

**CHILDREN WITH LEARNING DISABILITIES AND  
CHALLENGING BEHAVIOUR:**

**An IPA study exploring how key stakeholders construct meanings around  
challenging behaviour and how this affects people's relationships and  
experiences of giving and receiving help.**

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## **i: ABSTRACT**

This multi-perspectival Interpretive Phenomenological Analysis (IPA) study explored how people in the 'networks of concern' talked about how they tried to make sense of the challenging behaviours of four children with severe learning disabilities. The study also aimed to explore what affected relationships between people.

The study focussed on 4 children through interviewing their mothers, their teachers and the Camhs Learning Disability team members who were working with them. Two fathers also joined part of the interviews. All interviews were conducted separately using a semi-structured approach. IPA allowed both a consideration of the participant's lived experiences and 'objects of concern' and a deconstruction of the multiple contexts of people's lives, with a particular focus on disability. The analysis rendered five themes: the importance of love and affection, the difficulties, and the differences of living with a challenging child, the importance of being able to make sense of the challenges and the value of good relationships between people. Findings were interpreted through the lens of CMM (Coordinated Management of Meaning), which facilitated a systemic deconstruction and reconstruction of the findings. The research found that making sense of the challenges was a key concern for parents. Sharing meanings were important for people's relationships with each other, including employing diagnostic and behavioural narratives. The importance of context is also highlighted including a consideration of how societal views of disability have an influence on people in the 'network of concern' around the child. A range of systemic approaches, methods and techniques are suggested as one way of improving services to these children and their families. It is suggested that adopting a 'both/and' position is important in such work - *both* applying evidence based approaches *and* being alert to and exploring the different ways people try and make sense of the children's challenges. Implications for practice included helping professionals be alert to their constructions and professional narratives, slowing the pace with families, staying close to the concerns of families and addressing network issues.

**Key words:** challenging behaviour; children with severe learning disabilities, autism, behavioural, narrative, systemic, context, IPA, CMM, normalisation.

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**vii: Abbreviations:**

ABC chart	Antecedent Behaviour Consequences chart
ASD	Autistic Spectrum Disorder
Camhs	Child and Adolescent Mental Health Service
LD	Learning Disability
MLD	Mild Learning Disability
SLD	Severe Learning Disability
The children	Coding used for quotes:
F	Fraser
H	Hayleigh
S	Shirley
T	Tahir
Participants	
M	Mother
F	Father
P	Team Member (Professional)
T	Teacher



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## **CHAPTER 1: INTRODUCTION TO THE THESIS AND TO THE AUTHOR**

This research thesis explores the ways in which people make sense of children labelled as moderately to severely learning disabled whose behaviours can be experienced as 'challenging' and how this meaning making helps people to coordinate their efforts to manage these challenges and/or creates patterns of confusion and dissent. The research also takes account of the many contexts of people's lives including constructions of 'disability' and how these produce and constrain us all.

To begin this thesis I wish to be clear about where I position myself. To undertake qualitative research one takes responsibility for the reality he or she constructs, whilst being aware that this reality is only one possible construction among many (Krull, 1989). Important questions to ask are: What explanations does the writer have for choosing a topic? Why are certain arguments selected? Given the writer's values and beliefs, what other ideas might have been overlooked? I have reflected on these questions in order to create a multiverse of ideas, a position that is congruent with systemic thinking. These questions are addressed in various ways throughout this thesis. As a starting point I describe the "writer observing personal self" and the "writer observing professional self" (Fine and Turner, 1991).

### **1:1 Writer observing personal self**

During introductory family therapy training in 1988 I was asked, "What drew you to family therapy?" I have revisited this question many times over the years. Stories I tell myself include those from my family of origin, an attraction to a multiverse of ideas, an invitation to be endlessly curious and an attention to the uses and abuses of power. I have found it harder to answer the questions, 'What has attracted me to working with people with learning disabilities and children?' and, 'Why am I interested in this research topic?' Three things come to mind. Firstly, living with a challenging sibling as I grew up allowed an insider perspective on family life and a personal interest in this area. Secondly, learning disabilities services have always been a Cinderella service, not attracting funding or staff; aligning myself with the less able, the less fortunate and wanting to be different have been life long traits perhaps relating to family of origin issues and power. Thirdly, I found being a parent of young children hard and had little support from wider family in this task. Thus I wish to help those

who may feel alone and unsupported. I will return to these issues at times to explore how they both constrain my thinking and how they have created possibilities.

### **1:2 Writer observing professional self**

I have been very fortunate in my career to have worked in various settings, including large and small institutions for people with learning disabilities and mental health problems and in community settings with children labelled as having mental health difficulties (Camhs: Child and Adolescent Mental Health Services) and learning disabilities, and with adults with learning disabilities and those with mental health problems. I have really valued my learning in all of these settings, which linked to my enthusiasm and passion for systemic ideas, where multiplicity and variety are embraced.

#### **Position statement: Learning Disabilities.**

I began working in the NHS as a clinical psychologist based in a large psychiatric institution. My main role was psychometric testing which seemed to add little to people's lives. As a department of two, we also covered two smaller 'subnormality hospitals'. I found much more job satisfaction getting to know the men and women who lived in one of them. At that time (mid 70's) people who had been placed there many years ago as 'moral defectives' were being re-housed in the community. I recall Hilda and Harry's joy at their freedom when they moved into their own flat.

Following a period in Hong Kong being a mum of young children and working with children with disabilities who did not fit into the mainstream expatriate education system, I returned to working in a very forward looking learning disabilities service where I learnt about 'normalisation', a value base which challenges the discriminatory aspects of society. Following a brief spell in a very poor service (later the subject of a national enquiry), I moved to working with children, to an adult mental health service, then back to learning disabilities, initially in services for adults then latterly in the children's learning disability service which is the focus of this research.

I am struck how, in adult learning disability services, discriminatory aspects of services and society are writ large and how much of my work has been to challenge this. This bias is less obvious in children's services. Given my commitment to valuing people, I have kept this thought in mind while writing

this thesis in an attempt to avoid falling into ways of thinking and practice that are potentially devaluing of people.

**Position statement: Systemic approaches.**

I have chosen two quotes that begin to state my position in relation to the systemic ideas that underpin this research. Firstly, **the links between relationships, meanings and actions.**

A systemic approach explores the networks of significant relationships of which each individual is a part, considering the beliefs that give meaning to people's actions and the communication patterns between people as they interact with each other and with each other's ideas.

(KCC website, 2008)

As Dallos (1991, p.142) asserted, "action and construing are inextricably linked." This is an early systemic idea and has to some extent been overtaken by more social constructionist understandings of meaning making, where deconstructing the context is seen as essential. Thus the second quote below, is about **the importance of context:**

... it is not sufficient to focus only on the child or the child within the family; it is also necessary to consider the family within the larger social, economic and political contexts.....A critical aspect of this wider system is, of course, the service provision structure.

Keen and Knox 2004, p.56

My understanding of contexts is broad and includes awareness of self and others coordinating and creating meaning contextualised by various layers including; personal, professional, political, social and cultural forces. Inherent in these ideas is that changes of meaning at any level can have implications for meaning making at other levels.

**The importance of language** is the third guiding value that links the preceding ideas and underpins my thinking and writing. The first section of the literature review discusses labelling and language in more detail. I am aware of sensitivities around language when the words used attempt to encapsulate aspects of people's lives that can be discriminated against. I have, at times, used the language of families and of the other research participants. At other times I have privileged my own ideas. However, I am aware that we are all subject to influences that can inadvertently lead to language that excludes and discriminates against people. Terms are deconstructed and discussed at various points in the thesis.

The importance of language, meaning, relationships and context lies at the heart of the systemic endeavour for me. To bring forth these ideas I have drawn on the following systemic ideas that I have found useful over the years and have gained further richness and meaning through my work with families and other professionals. They are:

**Curiosity:** Selvini-Palazzoli et al.'s (1980) and Cecchin's (1987) papers on Hypothesising, Circularity and Neutrality were amongst the first papers I read when I originally encountered systemic family therapy. The core concepts of: openness to many ideas while being aware of one's own constructions; being experienced as on everyone's side and on no one's; and, introducing difference through hypothesising and questioning are still with me thirty years on and have underpinned all aspect of this research project. At its best, neutrality represents an active non-judgemental stance that challenges peoples' beliefs in such a way as to facilitate change (Cecchin, 1987). However, it is important to remember that, as MacKinnon and Miller (1987) argue, "social ideology is invisible to those immersed in it" (1987,p.148).

**Reflexivity:** Burnham (2005) defines self-reflexivity as;

A process in which a therapist makes, takes, or grasps an opportunity to observe, listen to, and question the effects of their practice, then use their responses to their observation/listening to decide "how to go on" in the particular episode or the work in general.

Burnham, 2005, p.3

Willig (2001) advocates for *reflexivity* (author's use of italics) when discussing feminist critiques of the claims of 'objective' research.

Researchers reflect upon their own standpoint in relation to the phenomena they are studying and to attempt to identify the ways in which such standpoint has shaped the research process and findings.

Willig, 2001, p.7

Dallos and Vetere (2005, p.50) also stress the importance of reflexivity in qualitative approaches suggesting that the interpretation of data will in part be shaped by "the researcher's own belief, experiences and attitudes".

**Second order, social constructionist approaches:** Lynn Hoffman (1985) drew attention to a shift in the systemic field in the 1980's from expert to non-expert collaborative approaches. The implication for therapists who wished to take this idea seriously was that they would have to abandon their

'objective' stance and immerse themselves in a larger system that included themselves, the family and the wider context (Hoffman, 1988). Gergen (1985) proposed that our understanding of the world is socially and historically situated and results from repeated social interactions. These ideas are gaining ground in the field of learning disabilities studies (e.g. Clegg, 1993 and Nunkoosing, 2000). Thus there is a shift of focus from the person with a learning disability to the wider systems in which they are embedded including "the system of power that maintains their disablement" (Nunkoosing and Laurelet, 2011, p.407).

**Power:** What interests me about power is a passionate desire to deconstruct the sources of power, to not abuse my power, and to help others to feel in charge of their lives. In order to deconstruct these sources I draw on those aspects of ourselves which may be discriminated against using Social GRRRAACCEEESSS<sup>1</sup> (Burnham, 2012). Of particular interest for this thesis are; ability (disability), gender, culture, and education, although other aspects may come into play when grappling with power and difference.

As I also want to hold in mind issues of health, medicalizing discourses and pathology, I have also drawn on the ideas of Michel Foucault. Foucault argues that power 'produces reality'. He is at his most devastating in his critiques of mental health services across the ages (Foucault, 1967). There are a number of writers in the systemic field who have drawn on Foucault's ideas. Of particular note are White and Epston (1990) who warn against locating our practices within those discourses that claim an objective 'truth' status including scientific, medical discourses of the mental health field.

**Evidence based practice and research:**

Part of the culture of the NHS currently is a drive towards the adoption of evidence-based practice. What makes a difference to whom? Systemic psychotherapy is developing a strong evidence base in some areas (Stratton 2005). However, there is little research into working systemically with people with learning disabilities. Purdy (2012) in his review of systemic approaches to learning disabilities argues that family therapists have much

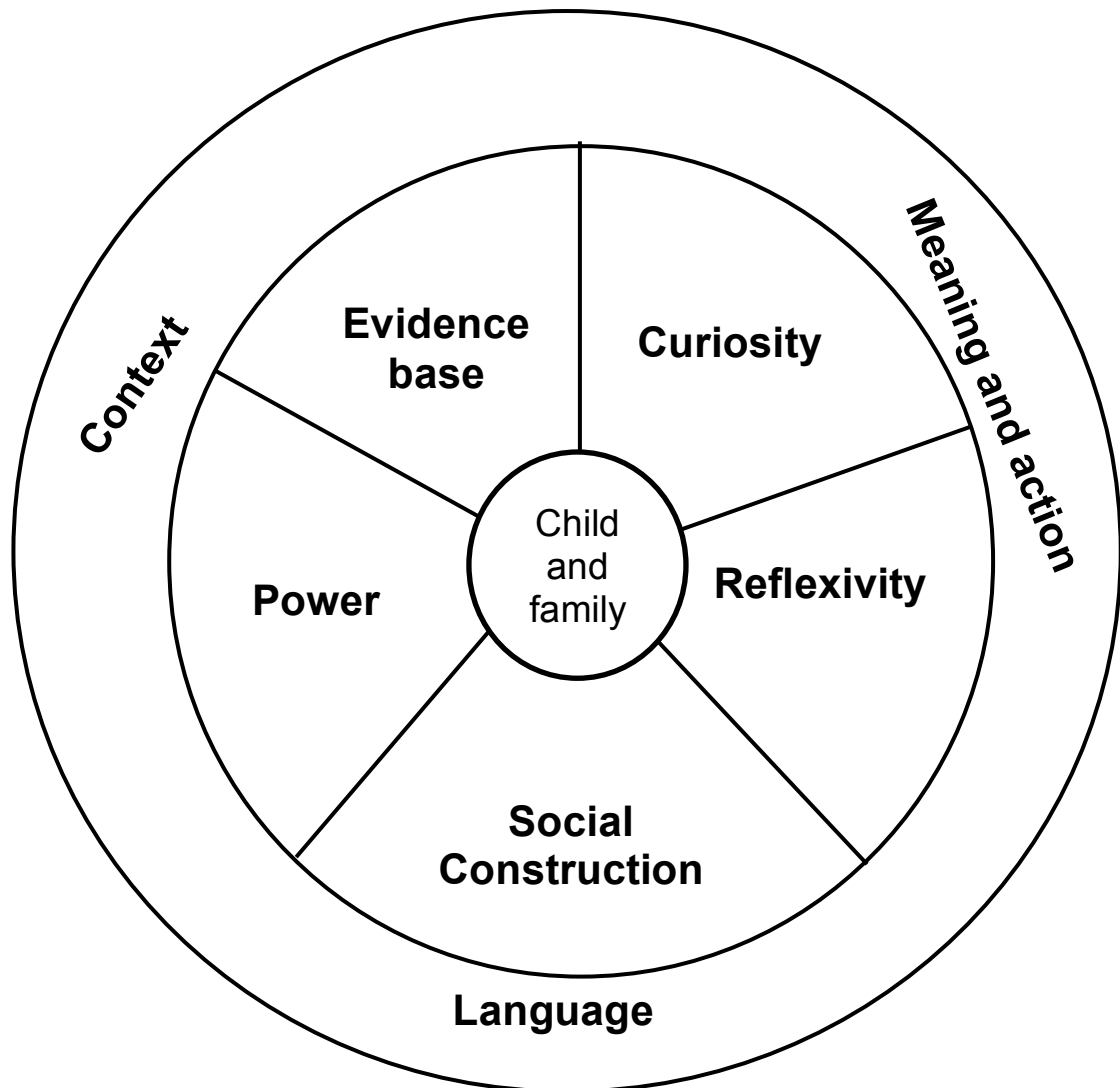
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<sup>1</sup> Gender, Geography, Race, Religion, Age, Ability, Appearance, Class, Culture, Ethnicity, Education, Employment, Sexuality, Sexual Orientation and Spirituality.

to offer the field, and I strongly agree. The research base is covered in more detail in the literature review.

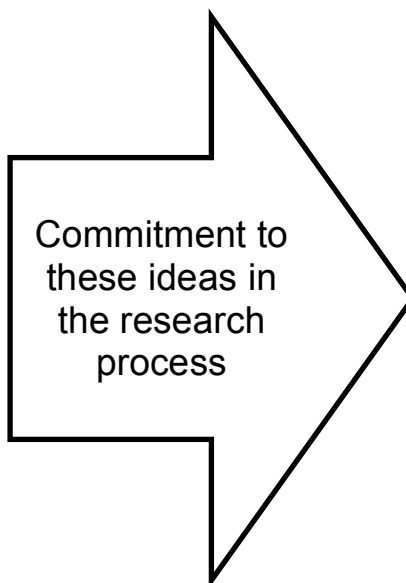
Figure 1 summaries these positions and places the child and his/her family at the centre of my thinking and practice. I have located the three key ideas of meaning, language and context in the perimeter to indicate how they contextualise the systemic ideas they surround; all of these ideas influence and are influenced by each other. I am committed to underpinning this research with these ideas although I am aware of how challenging this can be. However, I do hope that out of this work “More good things will happen; and, less bad things will happen” (Fullan, 2001, p.4).

**FIGURE 1: Key ideas underpinning this thesis: A systemic framework**



Research Principles

- Collaborative
- Emancipatory
- Sensitive
- Reflective
- Do-able





### 1:3 Key orientations for the psychotherapy researcher

Dallos et al (2005, pp.3-5) outline five core orientations for psychotherapy researchers. The themes are summarised below to illustrate how the systemic ideas outlined above are applied to this project:

- *Collaborative research: To actively involve participants and colleagues, and the wider systemic community in the development, analysis, dissemination and recommendations of the research. To do research 'with' rather than 'on' people.* In developing the research I spoke to colleagues in my team, systemic colleagues and the research group at the Tavistock Centre where the work was supervised. These conversations helped me to shape my ideas. On-going conversations with a variety of stakeholders helped me to develop and shape my findings and the generosity of others has assisted me in completing the analysis and write up. I am aware that I might have used parents more to develop my ideas but, as I was no longer working in the service, this proved to be too difficult.
- *Emancipatory research: To give participants, particularly as mental health service users and workers a strong sense of being listened to and that what they had to say was important.* I attended closely to this aspect: in developing the materials supporting the project (leaflet and letters); in the way that consent was gained; and, in the way that I interviewed people. As I concluded each interview I asked how people had found it. Most people mentioned positive aspects of the process.
- *Sensitive research: To be sensitive to the meaning and experience of the participants' connections with mental health services and the research itself. To explore what was/is helpful and unhelpful.* This aspect was at the heart of my interest, and is discussed extensively in the analysis and discussion sections.
- *Reflective research: To reflect upon the researcher's own experiences and the connections with the project aims, interpretation of results and relationships with the participants.* I have begun to do this in the section on reflexivity earlier in this chapter and continue throughout the analysis and discussion section, adding my voice as reflection and critique.
- *Do-able research: For the research to be practicable and connected to*

*the researcher's role as a clinician.* As stated above, situating the research in my team made this possible. I reflect later on the differences it has made to me as a clinician, the implications of the research and what had changed already. I have also reflected on the problems, as well as the possibilities, with undertaking my research interviews with colleagues. In planning the research I attempted to make it do-able, for example, by just interviewing one person. As I know from clinical experience, trying to find a quiet time at home when mums and dads are both available can be difficult. In fact I was fortunate in having two dads participate, which was a bonus. I had hoped that my chosen methodology (Interpretive Phenomenological Analysis: IPA) would prove to be fairly straightforward as the literature seems to present a step-by-step process for the novice researcher.

#### **1:4 Structure of the thesis**

This thesis is made up of 6 chapters.

Chapter 1 introduces the reader to the topic and to the systemic ideas that influence the author and begins to consider my orientation as a systemic researcher.

Chapter 2 outlines the national, international and local research contexts, arguing that services are often experienced as unhelpful and fragmentary. The research questions are stated, following a rationale for the research.

Chapter 3 summarises academic literature relating to: language and terminology used to describe people with learning disabilities and 'challenging behaviour'; common approaches to challenging behaviour; systemic approaches with people with learning disabilities and their families; and, how mental health researchers and practitioners make sense of challenging behaviour.

Chapter 4 covers all aspects of the research design including ethical issues.

Chapter 5 describes the analysis and findings in detail collating the results as a series of themes.

Chapter 6 discusses the themes as they relate to the existing literature and draws out implications, ending with ideas for further research, critiques of this study and some personal reflections.

## CHAPTER 2: RATIONALE FOR THE RESEARCH QUESTIONS

In this thesis I argue that there is a gap in our understanding of how the meaning making of people who form the “network of concern” (Vetere and Dallos, 2003, 182) around a child with learning disabilities, whose behaviours are experienced as challenging, promotes or constrains how people coordinate their actions to alleviate these challenges. Vetere et al. (2003) argue that families with a child with disabilities<sup>2</sup> may experience shrinking social networks and a concomitant expanding of professional networks. They advocate for a mapping of this ‘network of concern’ “showing clearly who is already involved with the family and why, what the history of liaison has been and what mechanisms exist for dealing with any differences and disagreements over the care of the child”. (p.182) I include family members in the ‘network of concern’ and wish to explore the links between context, meaning making and relationships and how these influence people, positively and/or negatively when trying to ameliorate difficult situations.

### **A small story:**

Glenda (not her real name) was referred to me some years ago because she was not eating. Glenda was a tiny lady with physical difficulties, bright eyes and an iron grip. She lived in a house with three other people who were learning disabled. She was thin and frail. She was said to be refusing to eat and would strike out at people who tried to help her at mealtimes. I quickly discovered that this was not always the case. If she took her meals in her room with a favourite member of staff she would eat and not hit anyone. Meeting with different members of staff I learned that people held lots of different ideas about this state of affairs. “She is trying it on.” “She has to learn to eat with the other residents.” “It is more important she eats so let her do what she wants.” “We can’t have one rule for her and a different one for everyone else” and so on. These different beliefs were a source of friction between staff members and prevented people from deciding what to do for the best for Glenda. The solution was not working with Glenda, but working with the staff.

<sup>2</sup> I have mainly used the term children with disabilities rather than children with a disability to indicate that the children in this study were labeled as moderately or severely learning disabled indicating many disabilities rather than one disability. It also indicates the many ways in which children and their families are further disabled by social, psychological and political factors.

This example illustrates how there was little disagreement about what was worrying the people who cared for Glenda (not eating and hitting). However people understood her behaviour in different ways and favoured conflicting solutions. Further, I found that this conflict had a negative effect on staff member's relationships with each other and with Glenda. I have had many similar experiences working with families, schools, professionals and children in the care system over the years. This piece of research explores these issues further.

## **2:1 National and International Context**

The government's white paper Every Child Matters (2008) identified:

We know from practice that children and families who require support from a number of specialist professionals often receive fragmented and sometimes contradictory services such as:

- Children and parents having too many professionals involved with them, sometimes giving conflicting and confusing advice on how best to meet the child's needs
- Children and young people receiving short-term, inconsistent or conflicting support from different professionals, and so losing trust and confidence in services or failing to receive the right support at the right time.

DCFS: ECM: 2008

Further, McGill, Papachristoforou and Cooper (2006) writing from the Tizard Centre in Kent reported that most carers of children with learning disabilities and challenging behaviour were dissatisfied with the support and the services they received.

In the USA, Marshak, Seligman and Prezant (1999, p.254) in their book 'Disability and the Family Life Cycle' end with a section on 'Therapeutic Interventions', citing various authors who report outcomes as 'discouraging'.

They list three problematic areas:

1. 'Failed communication': the use of jargon that distances people; disregarding the big picture and focussing on specifics; and, lack of information about the nature and implications of the child's disability.
2. 'Professional concerns': including burnout due to stressful jobs; anxiety evoked by disability; difficulties in empathising with the concerns of families; allowing interruptions e.g. phone calls which are experienced as disrespectful by families; and, biases towards certain family

members; and

3. 'Differing world-views': people coming from different perspectives which they argue puts people in conflict with each other. Darling (1991) argued that professional's worldviews are shaped by their clinical trainings and socialisation in a stigmatising society. She viewed this as leading to blaming the victim, belief in professional dominance and belief in the medical model. These points are still very pertinent 25 years later.

McGill et al. (2006) sampled parents, who were looking after seriously challenging children (their language), and who received some sort of professional intervention. They noted that much of this was experienced as unhelpful. They suggested that qualitative research would be well placed to explore this in greater detail.

Keen et al (2004, p.55) writing specifically about working with children with challenging behaviour and learning disabilities drew on 'family systems theory' and conclude that it is essential to consider the social, economic and political aspects of people's lives. Key aspects included are: the family as embedded in a societal system; the interrelatedness of family members; and, life cycle issues. They go on to talk about the need to empower families and to see them as the experts in their children's lives.

This literature paints a picture of families wanting support but experiencing professionals and services as either absent, inconsistent or unhelpful. Dunst, Trivette, and Deal, (1994) outlines four aspects of effective help-giving, which include good communication, good relationships, helping families feel understood and responsiveness to family values etc. (cited in Vetere et al, 2003.) The importance of the wider contexts of people's lives is also highlighted.

## **2:2 Local Service Context**

The finding that families experience services as fragmentary and giving contradictory advice has been replicated in work undertaken in the city where I work and forms the basis of the Disabled Children's Strategy (Disabled Children's Steering Group, 2006). This strategy was based on large-scale data drawn from national studies and local stakeholder events.

## **2:3 My Work Context**

In the last five years of my career I have been privileged to lead a

multidisciplinary team of staff working with children with learning disabilities and their families<sup>3</sup>. At the time of the research I was employed as a Clinical Lead and Consultant Clinical Psychologist in a specialist Camhs Learning Disability Service; a child mental health service for children and young people (age 0-19<sup>th</sup> birthday) with moderate and severe learning disabilities who were referred with 'mental health problems'. Most referrals to the team mention in some way 'behaviours causing concern' or 'challenging behaviour'. The team is situated in a large city in the middle of the UK, which had many areas of social deprivation and high numbers of people of different ethnicities, (population of about one million people). Referrals received often include people from black and minority ethnic populations (BME) and people living in poverty as these groups make up a significant proportion of the population. The team was made up of administrative staff, clinical psychologists, nurses, psychiatrists and social workers. The main models applied by team members were behavioural approaches and the medical model. Individual members had a variety of other interests and frameworks, including disability rights and systemic, psychodynamic and attachment approaches. As clinical lead, I was keen to embed this research in my team to promote the value of research, to make the findings as applicable as possible and to have some opportunities of influencing the practice of others.

I have stated that families experience services as unhelpful at times. Given my clinical experience I was interested to explore in detail what helped people in very difficult and sometimes dangerous situations and what was not experienced as helpful. Given my interest in systemic approaches I was interested in context, meanings and relationships. The overarching aim of the research project was to investigate the lived experience of caring for a child with learning disabilities and challenging behaviour and the experiences of professionals working with these children. Within this overarching aim I was curious about the sense people made of the behaviours, how this may or may not have led to ways of alleviating the impact of these behaviours and/or the distress of families and the young person, and finally, how people got on with each other and whether or not this was linked to how useful they found each

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<sup>3</sup> I retired from this role in August 2012.

other.

## **2:4 Research Questions:**

This study aimed to explore the following questions.

1. How do family members talk<sup>4</sup> about their child with learning disabilities, who has been referred to a Camhs Learning Disability for 'challenging behaviour'?
2. How do professionals in the 'network of concern', specifically teachers and Camhs team members involved with the child, talk about the child and their family?
3. Whether and in what ways this 'talk' is linked to strategies that are hoped to help the children live their lives without resorting to behaviours that are experienced as distressing or frightening;
4. How do people in the 'network of concern' describe relationships between them and how might different ways of 'talking' about the children affect these relationships?
5. In what ways are people affected by wider social, historical and professional contextual factors relating to disability?

The next section reviews relevant aspects of the literature, including: terminology; approaches commonly applied to people with learning disabilities experienced as 'challenging'; systemic approaches, and meaning making. I argue that there is a gap in the literature exploring these inter-related themes.

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I have use the term 'talk about' as a clearer description of my intention to interview people, although I assert that talk both represents meaning for people as well as social action. 'Talk about' includes descriptions of the behaviours, making sense of the behaviours and describing what was seen as helpful or unhelpful.

### CHAPTER 3: LITERATURE REVIEW

My clinical interest in the research questions came from long involvement working with children and adults with learning disabilities and their families. Often these referrals were framed in terms of 'challenging behaviour'. Clinically, I had noticed that people - parents, teachers, social workers, mental health professionals and others had different ways of making sense of the behaviours that they were experiencing as 'challenging' and that these constructions influenced whether ideas/suggestions were experienced as helpful or unhelpful, useful or not useful. Given my interest in systemic approaches, I have worked with these different explanations and believed that my involvement was rarely successful unless these differences could be acknowledged and accommodated into some agreement about a way forward, which positively incorporated people's views. It seemed that in systems where blame and counter-blame are rife, work rarely flourished. This perspective is supported in the following quote from a parent of a child depicted as "non-verbal" and having "a diagnosis of autistic spectrum disorder" (Anon, 2011, p.13). The writer is also a family therapist working with people with learning disabilities and posits a dual vision.

However I have been thinking more about 'relational reflexivity' recently. If we can, at least, acknowledge such differences arise from the complexity of systems organised around a particular challenge, and ensure all positions are heard and respected, then there are more possibilities to engage constructively with each other.

Anon, 2011, p.13

Further, Nunkoosing et al (2011, p.405) draw attention to the way in which referrals position the person, adults referred to a Community Learning Disabilities team in this case, as "a problem to be solved, as in need of surveillance, and show evidence of the routinisation of daily life, surveillance, and mortification of the self". Referrals rarely deconstructed the condition of people's lives and the power relations alluded to by Nunkoosing et al. (2011). In this literature review I argue that writings about the interconnected themes of learning disabilities, challenging behaviour, how people are embedded in powerfully devaluing contexts, and the effect that these have on meanings and relationships have had scant attention.



### **3:1 Terminology: Learning Disability**

Language can be problematic when writing about people who are labelled as learning disabled, intellectually disabled, mentally handicapped, or mentally retarded. If one is to take social constructionism seriously, one cannot act without an understanding of how constructions of disability and 'challenging behaviour' create and maintain our ideas, beliefs and actions. Valerie Sinason (1992) argues that we have struggled to find terms to refer to life-long impairments of cognitive and social functioning. Terms that to our contemporary ear sound pejorative, for example 'subnormality', were originally coined with honourable intentions. She makes the case that negative perceptions and feelings about disability become associated with the term so in an attempt to get rid of these negative connotations a new term is found. Inevitably because the original stigmatisation has not been addressed, the new term subsequently becomes stigmatising.

The World Health Organisation (WHO, 1980) distinguishes between impairment - the loss or abnormality of structure or function, and disability - the restriction resulting from impairment". This is echoed in the definition of 'disability' (WHO, 2001), accepted by 191 countries (Roosen, 2009), "as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers he/she may face". Restriction is viewed as both imposed by society, with the rights of disabled people lagging far behind those of other groups (Oliver, 1990 and Marks, 1999), and constrained by aspects integral to the person. Marks (1999, p.79), elaborating the social model of disability, "locates disability not in an impaired or malfunctioning body, but in an excluding and oppressive social environment". Oliver (1990) views people with disabilities as disadvantaged and marginalized in society and suggests the emphasis on impairments in medicine has encouraged a 'tragedy discourse' and oppression. Further Goodley and Lawthom (2005, p.136) critique psychology as, a "pathologising, voyeuristic, individualizing, impairment-obsessed discipline that has contributed to the exclusion of people with impairments". (Quoted in Roosen, 2009). Wilcox, Finlay, and Edmonds (2006) have summarised some of the main problems with labelling.

Research studies conducted from within a social-constructionist approach have suggested that constructions of learning disability and 'mental retardation' serve to demean those so labelled, and construct

them as objects of cultural fear ... legitimate the social control of people with learning disabilities through the construction of 'defective' identities ... silence the versions of events proposed by people with learning disabilities ... and move focus from contextual factors, to factors said to be inside the person.

Wilcox et al., 2006, p.199.

Mehan (1996) used a single case study design to look at how wider social knowledge and power regimes impact the creation of the identity of a boy as learning disabled. This approach drew on the writing of Michel Foucault and used an ethno-methodological approach<sup>5</sup>. Mehan (1996) plotted the process by which a child became labelled as learning disabled. He described the forms of expertise that were used to assign and manage this label and the power relations afforded to certain people. This approach is echoed in the work of Nunkoosing et al. (2011). They use Critical Discourse Analysis to explore how referrals of people with challenging behaviour are positioned as problematic and legitimise various oppressive practices by paid carers and professionals. These critiques have led to changes in policy focussed on changing society rather than changing the individual (Disability Discrimination Act 1995 and 2005; Valuing People, 2001 and Equality Act, 2010). All of these apply mainly to adults.

The above paints a grim picture of an excluding society that further disadvantages people with impairments. These powerful discourses have been with me while undertaking this research. I have tried to hold them in mind but have at times been caught up in them, probably more in the interview phase. This is reflected upon as I develop my ideas.

Critiques of the social model of disability have focused on the exclusion of an understanding that people's impairments inadvertently place unrealistic expectations on people (Clegg, 2006). Goodley and colleagues (Goodley, 2001; Goodley and Lawthorne, 2006; Goodley and Roets, 2008) explore the complex relationship between individuals and their social worlds. These authors argue for the need to explore the space between the binary of medical and social models of disability. This is of particular interest to me, as an exclusively social constructionist view of disability does not sit easily when I see how affected the children I have known can be. Adopting a both/and position will be argued later. Roosen, 2009 goes further outlining the need to understand our different models of disability. These include: the medical model - the impaired; the social

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<sup>5</sup> Taping meetings, looking at records, observing in the classroom etc.

model - the oppressed; humanistic model - the human; and, the cultural model - the Crips (her word as a disabled person, perhaps designed to shock although not further elaborated). She argues that there are possibilities and restraints in all of these positions. Finally, she proposes 'A Disability Affirmative model', where the task is to draw out the client's understanding of disability (and I would add the family's), to explore the positive aspects of the disability, whilst acknowledging that disability is not a unitary context. Tierney (2011) summarises this debate in her doctoral thesis, saying,

The word dis-ability is hyphenated throughout to deconstruct and provide challenge to the application of static constructs of dis-ability and to examine/highlight, the simultaneous multiple occupancy of other positions. It is also used in this way to highlight the disabling nature of labels, and places a focus on the dichotomies of ability and dis-ability.

Tierney, 2011, p.1

The term most often used in the UK at this time is 'learning disability'. The terms mental retardation and/or developmental disability are used in the USA. The term 'intellectual disability' is found in much of the international literature and is favoured by the International Association for the Scientific Study of Intellectual Disabilities (IASSID), an interdisciplinary non-governmental body connected to the World Health Organisation. Throughout this thesis, the terms children or people with learning disabilities are employed. I have chosen learning disabilities as it is generally adopted in the UK and as Baum (2006) states, "a concept of "learning" seems to encompass a notion of social activity and relatedness". In talking about a child with learning disabilities I recognise that that people with learning disabilities prefer to have the word 'people' first. I have chosen not to use the term dis-ability as suggested by Tierney (2011). I really like and agree with the implications of this term but feel that I wish to stay close to the language of the participants in this study, including my own. I agree that, "... labels serve to avoid acknowledgement of power differences" (Marks, 1999, p.150), and that whatever label is used it will be subject to the difficulties identified by Sinason above. In adopting these labels I am mindful of the importance of the social construction of language and will reflect on the societal dimension of how I, and others, use language and construct meaning. From a systemic perspective, I am interested in these contextual factors and how the construction of 'damaged identities' might affect the understandings of

and relationships between those people caring for and working with children with challenging behaviour, including myself.

### **3:2 Terminology: Challenging behaviour**

Challenging behaviour is the term that has been coined within the learning disabilities field to attempt to place behaviour experienced as problematic and dangerous to self and others as a challenge to services, families and carers rather than inherent in the person concerned – a hopeful, relational definition. However, the following most commonly used definitions imply that the behaviours originate within a person or persons and prevent their access to wider participation in society, rather than an appreciation that many intrapersonal, interpersonal/relational and contextual factors might be involved.

‘Challenging behaviour’ is defined as ‘culturally abnormal behaviour of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities

Emerson, 1995, pp.4–5

Severe behavior problems in individuals with developmental disabilities include self-injury, violent tantrums, aggression against others, and property destruction. These types of behaviors are dangerous to the individuals themselves as well as to others and prevent participation in the community. Hence, these behaviors limit the individual's opportunities for community living, employment, and education

Reeve and Carr 2000, p.144

These statements describe both the behaviour itself and the consequences of the behaviour, however they lack the interactional or contextual focus which the term ‘challenging to others’ initially promised. Nunkoosing (2000, p.58) describes how challenging behaviour is a term limited to learning disabilities and suggests “people with challenging behaviours are also people who have exhausted the limits of our knowledge and actions” (Nunkoosing, 2000, p.58). He suggests that the initial hope that the term ‘challenging to services’ has been lost through the “colonisation of the person by the health care enterprise”. There has been little research that has drawn on a social constructionist view of challenging behaviour, although recent NICE guidance (2015)<sup>6</sup> states,

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<sup>6</sup> Worryingly, this guideline is limited to care settings provided by health or social care, thus excluding children living at home, who may end up in long term care when families can no longer cope. Rather too late perhaps.

“Challenging behaviour’ or ‘behaviour that challenges’ can therefore be seen as a socially constructed concept that is the product of individual and environmental factors interacting”. I have continued to use the term challenging behaviour throughout this thesis, partly as it is the language of services in which I am embedded, but also as an attempt to reclaim its initial meaning and to reflect more on the relational and contextual nature of the term.

### **3:3 Approaches to challenging behaviour**

#### **3:3:1 Behavioural Approaches**

There is an extensive literature on interventions with adults and children who are experienced as ‘challenging’. Initially the work applied operant conditioning principles to autistic children and people with learning disabilities (Azrin and Holtz, 1966, Yule and Carr, 1980). These approaches, founded in behavioural analysis, were based on the principles of operant conditioning (Skinner, 1972). They asserted that all behaviour was triggered by environmental events or maintained by the behaviour of others, a potentially contextual approach. However, this led to heavy reliance on punitive methods. This has been replaced by positive behavioural support, including the importance of the family’s quality of life, support, and an exploration of the communicative aspects of the behaviour (Koegel, Koegel, and Dunlap, 1996; McGill and Toogood, 1994). This shift has been influenced by the closure of the large institutions, the ideology of normalisation (Wolfensberger, 1972), later re-named social role valorisation (Wolfensberger, 1983), the rise of the advocacy movement (Simons, 1992) and the disability right movement (Marks, 1999). Positive behavioural support recruits professional carers or families to become part of the ‘treatment’ of the person. This approach includes:

- Assessment, focussing on an analysis of the environment, considers the fit between the needs of the person and the contexts in which they operate. For example, finding out that someone with autism, who is very stressed by crowds, spends a significant part of his or her time in busy and crowded environments.
- The teaching of new skills which attempt to help the person learn new ways to engage in more meaningful and enjoyable activities, to be able to communicate their feelings more appropriately and to learn skills in tolerating life’s stresses.
- The application of positive behavioural support in the form of schedules of

reinforcement targeted at reducing the occurrence of challenging behaviour.

- Reactive strategies which help parents or carers avoid or escape from dangerous situations
- ‘Mediator analysis’, which considers how possible it is for all people concerned to adopt these ideas, mainly from a practical point of view.

(LaVigna and Donnellan, 1986).

Whilst this approach is underpinned by a behavioural<sup>7</sup> epistemology, there are limited overlaps with systemic approaches in the environmental fit and mediator analysis sections. However as Rhodes et al. (2011) asserts:

One of the current limitations of applied behaviour analysis is its failure to adequately consider the complexities of family relationships. Traditional models of mediator analysis (LaVigna & Donnellan, 1986) do not sufficiently differentiate between employed professionals and family members.

Rhodes et al., 2011, p.72

Additionally, I would argue that this approach has little interest in family beliefs about parenting or their past experiences of help or professionals - areas of interest to the systemic practitioner. Neither does it include a critique of a ‘disabling society’. Much of positive behavioural support research has been conducted within a traditional scientific paradigm, and researchers have sought to gain access to ‘truths’ which are presumed to exist, independent of those seeking access to them (Wilcox et al., 2006).

There are many journals packed full of ideas for working with children with challenging behaviour, which draw on behavioural and cognitive behavioural principles. The dominant discourse concerning behaviourally based practice cannot be ignored when working with children with learning disabilities as it has been shown to be effective, albeit within a positivist tradition which I critique in chapter 4. Sturmey (2005) goes so far as to claim that psychotherapy for people with learning disabilities has a poor evidence base and should be avoided in favour of behavioural interventions. I do not agree with this position, as clinically I have found systemic psychotherapy of great value and have had good feedback from families. There is also an increasing literature to support a wide range of approaches, including systemic psychotherapy.

As stated previously, one of the dominant discourses in the team I worked

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<sup>7</sup> Behaviourism is firmly rooted in positivism, where there is assumed to be a reliable, predictable relationship between world and our understanding of it.

within and the wider learning disability field is behavioural. My initial training as a psychologist was heavily biased towards these approaches. However, when I came to apply these ideas, I found that they sometimes worked well but that there were times when people disengaged or couldn't apply the ideas. Rather than put this failure down to families, I wished to look for different approaches that offered more hope and success. It was at that time I was attracted to systemic ideas, which offered different ways of thinking and practising. Much of the work in the Camhs LD Team remains behavioural, from simple suggestions about reward charts and time-out, to complex multi-faceted behavioural support plans as outlined by LaVigna et al. (1986). So while there is evidence to support the use of behaviourally based programmes, I agree with Rhodes et al. (2011) that families can rarely successfully implement these complex programmes in full, as they require controllable environments and few other demands. I argue that other ways of working with people are needed. In my view, if we only offer behavioural and medical interventions, this will leave some families feeling frustrated and dissatisfied.

Behavioural interventions focus on a thorough assessment of the person who is experienced as challenging, not on the people who find the behaviour difficult. Interventions are designed to change the environment in many ways. That is the people around the child are expected to change and do things differently. Systemically, this seems flawed in a number of ways. There is no exploration of people's beliefs about the behaviours and why they are considered to be difficult. Although there is a nod to 'mediator analysis' there is little consideration of whether the changes suggested are acceptable to or manageable by the people who are expected to implement them. Questions about how the ideas fit for people and how easy or difficult they are to implement are not included. In my experience, behaviourally focussed clinicians who attend to these contextual factors are more likely to be successful compared with those who make suggestions with little or no exploration of other factors. I am not aware of any literature on this topic and thus hope that my research will illuminate some of these issues.

As a researcher, I have attempted to be curious about the approaches of my colleagues and other professional and to explore this fit for families. However, as a clinician, I have found that my experiences have at times drawn me to

judge the work of others. Working systemically promotes greater systemic empathy and curiosity of these different approaches.

