		
Communication device		
Communication book		

A sub-mat was used to elicit his further views on his communication device. This showed he was positive about his communication device and used it at home and school with a range of adults and children. Using the device in the playground and carrying the device he placed on the negative side of his mat. He also indicated he did not like the quality of the voice and used his communication device to indicate he thought the voice was ‘funny’. On discussion with his mother she confirmed he did not like carrying his SB10 but this was not specifically related to his communication device as he also disliked carrying his school bag and his coat as well. She planned to review the quality of the voice on the communication with her AAC team.

Positive	Unsure	Negative
Using at home		Carrying device
Weight of device		Voice on device
Words (vocabulary)		
Using at school		
Size		
Using with family		
Charging		
Ease of use		

Reflections

All of the children engaged with the researcher and enjoyed the adult attention both prior to data collection and during the Talking Mat.

The children had different levels of understanding and used a range of communication systems. For some of the children their understanding of language was at a ‘concrete’ level operating only in the here and now. Two of the children had more abstract understanding and sub-mats to explore particular features of their communication system were used. The top scale was limited to two or three symbols but interestingly those children who had the /unsure/ symbol available did not use it during the interviews.

The children had varying levels of attention and some engaged for limited amounts of time and as a result the number of symbols to be placed was reduced accordingly. The introduction of Talking Mats was new for some of the children, parents or teaching assistants who on completion of the interview believed they could be a useful tool for the child to express their opinions.

Due to limitations in time, the children were only seen on 2-3 occasions and the Talking Mat provided only a snapshot of their views. The use of Talking Mats over a longer period time may help support the children further when expressing their thoughts and views on their communication systems.

References

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Cameron, L and Murphy, J (2002). Enabling young people with a learning disability to make choices at a time of transition, *British Journal of Learning Disabilities*, **30** pp. 105-112.

Cameron, L and Murphy, J. (2000). *Making Choices at the time of transition for young people with learning disability* [online] http://www.talkingmats.com/research-consultancy/research/

Clarke, M. McConachie, M. Price, K. and Wood, P. (2001). Views of young people using augmentative and alternative communication systems. *International Journal of Language & Communication Disorders,* **36**, pp. 107-115.

Grove, N. Porter, J. Bunning, K. and Olsson, C. (1999). Interpreting the meaning of communication by people with severe and profound intellectual disabilities: theoretical and methodological issues, *Journal of Applied Research in Intellectual Disabilities*, **23**, pp.190-203

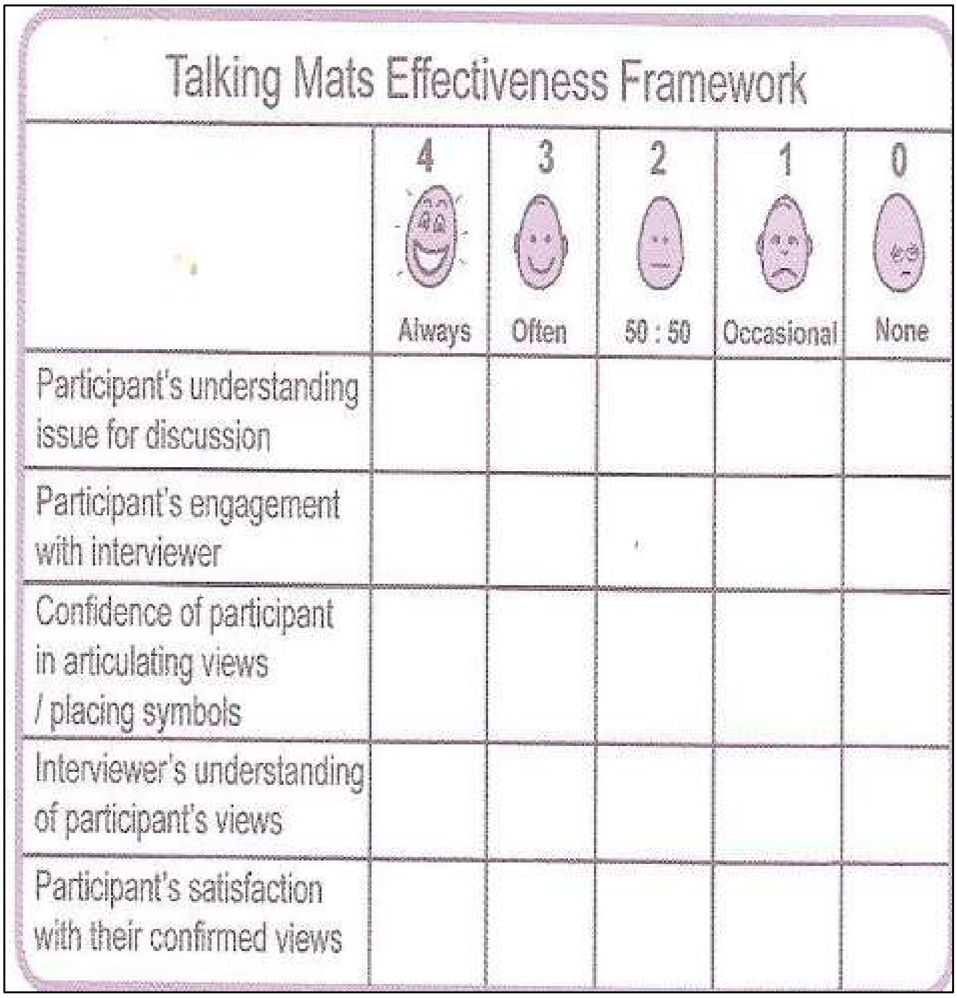
Mackay, M and Murphy, J. (2011) *Talking Mats and The World Health Organisation (WHO) International Classification of Functioning Disability and Health Children and Youth(ICF-CY): a unique tool for helping adolescents set targets* [online] http://www.talkingmats.com/research-consultancy/research/