### **3:3:2 Family Supports**

A second approach, predominantly developed in the USA, puts significant effort into providing quality support to families who have a child with a disability. Building cohesive and reciprocal family relationships is seen as the goal, offering support in the form of respite and providing practical help in the home are seen as ways of alleviating stress and reducing family breakdown (Turnbull and Ruef 1996 and 1997). Seligman and Darling (1997) applied a systems approach to childhood disability. They drew on the structural ideas of Minuchin (1974). Turnbull and Turnbull (1990) write about family structure, family interaction and family function. Carter and McGoldrick, (1989) explored the concept of family life cycle suggesting that problems often arise at points of transition. This approach is further developed by Marshak and colleagues (1999) who devoted a book to 'Disability and the Family Life Cycle'. I note that this work was some time ago and was not present in the current literature.

### **3:4 Systemic approaches with persons defined as learning disabled**

Published articles and books applying systemic approaches to working with people with learning disabilities are limited in number although the field is growing. There is little discussion of working with school-aged children with learning disabilities in the UK, although more from the USA and some from Australia. The lack of systemic research into children with learning disabilities in the UK context is a major gap in research and practice.

The following literature comes predominantly from working with adults.

Evans and Midence (1999) suggested that family therapy can be useful for people with a learning disability for a number of reasons, including:

- Family therapy aims to facilitate social relationships (an area where people with a learning disability commonly experience problems);
- Psychological therapy from other fields has been shown to be of value; and
- Families of a person with learning disabilities may experience particular types of stress.

Vetere (1993) proposed a structural model of family therapy. This was considered appropriate for people with learning disabilities due to the focus on



problem solving and establishing boundaries between generations. More recently narrative therapy has been the focus of various articles (Robbins 2004, Lyngaard & Scior 2002, Scior & Lyngaard, 2006, Hoole and Morgan, 2008). Coles (2001), writing in the context of counselling in Australia, advocated a solution-focused approach. None of these approaches include the importance of wider contexts or our constructions of disability. Rhodes and colleagues (Rhodes et al. 2011, Rhodes et al., 2014 a and b.) propose a network consultation model, which has been thoroughly research and shown to be effective. This is discussed in greater detail in the discussion and implications chapter.

A range of practice-based papers provides useful examples and illustrations of family therapy with this client group. For example, Halliday & Robbins (2006) described a lifespan family therapy service, where family therapy is offered to all client groups, not exclusively learning disabilities. In doing this they comment on the similarities in themes that emerged and the parallels in resources that people had to help them change (determination, creativity, resilience). Fuchs, Mattison, and Sugden, (2003) and Donati et al., (2000) have written about other examples of family services. Common themes include: reflections on issues of power for people who are traditionally disempowered, themes of loss, grief and adjustment (Goldberg et al., 1995); communication, which is a particular issue for people with learning disabilities; life cycle issues; and, working with complex networks (Vetere and Dallos, 2003). Dowling and Dolan (2001) draw attention to socioeconomic inequalities experienced by families with a disabled member. Fidell (2000, p322) concluded that a team had more difficulty in remaining 'systemic', possibly due to 'the number of different perspectives which need to be held in mind at the same time in order to be successful'. Much of the above literature is descriptive and based on clinical experience. Whilst not being rooted in rigorous research methodologies, they provide ideas and inspiration for further exploration. There is little process or outcome research, although Pote (2006), Baum (2006), and Rikberg Smyly et al., (2008) provide a few examples, all concluding that systemic work can be very valuable.

This brief review of UK literature demonstrates that what has been written mostly concentrates on systemic work with adults with learning disabilities and their families/care environments. Further exploration of these ideas as applied

to children with learning disabilities is needed and should become part of the agenda for systemic practitioners and researchers.

Harris (1982, 1984 a & b, 1987) in the USA was perhaps the first person to describe the application of family therapy to working with children with learning disabilities, autism and challenging behaviour. Working structurally (Minuchin, 1974), Harris identified structural deficits which involved problems between parental and sibling subsystems. These included, stresses in the marital subsystem, with one parent becoming 'over-involved' and the other disengaging, 'parentified' siblings, and over-involved or under-involved grandparents. She also examined the potential difficulties when professionals applying behavioural techniques failed to be sensitive to the context. The solution to these issues was seen to be parent training. These ideas originated at a time when narrative and postmodern ideas had hardly influenced the field. In my view these ideas sound too certain and 'expert'. However, such hypotheses may be useful if co-constructed with families.

Birch (1985), in Australia, developed the concept of 'timelessness'. He saw parents getting stuck at particular points in the family life cycle, unable to move on. This echoes the ideas of Goldberg and colleagues (1985) working with adults in the UK, who developed four linked hypotheses relating to 'stuckness' around grief. These hypotheses are: that families may have had long experience of working with professionals over many years; that the family has difficulty in moving to the next life cycle stage and that this is related to issues of protection; that patterns of grieving are related to intergenerational patterns of relationships over the years; and, that each life cycle transition involves loss as well as gain (Goldberg et al., 1985).

Mitchell and Winslade (1997) saw as critical the understanding of the meanings or stories underpinning the interaction of the various systems around and within families. Trimble (2001, p.473) applied an "an integrative, multisystem clinical approach to the psychological and relational problems that develop around learning disabilities". He describes working across the boundaries between children, families and schools, and describes soothing "inflammation at the boundaries". He advocates for specialist knowledge of working with families and a good understanding of neurodevelopmental issues. Two specific methods are described: charting strengths and weaknesses and mapping learning functions.

He sees this approach as deriving from post-modern narrative traditions while retaining modernist scientific knowledge. He draws attention to the potential for 'shaming and blaming' narratives to arise as children struggle to learn. This accords with some of my ideas and experiences from clinical practice, which underpin this research, although the children spoken about in the article had what, in the UK, would be referred to as 'learning difficulties' not learning disabilities.

Finally, I mention Purdy (2012) who brings together many of these ideas in an amusing and thought-provoking article. He reviewed the systemic literature on working with adults with learning disabilities and argued that many standard systemic 'approaches, methods and techniques' (Burnham, 1992) are both applicable and useful when working with people with learning disabilities although may need some modifications. For example:

Using simplified language, a slower pace, checking understanding frequently, concretizing processes and concepts of time and not privileging verbal language over other forms of communication such as behaviour, the use of drawing, showing, genograms, photos or video.

Purdy, 2012, p.424

In considering the systemic literature with people with learning disabilities I wish to highlight the following. Much of the published material was written in the last thirty years, with little being written very recently. Most of the published material is descriptively clinical and generally does not discuss the methodological position of the writers. There is limited consideration of some of the dominant narratives around disability and their effect on clients, the writers or their work, and most of the work especially from the UK is about adults often living in care homes and not about children living with their families. There are many useful ideas of interest to the clinician and I have drawn on much of this work in my practice, however as a researcher I found less that I could connect with, although have used these ideas where possible in considering my findings..

### **3:5 How people make sense of 'challenging behaviour'**

The idea of making sense of challenging behaviour can be viewed through the lens of attribution theory (Heider, 1958). This is concerned with the thoughts

people have about events and what causes<sup>8</sup> them (Munton, et al., 1999). Dix et al. (1986) using attributional models of social cognition, examining parents' inferences about everyday child behaviours. They assert that:

Parents must frequently assess what is going on with their children. They must determine why particular child behaviors are occurring; infer the needs, motives, and limitations in their children that may underlie those behaviors; and select parenting responses that they think their assessments of behavior imply.

Dix et al., 1986, p.879

This statement lies at the heart of my hypothesis that parents' responses, emotional and practical, to their children's challenging behaviour are mediated by their meaning making about the child's 'motives, needs and limitations' - an example of mentalization as described by Fonagy et al. (2002), an approach which is gaining interest in the systemic field. Hassall and Rose (2005) in their literature review of 'parental cognitions and the demands of caring for a child with an intellectual disability' conclude that'

There is good evidence from a large range of studies that parents form attributions for their children's behaviour and that significant associations can be established between these attributions and both parent and child characteristics (Miller, 1995).

Hassall and Rose, 2005, p.77

They also suggest, "there are few published empirical studies looking at the attributions made by parents for children with an intellectual disability". (Hassall and Rose, 2005, p.80). There are, however, a few examples. Himelstein, Graham, and Weiner, (1991) found that mothers of children receiving special education were more likely to attribute good behaviour to internal characteristics and negative behaviour to external causes. Similarly a study from the USA of Latino mothers of children with developmental disabilities found that most mothers did not view their children as being responsible for their problem behaviours (Chavira, et al., 2000). Dix et al., (1986) found that, as children get older, parents are tend to hold the children responsible for their actions. They suggest that this is linked to the parents seeing,

"advances in development in children's knowledge, ability, and control over behavior and, second, because they hold beliefs, in part culturally determined, about when human competencies emerge"

Dix et al., 1986, p.889

Dix, Ruble and Zambarano (1989) also found that as parents begin to hold their

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<sup>8</sup> Causality is rejected within systemic epistemologies which favour more circular recursive connection.

children responsible for their behaviours they are more likely to use assertive and powerful forms of discipline. Although Dix et al.'s (1989) research does not look at the parenting of children with disabilities; their work might imply that parents of developmentally delayed children are less likely to hold the children responsible for their challenges. This is supported by the previous two studies quoted. However, Armstrong and Dagnan (2011) applying Weiner's attribution model (1995) to the responses of mothers to the challenging behaviour of developmentally delayed children, found that;

Mothers rated their children as significantly more in control of, responsible for, and felt significantly more angry about aggressive behaviour than stereotypic behaviour and were significantly more likely to punish aggressive behaviour than self-injurious or stereotypic behaviour.

Armstrong et al., 2011, p.459

Their work inferred that parents are more likely to hold their children responsible for aggressive behaviours. Their sample drew from parents of "children who had a statement of special educational needs because of intellectual disability" (Armstrong et al., 2011, p 460.) The range of intellectual ability, using this sampling method, was likely to be wide and will have included children who are considerably less developmentally delayed than in my sample, i.e. children with mild, moderate and severe intellectual disability. Using Dix et al.'s (1986) findings, it can be argued that children who are more 'competent' developmentally are more likely to be held responsible. Fiske and Taylor (1984) proposed an attributional grid model that distinguished between parents seeing children as responsible or not for their behaviour and, parents feeling the child was responsible or not for the solution. Where the child is neither seen as responsible for causing the problem or responsible for the solution they refer to this as 'The Medical Model'. Miller (1995) used Taylor and Fiske's model to examine the attribution styles of teachers dealing with children with difficult behaviours. These were not children with a learning disability but were young children. They found that teachers do not share a common attributional style, however, they tended to see themselves as responsible for the solution regardless of the responsibility for the cause. The teachers also saw parents and children as not responsible for the solutions regardless of the cause. Miller (1995) reflected on the frequent mismatches of parents' and teachers' different attributional styles and proposed a systemic model of consultation to address

these difficulties. In summary, attributional research indicates that parents are less likely to attribute blame or responsibility for challenging behaviours if their child is young or developmentally delayed and that Weiner's model (1995) can be usefully applied to considering the link between attribution and behaviours aimed at addressing the difficulties. This literature draws on positivist traditions of research and precludes broader social and cultural understanding of meaning making. I find the assertions about 'responsibility' interesting and useful and these will be linked to the data in the discussion chapter. I do not wish to argue that all parents will hold these views but that an exploration of responsibility for challenges is useful. However, the absence of questioning of 'taken for granted' narratives about behaviours seen as problematic lacks a thorough critique of our professional discourses and whether they perpetuate historical and current processes of marginalisation or liberate people from these pathologising discourses.

Extensive research has also taken place with people working in adult learning disability care settings. Although this is not directly linked to my study, the literature offers some useful ideas that complement work with children. Willner and Smith (2008), reviewing the literature on attribution theory as applied to adults with learning disabilities who challenge, conclude,

The literature is inconsistent and provides at best partial support for the theory. This situation differs from that seen in the general population, where the predictions of attribution theory are broadly supported.

(Willner et al., 2008, p.150)

Snow, Langdon, and Reynolds, (2007) used the Leeds Attributional Coding System (Munton et al., 1999) and found that staff tend to believe that self injurious behaviour is caused by factors which originate within the person but are not controllable by them. Additionally, Tynan and Allen (2002) described how carers attributed more internal control of aggressive behaviour to a person described as having a mild disability compared to an individual described as having a severe learning disability's. However, Dilworth, Phillips and Rose's (2011) work did not support this finding. They also found that, " staff attributed challenging behaviour as being less under personal control if the organization was of a better quality" (Dilworth et al, 2011, p.35). They suggest, using Weiner's model (1995), that if staff perceive the person to be less in control they are more likely to engage in helping behaviour. They also suggest that where

aggression is seen as within the person's control, staff are less likely to be helpful.

To summarise, the literature concerned with attributions made about the challenging behaviour of adults with learning disabilities in care settings indicates:

- That attribution theory is only partially supported.
- That self-injurious behaviour is not seen as under internal control.
- That aggression is more likely to be seen under the person's control.
- That aggression is less likely to be seen under internal control if the person has a severe learning disability, although there is conflicting evidence for this.
- That where aggression is seen as under internal control it is less likely to elicit a helping response.
- That aggression is less likely to be seen under internal control where the organisation is of better quality.
- That this literature lacked a social constructionist critique of the marginalisation of people's identities.

Attribution theory can be seen to be underpinned by:

*A positivist epistemology*, that is, people's attributions are seen as accurate representation of their inner worlds.

Or it might be seen to lie at the 'light end of the constructivist<sup>9</sup>/social constructionist<sup>10</sup> continuum, with its emphasis on individual cognitive processes.

Or it might be seen to be within the narrative tradition of exploring meaning making, although it lacks a contextual focus and can be seen as static rather than exploring how human subjects are shaped and constrained by societal discourses. Nor does it take account of the fluid and changing nature of identities shaped by wider contextual forces.

From my position, all of these epistemologies neglect to critique: how these ideas might be culturally mediated - especially how we construct 'learning disabilities', 'challenging behaviour' and normative child development; and, a concern with how a researcher can accurately represent such inner worlds.

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<sup>9</sup> A focus on individual cognitive processes.

<sup>10</sup> A focus on language use and communication practices, including a critical stance towards taken for granted knowledges . (Kogan, 1998, p.229 )

Avdi, (2005, p.494) draws attention to the idea that, “ ‘Dysfunction’ tends to be associated either with extreme rigidity in the use of a limited repertoire of discourses and subject positions, with the resultant silencing of vital aspects of experience and subjectivity, or with chaotic incoherence in the use of the various subject positions of the self”. Avdi (2005) uses discourse analysis to explore the process of psychotherapy with a family whose child has a diagnosis of autistic spectrum disorder. She draws attention to the ‘powerful hegemonic discourse’ of psychiatric diagnoses and to how these render available discourses as not equal in terms of power. As psychiatric, medical discourses are powerfully present in my data, the argument that other discourses are rendered less powerful is an important one. In order to bring forth alternative ideas and give them equal weight it is important to hold these ideas in mind.

Only two articles were found where the meanings of challenging behaviour were specifically considered within a social constructionist paradigm. Firstly, Wilcox et al. (2006) used discourse analysis to explore how care staff constructed the aggressive behaviour of men and women with learning disabilities. They found that staff used “two main discourses: an individual pathology discourse which constructed the behaviour as originating from factors stable and internal to the client; and, a context discourse which constructed the behaviour as a response to the client’s circumstances.” (Wilcox et al., 2006, 197). Further they noted that people spoke about men and women in different ways. Secondly, Nunkoosing et al., (2011) used Critical Discourse Analysis (CDA) to examine written referrals to a Community Learning Disabilities Team. They sought to deconstruct the sources of power and explore “how language is used to manage identities and to justify actions” (Nunkoosing et al., 2011 p.408). Using various examples, they concluded that the ways that referrals were written cast the person with the learning disability as the problem and legitimized powerful ways of controlling people’s lives.

Avdi, Griffin, and Brough, (2000, p.242) concluded, “There has been limited constructionist work in the area of learning disabilities (e.g. Clegg, 1993) and virtually no empirical research.”.

As ‘meaning and action’ is one of my particular areas of interest, I have spent some time reviewing this literature. The work on attribution has led to some



interesting ideas about responsibility that are considered later as they seem important when considering how people respond to their children's challenges. Although, the lack of a consideration of how such meaning making is constructed needs to be borne in mind.

### **3:6 Summary of the literature review findings**

In this literature review I have summarised various areas relevant to this study. In recursively weaving my way through this literature, my analysis and findings I am aware of moving to a more self and relationally critical stance. Curiosity (Cecchin, 1987) has allowed further positions to be incorporated. Thus the literature has served to widen my lens and to consider how much I am exposed to and influenced by these powerful discourses.

Given my interest in power and language and their role in constructing and co-creating the realities of people's lives, I began with an exploration of the terms used to describe, define and potentially limit children labelled as learning disabled and described as 'having challenging behaviour'. This literature strongly argued for a disability rights focus. In my view, this is crucially important although largely absent from much of the literature concerning children. However, I wish to adopt a both/and stance where impairment is not ignored or denied but is seen as one of the factors affecting the lives of children and their families.

I reviewed the literature on empirical research into behavioural interventions with children with learning disabilities and challenging behaviour. This approach draws on a behaviourist epistemology and is firmly rooted in quantitative, positivist traditions of research. As one of the dominant discourses in the field and in the team within which I worked, I argue that it is important for me to be clear about how viewing things through this lens can potentially limit and define people in unhelpful ways, whilst acknowledging that much had been written on how effective such approaches can be.

Systemic ideas are beginning to be explored with this client group through the provision of family therapy and systemic approaches in the UK and beyond. The application of support services for families and guidance to professionals is prevalent in the USA. While Rhodes and colleagues have pioneered network consultation with this client group. These approaches draw on a range of systemic ideas, including structural, narrative and life cycle traditions, but offer

little empirical research to support evidence-based practice.

I have highlighted that there are a few studies using rigorous qualitative designs drawing on radical constructionist positions. I found these useful as a researcher when examining how I, and others, might be caught up in the dominant marginalising discourses highlighted in the section on terminology. The literature on caregivers' meaning making with people with learning disabilities who challenge services describes the use of attribution theory. As discussed earlier, the approach is broadly cognitive, drawing mainly on theory that moves epistemologically between positivist notions of the world and constructivist ideas<sup>11</sup>. This work has provided some useful ideas when considering the meaning making of parents and carers faced with children with a learning disability whose behaviour is challenging although lacks a critique of wider contextual factors. There are some interesting findings about how responsibility for aggression and challenging behaviour might be viewed by parents and carers. There is general support for the idea that young children and children with severe disabilities are not held responsible by teachers and parents. Locating responsibility affects people's help-giving behaviours. There is little or no research on the link between meaning making and carers' experiences of relationships. There is however general agreement that many families have negative views of professional help. As one of my hypotheses is that lack of agreement between key stakeholders can affect relationships between people, I have become aware that I need to keep an open mind to this – to hold a both/and position and to explore the richness of positions.

The implications of the literature for this study are as follows.

- My language and the language of others is not neutral and can be seen to construct and co-create narratives of disability and behaviour influencing meaning making and action.
- An understanding of context is important if this meaning making is to be considered within broad social and cultural frames.
- Opening space for these different narratives can invite the hearing and construction of alternative, less oppressive stories about people's lives.
- Through talking with people in the 'network of concern', I hope to bring

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<sup>11</sup> Positivist: that is there is a real world to be discovered. Constructivist: that there is a real world but we can only know it through our constructions.

forth different narratives and through a thorough analysis lead to: some understandings of how we construct 'disability' and 'behaviour'; what ideas people draw upon to make sense of such difficult situations; and, to consider whether and how this influences people's relationships with each other.

The next section, considers how these many ideas are woven through my research design. Reflecting back on the topics I have chosen to foreground in my literature section I am aware of choosing elements that are longstanding topics of interest for me, apart from making myself consider the work on attribution theory, which seemed too certain and epistemologically different from systemic, constructionist positions. These ideas led to this study and therefore are important to elaborate, particularly as a systemic researcher, where owning and reflecting on one's beliefs is important. Writing this has led to a greater awareness of my participation in practices, which risk marginalising people, and, has 'fed forward' into my work as a researcher and as a clinician.

## CHAPTER 4: RESEARCH DESIGN

I will begin this section on research design with a discussion of epistemology, which questions what knowledge is, how it is acquired, and the possible extent to which a given subject or entity can be known. Morse (1994, p.221) states “theory is used to focus the inquiry and give it boundaries” and Salmon (2003, p.26) states, “epistemologies describe the use to which methods can be put not which methods can be used”. Willig (2001) makes a distinction between epistemology, methodology and method<sup>12</sup>. She suggests that epistemology will inform the general methodological approach to a topic that in turn will constrain the method or specific research technique. I shall explore each of these themes in considering the research design for this study.

### 4:1 EPISTEMOLOGY

**4:1:1 Qualitative or Quantitative?** For many years, quantitative research has been seen as the 'gold standard' (and in some contexts probably still is, e.g. NICE guidelines). However the rise of interest in qualitative approaches has been driven by various critiques (Guba and Lincoln, 1994). Problems include: context stripping; exclusion of meaning and purpose; disjunction between grand theory and local contexts; and, difficulty in applying general data to individual cases and the exclusion of data which doesn't fit reducing the capacity to 'discover' new things. Guba and Lincoln (1994) further assert that, with sufficient rigour, these issues can be addressed. However, other challenges pose more fundamental problems to a quantitative-only approach. These challenges include: hypotheses being tested are not independent, that hypotheses can only be disproved, never proved; theories and facts are value-laden and not value-free as claimed; and, that the act of observation implies an observer who is inextricably linked to the process of observation. (Guba and Lincoln, 1994, pp.197-200). In addition, Willig 2001 offers a feminist critique including the male as norm and, that claims of objectivity obscure the standpoint of the researcher.

Taking each of these points in turn I argue for the use of a qualitative approach in this study.

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<sup>12</sup> **Epistemology** is concerned with the theory of knowledge and attempts to address the relationship between the knower and what can be known. **Methodology** is the general approach to studying research topics, which defines the research problem and how the research will proceed. **Method** is the strategy or technique that is actually adopted. (Guba and Lincoln (1994), Henwood (1996) and Willig (2001)

As claimed in the preceding sections a consideration of *context* is vitally important if we are not to fall into tacitly accepting taken-for-granted truth claims and locating problems in a person, rather than see them as existing between people. As a systemic clinician, I consider that: context is essential; that I am reflexively implicated in the act of observation and interaction; and, that meaning is shaped by the values and mores of the culture. Thus I consider that qualitative approaches fit well with the systemic endeavour.

Talking with people as a starting point and using an approach which is dedicated to making sense, phenomenologically, of people's life-worlds, I hope to avoid imposing '*grand theories*' with their totalising effect on us all. This idea also links to an interest in language and how it constructs our thinking and action.

Additionally, I am interested in the multiverse of people's varied descriptions with their inherent contradictions, which provide the data for qualitative methodologies.

At the beginning of my research journey, I had some preliminary ideas that guided my research. I wished to ask open-ended, exploratory questions about meanings and relationships, and I thus hoped that I might elaborate something of the quality of people's experiences in relation to the topic of challenging behaviour and children with a learning disability. This was partly guided by personal preference linked to my work context but also driven by what I perceived as a gap in the literature in bringing forth the voices of an often-marginalised group of people. I was also personally and professionally interested in furthering my knowledge and experience of qualitative research.

**4:1:2 Epistemological position - my choice to use IPA:** Qualitative research is not a unified field. There are a number of different approaches that are informed by overlapping but distinct theoretical commitments (Smith and Osborn, 2003). These range from positivist notions of the world, which can be uncovered, to a social constructionist view, which includes a critical stance towards taken-for-granted knowledge, historical and cultural specificity, knowledge being sustained by social processes, and knowledge and social action going together (Burr, 1995, pp3-5). IPA is closer to the constructionist, relativist end of this continuum.

Phenomenology predates constructionism, and it sets up the idea that rather than being interested in 'what happens in the world' per se (e.g

the correlates and causes of events, as in realism and empiricism), we could/should be interested in the 'meaning' or 'perception' of what happens.

Larkin, 2014

Husserl formulated phenomenology in the early 20<sup>th</sup> Century (Willig, 2001). He was interested in how people, within particular contexts, perceived and experienced the world at particular times. The later hermeneutic phenomenologists, e.g. Gadamer and Heidegger, saw phenomenology as interpretive, rather than descriptive and include an additional emphasis on the contextual and embodied nature of meaning making. IPA can be distinguished from Discourse Analysis (DA) as it is primarily interested in personal meaning making in context, whereas DA is more interested in the social, historical and cultural aspects of meaning making (discourse). So IPA is broadly 'relativist' in that it privileges personal knowledge over other forms of knowledge, however DA is more social constructionist, although there are commonalities. Both approaches however implicitly accept that there is a real world out there (ontological realism) (Larkin, 2014). I have made this distinction as I consider the influence of social and cultural constructions to be important when exploring issues of disability, whilst being aware that I may be drawing on different epistemological traditions.

IPA is underpinned by an interest in the relationship between the person and the things that matter to them. As Larkin and Thompson (2011) state;

Interpretative phenomenological analysis can illuminate the importance of situating embodied personal experience in the context of meaning, relationships, and the lived world.

Larkin al., 2011

Given my strong interest in meaning making, context and relationships, I chose to use IPA, whilst concluding that I needed to add a social constructionist critique to the ideas being developed.

## **4:2 METHOD**

### **4:2:1 Context**

I chose to undertake my research in my own team to aid recruitment, to engage people in the value of research, make things more manageable for myself and to use my findings for the benefit of the families we worked with. In doing this I was mindful of the effect of being the clinical lead and from one professional

group and the effect this may have on others. This aspect will be considered later.

#### **4:2:2 Design**

The design was multi-perspectival, in that it drew on data from three different perspectives. The three perspectives were: the parents of children who had been referred to the team for 'challenging behaviour'; the children's teachers; and, the team members who were working with the child and their family.

Through obtaining these different perspectives, I hoped to explore relationships between people and how meaning making might affect these relationships. As a systemic psychotherapist I am used to inviting those people who are important in dis-solving a problem. I thus decided to invite people who were important in the network of concern to talk with me about the children. In retrospect this made life much more complicated than perhaps I had anticipated, as these types of design in IPA are, as yet, unusual. However my commitment was to get different perspectives on the 'objects of concern' and to explore how they fitted or did not fit, given my interest in competing or complementary understandings. I initially undertook two 'pilot' interviews. These helped me to move from the position of clinician, with a focus on trying to be useful, to the position of researcher, and to check that my interview questions were bringing forth the data I was interested in. These interviews were not used in the final analysis. A total of thirteen interviews were then conducted, focussing on 4 different children who had been referred to the service within which I work. I conducted semi-structured interviews with parents, teachers and Camhs Learning Disabilities team members, plus a member of staff from a residential unit at the school of one of the children. This came about at the request of parents. I obtained additional ethical consent for this.

I interviewed three people about each child: a parent, the child's teacher and the team member working with the child. The referred/identified problem for this research was 'challenging behaviour'. Children had other diagnoses and were considered to have moderate to severe learning disabilities, as that was the criteria for the team. In recruiting participants I did not specify the gender or age of the children but was mindful that gender has been found to be significant when talking about challenging behaviour (Wilcox et al., 2006) and that age is important when considering life-cycle issues (Marshak et al., 1999). I did not

include families where I was the lead clinician undertaking the therapeutic work. I did not include children who were in the care of the local authority.

The following table summarizes the details of those interviewed and the children. All names have been anonymised<sup>#</sup> although I have attempted to be culturally sensitive to the background from which people came rather than erase this information from the study.

**Table 1: The details of the children and people interviewed.**

	<b>Child 1</b>	<b>Child 2</b>	<b>Child 3</b>	<b>Child 4</b>
<b>Name<sup>#</sup></b>	Hayleigh	Shirley	Fraser	Tahir
<b>Gender</b>	Female	Female	Male	Male
<b>Age</b>	16	7	10	14
<b>Ethnicity</b>	White British	Afro Caribbean British	White British	South Asian British
<b>Family make up</b>	Mum, Dad, one older brother	Mum, Dad, one older sister, one younger sister	Mum, Dad, one older brother	Mum, Dad, one older sister, one older brother
<b>Diagnoses named</b>	Autism Severe learning disabilities	Autism ADHD <sup>13</sup>	Severe Autism Severe learning disabilities	Autism Tourette's
<b>School</b>	SLD*: All age	SLD* Primary	SLD* Primary	Autism Specialist all age
<b>Teacher</b>	Male also deputy head	Female	Female Temporary staff member	Female also member of senior team
<b>Time as Child's Teacher</b>	2 years	5 terms	Less than 1 term	5 Terms
<b>Carer</b>			Residential Unit at school	
<b>Team member interviewed</b>	Clinical Psychologist: Female	Senior Learning Disabilities Nurse: Female	Clinical Psychologist: Female	Consultant Psychiatrist: Male
<b>Family's</b>	5 years +	4 months	2 years	2 years

<sup>13</sup> ADHD Attention Deficit Hyperactivity Disorder



\*SLD Severe Learning Disabilities

**4:2:3 Sampling:** Smith and Osborn (2003) recommend the use of fairly homogeneous samples when using IPA. They suggest the use of purposive sampling to find “a closely defined group for whom the research questions will be significant” (Smith et al., 2003, p.54). As my topic of interest is children with learning disabilities who have been referred for challenging behaviour I consider that my sample met the criteria for homogeneity.

In the planning phase I was mindful of attempting to reduce complexity. For this reason, for each child referred, I decided to interview one main family carer<sup>14</sup>, one teacher<sup>15</sup> from school who has known the child well for at least 3 months and one team member, who has also known the child for at least three months. Although it was tempting to offer conjoint interviews, I reasoned that this might make data analysis problematic and so I excluded this option, although Fraser’s dad joined us for the second interview. (My recorder had failed half way through the first interview and on my return Fraser’s dad had chosen to join us) and Hayleigh’s dad also joined the last fifteen minutes of my interview with her mum. These issues are further discussed in the analysis section. I did not exclude single carers although all children were cared for in homes where both parents lived together. I excluded people who required an interpreter as I felt that this would add a level of complexity which would render the material less manageable (Raval and Smith, 2003). Initially, I planned to interview people around six referred children, leading a total of 18 interviews. As the process developed it became clear that interviews concentrating on four would provide a varied and sufficient source of material. This was discussed and agreed in supervision.

**4:2:4 Recruitment to the study:** I chose to work with my team for three reasons. Firstly, I hope that pre-existing relationships would help people feel more confident in exploring their work with someone they knew and, hopefully, trusted, thus aiding recruitment. Secondly, I wanted to use the findings to

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<sup>14</sup> I excluded step-parents and adoptive parents as these relationships bring additional issues not directly related to this study.

<sup>15</sup> The teacher is the person from the school who usually has regular contact with the home and is therefore most likely to form an on-going relationship with parents /carers.

feedback to the team hopefully to influence and improve our practice. Thirdly, I was based in and familiar with the city within which I worked and could thus find my way around, reducing complexity. I will address the issue of working with my immediate colleagues in the ethics section.

I had heard that obtaining participants seemed to be a major problem for many of my fellow researchers. In the hope of increasing the likelihood of engaging people, I decided to use my personal connections with fellow team members to invite them to both volunteer to be interviewed and to help recruit families. I began the process by giving a talk to all team members describing the research, outlining the benefits to us as a team and explaining what I needed from them. I provided a brief explanatory letter about the research (Appendix 1). This was handed to families to allow them to give the matter some thought before giving initial consent for me to contact them. At this point I requested permission to telephone people. I hoped that a personal approach would be more likely to be successful than an impersonal letter which may well be ignored in people's busy lives. Initially, I hoped that teachers would be willing to participate if family members had agreed, however the Local Research Ethics Committee challenged this assumption. They required me to obtain provisional consent from teachers before approaching parents. I asked colleagues to give information to teachers and head teachers so that they could give consent in principle before identifying the child in question. As consent was given in all cases colleagues then approached parents. Again, parents seemed keen to take part. A letter to teachers explaining that parents had consented and giving further information can be found in Appendix 2. To proceed I required permission from all three participants for each child to undertake the interviews. A leaflet was produced (Appendix 3) that was used at all stages of the process.

**4:2:5 Data collection:** "IPA works with transcripts of semi-structured interviews" (Willig, 2001, p.54). Smith et al. (2003) suggest that when using semi-structured interviews it is important to establish rapport with the participant and that;

- The ordering of questions is less important.
- The interviewer is freer to probe interesting areas that arise.
- The interviewer can follow the respondent's interests or concerns.

Smith et al., 2003, p.56

Drawbacks identified are that the interviewer has less control over the interview;

it takes longer to conduct; and, can be harder to analyse. They go on to recommend that interviews should be carefully planned in advance. Questions should allow the person to tell their story with as little intervention from the interviewer as possible. Prompts are seen as helpful to ensure that the interviewer has invited the person to cover all the areas of interest to the researcher - the interview, at its best, should feel like a conversation.

More specific guidelines included:

- Questions should be neutral rather than value-laden or leading.
- Avoid jargon or assumptions of technical proficiency.
- Use open, not closed, questions.

As a systemic psychotherapist I am familiar with these processes and attempted to use my existing skills when conducting the research interviews. One of the things that I found most difficult was refraining from attempting to be helpful during the interviews, either by offering information or suggestions or by inviting people to explore their ideas picking out positives and exceptions. This was apparent in my pilot interview and although I made lots of efforts to hold back I noted in my analysis that this was not always completely successful. Potter and Hepburn (2005) raise a wide range of concerns about semi-structured interviews. They are of two types, contingent and necessary. I will outline each of their reservations and where possible say how I addressed these problems, whilst being mindful that the author's methodological commitment is different to my own (Discourse analysis and IPA).

Contingent problems:

1. *The deletion of the interviewer.* This is an issue of transcription where, in some studies, the interviewer's talk has been absent from the transcription. I used a full transcription of the text but not in the detail represented in Jeffersonian<sup>16</sup> transcription. This is because IPA does not demand as detailed a level of transcription as say conversational analysis.
2. *The conventions representing transcription.* Potter and Hepburn (2005), with their commitment to Discourse Analysis and Conversational Analysis argue that, without the detailed transcription conventions mentioned above, much important conversational material is missed. I am in agreement with this position and acknowledge that each person may shape the responses

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<sup>16</sup> See Potter and Hepburn (2005) for an example.

of the other, however IPA does not require this detailed level of transcription. I have thus adopted a less time consuming option to be able to gather a wider range of material.

3. *The unavailability of the interview set up.* This covers two aspects. First, lack of clarity about what category participants have been recruited under? They recommend that this is made clear at all stages of the process. In the analysis I needed to be mindful that identities can be fluid and that, for example, a teacher may have been speaking as a teacher, but may also have spoken as a parent or that parents may also speak as professionals or informed lay persons. Second, clarity is required about what people are told about the interview, what it is for etc. I will address this issue further under ethical considerations.

Necessary problems:

4. *Flooding the interview with social science agendas and categories.* This involves the inadvertent inclusion of technical or value-laden language. In constructing the questions I was mindful of this and generally avoided using psychological or diagnostic terms unless the participant used them first.
5. *Interviewer and interviewee's footing.* This concerns the category to which the interviewer and interviewee are consigned. The point is made that statements or questions can, for example, confuse personal and professional membership. This made me think about the importance of how I introduced myself both as researcher and team member, and to be clear about my investment in the research and outcome of the work. This is addressed in the introductory letter. However, I am also mindful that how I am positioned by others and how I position myself constructed the interviews undertaken (van Langenhove and Harré, 1999)<sup>17</sup>.
6. *Interviewer's and interviewee's stake and interest.* It is argued that people respond to other based on particular interests, this included the researcher as well as the interviewees. As a researcher I am interested in the topics discussed and have a stake in the outcome. I have assumed that those I interview also have a stake and interest in the topic, although different from my own. The issue is not to attempt to delete the interviewer but to ensure

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<sup>17</sup> Positioning theory is contrasted with role theory, and refers to the dynamic positioning of participants in ongoing episodes of communication. Others can position us and we can position ourselves. Positioning allows a consideration of power dynamics in an interaction.

that the constructions of the researcher are clear and separate from the interests of the participants as far as is possible. IPA with its dual concern for the phenomenological aspects of participant's lived experience and the researcher's interpretive stance has the capacity to take this concern seriously.

7. *Reproduction of cognitivism*. This makes the assumption that you ask interviewees what they think and they will be able to tell you. However, this cannot be seen to represent their thoughts and actions at all times and in all places. IPA, as discussed earlier, attempts to counteract the issue of cognitivism by engaging phenomenologically and interpretively with the text, acknowledging that what are issues for concern, at any one time, are fluid and subject to change.

Potter et al. (2005) come from a particular epistemological position which privileges 'naturalistic' interaction. The issues raised are important and useful and need to be considered. However, I did not chose to use naturalistic interactions but to be more actively involved with talking with people around topics that interested me. I thus conducted and tape-recorded semi-structured interviews. (See Appendix 4 for questions). I used the same basic interview questions for all participants: family member, teacher and team member. These questions were refined further over the course of the interviews. The two pilot interviews, one with a professional colleague and one with a parent who kindly offered to help out helped me to think about whether the questions yielded data relevant to my research interest, to reflect on my position as the interviewer and to obtain feedback from participants about the process. The interviews also indicated how long the interviews might take so that I could make this clear to people at the outset. Feedback included that people really like talking and telling their stories and that they found the style of questioning useful. After the first set of interviews I deleted asking about other services, as this seemed to produce a lot of factual information rather than elaborating what was concerning people.

**4:2:6 Transcription:** Within an IPA tradition Smith, Flowers and Larkin. (2009, p.74) suggest that texts do not need to be "a particularly detailed transcription of the prosodic aspects of the recording". All interviews were transcribed using basic transcription conventions (See Appendix 5).

### 4:3 METHODOLOGY

I used IPA to investigate and interrogate my data, which is drawn from semi-structured interviews. IPA facilitates the bringing forth of themes from interviews, allowing an exploration of how people make sense of major life experiences. As Larkin et al. (2011) say, “In the case of IPA, meaning making is conceptualized at the level of the *person-in-context*.” Thus I hope that my concerns with the importance of language, meaning making and context can be thought about and connected to people’s relationships within the network of concern. Additionally, the analysis can use the interpretative aspects of IPA to consider a range of systemic and psychological models and include a consideration of how meaning is socially constructed and how we are all caught up in webs of power and influence, often beyond our awareness.

#### 4:3:1 Why IPA?

Smith, et al. (2009, p.4) identify three “theoretical perspectives which are central to IPA: phenomenology, hermeneutics and ideography<sup>18</sup>”. Smith et al. (2003, p.51) stated; phenomenology “is concerned with an individual’s personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself”.

They assert that:

- IPA is concerned with the detailed examination of human lived experience.
- Experience is expressed in its own terms rather than according to predefined category systems.
- Phenomenological enquiry is from the outset an interpretive process.
- IPA pursues an idiographic commitment, situating participants in their particular contexts and exploring personal perspectives, starting with a detailed examination of each case before moving to more general claims

Smith et al., 2009 p.32

IPA frames the research process as a dynamic and generative process, within which the researcher attempts to get close to the participant's world whilst acknowledging that he or she will always do this through their own interpretive frame. This is similar to systemic psychotherapy where one begins by attempting to make sense of the clients' difficulties from their perspective,

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<sup>18</sup> Phenomenology is a movement which accommodates a range of distinctions and differences. It offers a model of consciousness which does not rely principally on inner representations of an independent reality. Indeed, it is more accurate to describe it as a model of being-in-the-world, or relatedness-to-the-world. (Larkin et al. 2011)

Hermeneutics: the study of the theory and practice of interpretation. It encompasses everything in the interpretive process including verbal and non verbal forms of communication.

Ideography: a concern with the particular, rather than nomothetic which is concerned with making claims at the group or population level.

perhaps using the team to be alert to one's own assumptions and prejudices. My research questions aim to explore how people make sense of their personal and social worlds in relation to a child with learning disabilities and challenging behaviour. Raval and Smith (2003) assert that qualitative research methodology facilitates an in-depth exploration of phenomena. This is an important starting point for a systemic exploration of a topic. They go on to describe IPA as, "developing an explanatory, contextual, interpretive, critical, phenomenological understanding..." (Raval et al., 2003, p.8). This aspect of IPA, which situates exploration within an interpretive contextual frame, fits well with my systemic understanding as stated above.

Willig (2001) cautions that phenomenology is not a unified theory, has undergone various revisions and has generated a number of different methodologies. One of these is IPA. IPA is concerned with "how people make sense of their major life experiences" (Smith et al., 2009, p.1), whilst accepting the impossibility of gaining direct access to people's 'life worlds' (Willig, 2001). Larkin, Watts, and Clifton, (2006) characterise the two aspects of IPA. They are, "the phenomenological requirement to understand and 'give voice' to the concerns of participants; and the interpretive requirement to contextualize and 'make sense' of these claims" (Larkin, Watts & Clifton 2006, p.102). Willig (2001) suggests that the systematic and detailed descriptions of the analytic process have made it an increasingly popular approach. However, she draws attention to its conceptual and practical limitations. These include

- The role of language: The impossibility of language 'representing' people's inner worlds. Indeed a more radical social constructionist position would assert that there is no inner world to discover: the idea that language constructs rather than reveals reality. This view of phenomenology is challenged by Larkin et al. (2011). They view this as an oversimplification of phenomenological theory and more a critique of cognitivism.
- Suitability of accounts: IPA attempts to capture the experiences and meanings associated with a phenomenon. Traditionally this was approached through introspection. However IPA relies on people's descriptions often through being interviewed. This raises the question to what extent people are able to describe the diverse texture of their

experiences and their relationship with those experiences - this may be especially problematic when people are not used to expressing their thoughts, feelings and experiences. This fails to address the importance of context including a concern with the effect of the interviewer on the ideas expressed.

- Explanation versus description: Phenomenological research tends to describe and document the lived experience of participants; it does not attempt to explain it. Willig (2001, pp 64-65) suggests that, “if we want to move beyond sharing an experience with our participants, and understand their experiences well enough to explain them, we need to be aware of the conditions that gave rise to these experiences in the first place”.

Whilst there is no easy way to address these issues within IPA, I intend to draw on other sources of material in the interpretive phase which may illuminate some of the ‘conditions’ mentioned and also to consider the wider discourses on disability to consider how we may all be embedded in contexts of power and discrimination.

#### **4:4 RESEARCH ETHICS: CONSENT AND CONFIDENTIALITY**

As I worked in the NHS and wanted to interview parents of children who had been referred to an NHS service, I was required to obtain consent from the NHS Research Ethics Committee. This was useful in ensuring that I conducted the research in a non-harmful way. (See Appendix 6 for the letter of the consent and my response to the questions raised). All letters and the leaflet etc. were scrutinized by the Committees and were passed as acceptable, although the form (see Appendix 7) needed initials in all boxes not just a signature at the end, and they queried whether I was including adopted or looked after children. I went through a similar process in the NHS Trust within which I worked. The way of approaching teachers and parents was modified following helpful feedback from the Committees on the potential for coercion or disappointment by contacting parents first and hoping that teachers would fall in line. See Appendix 7a for University Research Ethics Committee letter of approval.

##### **4:4:1 Consent:**

Having obtained these approvals, I began by introducing my research to my colleagues in my team. This was accompanied by the leaflet. I asked if people



felt able to participate. I left it with them to approach me hopefully avoiding any aspect of coercion or pressure, although recognising that colleagues would want to help me out or perhaps as please me.

**Research with colleagues: Some reflections.**

I was at this time the clinical lead for the team. I managed the other four psychologists and was part of the team's management group. In planning to interview my colleagues I was aware of the potential power differentials within the team. Clearly conducting research in one's own agency raises issues. Robust self and relational reflexivity was important at all points in the process. As a systemic psychotherapist, I have always been concerned with exerting power over people. In my initial systemic training I wrote my dissertation on this topic, concluding that we cannot act outside of these power dynamics and being 'collaborative' does not mean one dissolves these forces. However, by deconstructing one's potential sources of power through self and relational reflexivity one can avoid inadvertently misusing power and coercing or damaging people. In thinking about this, I drew on the ideas of Karl Tomm and his ethical postures (Strong et al. 2008). Tomm argues that ethics is concerned with the wellbeing of clients and I extend this to research participants. He states; "When these initiatives are taken to deliberately enhance the wellbeing of our clients they may be regarded as ethical". (Tomm, Birmingham, 2014). This can be divided into ends and means. In terms of my overall purpose (ends), I would argue that my underlying intention was to improve service delivery and so hopefully to enhance the wellbeing, through job satisfaction, of my colleagues. Means, or the process of gaining consent and interviewing people, was done with the utmost care as outlined above. Interestingly, two of the people who came forward were my peers on the management team; the other two were psychologists who I supervised, who were familiar with my ways of working. I discussed these issues before obtaining consent to interview people. I hoped that this would suffice to address the imbalances.

Feedback from team members interviewed was positive and I believe that I was seen as helpful and supportive, although acknowledge that our pre-existing relationships would have shaped our conversations. I have

reflected on this later.

When team members said that there was a family who fitted my criteria and that they might be interested in participating, I asked the team member to pass on a letter and leaflet to the head teacher of the child's school. This was followed up by a phone call from me explaining the process and asking if they were comfortable with me sending this letter to the child's teacher. The child was not identified by name at this point. If both parties were in agreement I asked the team member to talk to the child's parent/s and pass on a letter and leaflet. If they consented to me talking with them I then made direct contact both with the child's teacher and the parents, usually by phone to explain further aspects of the research. A detailed description of this process can be found in Appendix 8.

**4:4:2 Confidentiality:** I stated from the outset that all participant's contributions would be anonymised. It was likely that participants reading my final material would be able to recognise their own contributions, however I was confident that they would not be able to identify anyone else's. I have needed to revisit this during my analysis. The young people were given pseudonyms to bring the data to life and made the findings easier to follow. However, it became clear that this allowed recognition of others speaking about the same child. This is discussed later.

I also needed to be clear about the limits of confidentiality. I explained that if I was told something that led me to think that there was a serious risk to a child's health or well being (emotional or physical), I would need to report this. This did not happen.

#### **4.5: HOW I ANALYSED THE INTERVIEWS**

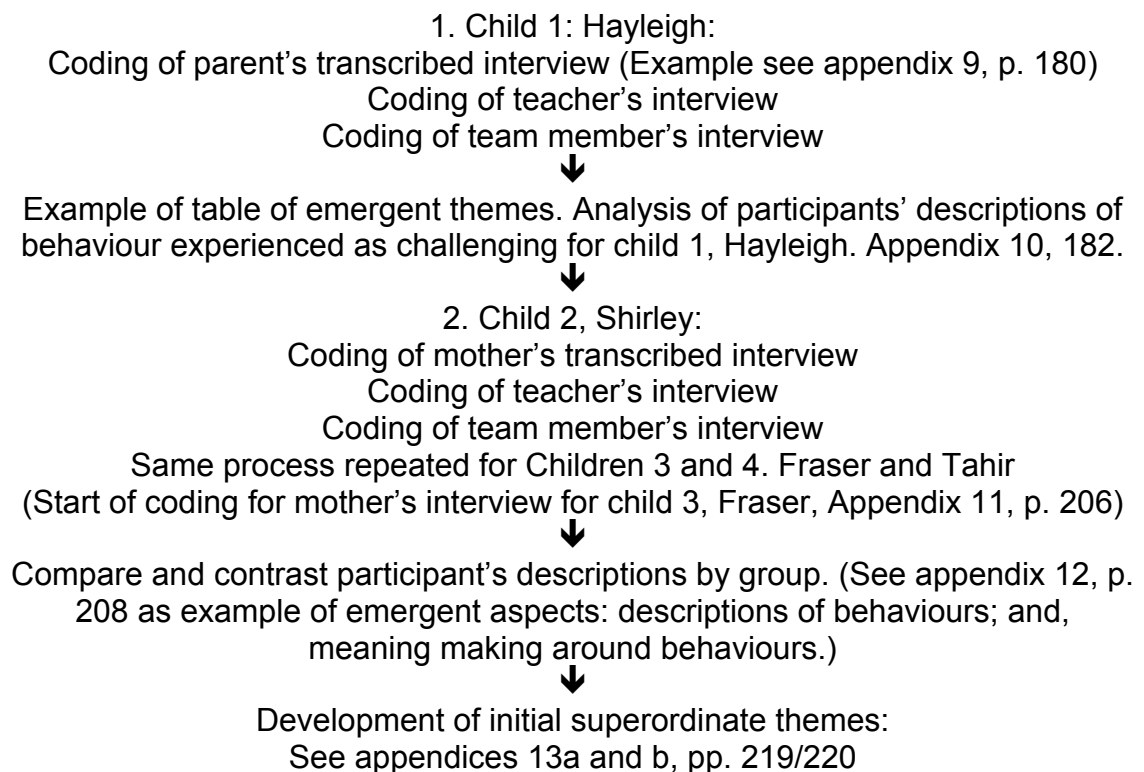
Initially, I held back on beginning any analysis until I had completed all my interviews. This was advised in supervision and seemed to be a generally accepted approach in IPA based on the idea that analysis will begin to organise the researcher's ideas, perhaps reducing curiosity and complexity in later interviews. One might be looking for themes rather than engaging fully with the concerns of the participant. Thus my analysis did not begin until the interview phase had ended. I question this approach as I found that beginning to analyse the data led to a much deeper understanding of the method and of my own positioning. Thus I would have found it helpful to begin analysis perhaps after

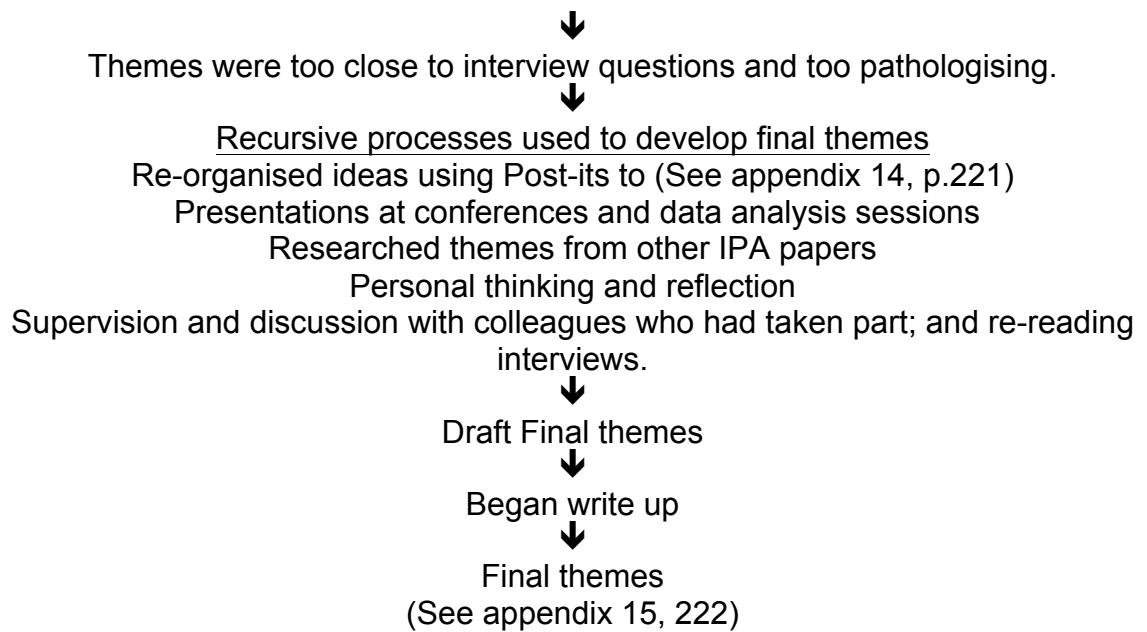
the first set of interviews. Systemically, I was influenced by previous interviews and to begin analysis might have invited a more self and relationally reflexive position and encouraged me to explore issues in much greater depth. Rather than reducing curiosity, I believe that this would for me have increased my interest in the concerns of clients, although I can also see that this might have changed my focus slightly.

I completed 16 interviews however only 13 were used. Reasons for not including these interviews included: failure of the recording device; extraneous noise during the interview; and, accidental deletion of an interview. All other interviews were transcribed. Fortunately, these interviews concerned only one child.

One of the reasons that I originally chose IPA was that I perceived it be a straightforward and clear way to analyse data. However, this has proved to be an incorrect assumption. As described above, the stages of ethical approval, recruitment, interviewing and transcription were fairly straightforward although took a long time. However, the analysis proved to be complex. The flow chart found below in Figure 2 shows how the analysis proceeded. Various Appendices give examples of each of these stages.

**Figure 2: Flow chart to show the process of IPA data analysis:**





I analysed all the interviews around each child. Parents were first, as I wanted to foreground their voices; the teacher and then team member followed this. I decided to take the interviews in the order that I had conducted them. This was because the first set of interviews offered detailed accounts and thus yielded a wealth of ideas.

'IPA works with transcripts of semi-structured interviews' (Willig, 2001, p.54) and involves a detailed analysis of these transcripts. Willig (2001), Smith et al. (2003), Smith et al. (2009 p.79) and Larkin et al. (2011) describe in detail the steps required to carrying out the interpretive phase of work. In the first phase, one transcript was read and re-read a number of times. I also listened to the tapes again checking for accuracy of transcription.

In the second phase, I began to note initial thoughts and observations about what had been said. Willig (2001, p.54) lists a number of types of thoughts including, "associations, questions, summary statements, comments on the use of language, absences, descriptive labels and so on". These notes were wide ranging at this initial stage. Having read and re-read the first interview, I went through the transcript line by line. I adopted the coding system outlined in the chapter on analysis from Smith et al. (2009). The categories I started with were:

- *Descriptive* comments focused on describing the content of what the participant has said, the subject of the talk within the transcript.
- *Linguistic* comments focused upon exploring the specific use of language by the participant.
- *Conceptual* comments focused on engaging at a more interrogative and conceptual level.

I found myself getting caught up in classificatory dilemmas: what was linguistic, what conceptual, etc.? Following a supervisory meeting, I adopted an approach that made more sense to me, though highlighting,

- a) Objects of concern: things that matter to the participant.
- b) Experiential claims: meanings that participants attach to the objects of concern.
- c) Stance/positionality: relationship between the person and the object of concern.

Larkin, 2012

The third phase involved returning to the start of the transcript developing emergent themes. These themes are intended to capture the 'essential quality' (Willig, 2001) of what is represented in the text. Smith et al. (2003) suggest that these themes are at a higher level of abstraction and may include more psychological terminology. Smith et al. (2009) emphasise convergence and divergence, commonality and nuance. Connection back to the participant's words was always essential. This process was continued for the whole of the first transcript.

The fourth phase involved bringing the themes together. Ideas from the literature include: listing the themes chronologically on a piece of paper (or perhaps 'Post-Its' to allow re-positioning). The researcher then develops a more analytical or theoretical structure by clustering themes together. There may be hierarchical levels of themes, with some themes being subsumed in a higher order theme. Clusters of themes need to be given labels at this point. It is important to check back with the text to ensure that connections being made between themes are also reflected in the respondent's account. Smith et al. (2003, p.72) state:

This form of analysis is iterative and involves close interaction between the reader and text. As a researcher one is drawing on one's interpretive resources to make sense of what the person is saying, but at the same time one is checking one's own sense-making against what the person actually said". This stage also develops the "dialogue' between the researcher, their coded data and their psychological knowledge, about what it might mean for participants to have these concerns in this context... leading to a more interpretive account.

Smith et al., 2009, p.79

Subsequent transcripts can be analysed in two ways. Transcripts can be analysed from scratch using the method outlined above. All of the themes are then collated to create an inclusive list of super-ordinate themes. Or themes

from the first analysis can be used to orient the researcher when analysing subsequent transcripts. In the latter method, themes are used to code subsequent transcripts, adding or elaborating themes as appropriate. In both cases the recursive process of checking back with the original material is essential. The aim is to respect and record both similarities and differences between respondent's accounts. In this final interpretive phase themes are prioritised and reduce.

I chose to use the emergent themes to code subsequent transcripts, adding themes as I continued. Smith et al. (2003) argue that the content and complexity of meaning is central to the aim of IPA, thus the analysis phase will inevitably involve the investigator engaging in interpretation. This they state "...must be obtained by sustained engagement with the text and the process of interpretation" (Smith et al., 2003, p.64). Larkin et al. (2006, p.113) assert that the development of the final themes is not purely descriptive; indeed they are critical of this 'first order' approach. They consider that "IPA researchers are necessarily balancing representation against interpretation and contextualization". The researcher using his or her professional and/or theoretical knowledge is also offering an interpretive account of "what it *means* for the participant to have such concerns, within their particular context" (Larkin et al., 2006, p113). Smith (2004) is concerned that the researcher produces a theoretical framework that is based upon, but transcends the participant's original account. Smith et al. (2009) add the importance of supervision or collaboration to audit, test and develop coherence of the interpretation and exploring reflexivity, the development of a narrative and the addition of one's own reflections. It is argued that there is an assumption that we cannot separate the researcher from the process of reflexively creating and interpreting the subject matter. Our thoughts, beliefs and meaning systems will be inextricably linked to our acts of interpretation, thus it is essential to be as clear as possible what we bring to the whole process. Our decisions will have implications for the research, our choices will be linked to our pre-existing interests and knowledge and the choices we make will limit and constrain what is and can be brought forth (Larkin et al., 2006).

I analysed the interviews in this way collating the findings in tables and exploring convergent and divergent themes. An example of this can be found in

## Appendix 10.

At this point, I felt concerned that the themes were too closely linked to my interview questions. They seemed to lack something important and failed to represent the variability and complexity of participant's accounts. I also wished to include my concerns about context, language and labelling. In order to address these concerns, I tried many things. I attempted writing lots of statements on post-it notes (see appendix 14) as described above and arranging and re-arranging them on large sheets of paper. I went back to reading a variety of papers that had used IPA, and obtained ideas from the themes people had written about. I read and re-read the interviews and my summaries thus far. I tried collating the data in summary sheets (see Appendix 12 for an example). I talked to colleagues and supervisors and presented my findings at Doctoral meetings, in data analysis sessions and at the Association for Family Therapy Conference in 2011. I read more about devaluation and disability rights and thought about the conditions of people's lives. I reflected on what I was hearing from families I met in my clinical work. This led to an initial list of themes, which allowed me to write the analysis and discussion sections See appendix 13b. As I have continued to think and write the themes have changed again. I began by using more psychological and diagnostic terminology and adopted rather certain descriptions, that lacked the curiosity I had hoped to employ. I am confident that the final themes better reflect both the concerns of participants, my own interests and elaborates the contextual issues I have discussed. This perhaps reflected the process that Smith et al. (2003, p.64) refer to as "...sustained engagement with the text and the process of interpretation". The final task was to create a summary table (Appendix 15). The five themes identified are described and discussed in the next chapter.

## Chapter 5: RESULTS AND ANALYSIS OF THE DATA: THEMES

### Making a quilt:

The 'quilt' metaphor was taken from the moving account by a parent of a child with Down's syndrome (Andrews and Istvanffy, 2012). In the chapter entitled Intellectual Disability, the mother described the highs and lows of parenting a child with Down's Syndrome. In her piece entitled, 'Perfection in Imperfection', she writes:

I would say it has been more like crafting a quilt. The quilt is woven from experiences over time. Each experience you have becomes a block in the quilt. When you have only one or two blocks in that quilt (a few experiences), the one or two blocks truly stand out and you can't quite imagine the end product. However, as more and more blocks are added, the quilt becomes bigger, the pieces start to come together, and it begins to take form.

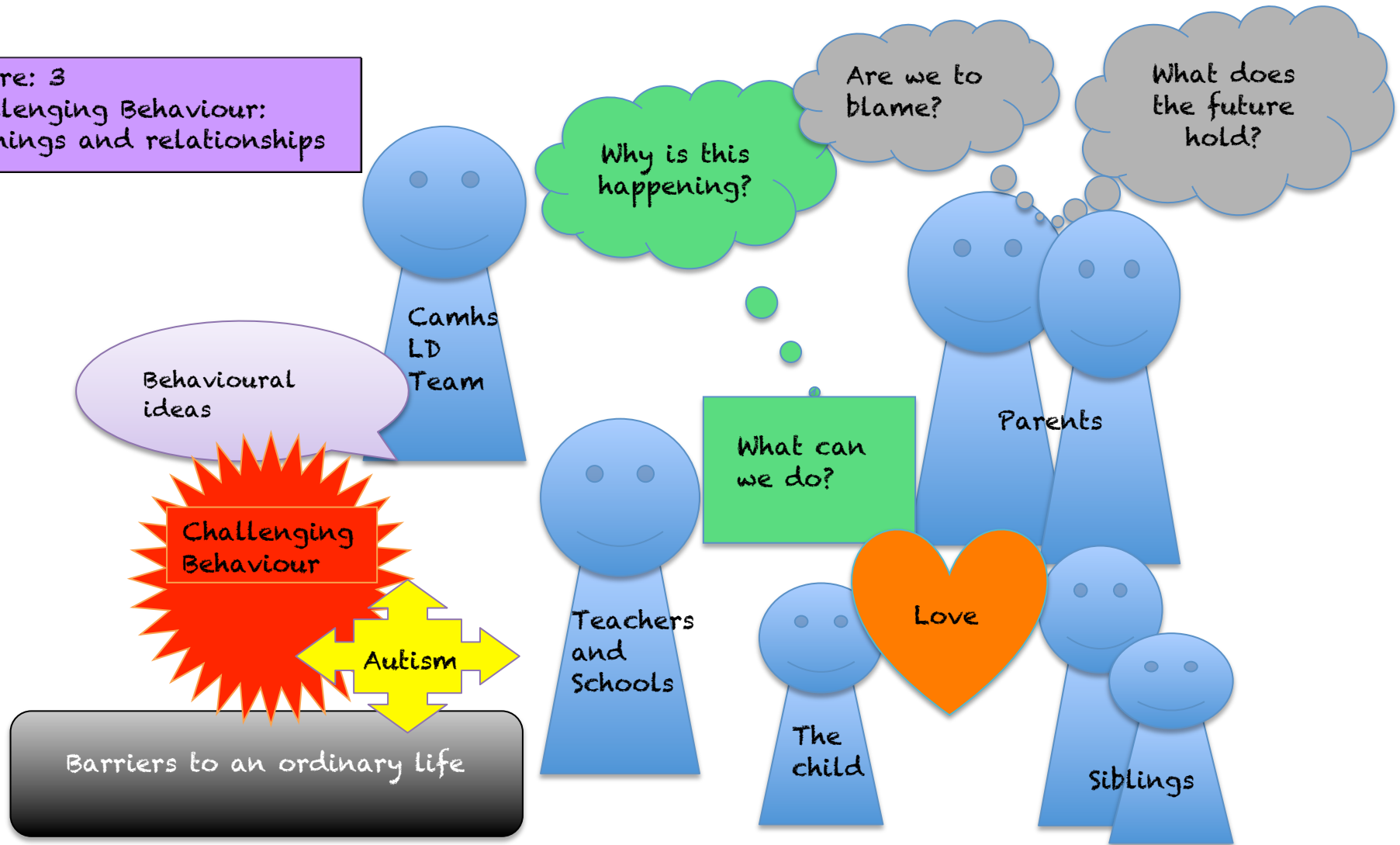
(Andrews et al, 2012, p.172)

This description could not have better summarised the process of engaging with the data and developing the final themes. The themes are my 'blocks'; patterned together they represent a 'quilt of ideas'. Figure 2 below shows the three groups of participants and some of the concerns, which have become the themes. Love is placed at the centre of the family and is the first theme I discuss. The worries and concerns of living with a child who is experienced as challenging becomes the focus of the second theme, while the third theme explores the wider contexts in which people live (Barriers to an 'ordinary life'). The fourth theme considers how important it is for participants to make sense of the difficult behaviours and considers the narratives that people draw upon to try and make sense of the challenges. The chapter ends with a consideration of the importance of good relationships in the networks of concern and what sustains them in their day-to-day lives.

The process of analysis using IPA is well described by Larkin et al. (2011). Whilst the end product looks fairly neat and tidy, the process of the analysis was protracted and messy. On reflection, some of my difficulties may have been associated with my reluctance to face the often exhausting, difficult, daily reality of the lives of the children and their families. I have learned a huge amount through this process, ideas which I have begun to use in clinical practice and supervision. Like any (beautiful) quilt, it now needs a place to be displayed, and used. My discussion and implications chapter aims to do this.



Figure: 3  
Challenging Behaviour:  
Meanings and relationships



I begin this chapter describing with the voice of one of the participants. Lucy, the team member working with Hayleigh, is trying to see the meaning of the challenging behaviour from the child's point of view.

I do think that it is Hayleigh's way of saying something's not working for me right now, or I don't understand what on earth's... why this can't happen right now, or what's going on?

H:P109

I have chosen to start here in order to highlight that the voices of the children are absent in my analysis. It was not possible to talk to any of the children directly as they found strangers difficult, had little language and I was wary of upsetting them, making life more difficult for their parents or teachers. Thus their 'life worlds' were only accessible to me through the words of others. However, my analysis does foreground the descriptions of the children's behaviours. Behaviours, in this context, can be seen as communications and participants were often trying to make sense of these in order to help make sense of the concerns (life worlds) of the children. My analysis relies on the voices of the children's parents, their teachers and members of the Camhs Team working with the children.

The following issues arise from my research questions:

- The ways that people try and make sense of the children's challenging behaviours;
- Whether and in what ways this meaning making is linked to strategies that are hoped to help the children to live their lives without resorting to behaviours that are experienced as distressing or frightening;
- How might these similar or different meanings and strategies affect how people get on with one another;
- How might the contexts in which we are all embedded and the language we use constrain or promote our meaning making, ways of coping and relationships; and,
- How might these ideas and findings aid us in delivering more responsive, effective services?

Themes 4 and 5 address these issues directly. Themes 1–3 capture other important aspects of living with children whose behaviour is experienced as challenging. The remainder of this chapter describes each theme in turn, comparing and contrasting the different perspectives of the parents, the

teachers and the team members. Over-arching themes are broken down into sub-themes, which are elucidated in each section as follows.

**Table 2: Summary of Themes:**

A:	Loving and affectionate descriptions of the children		
B:	Life can be difficult with a challenging child		
	a:	The children behave in frightening and worrying ways	
	b:	The effect of blaming or not blaming on relationships	
	c:	Strain on family life and family relationships	
		i:	Guilt and concern for siblings
		ii:	Marital tensions
	d:	Worry about what the future will bring	
C:	Life can be different with a challenging child:		
	a:	The children and their families as special and different	
	b:	Services help us keep going	
	c:	Services can really frustrate and let families down	
	d:	The world can seem an unpredictable and hostile place	
D:	Making sense of the challenges is important to people		
	a:	Behavioural Narratives	
	b:	Diagnostic Narratives: Autism	
E:	The value of good relationships in the 'network of concern'		

In using IPA to analyse the data, I have attempted to stay close to the things that matter to participants, the experiential claims made and the relationships between person and their concerns (Larkin, 2012). This represents the phenomenological aspect of IPA. However, the act of observation and sense making is mine and represents the interpretative aspects. I do not see interpretation as a single process but as evolving from close engagement with the concerns of participants to a wider consideration of the contexts of people's lives. This including the 'hegemonic discourses' referred to by Avdi (2005) and connections with academic literature.

### **Theme A: Loving and affectionate descriptions of the children**

I begin this section by introducing the four children from my study although I didn't actually meet any of them for more than a moment or two, but feel I got to know something about them through the descriptions of others.

Hayleigh was a tall willowy young woman with a mass of blonde hair. She was 16 years old and lived with her mum, dad and older brother in a pleasant semi-detached house in a leafy suburb. She seemed like a pent up spring ready for action and had little interest in me in our brief meeting except perhaps some vague irritation that someone she didn't know was sitting in her living room talking to her mum and dad when she got in from school. Her family were white British and had been born and brought up in the Midlands.

Shirley lived with her mum and dad in a little open plan house with her two sisters, one older, one younger. I met her for a few moments and have a picture of a bubbly, energetic little person who loved to get into mischief. Her mum and dad had their origins in the Caribbean and retained links with family there.

I didn't meet Fraser, who was 10 years old but had a sense of him of being a beautiful boy who was happy in his own world but perturbed when things didn't go his way. He lived with his mum, dad, older brother and bouncy dog in a detached house just off a busy main road. He also lived at school for part of the week in a unit with one other child. His family's links to Scotland seemed strong and they described spending holidays there.

Finally, there was Tahir, whom I did not meet. I wondered if he was like his mum and dad who were tall and slender with dark hair. He lived at home in a terraced house with his older brother and sister, which was probably larger than it looked from the outside. His family lived in area where people from the large south Asian community occupied many of the homes.

Writing this I wonder how I might have thought about the young people differently had I got to know them better. However, what interested me was the ways in which people talked about them, rather than my impressions of the young people themselves.

My interviews began with the question, "So if you could start by telling me about *name*, just to help me get a sense of who s/he is as a person". This question often elicited positive descriptions of the children. All of the children

seemed very much loved by their parents, and were spoken about in positive ways by the teachers and team members. Some comments were based on attractiveness or a lovely personality; others mentioned the children's affectionate or funny natures, others focussed on their skills and abilities. The question also elicited factual information for example, age and physical appearance. Tahir's mum started by describing her son as "A bit of a teddy bear in the sense that he's very affectionate and loving." (T:M3) and a little later "He's a gorgeous looking chap" (T:M7). Fraser's mum said,

He's incredibly affectionate for an autistic child, because the autism's pretty severe and I know lots of parents don't have that link with their child when they're autistic, but he's always been very, very close to all of us - which is lovely - and just really affectionate.

F:M6

The account of this theme is relatively short indicating the paucity of positive descriptions of the children, perhaps because the title and focus of the interviews was 'challenging behaviour' or perhaps because it was hard to be positive about children when their behaviours were experienced as very challenging. All parents however offered positive descriptions of the children. Sometimes these comments came after a particularly harrowing story. For example, Fraser's mum said, "Ultimately, there will come a time where he will be too big, too strong and too aggressive to manage. But he is just a gorgeous little boy". (F:M20) Sometimes the positive comments were interspersed throughout an interview, and sometimes people started with positive descriptions. Some parents juxtaposed positive and negative comments, with the negatives outweighing the positives. Shirley's mother typifies the conflicted nature of these descriptions.

Shirley's mother, Sonia

Well, she's a loving child. Say (1 second pause) well with her, there are times when the negatives tend to outweigh the positives with me. I'm trying not to be unfair describing her. She's fun; she's loving; she's kind as well. However I can't say to you that she's considerate; she doesn't really know what that is.

S:M15

I had a sense of people feeling a tension between being disloyal talking about their child in negative ways and on the other hand wanting to explain how difficult things could be and to answer my questions about challenges. Positive moments were celebrated. Kirstie, Fraser's mum tells a lovely story

about going to the library to choose books. Fraser was actually interested in the DVDs and 'shoves one' in Kirstie's bag. She then tells about how they share a book together.

Kirstie, Fraser's mum:

When we were there, actually, we hadn't realised that he knew all the months of the year, and there was a lovely book with all the seasons and things, and he just beamed from ear to ear and went, "January, February, March ..." and it was amazing - he was so pleased. And I know the expression was, "I'm pleased, and you're pleased", and that was lovely.

F:M36

Kirstie's joy seems to be in her son's pleasure and his knowledge of the seasons, but most importantly it was sharing a moment together, a rare instance of pleasurable communication. In the section, C:a 'The children and their families as special and different' Nick tells a similar story of pleasure about Hayleigh's part in a dance show. Love and affection was also clearly expressed in the many ways that parents had fought for the best services for their children. Hayleigh's parents spent years challenging the system, at great personal cost, because they believed that her autism had been caused by the MMR (Measles, Mumps and Rubella) vaccine. They also spent years fighting the education system to obtain the right education for Hayleigh. Fraser's parents were currently trying to get the local authority to decide on a secondary school for Fraser and Shirley's mum spoke about pushing for respite for them so they could better care for Shirley. These issues are discussed further in the section C.c Services can really frustrate people and let them down.

The four teachers all had at least one positive thing to say about their pupils. Descriptions included comments; about the child's skills and abilities; and, how well they behave in class. For example, Tahir's teacher says, "He's a really, really sociable, lovely boy. Um ... He really likes adult company. He's got a real gentle side to him." (T:T6). Other comments were positive but were then modified by a less positive attribute. Shirley's teacher says, "a lovely girl, very self-directed. Likes to do things on her terms." (T:S14). Like the parents some positive comments came after descriptions of very difficult situations. For example Fraser's teacher spoke at length about difficulties with Fraser and

then said, "I really do like Fraser. He can be very loving and very affectionate at times". (F:T498). Finally, Hayleigh's teacher noticed changes over the years. He said, "I think she is turning into a charming, pleasant individual and it's nice to see that." (H:T507)

Fraser's residential unit staff member described him as a happy and affectionate child when he was settled, modifying this with an acknowledgement of his autism and how this constrained him. She also said that he made her laugh and told a lovely story of some unusual abilities for a child with very limited communication skills... "For example when we had an Ofsted inspection they asked him how he liked it, and what was his reply? This place is fantastic?" (F:C73)

The team member's descriptions of the children were generally more problem-focussed. Three of the four interviews began with some factual information about school, referral, etc. and include some positive things about the child's appearance or personality. Fraser's worker, Jane, says, " He's got floppy brown hair and he's quite a looker." (F:P8) and Lucy, Hayleigh's worker, gave a very full description of Hayleigh which included lots of positive things. She ended by saying, "So I've not seen the Hayleigh that you might see described in reports" (H:P13). Andrew, consultant psychiatrist, was focussed on Tahir's interesting and unusual presentation rather than more general descriptions of him. There were fewer positive comments at the end of problem-saturated stories; perhaps the team members were used to telling problem-saturated stories? Perhaps this has also been true for me as I came to the idea of positive descriptions late in the process of analysis despite seeking out more hopeful narratives in my work with people. (See reflections on page 61). I also wonder about the meaning of talking to a colleague where such problem saturated discourses are familiar.

#### Summary and reflections: Theme A: Loving and affectionate descriptions of the children

In summary, it seemed important to most people, including myself to include some description of the children's positive attributes. In general, parents' descriptions were underpinned by love and affection; teachers focussed on skills and good behaviour in the classroom and team members gave factual information and appreciative comments. In addition, all interviewees talked

about some positive characteristic of the children. I have chosen to foreground these, wanting the children to be seen as people in their own right with a range of positive features rather than problematic burdens or objects of 'cultural fear'. My interviews invited problematic descriptions, however, I was also keen to elicit a balanced picture of the children concerned.

**Reflections on my limited use of 'appreciative enquiry'.**

Why was I not more focussed on positive descriptions of the children? As a clinician I am always interested in people's positive descriptions about their resources, talents and interests. Where possible, I spend time enquiring about these when I first meet families. I amplify moments of hope and success and do not elicit much problem-saturated discussion unless led by families. I wonder if as a novice researcher, I took a direct approach to my subject of interest, forgetting the value and importance of a more appreciative enquiry (Cooperrider and Srivastva, 1987). Perhaps also I focus on positive elements in my work as ways to address difficulties in people's lives and I was concerned not to slide into 'therapy' mode of trying to be helpful. Considering this now, I wonder what different discourses this might have been bought forth had I used an appreciative enquiry approach.

**Theme B: Life can be difficult with a child experienced as challenging**

As I was interested in exploring people's meaning making around children described as exhibiting 'challenging behaviour', this was the focus of my interviews. In this section I summarize how participants described the many demands of life with a child experienced as challenging.

The first sub-theme describes the behaviours experienced as challenging, an 'object of concern' for all participants and myself. This is followed by a discussion of where the responsibility and blame for the behaviours was placed, an idea that linked to the literature review. Next, the strain that the difficult behaviours placed on family life and family relationships is discussed. These concerns included: guilt and concern for the brothers and sisters of the children with disabilities; the strain placed on parents leading to marital tensions; and, the particular burdens placed on women as the main carers. Finally, I outline people's concerns and worries about the future. This theme is



about the difficulties of living with a child with learning disabilities who is experienced as challenging. One remarkable aspect I noticed was how accepting and thoughtful people were in the midst of these difficult situations.

**Reflection on my lack of critical awareness of labelling children as ‘challenging’.**

In retrospect I recognise that I was caught up in these descriptions (e.g. “exhibiting challenging behaviour”) as much as my colleagues. The leaflet and letter inviting people to participate mentioned ‘children with challenging behaviour’, thus positioning myself and others within this ‘dominant discourse’. As Nunkoosing et al. (2011) point out, referral texts organise and constrain action, preventing a fuller understanding of and interest in people’s lives and potentially leading to further pathologising and damaging people. However, I can take heart from a belief that I wished to talk with people using their language. Checking the parent’s interviews, I only used the word challenging when parents had used it first, which in all cases they did, perhaps indicating the ubiquitous use of the word. The analysis and discussion provided an opportunity to explore the data holding in mind the language used and how this might constrain us all.

***B:a The children behave in frightening and worrying ways***

My interviews specifically enquired about behaviours experienced as ‘challenging’. All of the parents interviewed described the difficult behaviours of their children using powerful and evocative language. These descriptions at times simply named the behaviours, at other times the parents, mostly the mothers, spoke about how the behaviours made them feel. The behaviours were discussed in terms of their severity and frequency, and the risks posed to the child and others. Teachers, team members and the carer from the residential unit at school described the behaviours either from first hand experience or from the descriptions of others, usually parents. These descriptions tended to use more technical, global language and were less relational, although they did reflect on the effect of the behaviours on family members. My analysis summarises the concerns of the parents as a group. This is followed by the descriptions of the teachers, the member of the

residential unit at school and lastly the team members working with the children. I have chosen to report the data in this way to highlight the similar and different ways each group spoke about the children's behaviours rather than to concentrate on each child separately, which might lend itself to a more clinical rather than research focus.

The parents:

Parents named many behaviours that they found challenging, including: kicking; head butting; scratching; hitting; shouting; loud, high pitched verbal 'tics'; poor sleep; lashing out; screaming; biting; pushing; pulling hair; punching; violent attacks and obsessions. Many of these descriptions were talked about as events of everyday life and the parents seemed to accept this as part of 'normal' life. Each of the parents also indicated the frightening and disturbing nature of these interactions. The following example from Hayleigh's mum is an example of this. Hayleigh at 16 was as tall as her mum, although of slight build. She had very little language and although the attacks were less frequent than in the past, the unpredictable nature of them and Hayleigh's size and strength almost made them seem worse.

Hayleigh's mum, Tricia:

When Hayleigh kicks off it is really dangerous, really violent she um kicks, head butts, she punches. There are numerous occasions. I'll be asleep in bed and Hayleigh will, she's got a thing about coming into our room and wanting to sleep with me and my first thing is 'no', I've got to get her out, I've got to get her to her own bed and I do, I do it and she will get really aggressive and Nick will say, 'no' let her come in. So its always like we're up and if she climbs into the bed and if I jump up and say 'no' then she'll start hitting me. If I am asleep um like what does she do, she grabs me eyes she's really, really violent. She's really wild.

H:M149

Fraser's dad recounted their current difficulties in an almost matter of fact way. He also alludes to the changing and unpredictable nature of the behaviours. He mentions how they have held Fraser in the past to contain him.

Douglas, Fraser's dad.

And he is certainly going into kicking more than ever before (1 second pause) because what he's moved on to is scratching your hands when you held his hands, so he would try and get you to release them. But now it's definitely kicking is his thing of the week.

F:MD724

These quotes indicate how physically and emotionally challenging the children

can be and how difficult it is for parents managing as their child grows up and becomes stronger. Hayleigh's mum<sup>19</sup> was concerned that she and her husband have different responses and that perhaps this makes things even more difficult. Fraser's dad is perhaps more matter of fact. He mentions holding, indicating the need to keep Fraser and others safe, perhaps.

**Reflection on the tension for a clinician becoming a researcher.**

Writing this section I am struck by two things. As a clinician, I was familiar with these descriptions, although perhaps the context of the research interview invited greater detail than I was familiar with. Staying with the topic, rather than moving towards solutions, leads to rich descriptions from the parents, something worth remembering. Secondly, my desire to be helpful sometimes overrode my desire to be a 'good researcher'.

Interestingly, the few thoughts I offered were mainly not taken up. I wonder if, for the participants, the context of the discussion as 'a research interview' changed what was expected, possible or useful. Perhaps changing the nature of the relationship changed the nature of meanings. So suggestions were just that, whereas clinically one's suggestions may be experienced more as injunctions - a useful idea to hold onto.

Reflecting on my desire to be helpful, leads me to think about how, as a clinician entering a space where people feel helpless in the face of violence, can be acutely uncomfortable.

The teachers:

Three of the four teachers said that they had few problems with the children at school, but acknowledged that there had been difficulties in the past and that parents experienced lots of problems at home. Hayleigh's teacher, Martin had known Hayleigh for a number of years. He had known her in the days when she had posed more challenges at school. His experience exemplifies that of three of the teachers.

Hayleigh's teacher, Martin

Because yes there were some incidents, they were very minor, a couple of occasions not so minor, but we got out of them or enabled Hayleigh to get herself out of them. And actually then she was very

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<sup>19</sup> Often in my thesis I have referred to someone as the child's mum, rather than use their name/pseudonym. I do not wish to imply that they have no identity apart from their status as mother, something that can annoy me, however for the sake of clarity and lack of repetition I have often signified the women in this way.

pleasant almost all the time.

H:T414

The remaining teacher had been at the school for some time but had only been the child's class teacher for a short period. She named lots of concerns including; pushing, squeezing her face and throat, kicking things, throwing chairs, head butting, fighting, threatening and intimidating behaviour this being very tiring and wearing. She described the child in quite negative ways; for example as lazy and 'going ballistic'. The relational effect of this negativity was not clear, however the teacher reflected on how her view of the child coloured her approach, seeing the child as 'disabled' leading to more compassionate ways of responding. She said that initially there had been few problems and that they were increasing but that she seemed to manage reasonably well but other staff really struggled with him.

Three of the teachers were in senior, permanent positions in their schools. The fourth described being in a much more unsettled and unsupportive environment. It was this person who seemed to struggle the most. I wonder if lack of a containing environment makes it hard to contain the difficulties described. Research quoted in the literature review indicates that, in a supportive environment, staff were more able to develop compassionate ways of viewing things and to respond in less punitive ways. At the time of the interviews, the parents seemed unaware of this situation or at least did not speak to me about it. I guess that that they would have found it distressing and thus I have not identified this child. The importance of transparent communication between home and school is highlighted later. Descriptive and sympathetic comments were made by all of the teachers about the behaviours at home, which were acknowledged to be difficult.

**Reflection on the effect the differences in behaviour between home and school might have on people's relationships.**

I wondered whether parents felt failures in the light of their children's lesser problems at school. However, this did not seem to be the case. I am influenced both by my clinical experience and the literature that suggests that letting go of a vulnerable person into the care of others is fraught with difficulties. So parents seemed relieved that their children were settled at school, rather than concerned with the comparison. Parents also acknowledged that the structure of the school day and the number of

adults around were very different from the home situation. Thus relationships between home and school seemed generally cordial or were seen as supportive and helpful.

#### Unit Staff:

Sophie, Fraser's keyworker on the unit, described him in very positive ways alongside recounting some of problems with his behaviour. He was described as unpredictable and Sophie said that, "he can get quite frustrated and aggressive, both verbally and physically" (F:C18). She reported that Fraser was well managed on the unit and that they saw very few problem behaviours. She acknowledged that this was very different at home. The relationships between home and the unit were described as very good by parents and staff.

#### Team members:

The four team members had spent some time with each of the children, however, their main point of contact was the parents. This was usually the child's mother but had also included fathers, when possible. Their accounts arose from their direct experience with the child and their contact with parents. The behaviours described were generally similar to those portrayed by parents although perhaps using more professional language and diagnostic labels including: oppositional defiance; property destruction; classic challenging behaviour; agitation; ADHD; Tourette's; and, hyperactivity. Tania, Shirley's worker, illustrates the use of professional language.