Siegelman, C.K. Budd, E.C. Spanhel, C. L. and Schoenrock, C.J. (1981). 'When in doubt say yes: acquiescence in interviews with mentally retarded people' *Mental Retardation* **19** pp.53-58

Watson, D., Abbott, D. and Townsley, R. (2006). Listen to me too! Lessons from involving children with complex healthcare needs in research about multi-agency service. *Child: Care, Health and Development,* **33**, (1) pp.90-95

Whitehurst, T. (2006). Liberating silent voices-perspectives of children with profound & complex learning needs on inclusion *British Journal of Learning Disabilities, **35***(1), pp.55-61.

Appendix 15: Effectiveness Framework for Functional Communication



Talking Mats Effectiveness Framework

	4 Always	3 Often	2 50 : 50	1 Occasional	0 None
Participant's understanding issue for discussion					
Participant's engagement with interviewer					
Confidence of participant in articulating views / placing symbols					
Interviewer's understanding of participant's views					
Participant's satisfaction with their confirmed views					

Permission gained to use image from www.talkingmats.com

Appendix 16: Communication Systems used by the children and families in the study

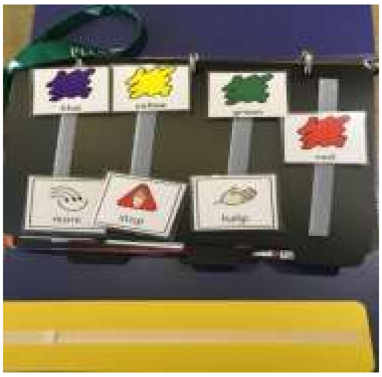
Low Tech AAC used by the children in the study

PODD communication book: PODD stands for Pragmatic (ways that we use language socially), Organisation (words and symbols arranged in a systematic way), and Dynamic Display (changing pages). Devised by Gayle Porter, a speech pathologist with the Cerebral Palsy Education Centre (CPEC) in Victoria, Australia.

Communication books are a way of representing speech / sentences and usually contain a large variety of symbols and words organised into different categories. The individual is required to point to the symbols to make up the sentence: they may or may not be able to speak the message as they do this. One of the most common formats in the UK are category based and many based on *'Developing & Using a Communication Book'* by Clare Latham.

(By Various (www.joereddington.com/communikate) [CC BY-SA 4.0 (http://creativecommons.org/licenses/by-sa/4.0)], via Wikimedia Commons)

Picture Exchange Communication (PECs) PECS was developed in 1985 as a augmentative/alternative communication intervention package for individuals with autism spectrum disorder and related developmental disabilities. PECs begins teaching an individual to give a picture for a desired item and is based on verbal prompting and reinforcement strategies. There are six phases to PECs. It is used widely in the UK.



High tech AAC used by the children in the study

IPad series

(By Various (www.joereddington.com/communikate) [CC BY-SA 4.0 (http://creativecommons.org/licenses/by-sa/4.0)], via Wikimedia Commons)

The IPad was a popular mobile communication device with different apps. There are a wide range of AAC apps but those used by parents and children were:

- **MyChoicePad** uses Makaton, a language programme that supports spoken words with Symbols and Signs

- **Sounding Board** comes with pre-loaded communication boards organized in 13 categories such as Control (e.g. "Please stop!"), Emergency Help (e.g. "My home address is..."), Expressions, Money, Reading, Shopping, and Workplace

- **Prologuo2Go** is a symbol-supported communication app designed to promote growth of communication skills and foster language development its vocabulary. Symbols are presented in category based pages.

Tablet computer

A small tablet computer was used by some children in the study with mainly The Grid2 software. The children were using the Grid 2 software for their communication with symbol talker A or B for communication. The Grid 2 software gives alternative access to communication, computer access and environmental control.