Tania, team member working with Shirley's family:

I think after about the second visit it became clear to me that she was showing signs and symptoms of ADHD.

S:P50

Other interviews demonstrated the use of more global psychological terms, like 'outburst behaviour' and psychiatric labels including diagnoses and symptoms, although there are also examples of specific behaviours e.g. throwing things, which echoed parents' accounts. I am unclear whether my team colleagues used a shared 'professional' discourse when talking to me or whether this language was used in different contexts including with the families.

In summary, parents and team members described some very disturbing and frightening behaviours, although used different language at times.

Professionals seemed to use global and professional discourses, while parents described incidents in more descriptive and emotive terms. White and Epston (1990) assert that: professional language can be used as a rhetorical device to assert power over people; to claim membership of a particular group; or, as shorthand for complex ideas, robbing them of local and marginalised meanings. The implication for me is to be wary of using and accepting these terms without thought and reflection and to invite and give space for thickened narratives of people's concerns.

***B:b The effect of blaming or not blaming on relationships***

This sub-theme explores the ascription of blame and responsibility for the challenges, an issue that is highlighted in the literature review. A summary table can be found in Appendix 12. The data indicated a relational shifting of responsibility from one person to another. One parent and one teacher described a child as naughty. Given this description that may locate responsibility and control of some behaviours as 'within' the child, the finding from the literature review argues that their responses might be punitive. These people did described adopting methods that were generally negative, for example 'time out'. Supporting this idea was data from some of the teachers who saw the teaching assistants as ascribing blame to the child for their difficult behaviours and as losing a compassionate and helpful focus. Parents were at times critical of their partner for lack of consistency or for getting angry and not staying calm, which was seen to exacerbate the behaviour. Team members indicated that parental conflict was unhelpful for the child, perhaps holding parents responsible at times. Individual participants are not identified for reasons of confidentiality. Ascription of blame and responsibility cannot be taken to be an overarching disposition; rather I see this as the expression of multiple positions of responsibility and non-responsibility, dependent on relationships and context. However, the data does indicate that when people ascribe responsibility to another, they find it harder to retain a compassionate outlook.

The participants often softened negative comments by saying that they did not want to be critical. There seemed a wish to promote positive relationships and a reluctance to be negative. I offer three example of this:

1. Comments from school about a parent included: "She doesn't stand firm,"

and “I think she can’t cope. No that’s wrong, cope is a wrong word. She can’t deal with it. Yeah, cope’s a bit strong”.

2. A story about one of the children not coping well at a summer play-scheme was qualified by a comment that the staff did not having the training or the resources to know what to do - a relational description.
3. And from one of the interviews a teacher said:

I think there were some differences at first. There was one lady who worked with us, who'd worked with her (the child) for a couple of years before, who has very strong views on how the situation should be managed. (An imposition of discipline, insist on the child doing something.) And I perhaps was more of the give them some time and calm and give them a bit of space point of view. But there was no real conflict of interest there I don't think. We were just perhaps feeling our way to what was a suitable compromise.

Based on my clinical experience, I was expecting many more critical comments about others in the system. The absence of this may indicate a number of things. I wonder if the research interview brought forth different descriptions aimed at showing each person in a positive, compassionate light. I wonder if the families chosen were different from my usual clinical work, where relationships had often broken down; perhaps my colleagues identified participants where relationships were good. In reflecting on this, I feel that there is as much to be learnt from positive descriptions and relationships as there is from problems and difficulties.

There were also examples of people speaking about the children as not being responsible for the challenges and not behaving in malicious or intentional ways. Andrew illustrates how Tahir is explicitly seen as not responsible for his loud vocalisations and big arm movement and how this understanding leads people to be more curious about the behaviour and to not blame the child.

He comes across generally as someone who’s not malicious in his loud vocalisations or movements, people like him and they are more likely to attribute those behaviours that will have an impact on other people’s functioning as to **not** being something that he’s being malicious in setting out to perform. Thus they make less attribution to him as, “This is Tahir doing it.” They are much more likely to blame it on something else, or be likely to try and think about it.

T:P67

I highlighted the issue of attributing blame and responsibility in the literature review. Where children are not seen as responsible the people around them are more likely to be curious and compassionate. This seems to have important

clinical implications which are discussed later.

Blame and criticism of wider systems was also present and this will be described under sub-theme C: Services can really frustrate and let people down.

***B:c: Strain on family life and family relationships***

In this section I have focussed on two aspects of family life and family relationships, which were strongly represented in the data. Firstly, all parents spoke about their concerns for their other children, the siblings of the child with disabilities. This is discussed under 'Guilt and concern for siblings'. Secondly, some of the parents spoke about tensions in their marital relationship. This was at times linked to managing the challenges of their child's behaviour and to more general tensions about handling busy lives, work, education, other children etc. This is described in 'Marital Tensions'. Participants have not been identified to respect individuals privacy and confidentiality. I have focussed on the concerns of the parents. The comments of teachers and team members are added to offer similar or different perspectives.

All parents spoke about the general stresses of living with a child experienced as challenging. Shirley's mum, Sonia, illustrates this with various comments:

- S:M48 I think the screaming is the worst thing. Oh gosh I can't take it, I just can't take it.
- S:M97 I don't know at times I feel as if I'm not living really it's all about her.
- S:M120 When I think about her behaviour in general it makes me depressed. It just makes me sad.
- S:M125 There are times when I'm just tired and I'm fed up; just fed up.

Sonia spoke movingly about how the challenging behaviours affected her life in a variety of adverse ways; tiredness, depression, sadness, and hopelessness. To say that she was "not living" was most concerning to me making it hard to stay in the position of researcher. I, too, experienced the hopelessness and anger of her situation. I am aware that afterwards I felt upset that the clinician was not doing more and was not attending to Sonia's concerns. This has reinforced my view that behavioural approaches, which were advocated at this point in the work, were missing the mark and points to the clinical implications of this study.

Issues identified by a few people included; extended family and friends, being



seen as both helpful at times and a source of concern at others; and, the financial burden on families.

### ***B:c:i Guilt and concern about siblings***

All of the families had more than one child. Hayleigh has an older brother; Shirley has an older and a younger sister; Fraser has an older brother; and, Tahir has an older brother and an older sister. Some of these siblings had their own difficulties or ill health problems placing additional strain on the families. All of this section has been anonymised to protect the confidentiality of family members.

Some parents spoke about the potential benefit for the siblings of the child with disabilities. However, the majority of their comments were negative. They indicate a wide range of concerns some of which are typical of many families, some of which were linked to the theme of disability or difference. These included: sibling rivalry and fighting; parental guilt; sibling resentment and embarrassment; concerns for the effect of the child with disabilities on their brothers and sisters identity and confidence; and, feeling different from other families. This data is summarized in Appendix 13.

The following quote from one of the mothers illustrates some of these concerns in relation to her son.

Mum: In the outside world he's too sensitive to comments or criticism um and that's probably a knock-on effect from how we've felt as X's parents um feeling failures you know there's times when you have felt you have failed and I think your children do pick up things as they grow up.

(X - child with disability; Y - sibling)

Mum goes on to talk about how the cards have been stacked against Y, how he has lacked confidence and despite this has managed some success in his life, which seems a big relief to her. She commented on his embarrassment at having friends round and paints a desperate picture of life when X had been particularly challenging. Feeling a failure perhaps echoes aspects of the blame and responsibility discussion above. Mothers are typically held responsible for the wellbeing of their children and feel blamed and are held responsible when there are problems (for example see Caplan, 1990 and Mulkeen, 2012). This is not to argue that fathers don't feel also responsibility, however, societally it tends to be mothers who attend appointments, do much of the caring and hold

themselves to account when things don't go well. The literature relating to different coping styles is discussed later. It also seemed really important to the parents that X and Y had a more affectionate relationship nowadays, an example of a positive description. The importance of siblings having a positive relationship is connected to the later theme of, 'Worry about what the future will bring'.

Guilt and concern about siblings was well represented in the parents' interviews. Guilt makes people feel bad. Mothers expressed a complex range of thoughts and feelings. They felt concerned about the effect of the challenging behaviours on their other children. They also expected siblings to help out more or to know when not to help. Tomm (2014) identifies guilt as; 'Reflecting on one's own behaviour that resulted in harm/injury to others' and "Reflecting on one's own deliberate acts of omission that are hurtful". A typical response to guilt is to apologize and make good the damage. However, how can you apologize for your child or repair damage perceived to have arisen your child's disability? Perhaps by trying to compensate. For example, Fraser's mum said,

The thing that gets Jamie is, "Why is Fraser always allowed to get away with these things?" That's the worst. And then we get, "Oh you love Fraser more than me", which I know he doesn't believe because ((laughingly)) there's not a more pampered pooch than he is.

F:M189

This clearly has implications for working with families. The literature on siblings with a brother or sister with a disability is reviewed in the discussion.

Responsibility and guilt were echoed in team members' accounts. Child protection concerns were expressed when parents had failed to protect a sibling. There was an acknowledgement of the difficulties for siblings whilst celebrating how they seem to be getting on with their lives. One team member reflected on how both children were affected by the child with learning disabilities, the older one being relied on for caring and the younger one beginning to mimic the behaviour problems.

In summary, challenging behaviour was seen to have an impact not only on parents but also on siblings and the wider family, a finding that does not surprise me as a systemic practitioner. Team members also express these concerns, although from a different standpoint. Some team members engaged

more actively in their concerns for siblings, for example, raising child protection concerns or involving siblings in sessions if possible. Others commented on the siblings but had not included them in any way.

### ***B:c:ii Marital Tensions***

The four sets of parents were all married and living together. Kirstie, Fraser's mum observed this was quite unusual as many of the people she had known with children like Fraser were no longer together. This section covers the overlapping themes of marital relationships and how the women felt about the impact of childcare on their sense of well-being and their lives.

I interviewed four women. One man joined his partner right at the end of an interview and I interviewed both parents of one child for half of one interview.

The four groups of participants all focussed on their marital relationship at some point in the interview. Varying degrees of harmony and disharmony were discussed although all four women stressed the importance of their partner as a source of love and support and spoke about their importance in the lives of their families. Teachers and team member's ideas are added as appropriate. Appendix 14 summarises the various concerns of participants and gives examples from the interviews.

All the women mentioned the drain of the child's behaviour upon husbands and how this worried them. This was seen as both emotional strain and physical strain, exacerbating pre-existing health problems.

One of the women about her husband:

He's quite a strong character, I'd say and most of the time he takes control of the situation, he does reinforce certain things, which is really, really good. But there are times when I see it takes a toll on him, I'm telling you, and when he breaks down he really breaks, it just pains me, it really does.

Teachers or team members did not mention this. Perhaps they had less contact with fathers so they didn't notice, or men were less able to discuss feeling exhausted and vulnerable. Indeed these reports came from women not the men themselves.

Women relied on their husbands for their physical strength. They valued men stepping in to manage risky situations when there were substantial incidents and their ability to take the children out, for example to swimming, when they no longer felt confident to do this. Alongside these expressions of concern and

appreciation there were comments resenting men's apparent freedoms. Three of the four women spoke about how tied they felt to home and caring. One mother typifies this when she said, "Yeah, they (the husbands) can just step out of it, they've got that luxury. I've had to be here, I've got no career now, the whole of my life has been sorting things out for X."

There were comments directly linked to the challenges they were experiencing and how this led to missing out on ordinary times, like being able to enjoy an anniversary and the more direct strain placed on the marital relationship by the child. Teachers and team members mentioned this more. Perhaps people outside a relationship are more able to notice things or perhaps the mothers felt less able to attribute responsibility for marital difficulties to their children. I am interested in the strengths brought by parenting children together and how this is not reported as much as marital disharmony and breakdown linked to disability or problematic behaviour. Do we fear falling into an agenda where marriage is valued more highly than other forms of relationship? Might we be trapped in discourses which pathologize families caring for troubled children? This returns to the point of the importance of asking about strengths and increasing the use of appreciative enquiry to balance these negative effects.

***B:d: Worry about what the future will bring***

All of the parents expressed some concerns about the future.

These worries included:

- The children getting bigger and stronger and therefore less easy to control or becoming too dangerous.
- The difficulty of staying connected emotionally to a child who was aggressive towards you.
- The toll on parents of relentless behaviour difficulties and a concern about being able to continue.
- Parents getting older or developing health problems so being less able to continue caring.
- Changes or loss of service provision either because the young person was moving out of children's services into less well-funded adult care, or a significant transition in education provision. This was closely linked to concerns about loss of relationships with service providers that had

been built up over many years.

- Concern for the child's siblings having to care when parents no longer can.

As Hayleigh was the oldest child, her parents seemed most aware of big changes on the horizon and they openly expressed their worries. Tricia highlights this:

I'm really frightened of when Hayleigh moves out to adult services because I don't know what's going to happen and you know that fear is there.

H:M395

Later on talking about the same issue, Tricia says, "You feel like time is coming to the end". She implies that something important was ending; perhaps her daughter's childhood? What does it mean for parents to face the differences of parenting an adult person with a learning disability, their different transitions, especially not leaving home and perhaps beginning to face their son or daughter needing long-term care.

Tahir was the second oldest child at 14. His mum spoke movingly about the difference between her 'lovely boy' and his age peers and she worried about a time when she will not be there.

So it happens every time around his birthday, the older he gets, and he has cousins who are the same age as him, the gap gets wider and sometimes when it's his birthday I get more kind of, it kind of clutches me then, I'm thinking, God, he's getting older and the deficits are huge, and how is he going to cope when I'm not around, and all the rest of it.

T:P56

Fraser was the next youngest child. His parents were concerned about the problems with lack of identification of an appropriate secondary school and his increasing strength and size. His dad expressed great frustration about not being able to find out about Fraser's next school, as transitions were seen as so difficult and important. Encompassed in this concern was the recognition that Fraser needed very specialist provision and they, as parents, were desperate to get this as right as it could be so that they could continue caring for Fraser at home.

Shirley was the youngest child. Day-to-day coping with her behaviours seemed to be the most concerning aspect of life for her mum. The focus on the future related to how they were going to get additional support.

Many of these concerns relate to the idea that children with learning disabilities will continue to need care into adulthood. Also, underlying these concerns, there seemed to be an anxiety about how long their children could remain as part of the family. These worries also changed as the child got older and were closely linked to life cycle issues.

Summary and reflections: Theme B: Life can be difficult with a child experienced as challenging.

This theme reflects the many difficulties of family life with a child experienced as challenging as reported by parents, teachers and the team members. I began by describing the difficult behaviours experienced by parents and teachers. I explored a key element of my original hypothesis, which was whether people blamed or placed responsibility for the difficult behaviours on themselves or others. The data was not extensive and I found that, in the main people, did not apportion blame. Where others were seen as being unhelpful, these comments were made in a non-judgemental way. The third sub-theme concerned the direct effect of the challenges on family members. The effect on siblings was described by mothers, and was mainly concerned with the adverse effects of the behaviours. Stresses and strains in marital relationships were then depicted. Some of these were typical of the lives of many families juggling, children, extended family and jobs, however the difficulties faced seemed to be exacerbated by the special needs of the children and young people.

Reflecting on the distinctions I have drawn, I notice that I have replicated something of my pre-existing knowledge and experience. I am familiar with inviting full descriptions of the challenges experienced by people. Through the literature and my experience, I am accustomed to hearing about, directly and indirectly, the effect of having a sibling with severe learning disabilities and difficult behaviour on their brothers and sisters. I have undertaken work with couples who are struggling with their relationship, linked to these issues. The learning disabilities literature is also saturated with narratives about parents worrying about the future, and I have experienced, first hand, parent's different struggles with how they provide long term for their son or daughter when they are no longer around. My main surprise was that people did not express more criticism of others. I have realised that children referred to me in my clinical

practice were those where relationships had broken down and blame was rife. This was not the case for the people who participated in this research project.

### **Theme C: Life can be different with a child experienced as challenging**

My focus in this theme moves from how difficult life can be with a child experienced as challenging to a comparative lens, discussing how life with a child experienced as challenging can be very different from a normative view of family life. My focus widens from life within the family to parents' views of services both as a great help and as a source of much frustration. I then draw together parents views about how the wider world can seem a difficult place for them and their child. The views of teachers and team members are juxtaposed, where relevant, to highlight a parental perspective or to offer a different position.

The following sections discuss both the supportive nature of service provision and also the frustrations with services.

I begin with an unvoiced aspect of this theme, which is how the children and their families might be constructed as special and different.

#### ***C:a The children and their families as special and different.***

This topic highlights the many ways in which the children might be seen as 'special' or different from their age equivalent peers, the possible implications of this and, how parents' and siblings' lives had become 'special' and constrained. I will discuss two aspects.

1. The children as the same and different from their peers:
2. The parents lives as the same as and different from other parents:

#### **The children as the same and different from their peers:**

All of the children lived at home with their families, although one of the children spent much of his time living in a residential unit at a special school and in a respite unit for children with disabilities. All of the children went to special schools. Two of the children used specialist respite units. All of the children had a range of professionals involved in their lives. Vetere and Dallos (2003) speak about the plethora of services involved with families caring for a child with disabilities. On the one hand parents clearly find this very useful, helping them to continue caring for their young person at home. However, seen

through the lens of normalisation (Wolfensberger, 1983), many of these services mark out families as different and thus they risk stereotyping and devaluation. This is considered in Chapter 6: Discussion and Implications. Parents and team members described using or advocating for approaches that were commonly used with many young children, for example 'timeout' and reward charts, although these were untypically being used with an eight year old. Parents and teachers also used a wide variety of 'special' approaches with the children for example, symbolized communication systems, visual timetables and restraint. Hayleigh's mum, Tricia, gave an example of this. When Hayleigh was little she was part of an intensive ABA programme. This was a 24/7 programme that involved a variety of people coming into the home on a daily basis.

The effort we put in for our daughter and the things that Hayleigh has been through that a normal 2-8 year old would never go through in a good education way but in a full-on way. You know I sometimes feel guilty about that.

H:M278

Guilt is expressed about doing what she thought was the best for her child, whilst acknowledging that it was different from other children. In naming these as 'special' approaches and conditions, the point being made is that they might have the effect of making the children stand out or be seen as different, not that these approaches aren't important and potentially useful.

#### The parent's lives as the same as and different from other parents:

Parents spoke about doing commonplace things like visiting extended family, going on holiday, meeting friends and enjoying their child engaging in ordinary things. For example, Hayleigh's dad speaks touchingly about celebrating a rare moment of ordinariness.

You know, I always take the good things, when she went, she went dancing and things like that, you know, I mean...the tunes that we had at the time and they took her dancing lessons. You know what I mean? And then we went to the show and she was dancing around, whew, tears of joy.

H:P74

Parents also spoke in greater depth about how their lives were on a different trajectory to what they might have expected. Examples of this included: not being able to go out because you can't get a babysitter to manage your child; giving up your career to care for your child; worrying about the effect that your



child has on elderly grandparents; having to attend numerous appointments about your child; your other children not being able to have friends around to play or being embarrassed by their sibling; having professionals involved in intimate aspects of your life; neighbours calling the police in the middle of the night due to the noise; continuing reliance on services into adulthood; and, being attacked by your child in your own home.

Shirley's mum illustrates this.

I think there's almost no social life. And sometimes it puts a strain on the marriage as well, because we can't like go anywhere; or the fact that if we could get somebody to look after the two, nobody will take Shirley yet. So, it's like nothing really. At times I'm just ((hesitates)) I don't know, at times I feel as if I'm not living really; it's just all about her.

S:M94

Sonia implied that parents can and should enjoy a social life separate from their children and that the lack of this was experienced as "not really living". Being 'special' acts in many subtle and undermining ways, such that parents experience themselves and their child as different. The ways in which culturally defined, normative expectations have the power to shape people's lives will be discussed further in the next chapter.

### ***C:b Services help us keep going***

Families accessed a wide variety of services aimed at helping them with their children. These include: attending a special school; respite provision; Direct Payments and paid carers; help from voluntary agencies; being referred to the Camhs Learning Disability Team, and to Social Services. These services were universally seen as helpful in a number of ways.

Respite care and paid carers offered families a welcome break. In the following quote, Hayleigh's mum talked about the benefits both for Hayleigh and themselves of accessing a respite unit for overnight stays.

We've had some really nice times now that we wouldn't have had before that give us a little bit more patience you know with Hayleigh. You know not patience as with there's a little bit of light at the end of the tunnel 'cause you have a little break soon. Whereas before it was like there's never going to be an end to this. We're never going to you know have a break from this or we'd be covered in bruises or just beaten really and feel shattered.

H:P253

Parents about the stress placed on them when they have to make a choice between their wellbeing and survival, the wellbeing of their other children and the needs of the vulnerable child. Some children enjoy respite in its various forms, others find it stressful. Hayleigh's mum describes this tension.

Because of Hayleigh's anxieties and how severe they were, it was suggested that we not tell her until the last minute which really helped. I felt that I felt bad I felt that I was lying to my daughter because she's say Monday expecting me to say it's home and Tuesday home you know I'd know where she'd be going but I felt it was for all of our best interests and she seem to have settled a bit since then

H:M50

Many parents, in my experience, refuse respite; Hayleigh's parents stated that for years they declined. We, as service providers, talk about child and family friendly services, however continue to offer traditional, inflexible, although well-meaning models. The lack of respite provision is also seen as a problem as mentioned below.

Various agencies provided parents, usually mothers, with emotional support and guidance. One school offers individual counselling for one of the mothers. This was provided by a separate agency. Tahir's mum talked about the value of the excellent communication with school, Fraser's mum echoed this in valuing the accessibility of the residential unit. She said, "I know if I wanted any additional help, Sandra (the manager of the unit) phones all the time, so I do, I do chat to her quite a lot. (F:M481). Fraser's mum said that she couldn't survive without respite and residential provision during term time. Team members were valued for their listening ear as well as providing strategies and ideas for helping with the challenges of the children. The importance of listening is highlighted in the discussion.

All of these services were seen to help parents survive and continue to care for their children in the face of considerable adversity. Fraser's mum sums this up by saying, "We want to have as much help as we possibly can, in order to have him at home for as long as we possibly can." (F:M27)

In summary, parents see services as a way of continuing to care for their children, however services were also seen as problematic at times.

***C:c Services can really frustrate and let families down***

Conversely, parents felt frustrated by a variety of things in relation to service provision, including: fighting for services; services damaged my child;

unresponsive services; poor services; and services making things worse.

These are discussed.

### Fighting for services

Fraser's mum talked about the lack of speech and language therapy, which was seen as very important in helping Fraser communicate more effectively. She saw communication as the key to making things better. In the end she gave up fighting as she realised that insisting on a service for Fraser would limit the service available to other children, as Speech and Language Therapy was a very scarce resource.

Shirley's mum reflected on the strain placed on her and her family in caring for Shirley, the lack of help from services and the isolation that she felt.

So, maybe that's why it's so tough; maybe that's why. We've got her 24/7 really, so no other input really, no one else to help look after her.  
S:M191

A little later I ask her about other services. She talked about the need for respite.

HH Does Shirley have anybody else involved with her? Does she use respite or have anything else?

Mum We're trying at the moment to sort that out. We're really trying desperately.

S:M205

Hayleigh's mum spoke about fighting to obtain the right school for Hayleigh. When she was young she had had ABA<sup>20</sup> (Applied Behavioural Analysis) at home. Her parents felt strongly that the school allocated was unsuitable as her skills deteriorated sharply and her behaviours worsened. Tricia described being devastated about losing their appeal at tribunal and said that "we lost Hayleigh" H:M284.

We fought to get her into Wellington School which was an MLD<sup>21</sup> school at the time and at the time it was really specifically for speech and language which is what Hayleigh needed. Her behaviours were - she wasn't showing signs of autistic behaviours when we wanted her to go to Wellington. That was the 2 years prior. That was the named school we wanted her to go to initially and we lost at Tribunal for that and that was really detrimental that was absolutely the worst decision ever.

H:M346

The devastation expressed was connected to the great changes in Hayleigh's

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<sup>20</sup> ABA: An intensive approach that applied behavioural approaches to people in naturalistic environments. It can be intensive with many people coming into your home to work with the child.

<sup>21</sup> MLD: Mild Learning Difficulties

behaviour. Tricia said that “she wasn’t showing signs of autistic behaviours” H:M298 however after going to the allocated school she was described at copying all the challenging behaviours of the other children. Her behaviour never recovered.

#### Vaccine destroyed my child

There is only one example of this topic however it was so strongly expressed and so important for those parents that it seemed important to include their story. Hayleigh's parents spoke at length about fighting the system in relation to their strong belief that the MMR vaccine had damaged Hayleigh. Tricia said, "literally the day after, she looked like a totally different child". (H:M642).

Initially, the parents<sup>22</sup> were unsure about talking about this, however they decided to go ahead and agreed to be recorded. Tricia began by saying, "I don't know, because it's the biggest, biggest thing I could say. I don't want to say, because it's so controversial. That if I say it, it's there. (M:H627). Perhaps she was expressing a concern that if she talked about this it became real; a painful reminder of a hugely difficult time when they felt that their child who was "developing normally" (HM640) was damaged irreparably. Perhaps it was seen as very political and that previously professionals had shut down these conversations, as there no evidence to support this belief. I have mixed feelings about this. Reflecting on my professional position, I feel concerned when parents take this position as it seems to take up so much time and energy which could be used for something more beneficial (indeed Nick states this later), and that it causes so much distress. On the other hand, it is such an important concern for some parents that it is important to be curious about what drives this belief, to give people space to talk about it and not to try and position myself as knowing the research evidence. Reflecting on my personal position, I am mindful that there are strong media stories that influence us all. I am aware that any research linking MMR to autism has been discredited, however I also recall being anxious when my grandchildren had their vaccinations.

Nick and Tricia continue with an emotive account of trying to get recognition that MMR had damaged their child. They spoke with great emphasis, often overlapping each other, of getting so far and then professionals backing off, of

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<sup>18</sup> Nick had joined the interview at this point

legal aid being withdrawn, and of the drug company threatening to take everything from them if they continued to fight. Tricia went on to say, " I've lost faith with everything" (H:M686) and Nick reflected on the emotional and financial cost of this.

And that divulged an enormous amount of time. Obviously we're not concentrating on Gavin as what we should have done and I think effectively that the guilt of that and everything else that you, when you come out the other side, that's the feeling I had, we weren't the family that was running in the park every Sunday. We was the family that was divulging into legal, legal stuff as well.

H:M703

They conclude their story by talking about giving up the fight but not giving up caring for Hayleigh. They touchingly say;

Tr. We have sort of give in the fight but we haven't give in caring for Hayleigh. But it's more like accepting Hayleigh.

Ni. That's what's happened.

Tr. We are just like accepting that this is Hayleigh.

H:M620

The belief, that MMR had damaged their child, led to years of fighting services and big corporations. I was moved by Tricia and Nick's commitment to their daughter and their bravery in the face of enormous opposition. I am also struck by their willingness to tell me about this even when they saw it as controversial and perhaps painful and their on-going preparedness to engage with services following these bad experiences.

Despite the amount of research into disproving that vaccine damages children and that not being vaccinated is potentially more risky, there is a lack of any research into the effects of this strongly held belief on parents. What is like for parents to believe that they have been party to giving their child something that has harmed them so irreparably? I wonder if such debate is shut down in professional communities, as it could be seen to fuel an irrational belief. I too am aware of trying to move away from these conversations clinically. Perhaps research showing that it is valuable to explore these ideas would help people be more curious about this issue

#### Unresponsive services

A number of people found services unresponsive and spoke about the additional stress this placed on them. The team member working with Shirley's family expressed frustration that the respite carer never turned up.

Fraser was aged 10 at the time of my interview in February. He was due

transition to secondary school that September. Douglas and Kirstie expressed huge frustration about not knowing which school Fraser will go to. Douglas, who had been chasing the issues for the last three months said;

Probably four or five phone calls at least, and all you get is, 'Oh, it will be next Friday.' Every week it will be next Friday. I mean he'll be 25 and they'll still be saying, 'Oh, you'll find out which secondary school he's going to next Friday.'

F:M534

Kirstie and Douglas emphasised the importance of this transition and the need to get it right. This included planning well in advance, Douglas said, "Why isn't that prioritised? Because it's a bigger transition for them than for the other people" (F:M567). Kirstie talked about how difficult the lack of a decision was for them, saying, "And I mean it is *hugely* stressful for parents and it is *nothing* like waiting for a secondary place for your normal child." (F:M537). Douglas goes on to say that he has lost all trust in the system.

And you can't trust what they say, because if they tell you: 'Unofficially you've got the place, and you'll know for sure next Friday,' and then six Fridays later you don't, how can you have any faith in the rest of the statement that they've given you?

F:M546

Other elements of the story included: having to persist and spend a lot of time to no effect; an awareness and anxiety about the reduction in funding to all services; the "laughable" excuses offered for not letting them know; the concern that the people making the decision did not know Fraser and therefore were not well placed to make decisions on his behalf; having to go to the Director to get anything sorted; the delay in the process reducing their time to appeal if they were unhappy with the decision; and, that the delay impacted on the amount of time available to get to know the school, for Fraser to begin to make this transition.

Throughout this recounting, Kirstie and Douglas agreed on every point. Their conversation flowed and they built on each other's comments seamlessly. There were many elements that seemed important. They felt angry and let down. They seemed very frustrated and worried. The literature review summarised parents' experience of services concluding that parents generally expressed a lot of dissatisfaction. Douglas and Kirstie's experiences accord with this and create a full description of all of the elements of this frustration. They wanted to do their very best for their son and they wanted people to do

their jobs well.

As a systemic researcher, I notice a number of things about the narrative about vaccine damaging Hayleigh and Fraser's parents struggle to get a decision about secondary education. I notice the concordant nature of the story-telling. Both parents know how the account goes and complement each other's contributions. These are stories that have been told many times, indicating that they are very important to people. Professionally, I am struck by how these narratives hold people together in the face of adversity. As a researcher, I could hear these tales differently. I did not have an agenda to be 'helpful' so was open to whatever people wanted to tell me about, indeed welcomed these descriptions. These contributions brought together many layers of context, including wider societal discourses of disability, education, damage and service provision, and had a special resonance for parents in their day-to-day lives. As a systemic practitioner, opening space for these narratives can be a productive source of clinical material. I also really valued having both parents present.

***C:d The world can seem an unpredictable and hostile place***

'The world' refers to being out and about in the community and negotiating everyday activities outside the home, e.g. going to the shops, catching trains etc. and the times when people outside of the family impact negatively on the young person. Unpredictable events, sudden changes for children who require stability, e.g. a train arriving late or needing to queue for a ticket were a trigger that might lead to the child becoming violent in a public place. Other difficulties related to the public intervening in unhelpful ways. These incidents included: neighbours calling the police in the night during a particularly difficult and noisy incident; the staff in the paper shop thinking the child was being naughty; a police community support officer telling the child off in MacDonald's for putting his feet on the seats and then being mortified to realise the level of the child's disability. Nazmeena talked about her husband taking Tahir swimming and talked about needing a 'thick skin' and about the 'cruel world'.

I think he has a very thick skin to be able to, he takes him swimming and stuff, and people can be very cruel.

T:M467

Parents also described their difficulties in accessing ordinary community facilities, although they made strenuous efforts to do this; a strong discourse

within the disability rights movement.

Parents expressed a number of feelings associated with these things. They included; embarrassment, annoyance, and concern for the child. Shirley's mum speaks of the concern for what people think.

HH She's still screaming?

S Oh so terribly. Even the dogs start barking. I said to myself I wonder what the neighbour thinks? But the good thing is she's outside so they can hear everything, they don't hear me battering her or something like that, they know that this child is just letting the steam off, put it that way. ((Sighs)) Oh dear.

S:M375

This statement seems to involve fear of judgement and fear of services intervening to remove her child. Discourses of child protection and Social Services were touched on in various interviews and involved concern that people who did not know the child would misunderstand the parent's actions and be critical and/or intervene unhelpfully.

Finally, parents talked about not taking the children out implying that the world was not equipped to including children with their challenges. This was at times expressed as the child's fault rather than reflecting on the inhospitable environment beyond their front doors. In the literature review, I discuss the ways in which Disabled Studies critique the disabling and excluding aspects of society. Society typically responds by creating events and services especially for groups of people with disabilities, e.g. 'autism screenings' at the local cinema or 'special needs swimming' at the local pool. Normalisation would see these as increasing community presence but not enhancing community participation. I know that families value these events but I am concerned that they do little to challenge wider societal belief and values. As a clinician within services it seems difficult to challenge these ideas and would be unethical to involve families in political action however as a researcher it is possible to critique these practices.

#### **Theme D: Making sense of the challenges is important to people**

This theme explores the importance to participants of trying to make sense of the behaviours they described as challenging and how this may lead to ideas of coping with difficult situations. I argue that the data indicates that making sense of the challenges is a key 'object of concern'. For example, Tahir's mum said, "I suppose I try and understand where it comes from, find the source, put



an intervention in place" (T:M241). Her comment also emphasises the link between making sense and addressing the problem.

In the interviews, I asked people "Why do you think .... (Name) behaves like this? What causes ... (name) to behave like this?" Everyone spoke about what might lead to or 'cause' the challenges at length, rendering varied accounts of their concerns. The importance of this to participants was apparent from the amount of time spent considering these questions. These conversations were also interwoven with descriptions of how they managed the behaviours and what helped them keep going. Often the love and affection for the children was emphasised by the strong wish to keep their children close even when the situations were felt to be almost intolerable. Parents also highlighted the importance of making sense when they spoke about how difficult it was when they were unable to understand challenges. For example, Hayleigh's mum talked about trying to make sense of her daughter's distress and how hard it was when she could not understand.

Hayleigh's mum Tricia,

Some things are obvious, some things are not. Um you know she could be watching something on the Internet that she's chosen to watch and suddenly start crying and start to get angry but still continue to watch this thing and we don't know sometimes what it is you know. I don't know when Hayleigh is really in pain or anything. I can only try and guess unless she can let me know. You know sometimes she will say water bottle and I will know she's got a stomach ache but other than that I don't know if she has a headache I don't know um what she's going through what she's going through um with her medication. I don't know what she feels um which is really hard you know to think you don't know what your child's going through and can't tell you if they are in pain if that's the reason she is kicking off I don't know, I can't explain.

H:M221

The pain of not knowing what is troubling her child is apparent from her words. Other parents said similar things about the problem of not understanding and how it left them feeling upset, frustrated and powerless. I hypothesised that not understanding one's child is a profound challenge to parental identity in addition to a more pragmatic concern that one cannot put things right. Teachers, team members or the unit staff, did not express the same feelings, perhaps because it was less of a challenge to their identity as professions where one might see one's job as working towards developing some understanding.

Initially, I analysed the data under three headings (see Appendix 9). Firstly I listed the words used to describe the difficult behaviours. This was developed into the section 'So many difficult behaviours'. I then collated the ways that people spoke about the sense they made of the different behaviours and finally, summarised the ways in which people described addressing the challenges. Participants meaning making moved between *influences that were seen as within the child*, through more *interactional and relational features to issues outside the family* to account for the difficult behaviours. Appendix 15 summarises these different types of constructions and gives examples of the words used by participants. I subsequently determined that this way of analysing the data was too static, was not relational and lacked the inclusion of the importance of context. I then interpreted the data further by drawing on the wider cultural and professional narratives that I saw as constructing participant's discourses. I have used the word 'narrative' to emphasise the situated and contextual nature of people's story telling, this links to my interest in language, power and context.

#### Analysis/Synthesis:

Parents accounts drew on a variety of narratives, which come both from broad cultural constructions concerned with raising children and professional/cultural discourses, including medico-scientific discourses related to diagnosis and disability. They included:

- Developmental or life cycle narratives - behaviour gets worse as children move into teenage years. E.g. Tahir's mum, "I know that it will pass, because I believe it is part of his growing up and he is 14" (T:M154).
- Sibling conflict; e.g. the behaviour of siblings seen as a trigger for conflict.
- Physical explanations; children behave in a challenging way when they are in pain or discomfort. In general usage, this idea probably has more currency with younger children who cannot say that they are hurting or in pain, e.g. toddlers being grouchy when teething.
- Family dynamics, e.g. parental disagreements can be problematic for the children.
- The importance of parents being consistent, with inconsistency being

linked to difficulties in managing children's disruptive behaviours.

- Wider contextual narratives, which are covered in 5:C:c: 'The world can seem an unpredictable and hostile place'.
- Diagnostic narratives including Tourette's, ADHD and autism. The latter was seen as creating communication difficulties, inflexibilities, strong interests and raised anxiety leading to frustrations and challenges for everyone.
- Medical explanations. E.g. vaccine destroyed my child, covered in sub-theme C.b. 'Services can really frustrate and let families down'.
- Behavioural narratives, e.g. parents described 'giving in' as rewarding 'bad' behaviours.

Reducing, managing and coping with the difficulties was a key concern for everyone, especially the parents. Appendix 16 summarises the ways in which parents tried to manage the difficult behaviours. Ways of managing described by parents included: solving problems for the child; trying some behavioural approaches and using ideas which came from an understanding of autism, both of which are discussed below; pragmatic solutions usually involved in trying to stay safe; having a break; physically managing the situation (this was usually carried out by the men); a strong emphasis on finding ways to communicate with the child; and, trying to stay calm as getting upset or angry was seen as exacerbating the situation. Medication was mentioned by the professionals but not by families. Appendix 17 makes suggestions about which narratives linked to ways of managing. As the only narratives that could be seen to be directly linked to the ways people tried to address the problems were narratives of autism and behavioural approaches, these are discussed in greater detail.

Teachers' accounts encompassed some similar constructions, however, they emphasised different aspects. Diagnostic categories were used extensively as explanatory frameworks, especially in relation to autism. The children's behaviours were compared to normative classroom behaviours in the context of special schools. Behavioural narratives of naughtiness, non-compliance, being spoilt and attention seeking differed from the other participants and located the problem within the child, and, on occasion, holding the family responsible. Contextual understandings differed from the parents, in that

parents spoke about the difficulties of the local community whereas teachers spoke about the school as the wider context. Teaching assistants were seen as both a source of support but also could be a trigger for the child's distress. For example, Tahir became distressed by the tone of voice of one person, another person was seen as overly harsh and handling things differently to the teacher.

The unit staff member focussed on autism as the main way she made sense of Fraser's behaviours, although she also commented on the effect of other children in Fraser's classroom and the wider expectations of school.

Team members also drew upon similar narratives. There was more emphasis on behavioural formulations from the psychologists, although they saw things through the lens of autism and medical/diagnostic constructions from psychiatry and nursing, although they also shared an emphasis on behavioural narratives. Team members used interactional, systemic narratives linked to family dynamics. Team members were generally non-judgemental about the children and parents, perhaps differing slightly from some of the teachers' accounts. There was little talk of the impact of the wider world on the child, and no critique of a 'disabling society'.

As diagnostic and behavioural narratives represented significant 'objects of concern' for all participants and were linked to how people tried to address the concerns, I have reported them in greater depth.

#### **Sub-Theme D: a Behavioural Narratives**

The core elements of a behavioural narrative include an assumed relationship between environmental events and subsequent observable behaviours. It also utilises the prediction and control of behaviours through the systematic, consistent application of schedules of reward and punishment and the manipulation of environmental factors. In a purist behavioural epistemology there is no interest in inferring the thoughts and feelings of the 'subject'.

Behavioural narratives were least well represented in the accounts of parents, however some specific ideas were mentioned included; Applied Behavioural Analysis, reward charts, ABC recordings<sup>23</sup>, and timeout<sup>24</sup>. Other comments

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<sup>23</sup> ABC recordings: Recording the Antecedents to the behaviour, what came before, the Behaviour, Consequences, what happened afterwards.

<sup>24</sup> Timeout from reinforcement, i.e. as far as possible everything is withdrawn that might reward the child. I consider this to be aversive so never use this, although it is popular with parents and has been promoted on TV programmes like Super Nanny mentioned by one of the parents.

implied a behavioural understanding. For example, Hayleigh's mum Tricia said that her son felt that they had made a rod for their own backs as they always gave in to her about her wish to watch DVDs. This was immediately followed by a description of the intensive behavioural programme that had been implemented when Hayleigh was little. Parents also inferred internal states in their understandings of the children. Words like frustration and anxiety were frequently employed to make sense of why a child might be being so difficult. This is contrary to a strictly behavioural model with its focus on observable behaviours. As professionals, we should take note of the importance of these parental constructions.

The importance of consistency was directly stated by all parents and was implied when people spoke about problems of inconsistency. Parents also said that being consistent was difficult and that, as parents, they were not always able to respond in similar ways. Shirley's mum talked about the struggle to be consistent. Sonia: Shirley's mum said,

Whenever Tania (team member) does visit and suggests something then we'll take it on board, we'll try, we'll run with it. However, afterwards sometimes it just goes all pear shaped because the consistency isn't there. I'm trying to do things that way and he's not really backing me up.

S:M400

Many elements are present in this account; the wish to follow the advice given by the team member, the idea that consistency is essential to prevent it 'going pear shaped' and the feeling that Sonia is not backed up by her partner.

#### **Reflections on 'consistency'.**

In the interviews I asked about people's views of consistency. Everyone asked agreed that it was important and some parents raised it directly. This question arose from both my clinical experience that parents and team members often seem to view this as important and was probably linked to my behavioural training, although many general child-rearing approaches also stress the importance of consistency.

Do I agree? Well in part. My experience with my own children indicated that being consistent routinely was beyond me, although with issues I felt strongly about it was easier. Did they grow up to be fairly reasonable people? Yes, I think so. Thus I don't think that I had a stake in there being a 'right answer' to the question. However I acknowledge that my question

about consistency might have perpetuated the idea that it is important and may have made people feel inadequate in some way. Consistency is such a dominant discourse within the area of parenting in our culture, which is perhaps why parents have judged themselves as failing in relation to this.

Team member and teachers all mentioned behavioural interventions in considerable detail. The teachers talked: about monitoring and recording behaviours in order to understand them better; using rewards and motivators; and, using planned ignoring of some behaviours. Behaviours were seen by the teachers as: a way of getting out of doing something; being triggered by being asked to do something the child didn't want to do; being stopped from doing something they did want to do; the child being seen as spoilt; and, seeking attention. At times teachers used more technical language for example 'non-compliance' or 'obsession'. Shirley's teacher describes how she used planned 'ignoring' to change her behaviour.

She would just scream to get your attention. We did just try and ignore it as much as we could if it didn't impact on the other children. And then she didn't have screaming.

S:T95

The two psychologists in the team spoke in detail about the behaviour support plans they had put in place and the nurse spoke about supporting Shirley's parents with reward charts and time out. The psychiatrist working with Tahir and his family also outlined several behavioural ideas, which he said had been influenced by some psychology observations, although his main focus for the interview was making diagnostic distinctions and medication.

Andrew:

I am starting to see that at least some of it is fitting in with some of the more classic models I suppose we would attribute to the challenging behaviour. So, that of wanting to seek attention or to gain validation for whatever task they are performing or whatever activity they are involved in.

T:T120

To summarise, parents drew least on a behavioural narrative and used this as an explanation of what can go wrong, rather than as a resource for addressing the difficulties they experienced. The teachers and team members used a

behavioural narrative to both 'explain' the behaviours and to link these ideas to possible strategies. Pure behavioural approaches do not take meanings into account. This has the potential to disqualify or deny important aspects of the child and parent's experiences. There is a delicate balance in creating and supporting environments that help disabled children manage their frustrations while making space for other constructions.

Shirley's mum commented on this divergence of ideas when she said,

Reward charts as well. I've only started that three weeks ago, however she hasn't gotten anything yet because she just didn't do the task or whatever. I don't know if I'm getting anywhere with that, it's just trial and error really.

S:M223

and,

So sometimes I just get tired of always documenting stuff, always being the one documenting, shading in what time she is sleeping, check this, oh yeah she went to bed at that time, she woke up at that time. And in the middle of catering for the other kids, Home life, work, it's just.... (she stopped at this point).

S: M404

She indicates that the ideas are not working for her or Shirley; that she perhaps has not grasped some of the underlying ideas; and, that the tasks are onerous, placing additional strain in her busy life. Everyone thought that consistency was important, although parents seemed to be more troubled by their perceived lack of consistency. Finally, parents, typically mothers, inferred more thoughts and feelings to the child or young person compared with the teachers or team members.

A exclusive focus on a behavioural narrative excludes a consideration of parenting styles and beliefs, leads to little curiosity about people's past experiences of help or of other professionals, which may shape parent's relationships with practitioners and an absence of any critique of a disabling society and how we are all influenced by this. These findings will be explored further in the discussion.

### **Sub-Theme D:b Diagnostic Narratives: Autism**

Autism as a word and as an explanatory device was used extensively in relation to the children and many of their behaviours. In this sub-theme, I capture the different ways that participants drew on this diagnostic category and consider what may be lost and gained by constructing the difficulties in

this way. As each child is a unique individual, I have deconstructed the way autism is used for each child in turn, considering how parents, teachers and team members used the term. I have drawn upon a commonly employed categorisation of autism (See appendix 19). I have not wished to constrain the wide range of descriptions of the young people, but was struck in my analysis by how most participants used these descriptions in their accounts.

#### Hayleigh.

All participants explicitly talked about autism<sup>25</sup> at length., Tricia (Hayleigh's mum), Martin (teacher), and Lucy (team member) mentioned "autism" or "classic autism" a number of times during their interviews.

Tricia's main 'object of concern' with regard to autism was that the administration of the MMR vaccine had directly caused Hayleigh's autism. This is discussed in 'Services can really frustrate and let families down'. This powerful narrative was however separate from Tricia's wish to understand and help her daughter. She said,

M. Yeah, I mean we understand that the autism gets in the way which makes it difficult

HH. Sure

M. but sometimes I think severe learning you know I suppose when you see other people with disabilities you compare and so um I suppose to me um I, I think she can learn given the right... if she's got the right not person but someone who's there with the structures and the patience to be goin' on.

H:M15

This idea that she did not have a severe learning disability was echoed later when she described being shocked when someone used this term. She felt strongly that her daughter could and should learn and she and her husband had spent years fighting for the right education. This idea that autism is somehow more acceptable than severe learning disabilities was echoed in other parents' accounts.

Martin sees things differently.

Hayleigh's classic sort of passive autism in that she would be very happy, would do certain short-term tasks with complete happiness especially one that she was used to and had done many times before. But if a sustained task came along that we required Hayleigh to do quite a lot of work in one burst she wouldn't really like that very much either. So she would exhibit some mildly challenging behaviour

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<sup>25</sup> I recall being careful not to mention autism first in the interviews, as I was aware of my pre-existing ideas and did not want to impose meanings on people. However, all participants referred to it frequently.



at those times.

H:T59

And later,

HH: And that's, you're putting that down to the autism label or I might have got you wrong there?

Martin: I think we are but we're being a bit over simplistic there or not I don't know.

HH: Okay, say a bit more about that.

M: Well it is quite an easy label to choose isn't it - Hayleigh has autism some autistic people are very passive and that's how Hayleigh displayed.

H:T159

Martin sees autism as contributing to Hayleigh not wanting to do sustained tasks, being 'passive', being happy to do things she is used to and that pushing her might lead to 'mild challenging behaviour'. A different narrative emerged later of Hayleigh being quite bright and that she was bored with the very simple work offered her in the class of less able children, something that Tricia had pointed out and had helped them to stretch her.

Lucy describes her understanding of autism as follows.

Well I think, you know, obviously the autism has a role to play in that I think some of the acts are done without social constraints and I think that's part and parcel to do with perhaps the autism and her not putting herself in other people's shoes and having quite a rigid view about what needs to happen and when.

H:P149

This description encompasses ideas of *impairment of social relationships* and *impairment of imagination*, which are aspects of a diagnosis of autism (See appendix 19). Lucy also saw difficulties in "bringing herself down" and poor self-regulation as aspects of autism. No specific strategies were mentioned by her to target these areas, although Tricia mentioned Camhs help in Hayleigh tolerating less TV viewing. Communication with Hayleigh was seen as problematic by all three participants, a common feature also used to 'diagnose' autism. School focussed on her unwillingness to communicate and passivity, whereas Tricia and Lucy directly linked problems with communication with incidents of challenging behaviour and named various 'autism friendly' approaches aimed at alleviating difficult situations. All three interviewees agree on a lack of social restraint leading to challenges and Hayleigh's difficulty in putting herself in the shoes of others, although Tricia spoke a number of times

of trying to put herself in her daughter's shoes. Everyone seemed to agree that Hayleigh had more cognitive ability that could be "unlocked". School mentioned that mum had given them useful ideas in relation to this. The three views of Hayleigh's challenging behaviour (or lack of it at school) through the lens of autism indicated general agreement. In conclusion, autism was a strong narrative for Hayleigh's mum and the psychologist, less so for her teacher. It was used to both make sense of some of Hayleigh's difficulties and to develop some ways of helping her and her family, although may also to have limited the curriculum she was offered at school initially.

### Shirley.

Shirley's mum, Sonia mentioned autism a number of times but said that she didn't really understand it and had had no experience of it in her life, although her husband had an 'autistic nephew'. She said, "Shirley is just who and what she is. So it's a case of everybody just accepts the autism." (S:M200) The statement "who she is and what she is" is interesting. It is as if autism was unexamined and not understood but accepted and that Shirley was perhaps more than this too. Did mum mean that she only saw her child through this lens, which made no sense to her or did she feel confused by her daughter? This confusing picture continues with Sonia struggling to make sense of her daughter's behaviours.

Because I know she's autistic, and yes research showed that they exhibit behaviour, that and that. But with her it's not like we are a violent family – we're not violent, we don't really... When I say argue, we're not like the top of our voice and scream down each other's throats. It's not like that, because everybody disagrees. We're not like that. We don't swear and we try and treat each other with respect and all that. So I'd say it's a typical I'd say normal family. ... Dad doesn't smoke he doesn't drink, he's yeah he's okay. We both work hard. I don't know to be honest I just don't know.

S:M155

Sonia seemed caught between a diagnostic category, which she felt that she didn't understand and her view of Shirley as a naughty child, who was doing things on purpose. She also talked about her confusion that Shirley could be violent although they were a peaceful and harmonious family. She had a positive view of her family and could not understand how her daughter could be so different.

Alison, Shirley's teacher mentioned autism in passing and Tania, one of the

clinical nurse specialists from the team mentioned autism on many occasions. She felt that Sonia perhaps does not see problematic behaviours as related to autism but felt that she was changing. She implied that an understanding of the behaviours in this way would be helpful. There seemed to be some convergence around the idea of autism as an accepted diagnostic label. How people saw Shirley's behaviours was at times specifically linked to autism and at other times drew on other interpretations, e.g. her strong and wilful personality. There was general agreement that communication difficulties were linked to challenging behaviour. There were some small examples of strategies which are typical of those used with children with autism, however many of the other ideas were straightforwardly behavioural and mainly punitive. How people made sense of the behaviours seemed mostly unrelated to the strategies tried or suggested.

#### Fraser.

Autism was a word used many times in all of the interviews about Fraser. It was seen as a strong descriptive and explanatory category linked to the challenges people experienced. Kirstie, Fraser's mum, used the concept of autism extensively in trying to make sense of Fraser's behaviours and how these linked to difficulties in communication. The family were focussed on using many autism-friendly ways of communicating and helping Fraser develop new abilities, including PECs (a symbolised communication system), visual timetables and, using simple verbal instructions to remind Fraser of upcoming changes, e.g. moving from watching TV to having a bath. These strategies were explicitly linked to preventing difficult situations.

There's lots of lower level incidents where we're trying to manage with PECs and timetables; I mean, just verbal instructions, because his comprehension, you know, has come on unbelievably really in the last little while; and just talking to him and letting him know in advance very clearly what you're doing, that's stopped a lot of the incidents that would have then gone on to, you know, be really violent eruptions.

F:M293

Douglas, Fraser's dad told a story of Fraser being told off by a community police officer for putting his feet on the seats in MacDonald's. He reported saying to the policemen, "Look he's severely autistic, he doesn't understand a single word you're saying to him". (F:MD548). This acceptance of autism was common to everyone interviewed about Fraser. Brenda, Fraser's teacher also

mentioned autism a number of times, although seemed less certain at others. She described the importance and significance of linking her meaning making to the strategies she might use. She contrasted her approach when she saw a child as 'spoilt' to when she saw them as 'autistic' (her words).

Fraser's teacher, Brenda.

HH If you thought it was about a spoilt child, Brenda, what would you do with that?

A Tell him to go and sit in a corner, cross his legs, think about what he's done, and then come back, and deprive him of certain things. 'No, you can't do cooking this morning because last week you tipped the cooking materials over the table.' Or 'You are not sitting with the group today at the dinner table because your behaviour is unacceptable; you will sit on your own.' That kind of thing.

HH So if it was the autism, what would you do differently?

A The autistic way: right, this child needs five minutes out, give him five minutes and then ask him to come back to the table, show him symbols, do it in a structured way, that maybe this child is trying to tell me something, but I can't figure out what it is.

F:T81

I find this a fascinating distinction. When the child is seen as spoilt the responses are punitive and excluding. However when the difficulties are linked to an understanding of autism the response is less punitive and tries to open up channels of communication, locating the difficulty in the relationship rather than the child. Perhaps this provides an example of the helpfulness of diagnostic labels. Sophie, Fraser's key worker from the residential unit at school was very autism-focussed in her responses. She said "And he's generally quite happy, as long as you stick to your routines with him, as most autistic children." (F:C15). She described using their understandings of Fraser's autism being translated into autism-friendly strategies, including; using symbol supports and visual timetables. She described letting him know through pictures who would be on duty, and gradually increasing the range of foods he might eat. Jane, the clinical psychologist began her interview by introducing the topic of autism. She seemed, throughout the interview, to both understand many of Fraser's difficulties through this lens and to be working on strategies related to an understanding of autism.

HH: What sense do you make of those behaviours? How do you understand them?

Jane: I think a lot of them are all very based on his autism and the difficulties that that poses for him.

For the parents, residential unit staff and the psychologist, there was strong agreement and understanding that Fraser's difficulties were linked to autism. All agreed on using autism friendly strategies, many of these were in place and were experienced as helpful. Fraser had a new class teacher, who had known Fraser for a while but not been his teacher until recently. She was struggling to make sense of his behaviours. She was unsure about whether he was being naughty or was struggling because of his autism. The lack of communication between home and the teacher really struck me as a real loss for Fraser. The helpful ways of managing his behaviours were not being communicated and the teacher was left to make sense on her own.

### Tahir

Tahir attended a specialist autism school. Everyone interviewed spoke about autism. His mum only mentioned it twice and agreed with this diagnostic category although this was not central to her concerns. She said, "I would say severely autistic because his language level is still at about single to two word level" (T:M11). His teacher, who described her class as including some children who had "classic autism", said, "His autism doesn't seem to be as prevalent as some of our other students." (T:T347). Autism was agreed upon but its effects were seen as less pervasive than some for other students. Andrew, from the Camhs team, mentioned autism a number of times as a 'taken for granted' explanatory category, although he drew on other diagnostic ideas as a way of exploring the 'cause' of Tahir's behaviours. In all of these interviews, autism seemed to be in the background rather than being the main explanatory category. Andrew had said that Tahir's parents seemed more comfortable with the diagnosis of Tourette's rather the label of autism. I wonder if, because Tahir attended a specialist autism school, the autism was a 'taken for granted' idea and was therefore less foregrounded. Or perhaps as Kate, Tahir's teacher said, "His autism doesn't seem to be as prevalent as some of our other students." (T:T297). Andrew also pointed out that Tahir was a complex young person whose difficulties had a variety of explanations, mostly diagnostic. As with all of the children, difficulties with communication were highlighted. While it does not seem necessary to identify problems with communication as 'being autistic', the helpful approaches designed to help

Tahir and those around him drew on a body of work which specifically linked the ideas as arising from a diagnosis of autism.

What are the benefits and drawbacks of using autism as an explanatory category?

'Diagnosis' is defined as the identification of a condition, disease, disorder, or problem. I argued earlier that it is also a social construct with many wider cultural meanings associated with to the label. Thus autism is both a negative descriptor, (contrary to the Disability Affirmative Model (Roosen, 2009) where disability is seen as valuable) and can be seen as a catchall term to encompass a wealth of characteristics, which serves to diminish each person's unique qualities. Indeed there is a burgeoning literature about being 'differently abled' which will be discussed later. However, impairment (the loss or abnormality of structure or function) is also a term used in this classification of autism. I have discussed that the use of this term may help people orient themselves to the difficulties the child or adult may have in negotiating the world. However there also needs to be a consideration of the difficulties resulting from societal restrictions and barriers, including people's attitudes. Further, I have argued for the need for a both/and perspective that begins to dissolve these binary distinctions. In this section, I have considered the different ways of using 'autism' and how it can be both a resource to people and a restraint. To summarise, some parents seem to prefer the term to the idea that their child has severe learning disabilities<sup>26</sup>, although Tahir's parents preferred Tourette's as a diagnostic label. Working with people's ways of knowing and seeing the world is essential to facilitate engagement and to begin to explore how they may be constrained by seeing things in a particular way. I have also argued that seeing the child as struggling with autism opens up a more empathic response to some very difficult behaviours and can introduce a wide body of approaches which seem to help people to communicate, a core issue identified as at the heart of the challenges. As Hayleigh's mum said, not being able to know what is wrong with your child is very painful. However, there is a danger that viewing the child through the lens of autism can restrict or reduce expectations, can leave people feeling hopeless and get in the way of appreciating the unique qualities of each

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<sup>26</sup> The identification of severe learning disabilities encompasses low IQ, diminished social and functional skills including limited communication, overlapping with autism in some respects.

person. Further critiques of this diagnostic approach can be found in the discussion chapter.

Theme D emphasised the importance to people of trying to make sense of the behaviours of the children and young people. Parents drew on a wider range of ideas compared with teachers and team members. Teachers and team members both drew on behavioural ideas in making sense of and in trying to suggest strategies to help the young people. Parents varied in their use of these ideas. They were seen as burdensome or had been helpful in the past when applied by others, or were absent. Communication or lack of it was seen as crucial, and I argue that some of the approaches drawn from the field of autism studies in this regard were found to be valuable. The importance of professionals needing to deconstruct the ways parents struggle to make sense of their differently abled children will be considered in greater depth in the implications section.

#### **Theme E: The value of good relationships in the 'network of concern'**

Theme E returns to my interest in relationships between people in the network of concern. As with a consideration of autism as an explanatory category, I have analysed the relationships between people on a child-by-child basis, rather than a more global approach.

##### Hayleigh.

Relationships were described as good between Tricia and Lucy, the Camhs worker. As Tricia said;

It was really, really difficult and as I say, her behaviour was really, really difficult and as I said through Camhs and Lucy we have come up with some things to work on and they've really helped a lot

H:M129

Tricia found the emphasis on developing 'things to work on. Tricia also valued Lucy listening carefully, working hard to see things from the family's perspective, and joining with them all in discussing ideas and approaches. As Tricia said,

We've talked about things together, and it's not like Lucy's come in and been this person who's gone: you've got to do this, this and this. She's sat, she's listened and we've talked about it together. We've talked about what is suitable for us as a family how that can fit in with us. I think it's been really good; it's good.

H:M593

This demonstrates some important points on how to create collaborative and supportive relationships. Lucy has not imposed her views, has not told mum what to do, rather she was experienced as carefully listening and trying to fit ideas for the whole family. Tricia's view of school seemed less positive. Tricia expressed frustration with school. She described going into school in the past to observe and to discuss incidents. She saw Hayleigh not engaging and not being extended in her abilities. This was in the past and she said that she didn't know how things were at the present, as she hadn't needed to go in Martin described valuing Tricia's input and had taken on board her suggestions for extending Hayleigh. Lucy and Martin both said that there was no need to meet as things were settled at school. I note that when things were going well there was little contact between home and school until there is another problem, when parents are contacted. The issue of not discussing successes seems a missed opportunity and will be picked up in the discussion. Hayleigh's parents described being very dissatisfied in the past with Hayleigh's education provision. They had fought hard for appropriate placements and saw her as having deteriorated, from being in the wrong environment and mixing with less able children, where her behaviour and abilities had deteriorated. School was viewed with some concern, as Tricia seems anxious about what is happening, perhaps influenced by her previous experiences of education. Indeed she says at one point,

Sometimes I'd like to be a fly on the wall to see what Hayleigh does during the day but that's like I say going back to we (1 sec) because we know that she was working when she was here, we know that, we 100% know that she was being taught, that she wasn't being minded.

H:M355

Tricia is expressing concern about how Hayleigh is learning when she is not there; perhaps an issue for her given her previous negative experiences. These concerns echo back to the initial theme of love and affection, which includes wanting the very best for your child. The importance of thinking with families about meanings, past experiences and wider contextual factors is elaborated in the Implication section.

#### Shirley.

Sonia, (mum) spoke about different aspects of her contact with Tania. She talked about the importance of taking on board ideas that were suggested by



Tania but said that, "Afterwards it just goes pear shaped" (S:M401). As mentioned above, she seemed frustrated by being asked to collect data and found this difficult in her busy life. Tania said that she had started by asking mum to complete ABC charts<sup>27</sup> but quickly discovered that, "The family weren't able to commit to the concentration" (S:P39). Sonia spoke of being busy and exhausted. This perhaps was an example of the difficulty of applying behavioural ideas within the family setting (Rhodes et al., 2011). Tania described her work with Shirley and her family as "early days". Tania was complimentary about the family researching things on the Internet and trying out the ideas, for example time-out, although she also said that this needed 'fine tuning'. She felt that she had a good relationship with Sonia, speaking of the importance of giving Sonia time to talk about a variety of concerns.

I get on really well with mum. Mum's always pleased to see me, and I think it's because she needs the time to offload what's been happening in the week, how her and Wayne have seen things or not seen things together, and basically how work is as well.

S:P332.

She also said that she thought that Wayne (dad) appreciated having professionals involved as it helped the family feel less alone. Mum did not mention the importance of 'offloading', although said that she found it helpful to talk with me, perhaps indicating the usefulness of talking and being taken seriously. Tania talked about the importance of including both parents in her sessions but said that this was difficult because they worked. To summarise, the relationship between Shirley and Tania was at an early stage. The team member saw it as supportive although mum perhaps experienced it as placing additional burdens although was keen for help and support. At this point in their relationship, there did not appear to be a shared common understanding of the difficulties, which seems to have been helpful for other families. This is not to imply that the parents should adopt the Camhs worker's ideas. Rather, it is essential for Camhs workers to explore the parent's beliefs and ideas and to coordinate their approach with these, while offering ideas that they believe may be helpful, without pressuring people to adopt them. Although I acknowledge that pressure might be felt due to the power differences between professionals and parents.

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<sup>27</sup> ABC Chart: A way of recording Antecedents, Behaviours and Consequences. So what happened before behaviour of concern, what was the behaviour and what happened afterwards.

Sonia said that there was not much communication between home and school. Sonia had found the previous head teacher really helpful in that he seemed to really understand Shirley, explain her behaviours in a positive way and give her quick tips on improving things. The teacher, Ann, said that they saw more of dad than mum. She added,

Yes, because parents have come and said, they have said that they have great difficulties at home and we give them strategies and we give them symbols and so we suggested a symbol timetable and things for them. I don't always know if it's taken on board ((laughs)) but she does like a structure and she's quite reliant on a timetable, she likes to know what's happening and what's coming next.

S:T57

These strategies are based in an understanding of autism, about which Sonia was unclear. This comment highlights the difficulty for busy parents in implementing poorly understood ideas in their busy lives. As Wayne was the main contact for school this may have disadvantaged Sonia from receiving another form of information and support. Given the differences between Sonia and Wayne, it may also be possible that information was not passed on, leading to further isolation. Tania did not mention school except to say that the teacher had filled in a questionnaire and that she understood that Shirley's day was very structured.

#### Fraser.

Relationships were described as very positive between parents, the unit at school, and the team member. Kirstie (mum) was very positive about the value of the Unit in terms of their care of Fraser and the benefit for them as a family managing to keep Fraser living at home, which they very much wanted but feared would not be possible as he got older. Kirstie described very regular contact with the unit with daily phone calls and visits once a week. Jane (team member) was mentioned in a number of ways, including giving advice about letting Douglas handle the aggression and suggested staying calm, suggesting a visual timetable, requesting recordings, and talking to Douglas at mum's request about the need to not get angry and "scream". Kirstie also highly valued being able to talk to people about her concerns, having a break from Fraser and feeling confident about the people caring for Fraser. Brenda, (Fraser's teacher) was not included in regular communications and was unsure about the best way to manage and teach Fraser at school. Kirstie and

Douglas had previously had both positive and negative experiences of schools, although were generally happy with Fraser's current school. Kirstie and Jane said that communication with class was limited and recognised this as a potential problem.

#### Tahir.

Relationships between Tahir's parents, Andrew (team member) and school were described as close and very positive by all parties. For example, Tahir's mother spoke of Andrew as "Fantastic" (T:M227). There were lots of examples of good communication focussed on problem solving around Tahir. Shared meaning making perhaps helped people to coordinate their actions. In Tahir's case people drew on an understanding of autism and used this to implement some strategies to support communication with him. However, there were other aspects that contributed to these positive relationships. People communicated on a very regular basis, holding Tahir's wellbeing as a central concern. Andrew and Kate were very respectful of the parents and valuing of their strengths and Andrew was interested in the wider family, which Nazmeena (Mum) appreciated. Nazmeena said that she valued her easy access to the teacher and appreciated her willingness to consider her ideas and to explain and reassure her if something went wrong.

#### Relationships within the classrooms.

All of the children came into contact with teaching assistants (TAs) at school. These people were not mentioned by parents or team members but were commented on by all of the teachers. Relationships varied considerably, however there was a common thread that the TAs often had different ideas about how to manage the children, which could be a source of conflict and cause some problems for the teacher and the child. For example, Fraser's teacher said,

A lot of them (TAs) are just so set in their ways, and they just won't budge for new people coming in, and they argue with you constantly, and I know it's not just me. But again, I'm quite willing to overlook that, but it does have a negative effect on the children, I think.

F:T165

And later in the interview

They'd (TAs) probably say he was spoilt. Again, there are three members of staff in that class, but I'll give you a couple of examples of why they think it might be. One example is that mum doesn't want him, so she just lets him get away with murder at home.

Other examples were less negative but differences of meaning and action were also seen as problematic. The implications for Camhs working with the wider network are discussed later.

I reflected earlier, that my being part of the same team may have constrained teachers and parents from speaking negatively about my colleagues.

However, I had a sense that people genuinely spoke warmly about each other, which is a contrast to what I might have expected based on my previous clinical experiences of conflictual relationships in systems. Undertaking this research has led me to consider that the children and families that I was typically referred, where relationships had broken down, is the work that is referred to family therapists and often relationships between people are more positive for my colleagues. Thus my initially assumptions embarking on the research were negatively skewed. However, the data did render interesting aspects of convergence and divergence and allowed a consideration of what worked well and what worked less well between people. These ideas are then taken forward for consideration in the implication section.

I began this thesis with the idea that the different ways we make sense of children's challenges may have an adverse effect on relationships. The data indicated that where there were some shared narratives, relationships were broadly cordial. Sharing similar constructions was valuable at times, for example, agreeing upon 'autism informed' strategies to aid communication. Parents drew on a wide range of narratives and constructions in attempting to make sense of their children's behaviours. Teachers and team members sense making was more narrowly defined and strongly influenced by their different professional backgrounds. Being listened to and taken seriously was influential in forming strong relational bonds. Regular communication was also important, and where it was absent it left some people feeling uncertain about how their child was progressing or feeling unsupported. I have framed as a lost opportunity. Parents spoke of the importance of making sense of the behaviours experienced as challenging and of developing strategies that led them to feeling more able to communicate with the children. Many of the parents also had many powerful stories of negative past relationships with services, which may still be impacting in the present. I suggest that it is

important to attend to these factors and elaborate these ideas further in the discussion and implications section.

## Chapter 6: DISCUSSION AND IMPLICATIONS

This study aimed to examine the meaning making around children with learning disabilities, whose behaviours were causing concern and the relationships between people involved with these children. My review of the literature identified that parents often expressed dissatisfaction with services *and* that there was little attention paid to understanding what may be contributing to this. I have argued that attention to this topic could highlight areas for improved service delivery, including the development of positive relationships between service providers and families. Following data analysis of the interviews with parents, teachers and Camhs LD team members, five themes were identified; loving and affectionate descriptions of the children; how challenging behaviours impacted on family life - within the home or school and in the community; the importance of making sense of the behaviours; and, the value of having good relationships between people in the 'network of concern'. I fore-grounded the accounts of the parents in my findings. The reasons for this were: that parents experienced lots of very troubling behaviours at home; the behaviours were less present at the school; that team members worked almost exclusively in the home setting; that most of the children spent the majority of their time at home; and, I also believe that parents are the most important people in the lives of the children.

Before embarking on the discussion, I would like to revisit, briefly, my concern with language. I am aware of using a range of terms including, challenging behaviour, autism and learning disability. As I discussed in the literature review, our language and the language of others can be seen as embedded within a "historical, political and moral context" (Avdi et al, 2000, p.242). Wilcox (2006) asserts that some terms serve to objectify and demean people. I have not qualified my use of terms each time I have used them, but would hope that the reader will bear in mind my concern to avoid objectification and the importance of including thinking about how the 'objects of concern' expressed by people are embedded in multiple contexts.

I repeat my research questions here, in order to keep them in focus when discussing my analysis.

This study aimed to explore the following questions.

- How do family members talk about their child with learning disabilities, who has been referred to a Camhs Learning Disability for ‘challenging behaviour’?
- How do professionals in the ‘network of concern’, specifically teachers and Camhs team members involved with the child, talk about the child and their family?
- How do these three groups of people describe their relationships with each other and others in the network?
- How might people’s meaning making and relationships with each other influence perceptions of the work being undertaken to help the child and its effectiveness, and
- In what ways are people affected by wider social, historical and professional contextual factors relating to disability?

The results indicate that making sense of the challenging behaviours was of importance to people and approaches aimed at ameliorating the situation were, at times, linked to the ways that people made sense. Relationships in the main were described as cordial, being underpinned by good communication and a genuine appreciation of the children and their families. However, I have derived many other important aspects from the data including; the importance of a focus on the child’s strengths and abilities; the value of acknowledging how much the children are loved; the impact of the challenges on the families; and, the impact of people’s past and current relationships with services. The discussion and implications chapter begins by using CMM to build a picture of how these aspects connect with each other.

### **6.1 Coordinated management of meaning (CMM)**

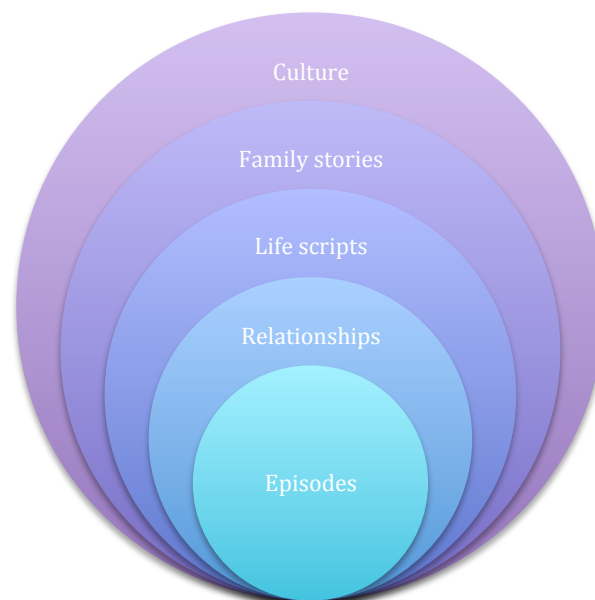
The Coordinated Management of Meaning (Pearce & Cronen, 1980) offers a framework for considering the multiple ways in which an episode or a number of episodes can be contextualised. As Oliver (2004, p. 128) argues;

Cronen and Pearce (1985) ... have provided a means, with their model of *layers of context*, to make sense of the relationship between meaning and action in patterns and stories of culture, relationship and identity.

As one of my primary concerns is the links between meaning and action, CMM provides a useful framework for bringing together the themes of this study. Cronen and Pearce (1980) argue that all conversations and interactions are

only given meaning by considering the multiple contexts in which they exist. It is further argued that these contexts create repeating patterns of episodes over time. The different layers of context include: the meaning of the relationship; life script or stories about ourselves; family and professional stories or stories about significant relationships; and, stories about culture and society. The layers can be hierarchically organised, or levels can shift to become the highest context marker depending on how meaning might change through on-going episodes or conversations. Downward 'forces' are known as 'contextual', upward 'forces' are called 'implicative'. Contextual forces shape the meaning of conversations, while implicative forces have the possibility of changing pre-existing meanings.

Figure 4: Coordinated management of meaning.



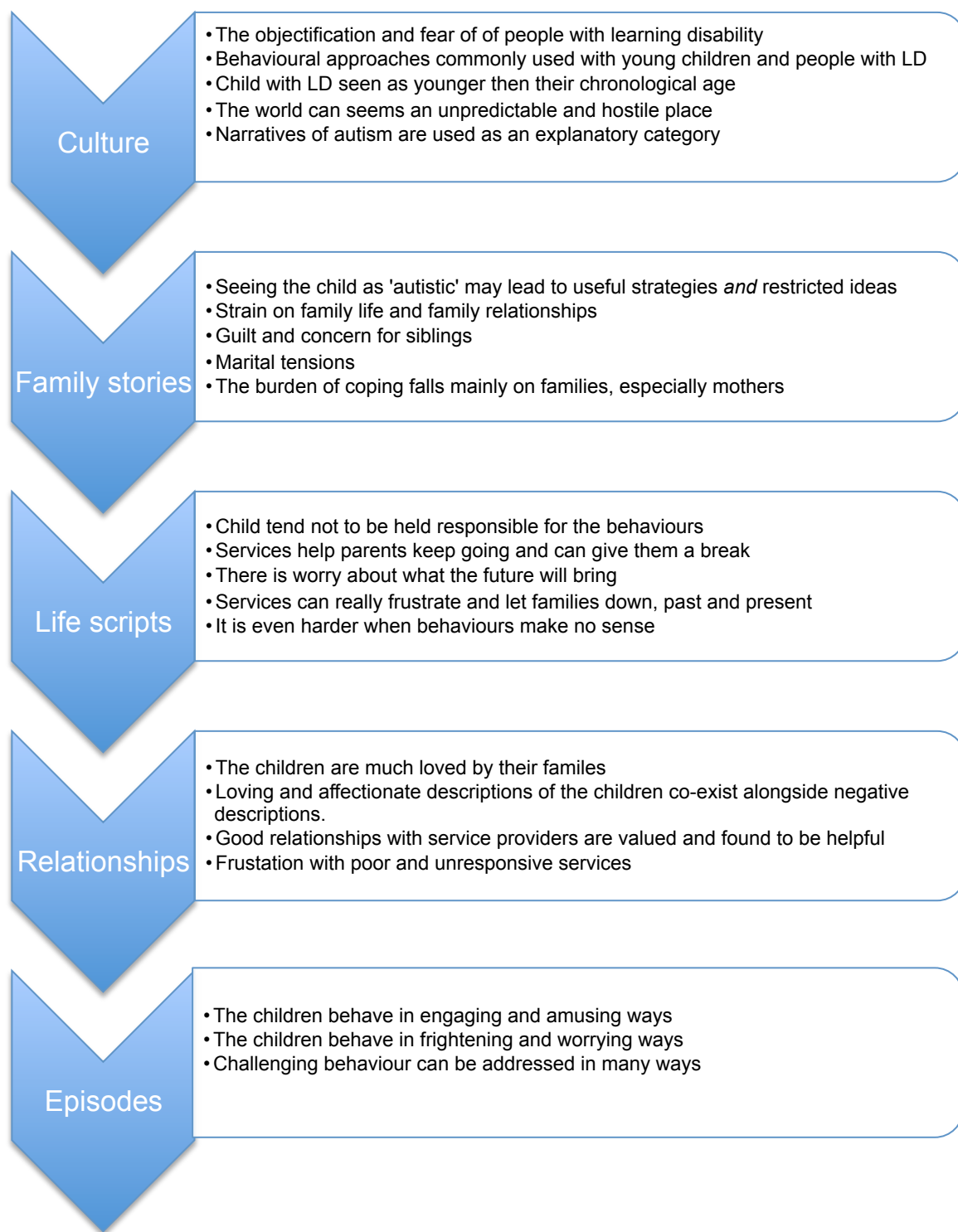
Each episode of interactions between two or more people is given meaning by the participants' past experiences at each of the levels. Some aspects will be common to everyone, for example societal beliefs, and other contexts will differ according to people's life experiences and current and previous relationships. Thus this study argues that meaning making by families and others in the network is influenced by wider societal beliefs about many aspects of disability and diagnosis. Participants will also have many stories creating meaning for them about their growing up, life experiences and relationships with significant others, including the young person with



disabilities. CMM posits that meaning changed at one level will have implicative and contextual forces at other levels. For example, if families have had numerous unsatisfactory relationships with service providers, they may initially be wary of a new person trying to help. If that person engages and connects with parents differently, this has the capacity to introduce new meanings about service providers.

Figure 4 below illustrates the application of CMM to the contextualisation of meaning making in relation to children whose behaviours are experienced as challenging using the themes and sub-themes developed from the data. This is a generic framework that pulls together many aspects of the results.

Figure 5: Meanings constructed about behaviours experienced as challenging



The following story told by Hayleigh's mum encapsulates some of these aspects.

I'll give you an example. Recently, I can't remember what it was over but she ended up kicking off really bad and really hurting me and chasing me round the bedroom. And I think Nick would have definitely got out of bed because he was like trying to calm Hayleigh down. And I think it would be something like, right we'll put the DVD on and you're sitting there at like half two in the morning watching a DVD to calm that down. But how we get to that point I don't know, if she's got me she's got me and she'll keep hitting me and she'll keep doing it until she just stops. Or if I can be shut in somewhere and Nick's like restraining her and he can distract her with something it'll be usually like that. It just depends, it depends where you are and what you're doing at the time. If it's in the early hours I mean most of the time you're that tired or you're thinking of the neighbours and it's what you can do to end the commotion as quick as you can. I dread to think what they think next door sometimes. Yeah, so it's either giving in to what she wants which is the only way you're going to get that and it's reinforcing the negative behaviour which we know because that's what we used to do when she was younger, this behaviourist thing and you'd ignore the bad, reinforce the good. But now because she's so strong, so if you were somewhere or you'd got the stuff on that would stop you being hurt or you were somewhere that didn't affect anybody else you could probably work through all these things like right, I'm not going to let her win with this but you can't.

H:M367

An episode is described. The frightening and dangerous nature of the behaviour is portrayed. She says that she is unsure why Hayleigh might suddenly be behaving like this but tries things that might help Hayleigh calm down and keep everyone safe. She worries about the neighbours. She talks about not being able to follow the behavioural advice given in the past, as Hayleigh is too big now. She indicates the support of her partner and the exhausting nature of the difficulties. Finally, there is a sense that she would like to handle things differently but is unable to do so because Hayleigh is too strong and as she can't avoid getting hurt. The word "win" is used suggesting the idea of a battle or a struggle of wills.

The next section of the narrative illustrates other points.

We have had police come because the neighbours have thought, you know... And I can't blame them because when it kicks off and you hear like screaming or banging and, you know, and then the police come and you have to try and explain that your daughter's 15, 16 and she's got autism. And I don't think they really know what it is but if you say... you have to say mentally disabled blah, blah, blah. And I have all these anxieties so every time... So if Hayleigh does kick off it's like... ((smilingly)) Sometimes it's like well just let her give me a good

beating so that everything can calm down or if I can't, just try and calm her down, we've got to think of the neighbours, I don't want Gavin to be involved, he might be trying to intervene and stop Hayleigh and it's like a vicious circle and at the end of the day I just want Hayleigh to calm down and everyone just to be calm. And it's a worrying thought really that if we can't ever find a way of controlling that then as we do get older, I'm 44 now, and I'm really feeling like that it's come to a point where although it's further between the aggressions, not as often, when it is it's bad and it's stronger and it's more violent. And how are we going to cope when we're like 60 and 70 and Hayleigh will be like a woman then? I don't know but we'll cope for as long as we can.

H:M401

This section captures more objects of concern including: the public's understanding of autism and disability; Tricia's dislike of having to explain and perhaps use words that others understand but make no sense to her; worries about Hayleigh's brother; her role in trying to calm things down; staying safe; and, worry about the future. Thus, the behaviours, which are experienced as challenging, are contextualised by a wide variety of issues, which are common to the parents in this study.

Oliver (2004) adds further ways of extending CMM. She has renamed 'Speech Act', which is the relational meaning of the communications within an episode as the 'Interpretive Act', which she argues reflects the interpretive aspect of meaning making. This idea clearly fits very well with an IPA framework. Within the interpretive act there are three elements. The first is **Feeling** (bodily response). On receiving a communication she argues that we respond bodily with emotional and sensory responses. This is followed by **Interpretation** (thinking response). These are the myriad of thoughts that can accompany our feelings, some offering positive ways of responding and others less helpful to others and ourselves. Finally she suggests **Choice of Action** (opportunity for reflexive response). Although the word choice is used she argues for habitual patterns of action, although choice also implies the potential to do something different in the sequence of communication. These ideas is elaborated using the concept of 'strange loops' (Cronen, Johnson and Lannamann 1982), a paradoxical pattern where different and incompatible meanings can be maintained in repeating patterns.

Considering the stories told by Hayleigh's mum, it is clear that she has many complex feelings and thoughts about what she is experiencing in these

episodes of challenging behaviour. The diagram below illustrates these ideas using aspects of the generic CMM diagram and Tricia's narrative.

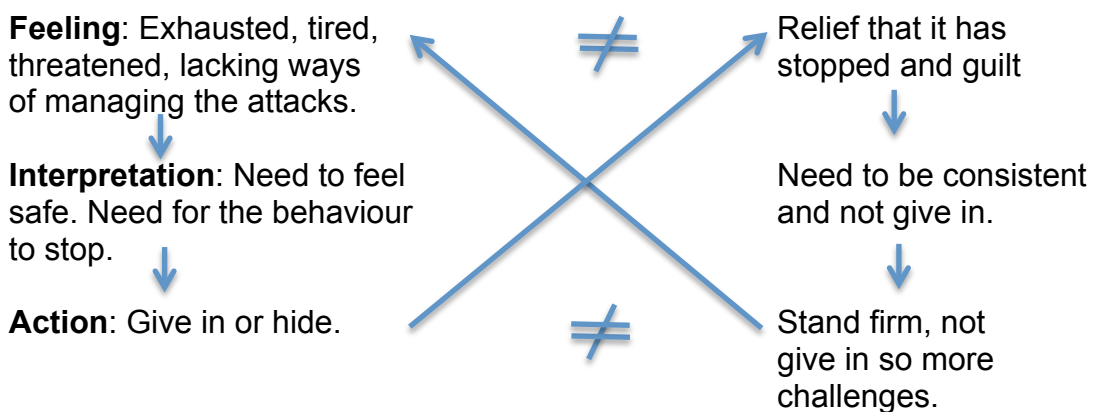
**Figure 6: Tricia's loop.**

Cultural story: Parents should understand and be able to manage their children.

Relationship story: I cannot manage my child in ways that I used to, as she has grown too big.

Identity story: I am not the parent I want to be.

Episode of challenging behaviour.



'Tricia's loop' hypothesizes the paradoxical positions she occupies which can lead to her feeling a failure as a parents at times or feeling hopeless and distressed. Identifying such layering of meaning and the ways in which conflicting feelings and ideas can powerfully organize people offers opportunities for intervention. In the section 'Implications for practice', I argue that it is important to explore these issues in depth with families.

In order to build towards how the data analysis contributes to developments in practice, I deconstruct each theme in turn. In each section, I make suggestions for the implications of the findings. These are collected together in the implications section where I draw on relevant literature and ideas from my clinical practice to reconstruct and amplify two main areas of practice.