Proxtalker

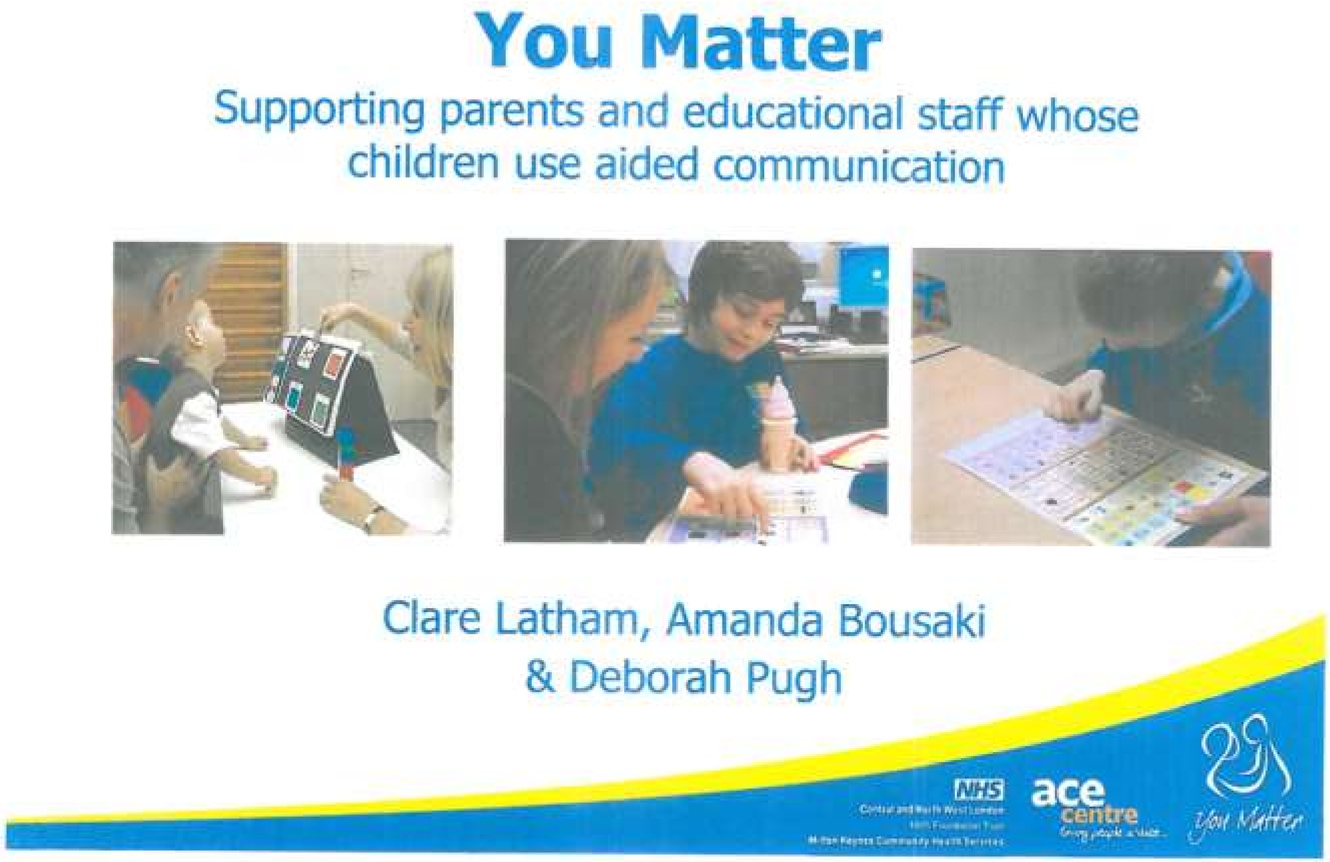
The LOGANPROXTALKER is a communication device which uses RFID technology to retrieve vocabulary stored on sound tags to produce real words. It has been used with Picture Exchange System (PECs) users and provides a link between low and high tech AAC

Eye-gaze Technology (children were using Tobii C12 series)

For many people who have difficulty physically using a computer, eye gaze technology can offer a quick and easy to understand way of accessing different software.

Appendix 17: Images of Research (University of Northampton)

Appendix 18: You Matter (revised 2015)



You Matter

Supporting parents and educational staff whose
children use aided communication

Clare Latham, Amanda Bousaki
& Deborah Pugh

NHS
Central and North West London
NHS Foundation Trust
Milton Keynes Community Health Services

ace centre
Giving people a voice...