## 6:2 THEMES

### **Theme A: Loving and affectionate descriptions of the children.**

Searching the literature for connections to this theme was like trying to find a needle in a haystack. I used combinations of the following words as search criteria; love, affection, intellectual disability, children, learning disability, parents. What I found was:

- Literature on the lack of friendship networks and loneliness for adults with leaning disabilities.
- Publications on attachment issues relating to learning disabilities, and
- A small number of publications that looked at the bonds of affection between parents and their children with learning disabilities.

Griffiths and Hastings (2014) undertook a meta-synthesis of the qualitative literature concerned with non-paid caring for a person with intellectual disabilities and challenging behaviour. Seventeen studies were included in the analysis. Some of the themes identified echoed the findings of this study including 'Love'. They reported, "The deep love for their family member underpinned much of the carers' talk". (Griffith et al., 2014, 411). They went on to say, however, that it remained unacknowledged and only explored explicitly in one study (Hubert, 2010). Their analysis links the strong desire of families to want the best services for their son or daughter, their wish for their son or daughter (most of these studies were with adults with learning disabilities) to be treated with dignity and respect and their frustration with services seeing the person as a list of traits which fitted with the diagnosis rather than the person they knew and loved. Like Hayleigh's mum, they drew attention to parents preferring to get hurt rather than see their son or daughter at risk.

They conclude,

The meta-synthesis most notably uncovered an absence of previous researchers' focus on the nature of the relationships between carers and their family member with intellectual disability and challenging behaviour, despite love for their family member underlying almost everything about which carers talked of.

Griffith et al., 2014, p.417

They recommend that training should take account of these bonds of affection and encourage workers to take a personal interest in families. This is a very recent publication and has led me to re-evaluate some of the aspects of parent's interviews. Love is not only expressed in positive comments, but in

the passionate way parents speak about their children despite the difficulties, for example a strongly expressed wish to keep the children living at home. Having this 'ear' when listening to families and acknowledging their attachment is clearly very important.

I found only two other papers reporting on this topic.

Kimura and Yamazaki (2013) in their study of Japanese mothers who had had more than one child with an intellectual disability, used IPA and elaborated three themes from their data. The last theme was, 'Searching for positive experiences in parenting multiple children with disabilities'. They said:

Participants reported finding positive features in their children and recognizing them as "treasures." This metaphor was expressed with feelings such as "grateful," "cute," "pleasure," and "unique," and participants looked back at their own lives and felt "thankful" and "happy":

Kimura et al., 2013, p.1315

This theme of the children being 'a gift' was echoed in the book, *Exceptional Life Journeys: Stories of Childhood Disorder* edited by Jac Andrews and Peter Istvanffy (2012). In the chapter jointly written by a young woman with Down's Syndrome, a mother of an eleven-year-old child with Down's Syndrome and a special school teacher, the mother writes at length about the many gifts her daughter has brought into her life. She concludes her essay by saying:

No matter what I write, at the end, I can truly say that Alexandra has changed our lives—mostly for the better. One day, I will thank her properly for what she has taught me, sometimes in painful ways, but always in ways that make me more human.

Andrews et al., 2012, p.177.

None of the participants in my study spoke directly of the children as 'gifts' or as bringing something unique and valuable into their lives. However, they did speak with great affection for their children and used some positive and loving words.

As has been discussed previously, positive comments about the children were very limited compared to the rest of the problem-saturated narratives about challenging behaviour, mirroring the wider field. Solution-focussed approaches (DeShazer, 1982) are an exception to this. Coles (2001) advocates this approach when working with children with learning disabilities and their families and Trimble (2001) encourages eliciting children's strengths as well as 'weaknesses'. Narrative approaches (White, 2007) also focus on unique

outcomes, thickening stories of success and achievement. Appreciative enquiry (Cooperrider et al, 1987) offers a way of exploring phenomena focusing on story telling, appreciating the best of what is, and envisioning and enacting a desirable future, more usually used in organizations. In my clinical practice, I am alert to these moments and ask people to say more to thicken these positive stories (White, 2007). Training others to be attentive to these moments is essential, as is inviting people to engage in positive talk about their children at the beginning of a family meeting, a practice familiar to systemic practitioners. I also suggest that listening out for the love and passion in more problem-saturated stories is also of value.

**Reflection of bringing forth negative pathologising descriptions.**

I have become concerned about this focus on problems. I wish to consider the idea that the research interview, my membership of the Camhs LD team and the questions I asked brought forth many negative and troubling descriptions. However, is that a methodological problem? I think not. The behaviours that were described were witnessed and described by all of the participants, thus they can be seen as significant 'objects of concern'. The constructionist principle, which underpins much systemic thinking and practice, posits that what we believe to be 'true' determines what we do, and that thought and action emerge through relationships. My research questions were designed to enquire about beliefs, actions and relationships constructed around children with learning disabilities who were experienced as challenging. Bringing forth such negative descriptions in a research interview is intended to illuminate the important and neglected subject of people's meaning making and their relationships around these troubling children.

**Theme B: Life can be difficult with a child experienced as challenging**

This theme reflects the difficulties of living with and parenting a child experienced as challenging. It begins by capturing the many descriptions of the behaviours that are found to be challenging.

***B:a The children behave in frightening and worrying ways***

Parents, teachers and team members listed a wide variety of behaviours, which were experienced as 'challenging'. The analysis indicated that more



difficulties occurred in the home setting. Team members tended to use diagnostic labels and psychological terms to describe the behaviours in addition to naming the behaviours. Parents used more descriptive, relational and emotive language.

A sample of four children cannot of course be seen as a representative sample; however, many of the concerns expressed are echoed in the literature (cf Adams and Allen, 2001). Bartlett, Rooney, and Spedding (1985) highlight the high prevalence of poor sleep associated with children with learning disabilities and ASD. The issue of sleep is further discussed under 'Strain on family life and family relationships'. The existing literature echoes my findings, with similar phenomena being described by others.

Behavioural interventions have evolved into sophisticated multi-element support plans. They are seen as the best evidenced method for addressing challenging behaviour (LaVigna et al., 1986; Scotti et al., 1991; Carr et al., 1999). Functional analysis, which sees the behaviour as serving an important purpose for the child, has led to detailed exploration of the ecological fit between the person and their environment (Meyer and Evans, 1989). As was discussed in the literature review, Rhodes et al. (2011) consider that these approaches lack a thorough consideration of family dynamics and do not differentiate between family members and paid professionals. They advocate for a reflecting consultation process as a way of helping clinicians consider a wide range of hypotheses and find a way forward at times of 'stuckness'. More recently Rhodes et al. (2014) have evidenced the transformative power of using systemic and dialogic practices in developmental disabilities services. This will be discussed in greater detail as I consider the potential application of my findings.

Clinicians using a behavioural approach often begin their assessment by eliciting lists and descriptions of challenging behaviours. Some parents I have worked with have found this initial focus on behaviour valuable. However, others have seemed to need to say how much they were struggling in a variety of ways. Clinically, we need to leave space for these concerns. I conducted the research interviews using similar questions to those I use in my systemic clinical work and attempted to elicit a wide variety of issues. Comments at the end of the interviews included the value of talking and being listened to, the

opportunity for more relational thinking and a strong focus on the child. This would imply that training clinicians to encounter people for the first time in a way that opens space for a wide range of concerns is useful. The Camhs service within which I worked, adopted the Choice and Partnership Approach (CAPA) (York and Kingsbury, 2009). This is described as a systemic approach to service delivery. The 'choice' interview paperwork reflects the wish to greet people in an open manner and provides a framework for exploring a number of systemic questions. The use of these prompts can help clinicians to join with families in developing a shared understanding of their concerns and to then agree ways of moving forward with those concerns.

***B:b The effect of blaming or not blaming on relationships:***

All of the parents in my study described being attacked by their children. The deeply upsetting nature of these incidents was described, but there were few comments directly 'blaming' or attributing responsibility to the child for these attacks. Most of the comments, where blame or responsibility was attributed to others directed blame elsewhere, including: teachers seeing problems with parenting; mothers complaining about fathers; parents' concern about school; and, teachers troubled about teaching assistants' behaviour and attitudes. Trimble (2001) describes this process as a typical feature of the struggle to help children with learning disabilities and advocates for helping networks to coordinate their activities through sharing their differences, similar to that advocated by Rhodes (2014 a and b). The literature reviewed earlier suggests that when parents and others see the child as not being responsible for troubling behaviours, they are more likely to engage in help-giving behaviours. This is a useful idea when working with children with learning disabilities who challenge, as parents and others may be more open to the idea that the behaviours are outside of the child's control and worthy of their help. For example, parents may be accepting of suggestions of positive environmental changes, rather than imposing negative sanctions and punishments, although it is always important to check this out. I suggest that the implication of these findings is to explore narratives of responsibility carefully and be open to people holding a range of ideas. This has been a strong theme recently in my work with 'mainstream' families where parents often spend time thinking about whether the child or the diagnosis is to 'blame'. Further to this are societally

driven discourses where parents see themselves to blame.

Dowling (1994) highlights the paucity of literature connecting home with school around various childhood concerns. She suggests that: parents may blame school; that schools may blame parents; or, that school and parents both blame the child. She argues that there is little exploration of the beliefs about the problem. Typically, people find someone who will label the child, often using diagnostic categories. She advocates for a 'joint system approach' that facilitates communication, clarifies differences of perception of the problem and works towards negotiating shared goals. This is strongly supported by this research.

***B:c Strain on family life and family relationships:***

In this study children's difficult behaviours are experienced as stressful by parents. Relationally, some of the parents considered that they transmit their strain to the child, resulting in increased tension for the child leading to challenges, in a repeating pattern, perhaps another strange loop as being calm is seen as helpful for the child. This is echoed in the work of Webb-Peploe and Fredman (2015, p.228) where they describe systemic empathy "as the ability to connect with one person while maintaining the possibility of connecting with other individuals in the system and at the same time tuning in to those people's connections with each other". I would add to this relational focus, the importance of considering the disabling nature of society and an appreciation of how service structures and service delivery impact on families also.

Keller and Honig (2004, p.337) made a distinction between the sources of maternal and paternal stress in families of children with disabilities. Mother's stress was associated with "children's demandingness and neediness for care" whereas father's stress was related to 'acceptability'. They suggested that services may need to focus on helping fathers become emotionally closer to their 'atypical' children and that mothers might need more respite service.

However, differences between mothers and fathers related to specific categories of stress. Mothers reported more difficulty with personal factors such as health, role restriction, and spousal relationships. Fathers reported more stress than mothers related to child temperament and other characteristics as well as more difficulty with emotional attachment to and personal relationship with their children.

Keller et al., 2004, p.338

Krauss (1993) also described similar levels of parental stress.

I had very limited data from fathers, however this led me to review my findings.

There was evidence, both from mothers and fathers, that the bonds of affection were strong. There may be other important differences when distinguishing between gendered positions. I consider that more research is needed which includes fathers. Also services should make far more effort to include dads and to be open to their different positions and to what those different positions might mean for their relationships with their partners.

Lack of sleep was a problem for some parents in this study and was described as stressful. There is a wealth of evidence that poor sleep is detrimental to feelings of wellbeing, etc. Lee and Hsu (2012) concludes:

Poor sleep quality as perceived by mothers was significantly associated with their stress, fatigue, and poor mental health.

Lee et al., 2012, p.958

Rzepecka et al. (2011), exploring the connections between stress, behaviour and sleep problems in children with intellectual disabilities and/or autism concluded that they were highly correlated and suggested that clinicians should consider assessing and addressing sleep problems. Thus, sleep problems are likely to be found in children with learning disabilities and/or ASD and parents' fatigue, linked to poor sleep, is seen as a major stressor. This was articulated by one mother who described poor sleep as one of her major problems and expressed how stressed she was feeling. The clinician was however more focussed on behavioural suggestions and medication. Another mother also spoke of being attacked during the night and of being exhausted because of this. This implies that clinicians need to invite different stories of stress, including lack of sleep and aggression, alongside stories of coping and resilience. Other sources of external stress found in the literature included poverty, isolation and relationship conflict (Hanson and Hanline, 1990). Relationship conflict will be discussed shortly, however, poverty and isolation were not found to be significant issues for these families, although was frequently reflected in the work of the team. Perhaps this reflected a sampling bias, in that families with more resources were seen to be able to contribute to my research.

Thinking about the psychological and physical health of the women I interviewed their mental and physical health was hardly mentioned.

### ***B:c:i Guilt and concern about siblings:***

Parents spoke about a range of concerns for the siblings of the four children in this study. There is a wide range of literature concerning siblings of children with a learning disability. This ranges from family focused web sites, for example Sibs: An independent charity to an International Review that has drawn from replicated studies in peer review journals (IASSID, 2012). Hastings (2014) reviewing current literature concludes that,

Although there is not yet enough research to be clear about these findings, it may be that overall the risk of increased problems for siblings of disabled children is small but the numbers with more concerning levels of problem are higher when compared to other children”.

Hastings, 2014, p.6

He goes on to say;

However, existing results are quite consistent in that siblings of children with developmental disability who are the most likely to have increasing levels of problems over time are those whose brothers or sisters have higher levels of behaviour problems (Hastings, 2007; Neece, Blacher, and Baker, 2010).

Hastings, 2014, p.6

Mulroy et al. (2008) compared large samples of parents of children with Down’s Syndrome and Rett’s Syndrome. Interviewing both sets of parents about siblings of the child with disabilities they found both advantages and disadvantages. The brothers and sisters of the child with Down’s syndrome were more likely to be seen to have more advantages in terms of personality characteristics, whereas the siblings of the child with Rett’s Syndrome were more likely to have more disadvantages. “Major disadvantages for siblings centred around parental and personal time constraints, relationships and socializing, restrictions, parental emotion and burden of helping”. (Mulroy et al., 2008, 216.) These findings accord with my data. The concerns identified by mothers were similar apart from ‘the burden of caring’, although this was identified by one of the team members.

Hasting (2014) identifies the lack of research on the effect of having a sibling with a disability on peer relationships in school and embarrassment in public. These were concerns mention by parents in this study. He advocates for more research to identify those siblings at risk of developing problems.

Much of the literature on siblings of children with disabilities focuses on pre-

existing standardised checklists. My study was not focussed on siblings, however, the effect of the disabled child, their behaviours and their interactions were clearly a worry for the parents. Most research has involved asking parents, mainly mothers, about their children. There are, however, a few studies where siblings themselves have been asked about their psychological and social problems. They usually report fewer problems compared to when parents are asked about their children (Hastings and Petalas, 2014; Rossiter and Sharpe, 2001).

There is clearly a role for learning disabilities team members involved with a family to enquire about other brothers and sisters and to think with the family about how to address any concerns. Practitioners often get caught up in only attending to the person with a disability effectively excluding siblings, When brothers and sisters are involved they are both an important resource and need to be attended to in their own right. Similarly, team case discussions rarely focussed on the wellbeing of brothers and sisters, apart from safeguarding concerns. This implies a training agenda and, perhaps, documentation, which prompts clinicians to ask about brothers and sisters during assessment (CAPA) and intervention. Such questions could become part of a mediator analysis (LaVigna et al., 1986) when suggesting detailed behavioural approaches.

### ***B:c:ii Marital Tensions***

The women I interviewed spoke about a number of concerns. These were summarised as: the child experienced as challenging placed a strain on the marital relationship; resentment at men's apparent freedoms; women worrying about the toll on their husbands; the value of men being stronger physically; the importance of agreeing about how to respond to the challenging behaviour; and, barriers to enjoying each others company. When their husbands were present, women did not talk about these things. The two men who joined the interviews did not discuss marital tensions, although both couples spoke very collaboratively indicating a high degree of agreement about their children.

All of the parents in my study were married and, it seemed, in stable relationships. However, Kirstie, Fraser's mum, talked about how many people she had known with a child with learning disabilities had separated because of

their disabled child. Longitudinal research at the University of Wisconsin's Centre of Excellence in Disability indicates that, for parents of older children with ASD, there is an increased likelihood of marital breakdown, 24% compared to 14% in a matched group with no children with disabilities. My view is that, if parents can have mainly harmonious relationships and work together, this enhances their quality of life and the quality of life of their children. The findings of my study indicate that women valued their men and worried about them, although some people also felt resentment about their apparent freedoms to come and go. Within the team, parents are referred for relationship issues but some team members seemed to feel ill equipped to address these concerns. This would imply that teams need ways to elicit such issues and, as a minimum, access to people who have the skills to work with couples and families and have a good working knowledge of the specific issues facing families of children with disabilities.

***B:d Worry about what the future will bring***

There were a number of worries expressed by parents about being able to continue to care for their child with learning disabilities at home. These worries included: the child getting bigger and stronger; the relentless nature of the behaviour affecting parent's ability to go on as they aged; and, the worry about transitions and lack of services for adults. Importantly, the wish to continue to care implies a commitment to and love for the young person, despite the difficulties. Many people with learning disabilities continue to live with their parents into adulthood and even old age (Walker and Ward, 2013). They paint a bleak picture of lack of services, social isolation and financial difficulties. Although some social policy is beginning to address these issues, for example Valuing People (2001) - a green paper delineating various aspects of good practice for adults with learning disabilities. Hayleigh's parents worried about the reduction in services as she moved into adult services. Their concerns are echoed by Walker and Ward (2013). Further, Griffiths et al. (2014, p.415) in their meta-analysis state, "The majority of carers looked towards the future care of their family member in adulthood with profound anxiety and fear". Their analysis projected further into the future to consider the horror that parents felt about no longer being there to love and care for their son or daughter. Similar concerns were also described including, poorer services for adults, lack of help

with transitions and poor funding. Enabling realistic conversations between people about the dilemmas they face may help parents to make informed decisions about what is best under their circumstances.

In the current climate professionals are under pressure to 'discharge' people from the service when goals have been met. Feedback from parents was that they valued intermittent but regular contact. They used these sessions to talk about how things had been going and to do a bit of problem solving. One man told me, that he believed that these meetings had literally kept his wife alive. In the latter part of my career, I was fortunate in being able to make autonomous decisions, in collaboration with parents and children, about when to say goodbye. It can be easy to forget the importance of on-going relationships as a protective factor when parents face multiple difficulties and transitions in their lives. We cannot necessarily change the future but we can help people face it. This stance is supported by the findings quoted in Griffiths et al. (2014) where parents expressed greatly valuing continuing support from available professionals.

Broadly, the existing literature supports the findings of this study. So how might my finding be seen to add to the existing body of knowledge? My study highlights the need to focus on all members of the family and wider service structures, including worries and concerns about the future. Where practitioners restrict their focus to the problematic behaviour and push for behavioural change this may be experienced as unhelpful and neglects important conversations that help families carry on in difficult circumstances.

### **C: Life can be different with a child experienced as challenging**

There are four sub-themes within this theme. These were: the children as special and different; finding services helpful; finding services unhelpful; and, finding the world to be a hostile place. I begin by drawing on the concept of normalisation to discuss how the families and children are framed as special and different to many other families, and the possible impact of this on them. In the results there is a short section on finding services helpful highlighting the support given by statutory and, to a lesser extent, voluntary services to parents and to the children. The dilemmas of using respite services are described. A longer section describes the frustrations and dissatisfactions with services. These included: having to fight for services; services being



unresponsive; and, for one parent, how vaccine had damaged their child and their long years of fighting for recognition. Finally, parents spoke about the world being experienced as hostile. The parents described how simple things like taking your child to 'MacDonalds' could become a trial and how the child's behaviour at home could lead to fear of what the neighbours may be thinking and embarrassment.

### **C:a The children and their families as special and different.**

This idea underpinned much of the data and yet was not spoken about explicitly. In social constructionist terms, it can be argued that the air we breathe is invisible to us and taken for granted and yet is vital to sustaining life. Beginning to deconstruct the idea of being special and different is important in order to give people a sense of agency and an appreciation of how their lives might be constructed by powerful and dominant discourses, for example, disability or autism. The mechanism of this form of power is the shaping of our lives through 'normalising truths' (Foucault, 1967). These truths are not independent or inherent facts about the nature of people but are ideas that are accorded a 'powerful truth status'. Foucault argued that these truths are normalising in the sense that they construct norms around which people are encouraged, even impelled to shape their lives. These 'truths' are also referred to as 'global and unitary knowledges' and collectively form 'dominant discourses'. This does not imply that such truths are universally accepted, rather that claims are made for their universality. Foucault (1980) maintains that there are an infinite number of 'knowledges' or truths. However some knowledges gain ascendancy over others and thus diminish or deny alternative knowledges. He singles out the objective reality of modern scientific knowledge as a particularly insidious example of such a unitary truth claim. White and Epston (1990) suggest that an example of this is the process by which people become labelled as learning disabled or mentally ill. They argue that the dominant scientific, medical discourse is applied to peoples' individual experiences such that their whole being, including their relationships with others become influenced by that label. I posit that the diagnosis of autism is another important example, as does Hacking (1999). White et al. (1990) describe this process as the 'manifestation of logico-scientific modes'. They argue that this includes: the elimination of peoples' experience in favour of

reified constructs and systems of classification and diagnosis; the assumption of objectivity and the exclusion of the observer from what is observed; and the construction of universal facts which are true for all times and all places. White et al. (1990) argue:

In accepting Foucault's analysis.....we become wary of situating our practices in those "truth" discourses of the professional disciplines, those discourses that propose and assert the objective reality accounts of the human condition. And since it is the isolation of these knowledges from knowledges at large, as well as their establishment in the hierarchy of scientificity, that endows them with their power, we challenge the isolation of the knowledges of the professional disciplines from the field of 'discontinuous', marginalised knowledges.

White et al., 1990, p.28.

White and Epston argue that, if we accept that we are simultaneously participating in domains of power and knowledge on us and over others, then we cannot take a benign view of our own practices. The implication of this is that we should: establish conditions that critique our own practices; work to identify the context of the ideas in which our practices are situated; and, explore the history of these ideas (White et al., 1990).

The ideas of normalization are also pertinent to the findings of this study. Wolfensberger (1972) developed a rigorous theory and critique of human services. Although this had its origins in the American de-institutionalisation period, it has sustained as a critique of how services are delivered, although I think it has fallen out of favour more recently. Normalisation is defined as " The use of culturally valued means in order to help people live culturally valued lives". (Wolfensberger and Thomas, 1983). This theory directs us to strive to develop socially valued roles for the people we work with, using means which are socially valued to achieve integration and other fundamental quality of life standards. It underpinned policies that led to deinstitutionalization and the integration of people with disabilities into mainstream society. Normalization is based in the idea that people are devalued in many subtle and less subtle ways and that we need to be alert to these and challenge them. It is argued that projecting negative images of people increases the risk of social exclusion and stigmatisation. He draws attention to these practices through the application of service evaluation manuals (Wolfenberger and Glenn, 1975 and (Wolfensberger and Thomas, 1983). PASSING considers four distinct levels: the person; the individual's primary social system, such as their family;

intermediate social systems including the local community and services they receive; and, larger society including broad service systems. These levels are then deconstructed in terms of how they enhance or devalue the person's positive social image and how they support the development of socially valued competencies. I argued in the analysis that some of the 'means' applied to the children were not culturally normative and thus risked devaluing the child and their family. For example sending your child to respite or going to a special school can be seen as not normative although had positive benefits by supporting family coping and providing appropriate education, increasing competence. Wolfensberger (1983) describes these dilemmas as 'trade-offs'. This is when two aspects, e.g. developing someone's competence and projecting a positive social role of the person are in conflict. Normalisation advocates using the least stigmatising method possible. Thus symbolised communications systems might be seen as positive as they help the person cope with difficult situations, whereas restraint would be seen as negative as it projects an image of the person as dangerous and should only be used in extreme circumstances. These concepts were prevalent in the 70s and 80s but are seldom referred to currently, however, these ideas are multi-layered (like CMM) and relational. The ideas link wider systems with the experiences of individuals and their families and espouse the development of positive relationships between people.

***C:b & C:c Contradictions in experiences of services:***

***Services help us keep going and Services can really frustrate and let families down.***

The results concentrated on the experiences of parents as the recipients (or not) of services.

There were positive comments about services. These included services providing what was described as support and a break from the challenges. There were a variety of unsolicited positive comments about how parents experienced the Camhs team members. McGill et al. (2006) summarised the literature on the perceived helpfulness of professional input as mixed, with more studies indicating a negative bias than studies indicating that input had been helpful. Comparing different interventions, including medication, psychological advice, and communication advice, they found that parents

valued communication advice most highly. From this study and the literature, I conclude that a focus on good engagement, building positive relationships and a systemic consideration of context are at least as important as the details of a behavioural analysis. Rhodes (2003) suggests that these aspects may lead to more formal systemic approaches, e.g. family therapy, if the family seems stuck in some way and/or unable to take on board the behavioural support plan. In later work, he advocates for reflecting processes being routinely used with wider networks (Rhodes, 2011; 2014a; 2014b). I would argue that they should regularly be included, not just when systems seem 'stuck'.

The positive experiences of services were, however, outweighed by the negatives. Fighting for services and fighting with service systems was spoken about in three of the four interviews with parents. This was more typical of the literature already reviewed and discussed in McGill et al. (2006). However, the common view that parents express dissatisfaction with a lack of services was not found in my study, although one mother highlighted to the lack of respite care. This may have been due (with the exception of one family) to parents already receiving high levels of services. The concerns expressed in my study were with wider service systems rather than with individuals. These included: services not being appropriately responsive; insufficient services; and, services damaging children. Muira and Goldblatt (2011 p.629) argue from a human rights perspective that, "Governments need to provide a whole of family and community support approach to ensure the human rights of all family members are met". I am concerned that it would be easy to say that such large changes to service systems are not within the purview of individual service providers. However, the way in which practitioners conduct themselves will have an impact on how over-extended parents receive the help that they hope to offer. Thus adopting an advocacy role, with people's consent would be a useful first step. One very valuable resource, previously available to our team, was the inclusion of social work colleagues, who could help with framing requests using language which was readily understandable and persuasive to service providers. Access to multi-disciplinary, multi-agency networks is very useful in accessing and coordinating service provision.

***C:d The world can seem an unpredictable and hostile place.***

Parents spoke about the difficulties in going out and about in the community

and the feelings of failure that this evoked. Emerson (1995) defined challenging behaviour as "... behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities". Through the lens of my study I am aware of ways in which this definition places the behaviour at the heart of the problem rather than an unwelcoming world.

Having listened to the parents of the children and having thought deeply about their concerns, voiced and unvoiced, it seems essential to bear in mind the multiple contexts of people's lives. A consideration of the wider world, including services, is crucial to avoid pathologising children and families and to consider how best to position oneself when working with them.

Pollack (2007), reviewing social policy in the USA, sums this up:

Neither of these studies captures the distinctive role played by persons with intellectual disability and their caregivers, or the interplay between the social politics of intellectual disability and the intricate web of institutions and interventions that serve these citizens and their families.

Pollack, 2007, p.96

As I move towards the end of this section, I continue to argue for the importance of context in our work including a consideration of the constructions of disability in society.

**Themes D: Making sense of the challenges is important to people and**

**Theme E: The value of good relationships in the 'network of concern'**

The study identified the cultural, diagnostic and professional narratives that participants employed to try and make sense of the children's behaviours.

These narratives were, in part, linked to participant's ideas of how to address episodes that they experienced as challenging. In addition, parents felt unable to understand their children at times. The study explored how the use of narratives of explanation influenced the relationships with the children, each other and the wider systems, and how people spoke about relationships in the network of concern. It brought together the ways in which stakeholders in the children's well being, emotional growth and development talked about how they made sense of and managed many disparate and troubling behaviours. Parents discussed facing situations that were highly unusual for most families, for example, being attacked by their child while asleep or rarely being able to

enjoy a family meal together because their children displayed difficult and sometimes dangerous behaviours. While many families experience these difficulties on a short-term basis especially with young children, these families often experienced these difficulties over very long periods with little hope that they would be alleviated soon. Team members, working alongside parents, focussed on helping parents and children make sense of and manage difficult situations and the teachers mainly focussed on providing an education in school. Team member's ways of formulating drew more explicitly on theoretical frameworks and included diagnostic conceptualisations. Behavioural understandings and strategies were represented in all groups, although least strongly for parents. Autism was also strongly represented as an explanatory narrative.

The Camhs Learning Disability Team had been working with three of the children for at least two years. These parents, teachers, unit staff and team members shared many common understandings although parents drew on a wider range of explanatory narratives. Relationships between the team members and the parents were described as positive and helpful. There was not much communication between home, teacher/school and the Camhs team, which lost the opportunity to build on positive, appreciative stories and share knowledge and different perspectives. Where good relationships did exist this led to high levels of satisfaction and good outcomes for the child, for example home being aware of problems that had arisen during the day at school and parents feeling understood and supported. These findings argue for consistent attention to the network that supports children, with parents as central to the process.

The analysis indicated the value of Camhs team members as: providers of advice and helpful strategies; good listeners; and, helpful in facilitating communication between partners, siblings and schools. These aspects of effective help-giving correspond to those identified by Dunst et al. (1994, cited in Vetere and Dallos, 2003). They summarised four aspects - good communication, good relationships, helping families feel understood and responsiveness to family values. This study indicates the importance of also offering strategies that fit with the family circumstances and are perceived as effective, in addition to hearing and responding to a wealth of other concerns.

It is important to pay attention to engagement with families, to work to understand the context of people's lives and the values that underpin them, and their past experience of 'help' in order to 'coordinate' when offering ideas and strategies.

The fourth child and her family were relatively new to working with the team and meanings and relationships were less established. I am not suggesting that there is a causal relationship between the time the team had been involved and achieving agreement or good relationships although this may be the case. However, I have reflected on, perhaps, a sampling bias in which team members chose families with whom they had good relationships. I am also interested in the ways in which professional ideas and formulations become part of the ways families view their child's difficulties. Further research would be required to explore these issues in greater depth.

#### **D/E:a Behavioural narratives.**

Behavioural narratives were a strong feature for all groups. The implicit and explicit adoption of behavioural understandings and strategies with children with learning disabilities can be considered to exist within multiple layers of context. In this section, I deconstruct the possible contextual influences in order to reconstruct implications for practice. I also reflect on the effect that this approach has had on me throughout the research process.

Behaviourism is based on the idea that psychology should concern itself with observable behaviour, not with unobservable events that 'take place in the mind' (Skinner, 1984). This approach predominated in the early part of the 20<sup>th</sup> century, being overtaken by cognitivism in the latter part. The majority of peer reviewed journals concerned with working with people with learning disabilities with challenging behaviour are dominated by behavioural approaches, whilst mainstream child and adolescent services, for example CYPIAPT (Children and Young People's Improving Access to Psychological Therapies) draw on cognitive behavioural formulations and treatments. This raises the question for me as to why behavioural approaches still dominate for children with learning disabilities while 'mainstream' children are seen to benefit from cognitive approaches, where thoughts and feelings are considered important. I have various hypotheses. Firstly, many of us are subject to a strong cultural belief that children with learning disabilities are not able to think, are disabled

cognitively, or cannot express their thoughts and feelings, although this is challenged in part by Kroese, Dagnan, and Loumidis (1997) who describe offering cognitive therapy to with adults with a learning disability. I contend that there is a strong contextual force acting on all participants to adopt behavioural rather than cognitive behavioural, systemic or narrative approaches with this client group. These approaches are applied to the person and do not require their active participation, thus potentially objectifying them. Secondly, behavioural approaches are often used for younger 'typically developing' children - witness the number of programmes on television, for example, "Super Nanny" and parenting packages which draw on these ideas, for example, Triple P. Thirdly, there is an excellent evidence base for behavioural approaches. This may be because research is much easier when there are a limited number of variables, (the behaviour and the strategies are required to be clearly defined and measurable) and there has been dominance in psychology for quantitative methodologies. There are many people carrying out this type of research, so students looking to progress their careers can easily find projects and supervisors. Applying models that have a good evidence base is a strong contextual force on professionals and this may influence team members and teachers. Finally, considering the relationships between people, it might be argued that a process of enculturation or professionalization has taken place, leading some parents to adopt these types of understandings.

In addition to behavioural understanding, parents drew on many other ways of making sense of their child. These different narratives were not always echoed in the accounts of teachers and team members. I would argue that spending time drawing out multiple ideas and solutions would be useful in building helpful relationships and successful interventions.

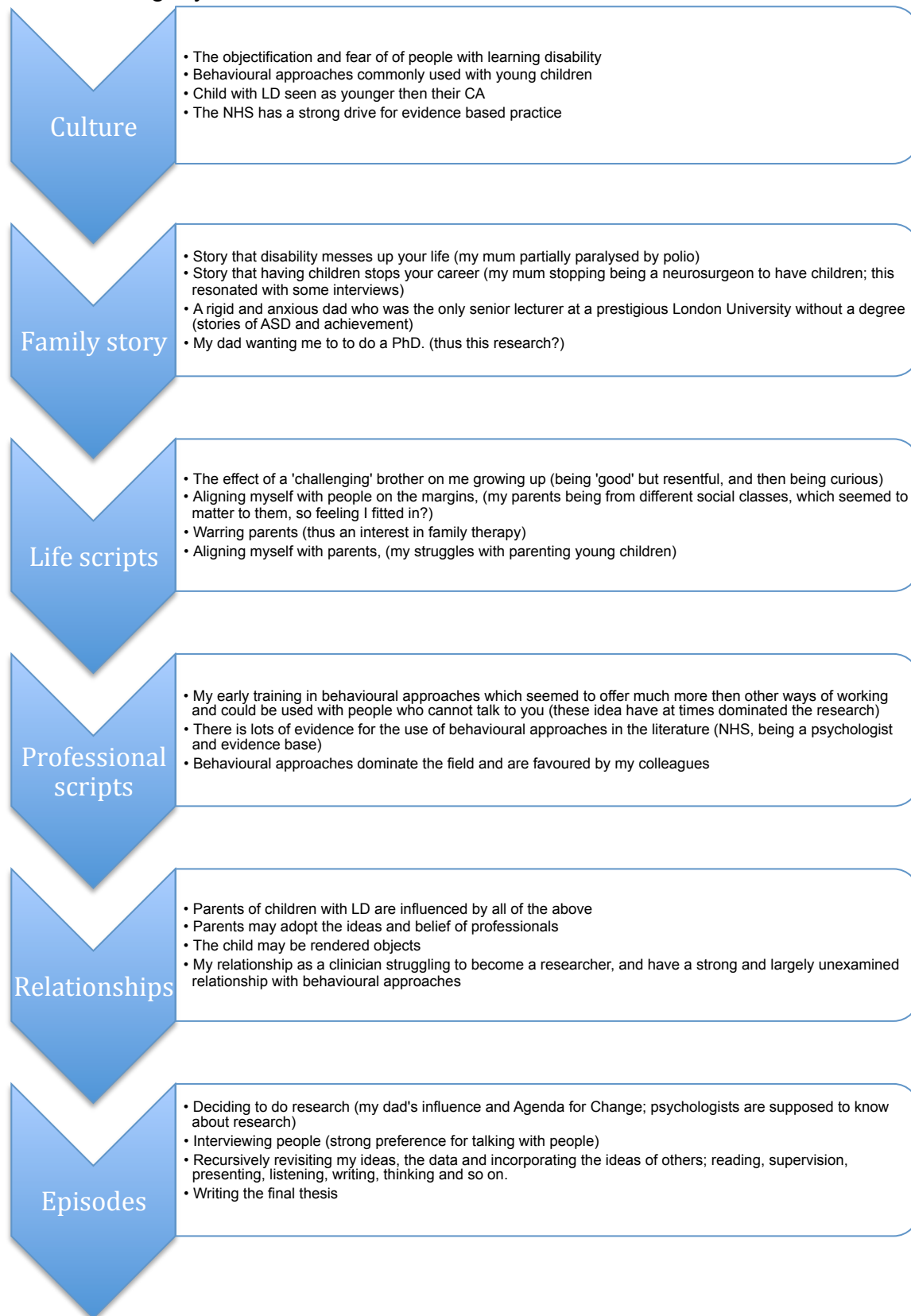
**Researcher reflexivity:**

I have further elaborated these ideas in Figure 5 below adding some ideas about what has influenced me in this research. Considering my family of origin issues has triggered thoughts about: how my mum was affected by polio and how she saw this as 'handicapping' her life; how my dad's and my brother's rigidity and anxiousness might be similar to those people I have worked with who have been labelled as 'autistic' leading to more compassionate ways of



seeing their behaviour; and, recognising the drive for academic success as coming from my mum and dad's life stories. All of these and other thoughts have shaped this research in ways that I did not anticipate. The diagram does not capture the dynamic ways in which meanings have changed and shifted through the multiple episodes that have made up this research. For example, the developing awareness of how my thinking as a psychologist has been strongly informed by behavioural ideas. I was largely unaware of this, and have come to recognise that my initial ideas about the research and the interview questions I asked were informed to some extent by this approach. The importance of reflective research (Dalloos and Vetere, 2005) was highlighted in Chapter 1. This research has given me a wider range of narratives to listen out for and connect with. I have also been interested in the effect of my life experiences, personal and professional, on the research, a feature of qualitative research. Coming to these understandings has allowed me to challenge some of my underlying assumptions and to be more curious about how both my colleagues and families see the world.

Figure 7: Reflecting on the representation of behavioural approaches in the research using my CMM:



## **D/E:b Diagnostic Narratives: Autism: Diagnosis as a strong contextual force**

Autism as an explanatory category was a strong and recurrent theme in the data, although other diagnoses were also spoken about as a way of making sense of some behaviours. While some authors argue that people with autism are differently abled, rather than dis-abled, many consider it to be a 'dysfunction' (DSM 5, 2013). In summarising her data, Avdi (2005) concluded,

An important aspect in clinical work with families with a member with a psychiatric diagnosis lies in decentring, or deconstructing, the dominant, pathology-maintaining accounts, and allowing for a wider range of less problematic narratives and subject positions to emerge.

Avdi, 2005, p.493

This echoes my earlier reflection in this study that I did not give sufficient space to less problem saturated narratives and had not encouraged more appreciative conversations. Thus, I contend that deconstructing diagnosis in an appreciative way is really important. Asking questions like, 'does this idea of autism fit for you?', 'how does autism show itself in your family?' rather than 'does this child have autism' may be more fruitful, perhaps escaping the rigidity suggested by Avdi (2005). Paradoxically, this study suggests that where people come together and understand things through a similar lens, in this case autism, relationships between people were described as positive. Where people have yet to settle on an agreement or disagree about the meaning of behaviours and their concomitant strategies, relationships may not be as positive, as suggested for the work with one of the families. Other ways in which people developed positive relationships were through careful listening, respect for people's lives and an interest in the whole family.

### The value of diagnoses *and* problems with diagnoses:

This study found that what helped people was contributed to by having a common shared understanding of the issues, including diagnostic and medical understandings. This finding is contrary to some systemic literature which suggests that people are oppressed by diagnoses and that the task of the therapist is to deconstruct the "dominant, pathology maintain accounts" (Avdi, 2005) in order to liberate people from these totalising discourses (White et al., 1990, Gergen, Hoffman, and Anderson, 1996). I would argue that, for systemic psychotherapists this represents a powerful contextual force. Given that my study indicates that sharing meaning making, including a diagnosis, can be

useful *and* that a diagnosis can be oppressive or limiting, it is important to adopt a 'both and' position. Hacking (1999) suggests not taking sides (diagnosis as helpful or unhelpful) but creating a space within which both ideas can develop. This raises the question as to how best to 'create space' for a variety of ideas within teams and between key stakeholders around children. Cronen and Lang (1994) offer some useful ways forward. These include adopting Wittgenstein's notion of 'Centre of Variation'. "Centre we see as referring to the consistency with past use whilst "variation" we see as related to the possibilities for elaboration in future use" Cronen and Lang (1994 p13.)

They suggest;

One of the things that becomes interesting for the therapist is to understand and enter the grammar of the particular symptoms as ways of living for each of the people who talk about such symptoms. Those circumstances and details will have elements radically different for each person and the contexts in which they arise will differ radically from one person to another. In therapy it is these differences which we work with.

Cronen et al., 1994, p15

They also suggest creating and maintaining contexts within which people can share ideas on an equal footing. The need to deconstruct different contexts is also important and includes a deconstruction of our own contexts and what we bring to our conversations with families and those supporting them.

The multidisciplinary team provides a helpful example of considering multiple professional views at one time, although power differentials need to be considered explicitly. Supervision and training offer ways to reflect on these strong biases and to broaden ways of formulating. Further, training professionals to be open to the rich ways in which parents talk about their children, rather than focusing in too soon on their own models and understandings, also seems important. Rhodes' work on employing reflecting processes will be used to elaborate these ideas when considering the implications of these ideas (Rhodes et al., 2011; 2014a; 2014b).

#### Contextual forces acting on statutory services

The Camhs Learning Disability Team is an NHS service funded by the taxpayer. The current focus on evidence-based practice emphasizes the need to consider whether teams make a significant contribution to positive outcomes for children. Every Child Matters (2003) outlined five key outcomes for all children and young people: being healthy; staying safe; enjoying and

achieving; making a positive contribution; and, achieving economic wellbeing. All statutory agencies are required to demonstrate how they are working towards these outcomes. Challenging behaviour stands in the way of most, if not all, of these outcomes. Thus, a focus on ways of addressing the behaviours is seen as a legitimate and an important goal. The children and young people in this study had few communication skills and significantly challenging behaviour, thus working indirectly via parents is the preferred option for the Camhs Learning Disability Team. Asay & Lambert (1999) identify the following percentages as contributing to successful outcomes in therapy: client factors, 40%; therapeutic relationship factors, 30%; placebo, hope, and expectancy factors, 15%; and model/technique factors, 15%. This overturns much of the received wisdom on outcome research, which focuses primarily on model and much less on clients and relationships. Bohart (2000, p.127) argues that it is the 'client's self healing' capacities that is one of the most potent common factors in what makes therapy work. This paper proposes a relational model of therapy, which values, "Consultation, collaboration, and dialogue", (Bohart, 2000, p.127). Although this author is discussing individual psychotherapy, this study also accords with these findings.

### **Summary of themes D & E**

In this section I have focussed on the deconstruction and reconstruction of the ways that participants make sense of the challenging behaviours. I have argued for a 'both/ and' position including appreciating the parent's use of diagnostic and behavioural narratives. This will be discussed further in the section on implications.

### **6:3 Summary of discussion**

Five themes were identified from the data using IPA. Each of these was explored and elaborated drawing on a wide range of writings from the fields of systemic psychotherapy and psychological theory and research. Many of the findings from the data were linked to existing literature. I highlighted the lack of writing about some areas, especially problem-free talk about children with disabilities, which is an important aspect of work with these families where conversations can be dominated by negativity. Novel ideas arising from the research included: the importance of a coordination of meanings in which diagnostic labels had their place in developing positive working relationships;

the importance of attending to the narratives that people employ in their conversations; and, the value of reflecting processes applied with 'networks of concern'.

### **6:3 Critiques and Limitation of the evidence**

As I progressed, the complexity of my design became clear. I was very keen to make my enquiry relational, I thus invited a range of people to participate. It became apparent that this multi-perspectival triadic design was uncommon within the IPA field. As a novice researcher, this was challenging. I became aware that participants stood in different relationship to one another and the children. Parents and teachers primary concern and sources of information were the children themselves, whereas the team member's sources of information were often at one step removed, drawing on their discussion with parents. Thus team members were describing what parents had said about the children, their families, and their situations. As IPA is concerned with participant's concerns, and the main concern of team members was the children, as well as their families, this did make the analysis more complicated. A further concern was the small number of cases. Although there were thirteen interviews, which is acceptable for this type of study, there were only four children. To avoid these problems further research could enquire about meanings and relationships with a single homogeneous group.

The triadic design may have restrained participants from commenting negatively on their relationships with each other, for example, parents knew that they were speaking about my colleagues. I also became aware that confidentiality could not be maintained within this triadic design, as it was clear who the others speaking were. I had not anticipated this at the outset and had not raised this issue ethically with people at the start of the interviews. I managed this by leaving out some material when confidentiality might be breached, by summarising issues in anonymised tables rather than in narrative form, and by deleting the identity of the speakers when this might breach confidentiality.

As the work with three of the four children was going well, I wonder whether there was an understandable bias for team members to identify families where good relationships existed. This could be avoided by direct recruitment of parents without this being mediated by team members.

A final concern has been how to become aware of my pre-existing models, especially behavioural understandings and how these shaped the research from the outset. This has been a helpful realisation, and although some aspects cannot be reconstructed, for example the interviews, my ways of analysing and construing the data have shifted considerably from my initial focus.

#### **6:4 Summary of implications for practice**

Throughout the discussion various practices have been highlighted. This section brings together these ideas and develops them further.

Burnham (1992) distinguishes recursively-linked levels referred to as Approach, Method, Technique (AMT). Approach “influences the way in which practitioners orient themselves towards all aspects of their work” (p.4) It also includes theoretical and epistemological lenses and emergent concepts.

Aesthetic preferences and personal prejudices were added (Burnham 1993). Method “refers to the organisational patterns or practice protocol used both to set forth and bring forth aspects of the approach” and technique “refers to those specific activities practiced by users of the approach”. (pp 4-5). I use these levels to consider the implications of this study.

Approach: I have suggested that adopting a ‘both/and’ position in relation to positive behavioural support *and* systemic approaches is important. Being aware that some parents and professionals seem to find diagnosis useful *and* being alert to the critiques of diagnosis offered by social constructionism and the disability rights movement will help practitioners be open to how children and their families may be further disadvantaged, and to counter ways diagnosis can close down curiosity and shape expectations. Normalisation offers an extensive critique of the many ways in which people are devalued and yet it has gone out of fashion in training. I assert that there is an argument to return to some of these ideas. I suggest including teaching on normalisation and introducing practitioners to wider contextual factors of power, disability rights and language would be valuable. Hopefully this will lead to people addressing or advocating for more valuing ways of supporting children. Using systemic ideas in training and supervision will aid professionals to remain open to the constructions of families as well as their own ideas. Systemic CYIAPT may be a useful framework which is already being implemented across the

UK.

Systemic psychotherapy alongside many therapeutic approaches stresses the importance of engagement and good relationships with clients which is linked to favourable outcomes. I have argued that focussing too tightly on agendas linked to applied behavioural analysis may reduce engagement associated with a lack of appreciation of the narratives employed by parents and significant others in the 'network of concern'. Helping practitioners consider these aspects in supervision or consultation will hopefully lead to open and enthusiastic professionals and more engaged families. Rhodes et al. (2011; 2014a; 2014b) suggest a reflecting team consultation process, which considers the multiple contexts of people's lives and invites practitioners to be open to a wide variety of hypotheses about their work. In a recent reflecting conversation with a family, the team I was working with offered three different ideas about the family's dilemmas, which they linked to different narratives (attachment, autism and trauma). The family reported finding this useful and were able to say which ideas they found fitted best for them.

Method: This study indicates the importance of convening the network of concern, beginning a piece of work with a detailed enquiry about the ways people construct difficulties, their relationship with services and 'help', past and present, and family values and relationships. Raising these issues when work is not progressing well is essential and can be done through team discussions and supervision.

Assessment at the beginning of a piece of work is a familiar practice for most professionals working within human service systems. This study has indicated a number of aspects to explore when first engaging with families, which may not typically be included in paperwork or processes. Sleep stands out as one example and enquiring about siblings is another. Fathers are an important resource to families. Wherever possible, fathers should be included at all stages of work with their child. This may allow space to address marital discord, which is negatively correlated with good outcomes for children and family wellbeing. Involving fathers may also permit conversations about different parenting styles and beliefs, thus increasing the likelihood of good engagement and the development of agreement about strategies for managing difficult children.



Communication between home and school has been highlighted as being useful to enable passing on ideas from home to school and vice versa - supporting for parents and improving consistency across environments. Dowling (1994) advocates for a 'joint system approach' that facilitates communication, clarifies differences of perception of the problem and works towards negotiating shared goals. It was interesting to note teachers saying that this would be valuable and yet they were not all establishing good links. It would be useful for Camhs professionals to facilitate this process. For example, meeting children in school and inviting parents, attending reviews and so on. This happens routinely in my local service.

The themes and sub-themes developed in this study provide a template for enquiring about a wider range of issues. Burnham (1992) suggests a recursive link between levels. By providing a context within which professionals begin to ask about a wider range of issues, there may be a shift in 'Approach' reinforcing a wider consideration of these issues.

Reflecting teams can be considered Approach and Method. Thus arranging consultations using reflecting processes as suggested by Rhodes et al. (2011; 2014a) would be of value in broadening thinking and developing some of the systemic skills highlighted as important. Rhodes et al. (2011) highlighted that multiple perspectives were useful in broadening practitioners' thinking to encompass a variety of views and meanings. Feedback indicated that this was experienced as helpful. The context of a multiple disciplinary team, which welcomes difference and diversity, can provide a similar resource to its members. Regular case discussions aid this process, although may be hard to achieve in today's world of reduced resources and pressure on waiting lists. Rhodes (2014b) evaluates the implementation of this approach across a broad service area in Australia, concluding that it has been highly successful in difficult to resolve situations. One of my colleagues in the Camhs LD is keen to implement this, and I hope to support her.

Supervision is key to helping practitioners make links between their personal and professional beliefs and their work with families. These conversations can connect what is going well and what might be a restraint or a problem, allowing an exploration of the fit between the ideas of parents and ideas of the practitioner. Supervisors will benefit from systemic training to facilitate this

process. This has been established in some settings.

This study has indicated that parents valued sharing diagnostic understandings with the teams they worked with. Pozo, Sarriá, and Brioso (2014, p.14) suggests that “professionals could work with families to improve parents’ “sense of coherence” through three components: comprehensibility, manageability and meaningfulness”. Sense of coherence is linked to psychological wellbeing and improved family quality of life. The steps they suggest include: providing clear and consistent information about autism, including a critique of diagnostic issues; reframing of challenges as forms of communication or demands and, providing information about resources. They go on to stress the importance of recognizing parents’ coping strategies and to be aware that mothers and fathers have different coping styles. This was touched on earlier and implies both a training agenda and the need for on-going consultation and support in all of these areas. These ideas represent both Method and Technique.

Technique: Questioning is a key tool within systemic approaches. Modelling different questions and offering training can increase the skills of others. I found it interesting that asking for feedback at the end of my interviews, people reported finding the discussions interesting and supportive and one person commented that it had opened space for more relational thinking about her work.

Prompting people to explore beliefs about difficult behaviours and diagnostic labels, for example asking, “What do you think your child is trying to communicate when s/he does that?” Also exploring sources of stress and support, and parenting styles will allow plans to be individualised, empowering parents to feel successful and validated.

Frameworks that encompass all levels of AMT: I recommend that training in narrative approaches or appreciative enquiry, with the emphasis on questioning about strengths, resources and unique outcomes, linking all levels of approach, method and technique. Two points from the discussion support this assertion. Firstly, the value of eliciting positive affectionate stories about children whose behaviour is experienced as very difficult can help parents acknowledge how much their children are loved and appreciated. Secondly, research indicated that 40% of the variance linked to success was related to

client factors. Clients in this context are parents. Finally, in developing these ideas I have, like Rhodes (2014b), become interested in the potential of Open Dialogue (Seikkula and Arnkil, 2006). Key aspects of this approach advocates the inclusion of and meticulous attention to the person who is the subject of people's concerns, and all key stakeholders, including parents, siblings, professionals and other carers and loved ones. As Rhodes et al (2014) states,

While the behavior analyst would interpret for communicative function (La Vigna & Donnellan, 1986), a dialogical approach would be more attuned to hearing stories related to social stigma, exclusion, and interpersonal relationships.

Rhodes et al., 2014b, p.10

An Open Dialogue approach responds intensively at times of crisis and meets in people's homes, developing a sense of agency for parents and carers. Importantly it values polyphony and uncertainty, and does not strive for consensus, but hears every person's voice and point of view. Hypothesising is abandoned in favour of active engagement with the network (Seikkula and Olson, 2003, p.410). They believe that "the meaning of people's suffering becomes more lucid within the immediate network". While this approach has been developed in Finland with people experiencing a psychotic breakdown, I feel that it has much to offer disability services. Rhodes (2014b) highlights the value of including people who lack verbal skills in meetings as Seikkula and colleagues include people who are experiencing a psychotic break.

### **6:6 Summary of intentions:**

It has always been important to me that the findings of this study can be used to influence the practice of my colleagues, trainees, supervisees and myself. I now also have ambitions to influence the wider field. I intend to do this in the following ways.

1. My practice has changed as a result of this piece of work. I am excited about developing the ideas further in my work with families.
2. I have already presented my findings to the Camhs LD team. I would hope that it would also be possible to present to the wider Camhs service.
3. I continue to offer training and supervision to a number of people. I already talk with people about these ideas, and have incorporated my findings in the teaching I provide.

4. I have made a commitment to publish at least one paper based on these findings. With the increasing interest in these ideas I am hope that this may be of interest within the field of learning disabilities.
5. Finally, I hope to present this work at conferences and professional meetings, although will need some time to collect my thoughts once this evaluative process is over.

### **6:7 Ideas for further research**

I offer three ideas which link to my interest in working more effectively with parents who are looking after children with challenging behaviour.

1. This study represented a snapshot of participants' views. Given more time, it would be valuable to repeat this study just with parents. Interviews every 6 months, starting before people engage in work, would be valuable in tracking some of the processes hypothesised in this study. It would also highlight issues relating to fit, enculturation and lack of fit and dissatisfaction, allowing for further learning.
2. Fathers were largely excluded in this study. When they did contribute this gave a different and valuable perspective. Just speaking to fathers might be of great value in learning more about what concerns them and may give guidance on how to incorporate them in future work.
3. As autism was a strong theme in this study, it would be useful to explore challenging behaviour where this diagnosis is not present - are similar themes found, what might that mean, etc?

### **6:8 Reflections and reflexive log: Glenda revisited**

There are many places to begin a story. Mine begins with Glenda; the lady I wrote about at the beginning. Two things strike me about this now. Firstly, the findings of this study have in part supported the idea that, when people hold similar ideas, relationships are experienced as helpful and supportive and that solutions are easier to agree upon. However this assumption was too simplistic. Secondly, I had an idea that exploring problematic relationships would bring forth lots of useful ideas. What I found, however, was a far richer quilt of ideas about what helps people manage very difficult situations. Through this piece of work, I have been humbled by the commitment and love of the parents towards their children. I have, at times, worried that I have not

done justice to the concerns of the children and their parents, perhaps, as I was too influenced by my pre-existing hypotheses. I am also concerned that the implications of this research seem almost simple and reinforce my worldview that thinking systemically is very important and central to work in this field. I remind myself that these ideas are not simple. This work has also challenged my views about diagnosis. I still hold them lightly, however I am now much more open to considering how they might provide a shared language for people and can lead to the adoption of some useful ideas. Throughout this process, I have kept notes about my initial thoughts, the interviews, the analysis, supervisory conversations, presentation feedback and ideas as they have arisen in other contexts, especially my clinical work. There are books of them. They represent a process of coming to these final closing comments. There are questions, worries, facts, summaries of papers, my ideas and the ideas of others, diagrams, lists of reminders and so on. They have been valuable at the time of writing, and also perhaps represent the stitching between the blocks of the quilt; a continuous thread holding the different parts together. Are there more blocks to be added? Undoubtedly, some of which I summarised in the section on Intentions above and others which will continue to emerge as I continue to work with families and colleagues.

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**Appendix 1: Letter for parents to explain the research and requesting consent to discuss with them further.**

**CAMHS Learning Disabilities Service  
40 Rupert Street  
Nechells  
BIRMINGHAM  
B7 4PS  
Tel: 0121 213 5050  
Hilary.Howell@bch.nhs.uk**

Date

Dear Parent,

If you are reading this one of my colleagues has already spoken to you about the idea of helping me with my research.

I am interested in talking with parents and professionals about living with a child who has a learning disability and additional problems with their behaviour. As you may be aware this can be a common difficulty. I am interest in finding out more about what parents find helpful and what makes life more difficult related to the help they receive from other people.

At this point I am asking permission to call you on the telephone to explain the research further. I will explain that I would like to meet with you for about an hour to ask you some questions. I am happy to send the questions to you before we meet. I will also explain about confidentiality and let you know in detail what the information will be used for and how I will ensure your privacy. If after our discussion you do not wish to go ahead, that will be fine.

I will also be speaking with your child's teacher and the person in the team who has given you this letter. This is not to check up on the information given but to get different people's ideas and to think about how helpful those ideas are to you and your child.

I am hoping that the findings of my research will be very useful for our team when working with other families in your situation. I will share my findings with you when the research is completed.

If you are happy to speak to me on the telephone at this point please either tell the person who has given you this letter or leave a message for me on the above number. If you could indicate when might be a good time to call please let me know. I very much look forward to hearing from you.

With best wishes Hilary Howell, Consultant Clinical Psychologist

**Appendix 2: Letter for teachers explaining the research and requesting consent to discuss with them further.**



**CAMHS Learning Disabilities Service**  
**40 Rupert Street**  
**Nechells**  
**BIRMINGHAM**  
**B7 4PS**  
**Tel: 0121 213 5050**  
**Hilary.Howell@bch.nhs.uk**

Date

Dear Teacher,

As you may be aware ..... (name) has been referred to the above team. I am currently undertaking some research into challenging behaviour. I am interested in talking with parents and professionals about living with a child who has a learning disability and additional problems with their behaviour. I am interested in finding out more about what parents find helpful and what makes life more difficult in relation to the help and advice they receive from other people.

At this point I am asking permission to call you on the telephone to explain the research further. I will explain that I would like to meet with you for about an hour to ask you some questions. I am happy to send the questions to you before we meet. I will also explain about confidentiality and let you know in detail what the information will be used for and how I will ensure your privacy. I am happy to come and meet with you at school at a time which is convenient to you. If after our telephone conversation you do not wish to go ahead, that will be fine.

I will also be speaking with parents and the person in the team who is working with ..... (name). This is not to check up on the information given but to get different people's ideas and to think about how helpful those ideas are when trying to address the difficulties. .... (parent's name) has already given agreed to meet with me.

I am hoping that the findings of my research will be very useful for our team when working with other families in this situation. I will share my findings with you when the research is completed.

If you are happy to speak to me on the telephone at this point please either tell the person who has given you this letter or leave a message for me on the above number. If you could indicate when might be a good time to call please let me know.

I very much look forward to hearing from you.

With best wishes Hilary Howell, Consultant Clinical Psychologist

### **Appendix 3: Text of the Leaflet Version 2. 4<sup>th</sup> September 2009**

#### UNDERSTANDING CHILDREN WITH CHALLENGING BEHAVIOUR

##### Research Information:

I would like to introduce you to my research. I would like you to understand why the research is being done and what it might involve for you.

##### *Who am I?*

I am the Lead Clinician for the Birmingham Children's Hospital Child and Adolescent Mental Health Learning Disability Team. Much of our work is with children and young people with moderate to severe learning disabilities whose behaviour is experienced as difficult, dangerous or upsetting.

##### *What I plan to do.*

I am interviewing people in depth about children referred to the team. I am interviewing parents, teachers and colleagues who work in our team. I will be asking about the child's behaviour, what ideas people have about what causes the behaviour and what they have found helpful and unhelpful and I will be asking about other people who work with or care for the children. I need people to talk with me for about an hour. This leaflet explains more about this.

##### *Why am I doing this research?*

This research idea has arisen from many years of clinical experience. I have learnt how relationships around a child are very important. So to find out more and to understand how people experience services I would like to talk to parents and teachers about their children and pupils.

This research is part of a Doctoral programme supervised by the Tavistock Centre, a centre of excellence in London and the University of East London. It has also been agreed by the research section of Birmingham Children's Hospital.

##### *What am I asking for?*

I am requesting your consent for various things. Firstly, I am asking you to agree to talk to me about your child or a child you work with. My colleagues in the CAMHS Learning Disability Team will identify families and teachers who they think might be interested in talking to me. They will probably have given you this leaflet. They may also have spoken to you about the research. A letter giving similar information will then be given to you if you would like to think more about participating.

In order to protect people's privacy, I will not know you have been asked to help until you have agreed that I can contact you.

At this point I will talk to you on the telephone to explain more about the research and give you a chance to ask any questions. There will be no pressure to proceed if you are not happy to be interviewed. If you do not wish to take part, services to you and your family will not be affected in any way. If you would like to be interviewed I will arrange a time and place which is convenient to you to conduct the interview. If you change your mind, that will not be a problem.

I will need your consent to record our discussion and to speak to other

professionals. When I write up our discussion I will change names and any other identifying information so that you and the child being spoken about will not be identifiable by any one else. I am bound by the ethical and legal practices of the NHS. If there is anything you do not wish included in the write up I will leave it out.

After the research is completed I will submit my thesis for academic scrutiny and hope to publish my findings. Before doing this I will meet with the people I have interviewed, parent groups, teachers and other professional in the field to talk about my findings.

*What if there is a problem?*

If you are unhappy with any aspect of the process, you can complain either to my supervisor at the Tavistock or to my manager at the Children's Hospital. I will give you details of this when we meet.

*and finally.....*

I hope that people will find it useful to have a conversation about their child. If for any reason the discussion is upsetting I will make sure you get the support you need afterwards.

If you are interested in participating or finding out more, please tell the person who has given you this leaflet or contact me by phone, letter or e-mail and I will call you back.

Thank you for taking the time to read this information and for your interest.

Hilary Howell  
Contact details



#### **Appendix 4: Question framework for the semi-structured interview.**

##### **Introductory remarks:**

Introduce myself and show my identity card.

Explain who else will be interviewed or has already been interviewed.

Re-visit confidentiality including complete anonymity in the write up and obtain written consent to use the tape recorder. I will also outline the limits of confidentiality regarding safeguarding children and young people.

Agree a time limit for the interview. (If insufficient time, request a second visit).

##### **Basic information:**

Record who is being interviewed and their relationship to the child.

Child's name, age, any diagnostic labels they know about, school attended, and teacher's name.

(For family) Family makeup - who lives at home, who is involved in looking after the child on a regular basis.

(For teacher) How many other children in the class, support workers (LSA) or other teachers involved with child.

Other services involved with the child e.g. respite, family support etc.

##### **Interview:**

"Tell me about ..... (Name)". Prompts: process of referral, whose idea, behaviour causing concern, who is concerned, effects of behaviour on family/other children. Focus also on strengths and positive attributes.

Summarise behaviour/s causing concern and ask, "What sense do you make of this/these behaviours?" "Why do you think .... (Name) behaves like this?"

How do you react when ..... (Name) is behaving in a difficult way. Can you give me a recent example of a time that was difficult?

Do think that other people share your views and your approach? What might

other people think? What do other people do? Prompts: family members, teachers, LSAs, Camhs worker, etc.

How helpful or unhelpful do you find this? Have your suggestions/ideas been taken up by other people. Do you think that most people agree/disagree with how you see things? What does this mean for how you get on with each other?

Who is your greatest source of support?

Do you think that there have been any improvements since ..... (Name) was referred to the team? If so describe.

Are there other important things we should talk about today?

### **Appendix 5: Transcription conventions:**

- All transcripts were typed and contained the spoken words of both the interviewer and interviewee.
- Inaudible speech was indicated and the timing of the speech indicated.
- Ums and eerhs, laughter, etc were written down as exactly as possible.
- Bold type was used to indicate a loud tone of voice.
- Interruptions or extraneous noises, which impinged on the interview, were noted. e.g. when someone walked through the room.
- Speakers were identified by pre-designated initials. All utterances were attributable to one speaker or the other.
- Each line and page was numbered, with space left on the right-hand side for notes. The analysis phase also developed further columns of interest for example convergence and divergence.
- Normal punctuation marks were used to clarify utterances where possible.

## Appendix 6: Ethical approval and response.

CAMHS Learning Disabilities  
0902 9017 21  
**NHS**  
**National Research Ethics Service**  
South Staffordshire Local Research Ethics Committee  
Medical Institute  
Hartshill Road  
Hartshill  
Stoke-on-Trent  
Staffordshire  
ST4 7NY

Telephone: 01782 714980  
Facsimile: 01782 714975

11 August 2009

Mrs Hilary H. Howell  
Consultant Clinical Psychologist  
40 Rupert Street  
Nechells  
Birmingham  
B7 4PS

Dear Mrs Howell

**Study Title:** Children with challenging behaviour and learning disabilities: Relationships between parents and professionals.  
**REC reference number:** 09/H1203/68  
**Protocol number:** 1

The Research Ethics Committee reviewed the above application at the meeting held on 05 August 2009.

**Documents reviewed**

The documents reviewed at the meeting were:

Document	Version	Date
CV for Supervisor		
Participant Consent Form	1	25 June 2009
Participant Information Sheet	1	15 July 2009
Letter of invitation to participant	1	25 June 2009
Interview Schedules/Topic Guides		
Peer Review		01 July 2008
Letter from Sponsor		10 July 2009
Protocol	1	25 June 2009
Investigator CV		25 June 2009
Application	1	15 July 2009
Peer Review		10 July 2009

**Provisional opinion**

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

This Research Ethics Committee is an advisory committee to West Midlands Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

The Committee delegated authority to confirm its final opinion on the application to the Chair.

**Further information or clarification required**

1. Will you include adoptive/foster parents etc thereby looking at outside influences e.g attachment issues?
2. You will need the permission of the parent before approaching other potential participants.
3. The tick boxes on the consent form should be initial boxes. They therefore need to be made larger and explain that they are for initials

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 09 December 2009.

**Membership of the Committee**

The members of the Committee who were present at the meeting are listed on the attached sheet.

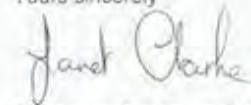
**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/H1203/68

Please quote this number on all correspondence

Yours sincerely



**Professor Tim Reynolds**  
Chair

Email: Janet.Clarke@uhns.nhs.uk

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.*

**South Staffordshire Local Research Ethics Committee****Attendance at Committee meeting on 05 August 2009****Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mrs Barbara Cannings	Co ordinator	Yes	
Mrs Sandra Chambers	Retired Head Teacher	Yes	
Mr Robert Edgar	Retired Engineer	Yes	
Dr Brian Hynam	Retired Director of Pharmacy Services	Yes	
Dr Kathryn Kinmond	Senior Lecturer	Yes	
Dr D Mulherin	Consultant Rheumatologist	Yes	
Professor Tim Reynolds	Consultant Chemical Pathologist	Yes	
Mr Victor Scofield	Retired	Yes	
Sister Elaine Stokes	Outpatients Nursing Manager	Yes	



The Birmingham Children's Hospital NHS Foundation Trust

Child and Adolescent Mental Health Service  
Learning Disabilities Service  
40 Rupert Street  
Nechells  
Birmingham  
B7 4PS

Tel: 0121 213 5050  
Fax: 0121 213 5051

Professor Tim Reynolds  
Consultant Chemical Pathologist  
Staffordshire Local research Ethics Committee  
Medical Institute  
Hartshill Road  
Hartshill  
Stoke on Trent  
Staffordshire  
ST4 7NY

04 September 2009

Dear Professor Reynolds

*Re: Study Title: Children with challenging behaviour and learning disabilities: Relationships between parents and professional  
REC reference number: 09/H1203/68*

Thanks you for your letter dated 11 August 2009. I will address the points raised.

1. *Will you include adoptive/foster parents etc thereby looking at outside influences e.g. attachment issues?*

There is some research which indicates that children with learning disabilities can show sign of disrupted attachments. It is unclear exactly why this might be the case but ideas include the frequent use of respite care and issues of bonding related to child or parent characteristics and disability. Thus I will be likely to draw on this research base when entering the interpretive phase of my data analysis. I am happy to include both adopted children and fostered children so long as they have been with those carers for at least one year. If these families are included in the study further links to the literature base for these children will be important. It will be very interesting to explore similarities and differences between carers, adoptive parents and parents although as this is not a quantitative study differences will be a matter for reflection and generation of ideas rather than definitive findings.

2. *You need the permission of the parent before approaching other potential participants.*



Of course. I have been careful in setting up interviews to not know the child's or family identity before obtaining permission to speak to parents. Before I interview parents and teachers I will ensure that I have permission from them to talk to others. There will be little point in proceeding if they are not happy with this. I have altered my initial letter to parents to specify this, have modified the consent form to make this explicit and have changed the leaflet to clarify this point. (Version 2 of paperwork enclosed).

*3. The tick boxes on the consent form should be initial boxes. They therefore need to be made larger and explain that they are for initials.*

See version 2 of the consent form (enclosed).

I hope this satisfactorily addresses the issues raised and look forward to hearing from you.

Yours sincerely

Hilary Howell  
Consultant Clinical Psychologist



**Appendix 7: Consent form:**



The Birmingham Children's Hospital NHS Foundation Trust



**Informed Consent for Audio Recordings.**

**Camhs Learning Disabilities Service.**

**Research Project: Understanding Children with Challenging Behaviour**

- \*I have been given a leaflet explaining the research
- \*I have had the opportunity to ask questions about the research.
- \* understand that I do not need to give consent if I am not happy for the interview to be recorded.
- \* understand that the interview will be transcribed for the purposes data analysis
- \*I understand that Hilary will leave out any comment I make which I do not wish to be recorded.
- \*I understand that I can stop the interview at any time and withdraw and that I do not have to explain why.
- \*I understand that if I withdraw this will not affect the service I receive in anyway.
- \*I understand that the data will be anonymised. i.e. all names and identifying information will be changed.
- \*I understand that this recording will be used for research purposes only and not shared with anyone else.
- \*I understand that others, (Parents, teachers and professionals) will also be interviewed for the research and that I have the right to decline to participate for this reason.

**Research Purposes**

I consent to my discussion with Hilary Howell, Clinical Psychologist being audio-recorded.

Signature..... Date.....

Name..... PLEASE PRINT

I undertake to ensure that every effort will be made to maintain professional confidentiality and to confine the use of tapes to the professional purposes consented to above.

Name...**Hilary Howell**..... Signature.....

Job Title...**Consultant Clinical Psychologist**...

Date.....

***\*Please initial all boxes if you are consenting.***

## Appendix 7a: UREC letter of Approval.

**EXTERNAL AND STRATEGIC DEVELOPMENT SERVICES**  
uel.ac.uk/qs  
Quality Assurance and Enhancement



Hilary Howell  
c/o Paru Jeram  
Academic Governance and Quality Assurance  
Tavistock Centre  
120 Belsize Lane  
London  
NW3 5BA

29 September 2015

Dear Hilary

**University of East London/The Tavistock and Portman NHS Foundation Trust:  
research ethics**

**Study Title:** Children with Challenging Behaviour and Learning Disabilities: Relationships between Parents and Professionals

**REC reference:** 09/H1203/68

I am writing to inform you that the University Research Ethics Committee (UREC) has reviewed the documents submitted by the Tavistock and Portman NHS Trust to the Chair of UREC, Professor Neville Punchard. Please take this letter as written confirmation that the Chair of UREC is satisfied that your research has gone through Ethical Review from a duly constituted NHS Ethics committee and received approval, and that UREC, if it had seen it at the appropriate time, would also have granted ethical approval on this basis.

For the avoidance of any doubt or misunderstanding, please note that the content of this letter extends only to those matters relating to the granting of ethical clearance, if there are any other outstanding procedural matters that need to be attended to, they will be dealt with separately as they fall entirely outside the remit of our University Research Ethics Committee.

If you are in any doubt about whether or not there are any other outstanding matters you should contact Mr William Bannister at the Tavistock and Portman NHS Foundation Trust (e-mail [WBannister@tavi-port.nhs.uk](mailto:WBannister@tavi-port.nhs.uk)).

Yours sincerely



Ducklands Campus, University Way, London E16 2FD  
Tel: +44 (0)20 8223 3322 Fax: +44 (0)20 8223 3334 MINICOM 020 8223 2803  
Email: [c.carter@uel.ac.uk](mailto:c.carter@uel.ac.uk)



**Appendix 8: Process used to contact people and gain informed consent following Ethic Committee comments.**

- To request consent to having a conversation with me, which would be taped and transcribed for the purposes of research. (See Appendix 6 for consent for audio recording.)
- That the material would be transcribed and analysed to identify themes around the topic of children with learning disabilities and challenging behaviour and relationships between people who look after and work with the child.
- That my thesis, any publication and material presented at team meetings, service meetings or conferences would be completely anonymised.
- That I would not be meeting with parents again except perhaps at the end of the research to feedback my findings.
- That I would not be offering them any advice or help. Should the family need a referral to psychology at some point in the future, then one of my colleagues would pick up the work.
- That I might be meeting with teachers again in relation to work with other children.
- That I work alongside my colleagues in the Camhs Learning Disabilities team.

CHILD 1: FULL INTERVIEW  
FIRST CODING APPENDIX 9

H. Parent Interview Full:

- 1
- 2 H. I'm talking with H's Mum T and H is how old now
- 3 T. 16
- 4 H. Is she really. Gosh OK. Has she got any um labels that you are aware of .. diagnostic labels
- 5
- 6 T. She was diagnosed classical autism but as far as that's concerned I know that's it the only one that I know from when she was diagnosed
- 7
- 8 H. Right
- 9 T. but at school reviews they've um (1 sec) they've mention her being severe learning um which was a bit taken aback because sometimes I think she isn't severe learning she's
- 10
- 11 H. OK
- 12 T. she's able to learn it's just that she needs that
- 13 H. Um
- 14 T. one to one to get it through but she's able to learn
- 15 H. So sometimes school have said severe learning disabilities but you are not sure about that
- 16
- 17 T. Yeah I mean we understand that the autism gets in the way which makes it difficult
- 18 H. sure
- 19 T. but sometimes I think severe learning you know I suppose when you see other people with disabilities you compare and so um I suppose to me um I think she can learn given the right... if she's got the right not person but the
- 20
- 21 H. the right structures.
- 22 T. someone who's there with the structures and the patience to keep goin' on
- 23 H. so H at the School and who's her current teacher
- 24
- 25 T. err (2 sec)
- 26 H. She's just got a new one this term?
- 27 T. she got a new one this term I can't remember his name
- 28 H. Who was it last term
- 29 T. She had um had two different ones
- 30 H. Oh right ok
- 31 T. I think her teacher's called M or M
- 32 H. There is a M so
- 33 T. M I haven't met him yet
- 34 H. Right um so who lives at home with you here
- 35 T. um N me husband and G H's brother

- things that  
- meanings / emotion / social part of story, concern  
- rel. between person & lifeworld "adjective"

diagnosis of autism / 'the only one'

severe learning - block

autism makes it hard to learn

Need people, structures or persistence (you get that)

info gathering in rels to my q's.

Severity word has salience where other people are placed re. other people w. it.



36 H. and G [redacted] now  
 37 T=18<sup>2</sup>  
 38 H. ok right so um and what other services are involved at the moment T [redacted]  
 39 T. We've got a brilliant service Resources for Autism where that's um like where H [redacted]  
 40 attends a youth club on a Tuesday night and it is just children who display challenging  
 41 behaviour on the severer scale it's brilliant it's our children for once going out to a youth  
 42 club and I just think they're great there's one member of staff for each child and they've got  
 43 music on and they run summer schools as well um H [redacted] attended one for a week during  
 44 the six week holiday and it was really good it was really structured and they didn't just  
 45 mind the children they got them doing things I was really pleased with it I think it is really  
 46 good.  
 47 H. mmm  
 48 T. really good thing  
 49 H. Excellent and um does she get any respite  
 50 T. Yeah she has respite she was originally supposed to have one week in every seven but  
 51 with Harriet's [redacted] 'nd and she was and found that her behaviour was really severe  
 52 um she was finding it she was getting really anxious and she was getting really challenging  
 53 and we found that she was less challenging and less anxious when it was a weekend and  
 54 also with the help of L [redacted] from Camhs who suggested that because of H [redacted]  
 55 anxieties and how severe they were suggested that not to actually tell her until the last  
 56 minute which really helped I felt that I felt bad I felt that I was lying to my daughter because  
 57 she's say Monday expecting me to say it's home and Tuesday home you know I knew  
 58 where she's be going but I felt it was for all of our best interests and she then seemed to  
 59 have settled a bit since then so she has 2 weekends in every seven  
 60 H. uh uh  
 61 T. so although it's not I suppose it's not a long enough break for us we probably feel like  
 62 we need a longer break we are just happy that H [redacted]'s relaxing and we can relax a little  
 63 bit more  
 64 H. So have you got a social worker who can organise all of this  
 65 T. Yeah well we've got a social worker at the moment her name's C [redacted] um can't  
 66 think of her surname she's got a really long name but that is that's one area I have been  
 67 disappointed in because she's had so many social worker in the time that so I never know  
 68 who the social worker is from one minute to the next unless I have someone contact me to  
 69 go through it all again because it's a new con a new social worker um  
 70 H. So having to tell your story over and over

Theme of Services good + bad

services /  
 things that are helpful  
 just for children like H.  
 + like other children  
 Cabers for her  
 actually doing things  
 structured. Quality good

Respite made her anxious  
 changed with help (Cumbel) to  
 be to more freq / less time  
 but tell her / lying = guilt

Respite / have a break  
 Not long enough for us but  
 Harriet ok / she could

She change / Don't know her  
 name  
 by appointment } ~~how to go~~  
 tell story  
 again

## Appendix 10: Analysis of participant's descriptions of behaviour experienced as challenging for child 1, Hayleigh.

Hayleigh: behaviours experienced as challenging

Descriptions of behaviours by parents/ teacher/team member: How it ends

Meaning making by parents/ teacher/team member

What helps by parents/ teacher/team member

Descriptions of behaviours by parents/ teacher/team member			Summary:
M39	Hayleigh attend a youth club on Tuesday night and this is just for children who displayed challenging behaviour on the severe scale	Severe CB implied and special setting appreciated	Mum: Severe CB which is unpredictable and really really difficult Behaviour almost too difficult to convey how awful it was Obsessive behaviours Frequent, terrifying attacks Kicks, head butts, punches, chases Mum round the house Pulls hair Attacks/violence when Mum asleep Dangerous behaviour e.g. in the car Targets Mum and won't stop until she has attacked her Mum can't protect herself Mum can't control her now, only husband Family battered and bruised So difficult neighbours have called the police Less frequent now but still very severe when they happen
M50	She has respite she was originally supposed to have one week in every seven but with Hayleigh's anxieties and she was and found that her behaviour was really severe	Severe CB Anxiety linked to CB?	
M117	so when she does change its like whoa M202 You never know when its going to happen	Unpredictable	
M126	I was asking for help and we were finding it really really difficult.... That it was all due to Hayleigh's challenging behaviour	Challenging behaviour really difficult	
M134	H was very very challenging and I had some really bad experiences in the car with her	Severe CB	
M136	(at initial assessment) I just couldn't do anything or say anything because H was so obsessive I was at my wits end	Relieved other people saw how difficult it was Obsessive	

M137	It was constantly constant constant and if I didn't answer her when I did it was just kicking off so she was displaying all this in front of the people	Constant behaviours 'Kicking off' In front of others (embarrassing?)	<p>Teacher:</p> <ul style="list-style-type: none"> <li>• Not much in school at this time but lots in the past, including;</li> <li>• "Severe CB", hitting out, kicking, pushing people,</li> <li>• Now mild behaviours, vocalisations, passivity</li> <li>• Can be forceful with her obsessions</li> <li>• Would take a while to calm down</li> </ul> <p>Team Member:</p> <ol style="list-style-type: none"> <li>1. Classical CB</li> <li>2. Outburst behaviour</li> <li>3. Hitting, damaging things, throwing objects</li> <li>4. Hitting Mum a lot</li> <li>5. Frequency has gone down</li> <li>6. More at home than school</li> </ol> <p>Mum mentions more specific behaviours. She lists lots of behaviour. She is more emotive in her language and perhaps feels scared and not able to control H.</p> <p>School sees much less challenging behaviours, although saw more in the past. Similar behaviours to home. Agreement on obsessional behaviours. School see reluctance and passivity as problematic. Agreement that she takes a while to calm down.</p>
M144	It was <b>really really</b> difficult as I say her behaviour was really really difficult	Almost too hard to describe how bad it was	
M149	When H kicks off it is <b>really</b> dangerous Really violent she kicks head-butts she punches there are numerous occasions I've be asleep in bed and Hayleigh will she's got a thing about coming into our room... She'll start hitting me if I am asleep unlike what does she do she grabs me eyes she's really really violent	Dangerous Kicks head butts	
M150	There are numerous occasions	Frequent terrifying attacks	
M155	-kicks, head butts, punches	kicks, head butts, punches	
M156	(describes being attacked in her sleep) if I'm asleep she grabs me eyes she's really really violent she's really wild	Violence to Mum when she is asleep	
M156	sometimes think other people don't believe me because she can be so placid	Worry people won't believe me	
M159	We say kicks off because she literally does its like everything goes kicking punching and she's chase me round the house	Severity (see separate section)	
M161	She won't stop until she has got what she wants or til she gets me	Doesn't give up until has hurt Mum or got what she wants	
M161	You can just be sitting with Hayleigh and	Unexpected	



	something will make her not happy and she will just punch like she punched Nick in the face when he was sitting looking at the laptop	Punches other people	Team member uses professional language and is not very specific. Mentions property damage which no one else has. Hitting mentioned but not other behaviours.  There is agreement that the behaviours are less frequent now, although mum sees them as severe as ever. This backed up by data from the professional.
M168	Tends to go for Mum: I don't know if she senses she can overpower me or that I am a bit frightened Now can't control Hayleigh (Husband tries to intervene)	Attacks on Mum, focus on Mum Getting too strong for Mum	
M172	I can't do anything physically to protect myself	Helpless	
M179	Bit less frequent now	Reduced in frequency	
M192	I'm (Mum) crying and got H yanking me hair	Pulls hair	
M199	more often than once a week but not full time	More than once a week	
M261	He (husband) doesn't like to see me getting hurt (relational)	Effect on others	
M265	if Nick has to step in it really is for my (mum) safety and to either restrain or to make sure I'm safely out of the way	Dad protecting Mum	
M258	We'd be covered in bruises or just beaten really you know beaten and feel shattered	Battered and bruised	
M426	Specific example given of attack at home	Attack at home	
M466	We have had police come because the neighbours have thought, you know... and I can't blame them because when it kicks off and you hear like screaming or banging you know, and then the police come and you	Difficulty of managing and explaining to others	

	have to try and explain that your daughter is 16 and she's got autism.		
T85	Severe CB would be quite physical, lot of kicking, a lot of hitting out. She was surprisingly powerful for slight frame, and seemingly mild mannered most of the time	Kicking, hitting Powerful, strong	
T87	Vocalise	Vocalisations	
T87	Take quite a lot of time to calm down, T93 Would take quite a long time to come back from that	Goes on a while	
T88	Would push past people (to get to whiteboard) wouldn't take no for an answer. So she would really try and force her way through to get to it.	Persistent/Determined using force	
T91	Put in quiet corner would come out again (different from other children)	Not complying with being excluded	
T94	Few occasions of severe CB in school "But I observed that rarely" Used to be more frequent	Much less frequent in school and frequency has reduced	
T94/5	Observed severe CB twice in whole year at school	2 severe incidents at school in a year	
T99	You know it's very rare these behaviours where are exhibited over the last 12 months.	"	
T101 T111	Mild behaviours; vocal, push you away, unwillingness to join in an activity (Reluctant), passivity Are you going to make me do that, do you	Passive Reluctant to join in Task avoidance	

	want me to do that. more her sort of thing.		
T237	Took a long time to calm down	Long time to calm down	
T414	Some very minor incidents, couple of occasions not so minor, we got out of them or enable H to get out of them. Actually she was pleasant almost all the time	A few minor incidents at school	
P34	H shows what you traditionally called challenging behaviour	Challenging Behaviour Care with term used	
P51	CB described as outburst behaviour. I think it sort of describes what's going on	Outburst behaviour	
P52	Lots of hitting out, damaging objects, throwing things. Hitting Mum a lot. I can't remember if self injury.	Hitting especially Mum, property destruction, Throwing	
P59	P thought Mum most concerned (about CB) then changed and said all the family were concerned	Family focus	
P258	Level of aggression is at a much lower level haven't had much to do with school other than in reviews	Not many probs at school	
P369	From behavioural perspective the frequency of outbursts has gone down	Outburst reduced at home Shared technical language	

Meaning making about behaviours by parents/ teacher/team member			Summary
M17	We understand that autism gets in the way which makes it difficult. Needs 1:1 to learn	Autism gets in the way of learning so need something special	Mum: <ol style="list-style-type: none"> <li>1. Autism seen as a key aspect of the difficulties</li> <li>2. Anxiety</li> <li>3. Obsessions interrupted and not understanding the things are broken</li> <li>4. Frustration at not getting what she wants</li> <li>5. Pain</li> <li>6. Hormones?</li> <li>7. Feeling unwell</li> <li>8. Having to do something she doesn't want which makes her anxious</li> <li>9. Unhappiness at not getting what she wants</li> <li>10. Focus on attacking Mum, because she can overpower or knows Mum is frightened</li> <li>11. lack of understandings</li> <li>12. can't communicate what is wrong</li> <li>13. Sees things on TV or Internet that upset her</li> <li>14. Bored, lack of stimulation</li> <li>15. Tired and expected to do something she doesn't</li> </ol>
M50	She has respite she was originally supposed to have one week in every seven but with Hayleigh's anxieties and she was and found that her behaviour was really severe	Severe CB Anxiety linked to CB?	
M108	But then she can just change and it's usually depending on could be something that she's watching all the DVD could break all she wants something or she can't have it so it's usually something to do with frustration	Frustration linked to changes or not getting something she wants	
M111	It could be her period are due and that has a big effect on Hayleigh then also change of knowing there's going to be a change life knowing she's going to respite and if she doesn't want to go	Periods Not wanting to go to respite	
M126	I was asking for help and we were finding it <b>really really</b> difficult... it was all due to H's challenging behaviour which all coincided ... She started her periods when she was 11 and there was was a lot of body is changing so there was a lots of presumption it was her body changing	Started when she was 11 (16 now) Linked to bodily changes	
M162	Something will make her not happy and she will punch	Unhappiness/can't get what she wants triggers CB	
M168	Tends to go for Mum: I don't know if she senses she can overpower me or that I am a bit frightened Now can't control Hayleigh I can move and I can roll up in a ball but I can't physically do anything um to protect myself so she knows that um so I think she goes for me (Husband tries to intervene)	Attacks on Mum, focus on Mum maybe because she can overpower (Control) or senses Mum is frightened (Frightening for her?)	