You Matter

Appendix 19: Reflections on the research journey

The Research Journey (October 2015)

I applied for the doctoral programme in July 2010 following the initial excitement at gaining a master’s qualification in Special Educational needs at MMU. However the place was not confirmed until October 2010, by which time I doubted whether I had the time or ability to complete a course at doctoral level. Five years seemed an incredibly long time to study as well as working four days a week. The first session of the doctoral course was particularly daunting with a lecture on epistemology and the theory of knowledge. I came away feeling I was definitely not going to achieve the academic standards necessary and questioned why I had applied in the first place. I initially considered studying at a doctoral level as a way to consolidate the skills I had gained through my master’s degree and viewed it as an opportunity to acquire more knowledge particularly on research methodologies to support my clinical work. After this first session, I think my decision to carry on was also based on my general approach of ‘not giving up’ at the first hurdle!

The first two years of modules suited my own style of learning and organisation where module deadlines needed to be met. Although each module had its challenges I found their application to my clinical practice (e.g. conducting an audit of the workplace) really helpful particularly in my role on a multi-disciplinary AAC team. As I entered the third year of study, I had high expectations for my research project, having selected a mixed methods approach using quantitative and qualitative data. However I soon realised this was unrealistic both in terms of time and the appropriateness of the methodology for my study. The aim of my research evolved from my own clinical experience of working with families who used AAC and the strategies they used to integrate AAC in the home. The challenge at this stage was to understand and use the most appropriate methodology. I researched many qualitative methods, attended seminars at the University and spoke to supervisors and lecturers. It was at this point I attended a Grounded Theory Forum and my interest in Grounded Theory was sparked. I also read an article on the use of Grounded Theory in Speech and Language Therapy (Skeat, 2008) and its potential for informing research and clinical practice. Attendance at the Forum and the many discussions in my supervisory meetings supported my understanding of grounded theory and the application of a Chamazian grounded theory for this study. It was important for me to develop the findings beyond description to a more conceptual understanding of the families' perspectives on AAC but also to retain the voices of my participants in the writing of the theory.

The experience of undergoing NHS ethics was time consuming and challenging. Although the attendance at the ethics panel was daunting, it highlighted the ethical challenges of interviewing families and children. It was with much relief that I had provided sufficient evidence and consideration of the issues involved. Following approval I started recruitment and was surprised how willing families were to participate and give their time to support the research. Undertaking the interviews was an inspiring experience, even though I work with families using AAC, the interviews were insightful and I felt privileged to hear the accounts and experiences of the families. In previous research I had used a semi-structured interview approach and I was a little apprehensive about using a more unstructured interview style and whether this would create awkward silences. The first interview was conducted one evening with a mother and father and I realised my worries were unfounded as they were extremely welcoming with the interview lasting over two hours. In the interviews with the families I was struck by mothers' advocacy for their children ensuring they were not 'written off' just because of their disabilities. The constant juggling and the multiple roles they held in the family was also evident. Most of the families adhered to more traditional gender roles.

For some of the families their child's health issues had a profound effect on their family functioning. I have also experienced the effects of long term illness with my youngest son being diagnosed with a childhood cancer when he was four years old. One of the striking elements of the interviews was the maternal guilt at not being able to do enough for their child and the significant steps taken to balance the needs of all the family. The interviews allowed me to reflect on my own practice and how particularly in the early years as a Speech and Language Therapist, I found it difficult to understand why some families did not carry out the advice given. The research has supported my belief in offering flexible services and encouraging communication and partnership with families in a non-judgemental way. The interviews showed me how difficult it is to bring up a child with a disability and the devastating impact of the initial diagnosis. Even families of older children still recalled the time of the diagnosis with much sadness even though they had seemingly adapted to having a child with a disability.

Throughout the process I have experienced the associated highs and lows of research. As a result I kept a journal allowing me space to record my initial reactions and decisions and to be able to look back at them and analyse the factors behind those decision making processes, to see how my thought processes changed throughout the course of the doctorate. Further challenges with the study were connected to using the procedures associated with grounded theory. These were especially time-consuming as data analysis and data collection was simultaneous. Arriving at a conclusion from the large number of codes which were initially generated and constructing a comprehensible representation of their relationships was also something which I found daunting. NVivo supported me in early initial and focused coding but theoretical coding was the most difficult aspect of the whole process. As a ‘novice grounded theorist’ I found it difficult to move away from a descriptive level of coding to look at more theoretical concepts. This final phase of the research took a very long time and caused many sleepless nights. I also resorted to having a notebook beside the bed to record any ‘eureka’ moments in the middle of in the night. The writing of the theory clarified some of the higher conceptual level concepts but a fine balance was needed between writing conceptually and describing the families’ experiences in the most faithful way.

Towards the end of writing the thesis I was again filled with self-doubt with changes in work (reorganisation and redundancy of posts) and family illness affected the amount of time available for writing and the subsequent later than anticipated submission date. However as I near the end of the doctoral process, although it has been challenging it has greatly supported my understanding of families using AAC and significantly developed my clinical practice.