M180	When periods are due	Physical/ pain	want to do
M181	It's usually when there's a problem with the electrical equipment or one of the DVDs won't work and there's nothing we can do really can't explain to her that it is broken that she really understands	Can't continue obsessional behaviour She can't understand	16. Picked up loads of undesirable behaviours from other SLD children
M212	Always try to put myself in H's position so I feel groggy she will too (Pre-menstrual)	Feeling unwell	17. Simply don't know what upset her sometimes
M215	Sometimes it's obvious it's the DVD and we can't mend DVD something so obvious	DVD breaks	18. maybe picks up on other's anxiety
M216	She could be watching something on the Internet that she's chosen to watch and then suddenly start crying and start to get angry but still continue to watch this thing	Sees things that upset her	19. Brother thinks she is spoilt, parents give in too much
M218	and we don't know sometimes what what it is she you know I don't know when H is really in pain or anything I can only try and guess unless you can let me know you know sometime she will say water bottle and I will know she's got a stomach ache	Don't know sometimes	20. When H younger pursued all sorts of explanations, e.g. Gluten allergy, vaccine damage.
M221	Other than that I don't know if she has a headache I don't know what she's going through, what she's going through with her medication. I don't know what she feels which is really hard to know to think you don't know what your child is going through and you can't tell if they're in pain. If that's the reason she is kicking off	Unclear if she is in pain very hard as a parent not to know and to be able to help Implies that pain might be a cause of CB	Teacher:
M232	Definitely frustration maybe if she can't get across what she wants	Frustration when can't get what she wants	1. Triggers; like..
M233	lack of stimulation	Bored	2. Objects which she fixated on and needed to finish.
M233	Tired and expected to do something (see T67) .. that'll get	Tired and demands made	3. Visual cues
			4. Classic passive autism; found it hard to sustain work
			5. Pain, discomfort, feeling unwell
			6. under-stimulated, not stretch at first
			7. Occasionally disliked her space invaded
			8. Teacher agreed

	her aggressive		<p>obsessions may be self soothing</p> <p>9. Autism seen as too simplistic a label to explain beh.</p> <p>Team member:</p> <ul style="list-style-type: none"> <li>• Entering teenage years</li> <li>• Parental conflict rubbing off</li> <li>• H's way of saying;</li> <li>• something's not right for me.</li> <li>• I don't understand</li> <li>• Why can't I have what I want?</li> <li>• Mum seen as person who can put things right</li> <li>• wants things to be put right straight away</li> <li>• Autism plays a part, lack of social constraints, can't put herself in other's shoes, rigid.</li> <li>• Not coping leads to anger</li> <li>• Behaviour gets her what she wants.</li> <li>• No more adaptive strategies</li> <li>• Poor self regulation</li> <li>• Venting makes her feel</li> </ul>
M317	(Mum on son) But what he said to us over the time would be you know well you let her have the video you let her have DVDs and you are making a rod for your own back	Mum feels her son is worried about them giving in	
M335	Using ABA she showed great signs of progress ... She was put you know in the special education needs school with severely autistic children and we lost Hayleigh	Starting SEN School, picked up from other children	
M368	Gavin would say, "yeah its cause she's got all these things and you buy heard these things", but asked that over H has got she hasn't got like, you know she can't go out with her friends and she hasn't got an iPod and she doesn't do this and whatever, she's just here at home and them are her things.	Gavin sees her as spoilt but Mum feels letting her do things (DVD TV) is all she's got	
M378	School is really below H's ability	Not stretched?	
M405	Re: school we would both know why when it was her she was suffering with her skin or when she on her period or she wants the computer ( don't know how they handle it)	Pain discomfort wanting computer but can't have it	
M584	(Dad) I don't know if we're anxious ourselves.	Implies this might make child more anxious	
M72 4	When child younger bombarded.. it could be gluten allergy, we did everything	Looking for a cause and a cure	
T52	There are certain triggers that I observe which would cause behaviours for H.	Triggers	
T53	She was fixated on computer and whiteboard and would want to complete things in a certain way.	Obsessions	
T54	There were certain visual cues that would upset H.	Visual cues	

T57	Example of task which upset her: own photo cut up child asked to re-assemble own face reacted strongly to that visual thing going on	Sensory? Confusion	<p>better</p> <ul style="list-style-type: none"> <li>• LD and autism combined</li> <li>• Ideas come from lots of sources</li> </ul> <p><b>Convergent/Divergent Themes</b> Mum has strong focus on pain as a causative factor. Mum also sees frustration as component. Autism seen as important contributor. Sees herself a main target of aggression. Not much contact between home and school although Mum initially was seen as helpful by school. Mum frustrated with schools in general lack of H being stretched currently. Behaviour much less frequent at school. Not really explained although teacher thinks maturation and past teaching are factors. Teacher thinks autism present but too simplistic to think of as causative. Obsessions named. Seen as helping to provide comfort in repetition. Not an idea shared anywhere else. Transitions difficult. People not knowing H hard.</p>
T59	She acted very strongly against that because of I assume her perception of herself and challenge to that, only an assumption I could be wrong.	Assumption that it was linked to her perception of herself	
T63	Hayleigh's classic sort of passive autism – would do short term familiar tasks (happy) sustained /lot of work wouldn't really like	Effect of autism on concentration	
T67	Being asked to do sustained task lot of work (mild CB)	Demands made	
T78	She wasn't too bothered about people being near her space but on occasions she would not like that and would let you know.	Sometimes didn't like space invaded	
T115	Whiteboard would play and replay obsessively + T128	Obsessions	
T145	Rubbing face and eyes, medical condition would lead to milder behaviours she would feel miserable	Pain discomfort	
T151	Reluctance rooted in feeling unwell	Feeling unwell	
T157	At first not stretching her enough, thought at first not willing then realised she was very capable	Bored/ under stimulated	
T181	Autism label as an explanation is too simplistic / T183 some autistic people are passive but relatively easy to encourage her out of it	Label too simplistic Passivity associated with autism	
T268	More obsessional/ T275 brought her comfort or pleasure	HH suggested as a result of stressed or bored self-calming : Teacher agreed T276 on	
T270	something she found comforting and therefore would want to replay and replay and replay from that point of view.	Repeating something was calming	

	Happened less when stretched		Team member seen as very helpful. Helpful bits are knowing H, listening, coming up with ideas. Team member has complex understanding including; family stress, teenage-hood, and viewing world through child's eyes. Agrees with Mum on focus on her, sees poor self regulation. Aspects directly linked to aspects of autism.
T417	new class/ change can be unsettling (you probably know this already) you have to sort of work your way into new relationships and that's certainly true of our class	Causes: new class vs. we didn't know her?	
P65	(at start of involvement) H obviously entering her teenage years	Being teenager seen as difficulty	Behaviour also works for her. Some agreement with son who sees parents as giving in to what H wants. Parents agree with this but explain why they do it. Mix of practicality and emotional compensation for disability.
P102	Tension between parents rubbed off on H	Relational understanding/ picking up on parental tension	
P144	CB is H's way of saying something's not working for me right now or 'I don't understand what on earths going on'; 'why can't this happen right now?' or 'what going on'.	Lack of understanding, lack of communication ability Expressing understanding from H's viewpoint	
P151	In H's mind if Mum's there Mum's the person who can make it right again'. Its got to be made right there and then.	Needs things done straight away. Can't tolerate waiting/ frustration. Mum as key person	
P165	Autism plays a role in CB. "Well I think, you know obviously the autism has a role to play in that. I think some of the acts are done without social constraints and I think that's part and parcel to do with perhaps the autism and her not putting herself in other people's shoes and having quite a rigid view about what needs to happen and when. So I think that plays a part in it"	Description of L's understanding of autism	
P169	H doesn't know how to cope so she lets the world know how angry she is about that	Can't cope leads to anger	
P172	Behaviour works for her. Doesn't always gets what she wants... there isn't another way for her to do it as effectively	CB sometimes gets what she wants, doesn't have an	



	.	alternative strategy	
P175	I think she does struggle with self-regulation. Don't think the self-regulation part is there.	Lack of self regulation	
P180	Lack of self-regulation mix of H, autism and LD. Behaviour for some reason just makes her feel better, with that frustration, when its vented	Lack of self-regulation mix of H, autism and LD. Venting makes her feel better	
P265	L building on the original meanings from Jess's assessment. Pooled info from home, school and respite. I think people were having a shared understanding.	L influenced by previous work Holistic/long term Shared understanding important	

<b>VACCINE</b>			<b>Convergent and divergent views</b>
M627	<b>Biggest biggest thing</b> I don't want to say because it's so controversial	Causation	<p>This section was only the viewpoint of the parents and was not mentioned by anyone else.</p> <p>However it was a very powerful theme for these parents</p> <p>Parents were aware of the strongly held views of many professional that MMR is not linked to autism but still passionately believed that it</p>
M638	main effect on H was MMR 1. not just us who think that in contact with other parents 2. Have medical records 3. Have videos and photos	Know this is controversial, parents back up assertions with different evidence	
M641	When she had the MMR literally the day after she looked like a totally different child		
M650	Know it was the vaccine, not allowed to say, made to feel guilty		
M645	Case against this belief "its a statistic"		
M646	Biggest shareholding thing in the whole world and we are never going to win (M648 first case won but won't help the child, won't make life easier	Conspiracy/about money  Does dad feel they	

M652	Fighting was another burden, another dysfunctional focus (M659) never a real clinical end	wasted their time, put themselves under extra pressure or anger?	was directly responsible for autism
M660	bitter at the end result (Mix of Mum and Dad)	Story still very alive for them, sought redress and an explanation and failed	
M667 on	(mum and dad overlapping in agreement, same story) trying to find causes, bowel, they put an end to it, legal aid removed so couldn't fight, threaten by Merck and solicitors they would take everything away from us, tied to make us sign, got around that, that was another story " <b>Which takes your life away</b> "	pointless	
Effect on relationships with professionals:			
M688	Man made vaccine by a scientist given to your baby How can they say these babies can't be damaged when you know anything can cause a reaction	Horror of science	
M693	Go to health visitor and they say 100% safe (M696) Are they paid just to get rid of the vaccines	Anger at professionals	
M686	I've lost faith with everything well not everything necessarily	Lost faith in things	
M700 on	Took loads of time from family life, obviously not concentrating on Gavin we should have done Guilt of that: come out the other side and "We weren't the family running in the park" "We was the family that was divulged on legal stuff" (Dad)	Wasted our time Guilt about Gavin Not an ordinary family	
M711	Gave up when H went to Calthorpe, give in the fight, not give in caring for Hayleigh, But its more like accepting Hayleigh No more fight in us M719	Acceptance of child with disability	

What helps or doesn't by parents/ teacher/team member		Summary	
<b>What been tried and what helps:</b> Practical stuff, people listening to us, using ABA approaches, being firm, giving her more interesting stuff to stretch her.		Mum: <ul style="list-style-type: none"> <li>• Adapting service provision to address child's needs helpful</li> <li>• shorter respite to lower anxiety</li> <li>• having strategies to work on. (Feeling more in control?)</li> <li>• Distraction</li> <li>• Mum escapes or lets herself be hit to stop the pattern</li> <li>• addressing H's pain (Hot water bottle, paracetamol)</li> <li>• Mum being available to put things right</li> <li>• Time with people and time on her own</li> <li>• Mum putting herself in H's shoes</li> <li>• Parents having regular breaks</li> <li>• Patience (ie. not reacting angrily)</li> <li>• Behavioural approaches including ABA: training strategies listed</li> <li>• Giving in to her sometimes</li> </ul>	
M53	In the context of more frequent shorter respite: And we found that she was less challenging and less anxious when it was the weekend and also with the help of the Lucy from Camhs who suggested that because of Hayleigh's anxieties and how severe they were that not to actually tell her until the last minute which really helped (Made Mum feel bad, like she felt that she was lying)		Ecological changes Not telling her in advance about going to respite
M145	Camhs and Lucy we have come up with some things to work on and make really helped a lot		
M174	If you can distract her with something		Distraction
M174	She can't get me (in the garden shed)		Mum escapes
M192	But I really feel sometimes that I'm the only one who can either put up with it all suffer and let it calm down		Mum feel completely responsible Mum feels powerless
M220	she will say water bottle and I will know she's got a stomach ache		Pain can be helped if Mum knows
M225	She does want me a lot, she does want us all a lot, she wants us all a lot, she seems to want to spend time with us but still being alone and doing her own thing		Wanting to be with people at times but also wanting to be alone and do her own thing. (Confusion)
M244	I always try and put myself in her shoes and think "Oh how does she feel"... and how would I feel?		Mum putting herself in child's shoes, how would I feel?
M246	Respite/ having a break I really need a break ... We have		Respite

	some really nice times now that we wouldn't have had this so that gives us a little bit more patients I think as well you know with Hayleigh ... There is a little bit of light at the end of the tunnel 'cause you have a little break soon		to manage a really difficult situation e.g. attacks and noise in the night
M263	I've probably got more patience than Nick has, so it will always be me I will always be the one to deal with H because I've got more patience but then if Nick has to step in it is really from my safety to either restrain H or make sure I am safely out of the way	Patience if possible Physical handing for safety	<ul style="list-style-type: none"> <li>• Structure and setting limits</li> <li>• Listening from someone who knows H, suggestions.</li> <li>• Help with problem solving</li> <li>• Counselling</li> </ul>
M322	Lots of stuff from the past about how ABA helped but was lost when she went to special school Strategies; Training, getting her to imitate appropriate behaviours, lovely school, small numbers, children who could talk, weekend behavioural things, speech and language things.		Very rich understandings and lots of things that can help but also some mentioned unhelpful things including lack of understanding from outside the home.
M365	Hayleigh does get her way, she does watch the telly, although we can sort of put limits on that now because of things that have been brought into the home, you know, like suggestions and things to work on from Camhs, things like that. So we have been able to get some structure into the home.	Giving in to her Having structure Put limits	Teacher: <ul style="list-style-type: none"> <li>• Maturation</li> <li>• Excellent teaching</li> <li>• Advice from Mum about stretching H</li> <li>• putting her with more able children</li> <li>• being clear what upset her and sorting it out</li> <li>• taking her out of the situation, giving her somewhere quiet to calm down</li> <li>• protection of other children: Giving her space, moving other away</li> </ul>
M429	Right we'll put the DVD on and you're sitting there at like 2:30 in the morning watching a DVD to come that down.	Give her what she usually likes	
M432	Or I can be shut in somewhere and Nick is like restraining her and he can distract her with something it's usually like that. It depends, it depends where you are and what you're doing at the time.	Distraction Situation dependent, varies	
M432	Yeah, so it's either giving into what she wants which is the only way you're going to get that and it's reinforcing the negative behaviour which we know because that's what we used to do when she was younger, this behaviourist and	Giving in Know this is unhelpful but have to do it because she is so strong	

	you'd ignore the bad reinforce the good. But not now because she is so strong ... I'm not going to let her win with this, but you can't.		<ul style="list-style-type: none"> <li>• learning what works, process of discovery</li> <li>• Being stern didn't help</li> <li>• Talking her down, prompts to be calm</li> <li>• Calm and reasoning approach</li> <li>• Staff team generally agreeing, consistency, getting on with each other is important</li> <li>• The knowledge of people who knew her well from the past</li> <li>• Physical management at times if others at risk, or she wouldn't leave situation</li> <li>• Person who knew her best was strict, controlling and stern which was unhelpful. Teacher seemed reluctant to criticise or assert his views directly, although he mostly agreed he was in charge.</li> </ul> <p>Team member: lots of use of shared professional language.</p> <ul style="list-style-type: none"> <li>• Distinctions between what helps the child directly, and</li> </ul>
M435	in the night try and end it as quickly as possibleH. Watch a dvd at 2:30 in the morning/or let her hit	Give in at night or let her hit Mum to stop it	
M436	I dread to think what think next door sometimes	What others think	
M466	Have had the police come because the neighbours thought.. you know the police come and you try and explain your daughter if 15 16 and she's got autism and I don't think they know what it is so I say mentally disabled blah blah blah	Embarrassment of others becoming involved and not understanding. Need to give in at night.	
M471	So if Hayleigh does kick off its like... Sometimes it's like well just let her give me a good beating (laughs) so that everything can calm down	Letting her beat Mum will calm her down (Other places too)	
M482	HH: So it feels like L would try and help just by listening, by thinking about it, and by making some suggestions... Mum: I think that's the only help that we do get in that sense apart from the respite which is packing Hayleigh off in a sense	Camhs listening, thinking, making suggestions Respite	
M489	On respite: it's not educating them all teaching them behavioural techniques, they're there to give us a break and they do a fantastic job.	Respite	
M492	If we were like Super Nanny on the telly look how good our children would be and that's what you need, someone to come in and give you the ideas.	Someone to come in and give you ideas	
M496	We planned a strategy to get H to wear a bra and Lucy knows that H wouldn't even look at a bra before and now she is wearing a bra like every day.	Strategy, unclear what	

M505	And she know she's got limited time on the computer and that, we've got some control, so that's really good, I really think Camhs is really, really good.	Restricting time on the computer Having some control Help from Camhs	<p>what helps the family, which helps the child, and what helps the network around the child.</p> <ul style="list-style-type: none"> <li>• H venting her frustration with CB seen as helpful.</li> <li>• Knowing the child well is important</li> <li>• Staying calm is the key but is seen as hard</li> <li>• Having one person in charge/ to sort things helps</li> <li>• Having only Mum to sort helps, harder if others around</li> <li>• Mum getting away if panic</li> <li>• Proactive stuff like visual timetable and social stories. Dad really likes these ideas.</li> <li>• Suggested stimulus change; doing something silly to interrupt the behaviour. Not really happening. Brother too cool, panic takes over.</li> <li>• High EE and marital tensions unhelpful and negative impact on H's behaviour. Things much improved and this linked to</li> </ul>
M512	I believe in behaviour techniques and behaviour analysis... but we'll break it (behaviour) down and then they'll be able to do it See what end it too	Behavioural approaches	
M534	We had to work on that as keeping her hands down, all reinforcing her keeping her hands down, until we could verbally reinforce that.	Use of positive reinforcement Verbal, physical, gestural.	
M537	It is those sorts of things that you need a behaviourist to sort of sit and work on things one to one with you.	Need one to one help from behaviourist	
M591	(Mum) The timetable, and the things we've worked on (Dad) Rules, the structure of her daily routine.	Timetable, rules, structure	
M594	Importance of professionals listening. Repeated in a number of places We've talked about what is suitable for us as a family how that can fit with us. I think it's been really good: it's good.	Professionals listening	
M599	And Hayleigh might have been really bad the night before, and I'm like feeling absolutely manic, and just to have that person to talk to who knows what H is like because they've been looking at her behaviour over time, that is good.	Importance of having someone to talk to who knows the child	
M602	When we had the counselling with yourself as well you know I found that really good. And I know Gavin did as well; he continued to have counselling at school.	Counselling, time to talk	
M740	(Dad) You know, I always take the good things... And then we went to the show and she was dancing around, phew, tears of joy.	Look at the good things too	

M759	(Dad) It's excepting where you are within the development of your child as well as trying to... I think it's just parenting isn't it.	Trying to just parent your child based on where they are developmentally.	<p>improvements in child's behaviour.</p> <ul style="list-style-type: none"> <li>• People singing off the same hymn sheet</li> <li>• Involving father and brother important.</li> <li>• Camhs service seen as important</li> <li>• Talking and listening at least as helpful as interventions. Space to reflect back and make sense of awful times.</li> <li>• Intensive support when H little seen as suffocating and stopping parents finding their own way through.</li> <li>• Practical support and respite good source of support.</li> <li>• Respite being flexible and creative helpful.</li> <li>• Brother understands her well and more realistic</li> <li>• Poor communication with school unhelpful for Mum</li> <li>• Continuity of people useful, hard when they go.</li> </ul>
T96	That I imagine either through the process of maturation for the process of excellent teaching by her previous teachers she was starting to master that a little bit. (Exhibiting CB)	Maturation Excellent teaching	
T132	Process of discovery re: whiteboard obsession: we didn't know straight away, told her it was time to finish, actually accept that, took 2 CB episodes to realise that	Process of discovering. Learning what works	
T162	In relation to early problems at school took her out put her in other groups/ T167 activities framed at her level got her more interested	Putting her in the right groups/ finding out what level of work was right	
T193	Because she might harm others, give her space move other children away/ T220 give her time to calm down and try and talk her down	Protection, give her space, move others away	
T205	Be very stern, didn't find that helped	Don't be stern	
T211	Try and draw that out of herself and make her realise that when she was calm and ready she could come back and join the group	Giving her time to calm	
T213	Be clear what was upsetting her and sort it. Facial recognition task	Understand CB and sort problem	
T225	Physical management/ Team Teach Needed to use as she wouldn't exclude herself. Restraint and putting her back in her space nb computer was there.	Physical management Teacher seemed reluctant to talk about this, needed prompting	
T225	Give her a safe space to retreat to. T233 New idea for her. T250 Wasn't defined in her head as a space where she	Safe space/get away from everything	

	could calm down. This did improve as the year went on I think she was getting the idea. T262 She didn't define that as a space to go and relax maybe that would be the next phase I didn't witness that		<ul style="list-style-type: none"> <li>• Leadership, continuity and coordination important.</li> <li>• Time to talk for the family and including everyone important.</li> <li>• Doing things outside the home and services coming on stream useful</li> <li>• Some sense of parents modifying their expectations and responding more to child's special needs. High expectations in the past put strain on things. Eg holidays.</li> <li>• Big group of friends seen as a source of support for parents/ seen a protective factor</li> <li>• Team member believes in being collaborative, building of people's ideas.</li> <li>• Network liking family, Mum in particular seems to make them want to help.</li> <li>• Believing that there is more to unlock in the child is seen as motivating people to try harder</li> </ul>
T294	She did listen I also found she listened with the calm and reasoning approach as well	Being calm	
T296	I think we thought along the same lines,	Consistency	
T285	Some differences at first. One person who know H well had strong views. (T would want to give her space to calm down not saying what the other did.) No conflict of interest just feeling our way to a compromise	Some differences at first. Consistency in staff team at school was important	
T290	I observed on some occasions ... more strict wouldn't say in my perception that was particularly effective (but..)	Being strict unhelpful	
T294	She did listen I also found she listened with the calm and reasoning approach as well	Listening and being calm	
T295	Other members of staff were new to H as I was	Newness, not knowing the child might be a problem	
T296	I think we thought along the same lines,	Consistency/ having the same understanding was important	
T332	somebody who'd worked with H for 2 years and I'd met H for 3 months at this stage it would be a way we would probably cope with that sort of behaviour with other members of the class and similar classes you know, give people time to come to their own realisation.	One person knew H for long time. Her approach was less helpful (conflicting views) Knowing child good but strict and stern not good. Need to give people time to agree (with teacher)	
T300	I suggested person would be more 'I'm in charge'. Teacher	Teacher agreed he was in	



	agreed but not as polarised as that... T306 element of that	charge but “not as polarised as that)	<b>Convergence and divergence:</b> Mum and team member seem to agree on many things: usefulness of talking and listening; making sense of things; having strategies, flexible responsive respite, practical things; staying calm; Mum getting away if too difficult. Implied disagreement about the value of ABA early on in H's life. Although elsewhere parents talk about how difficult that was. Teacher seemed rather separate but valued Mum's input, agreed on staying calm and on people having a consistent understanding approach. Teacher also emphasised teaching more self reliance and self management.
T309	She would be trying to model H's behaviour from the start, do this, be there, sit there, stop. A little bit more harshly than maybe I would have done. T314 Teacher would understand that as setting a pattern of to control behaviour so H would know to conform to certain standards (T325 do that first) which is perfectly reasonable	TA would be very controlling of the child, is a “bit more harshly”. Said it was reasonable, but didn't agree.  His leadership style/ what he wanted me to understand.	
T317	My approach would be more to help H learn that she can get herself out of a situation if she wants to and make her own choice about it.	Giving her skills to sort things out for herself	
P19	IABA comprehensive functional assessment recommendations. L to continue with the plan At first had to catch up as Jess knew H really, really well	Technical language between peers Importance of knowing child well (T)	
P34	(in past) family were really struggling to cope and a lot of family dynamics were influencing the behaviour at the time	Family dynamic affect the behaviour unhelpfully	
P38	Respite was sorted and .... practical support was prioritised at that point	Practical support and respite helpful	
P39	I was aware of Hayleigh requiring a service	Implies that Camhs service was going to be useful	
P60	The family have had a really intensive input an ABA style, having people there around the clock doing things (lost that due to funding) .... That was almost suffocating through to	Very intensive input, behavioural. Described as suffocating, but also loss of it	

	nothing, and lost their way. P118 I think that was suffocating and I don't think that gave them a chance to find their own way and to work as a team.	seen as unhelpful, "lost their way" Stopped parents finding their own way and working as a team	
P70	Family wanted H to be as normal as possible,	high expectations	
P79	Because at times Gavin seems more of the adult in the family and takes on "this is what you should be doing with Hayleigh" role. And at times I've heard him say that. He seems to have a good understanding of Hayleigh.	Brother being the adult, good understanding	
P86	(Gavin will) Appreciate and enjoy the moments that they have that are really warm and work, we without having so much of an expectation of....	Gavin accepting of sister and appreciating good times	
P101	Quite high expressed emotion within the family and lots of anxious energy in the family. So I think that tension has rubbed off on Gavin, the brother. And obviously must rub off on Hayleigh as well.	Tension, anxiety and high EE must rub off on both children unhelpfully	
P139	I think that network, in a way, could be a protective factor for keeping mum and dad together as well, despite all the stresses.	Network of friends helpful, in parents staying together. Good for H too?	
P147	And I think, Hayleigh's mind, if her mum's there her mum is the person who can make things right again.	Mum seen as putting things right for H, understands her?	
P180	And I think for some reason it just makes her feel better, with that frustration, when it's vented.	CB is venting frustration and helps H feel better	
P188	Ironically (Unclear why ironic) most useful thing is about <b>remaining as calm</b> as possible but doing it is really hard/ P193 Being calm is one of the keys	Staying calm but hard to do Calmness vital but hard	
P191	And I think when mum is on her own with Hayleigh she	Staying calm, not verbal stuff,	

	does what she can to rein it all in and keep herself calm and not fuel with verbal stuff and with reactions. But then when other members of the family are around then it's a bit more out of control. But being calm is one of the keys, for when things are happening.	This works best with Mum on her own, harder when other members of the family around. Then more out of control	
P194	So obviously we've put in a lot of proactive stuff in to prevent as much as possible: Visual timetable really worked marvellously. Mum positively reinforced by this because H responded so well. Become part of family life.	Proactive stuff, visual timetable IABA language	
P198	Did talk about stimulus change, for when things really terrible and introducing something off the wall that would interrupt the moment and give people a chance to catch their breath, regroup, reorganise, sort something out. In theory Mum took the idea. Gavin too cool to do it. Struggling to think what is silly. G understood but not prepared to try. Not sure about dad. Difficulty of putting into place is if family there panic takes over, which is why the calm stuff is so important	Doing something silly, not doing for various reasons. Calmness re-stated as important. Behavioural. Assumption of shared understanding of terms with me.	
P207	Only having one person deal with it.	Having only one person to sort helps	
P208	(If panic takes over) Space between Mum and H	Mum being away if panicked	
P229	Dad favours things that are more to do with H being more of a teenager and being more grown up and having dignity and things like that.	Dad finds proactive stuff easier, related to H being seen as grown up, ordinary	
P239	Initially dad not being around ... Dad more in the picture now P244 and Gavin involved too. Q: So its a big advantage having everybody involved? A: Yes	Importance of involving fathers	

P269	I think people were having a shared understanding (implied this is good)	Shared understanding good?	
P280	So I think communication's broken down a little bit with school.	Poor communication with school not good for Mum	
P281	I do think mum finds the respite very supportive.	Respite supportive of Mum	
P286	I know that Warwick House (respite) were really flexible and creative and thinking about what was a good fit the Hayleigh. (More frequent shorter stays)	Respite flexible and creative (child centred?)	
P300	Change of respite. Mum worried less activities and changes but H seemed less anxious. L did some work with them to pass on knowledge. P306 It started off really good, but when the key worker was off sick it wasn't so good. But recently we just got a new key worker and I've been back in touch with respite.	Continuity and main contact person important. Unhelpful when they go.	
P311	Respite using visual timetable and social stories for wearing a bra.	Visual timetable, social stories	
P312	I'm making it sound like I come up with the ideas, because I don't, because we're meeting with mum, Gavin and dad, they come up with the idea.	Collaboration, going with parents ideas important	
P313	The key workers have got their own ideas as well about things that might be really helpful for Hayleigh that we can shape up and incorporate.	Building on carers ideas important	
P324	You know people really like the family. Like Mum in particular. And I think that really helps	Team around the child really liking Mum and family really helps	
P336	And I think there's a sense that, you know, there is so... There is so much more that could be unlocked from	People believe H has potential and that motivates them. Makes	

	Hayleigh. And I think people want to see that,	them try harder.	
P350	And we've had a regular Chair for the LAC review, and he seems to be able to pull things together really well.... the cogs are oiled or whatever you call it. You know it's running smoothly.	Continuity, coordination, leadership useful in things running smoothly.	
P364	Family not complainers, Mum anxious. Network seek to make it OK	Network works well not because family complain but because people like Mum and seek to help her anxiety	
P373	(Wearing a bra) I don't think this is directly related to the interventions, but I do think it's related to the conversations that come out of our appointments.	Talking and listening is what makes the difference.	
P375	Doing more outside the house benefiting QoL. Made her more flexible. H enjoying it. "The family are enjoying H enjoying that".	Doing things outside the home helpful.	
P378	So... And it is also about opportunity as well. Because places become available. At a, you know, a Playscheme. So that really helps.	Availability of activities outside the home helpful.	
P385	(Holidays used to be a nightmare.) And there tailoring the breaks to be more Hayleigh-friendly. And I actually think that's positive. Because that's them, instead of expecting Hayleigh to fit into their world, they're making the adaptations to sort of fit... to move more towards Hayleigh.	Family adapting to H. Not expecting her to fit with them.	
P401	I think they do try to learn from their experiences, and I think when they have sat and reflected on the really bad times, at the point that they were raw, but also at the times it's not so raw, you know, and they've had a bit of space between a really terrible event and... I think they really do	Having appointments to think back of difficult times, tentatively seen as useful. Maybe modestly in not wanting to claim helpfulness.	

	try to think, "what's happened?" You know? "Where did we go wrong? What can we do differently?" And I don't know whether having a bit of protected time and space to think about these things helps. I'm not sure.		
P419	I do think one of the things that have spurred them on is that they have seen progress. In some areas that they thought they would get progress in. And that there's been a bit of a light at the end of the tunnel. And I don't know whether that's just read them up just to think about the world differently anyway.	Positive changes has created hopefulness and to see the world differently. Change of meaning.	
P428	I mean I think they were stuck. And I don't think they're stuck now.... I think because Dad's changed his job and he's around a lot more, and because they nearly broke up and they've renewed their wedding vows, something has shifted in their relationship.	Not stuck anymore. Dad around more. Marital relationship much improved	
P443	Q: Is improvement in marital relationship helpful to H? A: Yes	Links to improvements for H's behaviour.	
P452	H spending more time with family. Can still be high EE but .. "The rest of the time it's a bit more contained, I think. Emotionally containing.	Reduction in high EE and more emotional containment helpful.	

CHILD 3: FIRST CODING  
Mum (1) alone

APPENDIX 11

Initial reactions



1  
 2 HH OK, that should be recording now. I'll just need to keep an eye on it because the  
 3 other day, when I was talking to a teacher, ((mock-exasperatedly)) the battery ran  
 4 out in the middle.  
 5 A ((Laughs))  
 6 HH Right, OK, so if you could start by just telling me about F... just to, kind of, help  
 7 me get a sense of who he is as a person.  
 8 A Yep. He's 10, and he'll be 11 at the end of January. He's very tall, very thin,  
 9 because he doesn't eat a great deal. He's incredibly affectionate for an autistic  
 10 child, because the autism's pretty severe and I know lots of parents don't have that  
 11 link with their child when they're autistic, but he's always been very, very close to  
 12 all of us - which is lovely - and just really affectionate. The challenging thing is  
 13 obviously the behaviour and the lack of sleep. His behaviour has improved an  
 14 awful lot, probably over the last year, really, primarily because his language skills  
 15 have developed. He had no words, probably up until he was about six, I would  
 16 think. Or nominal; literally a handful. And he had very, very little understanding

out expected  
 autism +  
 affection

behaviour as  
 problematic

eh. due to  
 lack of language  
 & frustration

F... Mum (and Dad) Full

Blue - Object of concern  
 Orange - Experiential claim  
 Green - stance, positionality

- Description of child in terms  
 of age. + physical appearance  
 is this how all parents describe  
 their child  
 - affection & autism do  
 not necessarily go together  
 Cuteness & affection highly  
 valued  
 (unexpected?)  
 Behaviour improved / so it was be-  
 - because ↑ language skills  
 - Challenging thing: beh & lack of  
 sleep [obviously]

beginning of idea that probs in  
 communication lead to difficult  
 behaviour.



CB due to frustration

17 whenever anybody spoke to him. and that was obviously where all the frustration  
18 came from. But, because he now can communicate so much better, I think that  
19 has helped an awful lot with the behaviour.  
20 I mean, we still have incidents on a very, very regular basis, but they're not as  
21 extreme as they were. Usually, if we are having a better time with behaviour, we're  
22 having a worse time with, say, eating or sleeping or something like that. Like this  
23 weekend, ((laughingly)) I'm not functioning very well, because I literally haven't  
24 slept all weekend.

CB will mean he has to go

25 HH Oh, gosh, poor you!  
26 A But we didn't have the behaviour issues that we normally have. But we want to  
27 keep him at home (I know he's in residential, but we want to have as much help as  
28 we possibly can have, in order to have him at home for as long as we possibly can)  
29 because, ultimately, there will come a time where he will be too big, too strong and  
30 too aggressive to manage. But he is just a gorgeous little boy - he's got a great  
31 sense of humour, he really has, he always has had; a wicked sense of humour. I

CB/aggression will be unmanageable in future

as mix of opposites - dangerous/ vs clever & funny

think everyone would say that. Also, ((emphatically)) he certainly doesn't have a

beco mum feel bad about going too far with negative - wanting to stress positives

narrative about lack of words 'obviously where all the frustration came from'  
Finn Mum (and Dad) Full

Difficult behaviour due to frustration due to no way of communicating

So ↑ language better behaviour  
- what explanations are excluded  
- Can you do anything about lack of language? (narrative of hope or despair?)

better beh. means poorer other things eg sleep/eating  
Lslightly apologetic? - lack of sleep => poor function  
implication for not slept but didn't have beh issues

Lbig jump to asserting want him at home

Behaviour probs will ultimately mean family won't be able to have him at home.  
(too big, too strong, too aggressive)  
repetition of to underlie main loss of beh/aggression

After saying negative stuff underlines 'gorgeous little boy' he isn't at that pt yet (too -)

All agree he has wicked sense of humour.

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HE IS CLEVER (not how I'd)



## Appendix 12:

Summaries of behaviour experienced as challenging and participants ways of making sense of the behaviours:

Child 1 (Hayleigh)	Child 2 (Shirley)	Child 3 (Fraser)	Child 4 (Tahir)
Parent's descriptions of the behaviours			
<p>Severe CB which is unpredictable and really really difficult Behaviour almost too difficult to convey how awful it was Obsessive behaviours Frequent, terrifying attacks Kicks, head butts, punches, chases Mum round the house Pulls hair Attacks/violence when Mum asleep Dangerous behaviour e.g. in the car Targets Mum and won't stop until she has attacked her Mum can't protect herself Mum can't control her now, only husband Family battered and bruised So difficult neighbours have called the police Less frequent now but still</p>	<p>Harming self and others Throw herself around Push and bite Run into you Screaming Poor sleep</p> <p>Thin description of CBs. Sleep seen as major issue.</p>	<p>Child is so challenging people want to fix it Kicking Punching Scratching Obsessions: videos DVDs Poor sleep Hitting Banging (doors off their hinges) Damaging/destroys things Making lots of noise Can hurt people Odd behaviour in public Frequency: Very very regular Severity: Seem to be less severe at times 15 minutes, used to be hours Worse in school holidays Risk: Danger in the car when escaped from the seat belt</p>	<p>Has CB, lots of episodes, all fairly recent (last year) Lashing out/ hitting out.. full of force More hitting now kicking off Biting, people loud, high pitched, vocal tics Shouting targets brother and Mum Hogs DVD etc All this creates distance for Mum More CB now Behaviour in the past more property destruction</p>

<p>very severe when they happen</p>		<p>at 50 mph</p> <p>Lots of behaviours listed. Sense of behaviour ultimately leading to child not being able to live at home. Behaviour frightening for Mum who feels that she is much less able to cope now.</p>	
<p>Teacher's descriptions of the behaviours:</p>			
<p>Not much in school at this time but lots in the past, including; "Severe CB", hitting out, kicking, pushing people, Now mild behaviours, vocalisations, passivity Can be forceful with her obsessions Would take a while to calm down</p>	<p>Kicking out Throwing Refusing to move Screaming Flailing arms Obsessional, repetitive behaviours</p>	<p>At start teacher wasn't seeing CB Aggressive behaviour targeting teacher Holding someones head and squeezing throat with thumbs stuck in Pushing and squeezing Stamping feet Kicking things Throwing chairs Hitting out Makes a lot of noise Going ballistic Head butting Fighting Lazy Can be threatening and intimidating in his behaviour</p>	<p>Noise, shouting and other vocal behaviour Tics Doesn't target children only one staff member who has a stern tone Chase staff and slap her really hard Tried to kick teacher once Hand slapping, hurts him. People not worried about the behaviour at school, doesn't happen very often</p>

		Very tiring/wearing Autistic but different from other ASD children	
Team member's descriptions of the behaviours			
<p>Classical CB Outburst behaviour Hitting, damaging things, throwing objects Hitting Mum a lot Frequency has gone down More at home than school</p> <p>Not much direct description of CB</p>	<p>High levels of behaviour Poor sleep Dangerous risky behaviours, pushing M and D down stairs, put little sister in bath of hot water Stealing food Putting on weight Playing with knives Poor concentration</p>	<p>Aggression towards others;</p> <ul style="list-style-type: none"> <li>• kicking,</li> <li>• punching</li> <li>• head butting</li> <li>• hurt himself</li> <li>• hit his own head</li> <li>• destroys and damages property.</li> </ul> <p>Really got bad when his teacher was off sick. Behaviour through the roof. Services got involved. Always had CB since very little. Long term problems Challenging in all environments Behaviour unpredictable CB has negative impact on child (e.g. Mum can't take him out)</p>	<ul style="list-style-type: none"> <li>• Big high velocity movements with his arms</li> <li>• Screaming/ Noise. Concerns parents most, worried about the neighbours. School also affected</li> <li>• Frequency and intensity has changes up and down</li> <li>• Some oppositional defiant behaviour</li> <li>• Some aggression, increased last summer hit brother, also hits particular member of staff at school</li> <li>• Last summer increased agitation, hyperactive</li> <li>• Property damage</li> </ul>
		Carer: Physical and verbal aggression	

		<ul style="list-style-type: none"> <li>• Kicking</li> <li>• Hitting</li> <li>• Head butts</li> <li>• Kicks furniture</li> <li>• Stamps his feet</li> </ul> <p>Sensory: squeezing face of staff, messing with arms Not personal Unpredictable Long period of no probs in care, then slowly began Calms more quickly on the unit</p>	
Parent's meaning making about the behaviours			
<p>Autism seen as a key aspect of the difficulties Anxiety Obsessions interrupted and not understanding the things are broken Frustration at not getting what she wants Pain Hormones? Feeling unwell Having to do something she doesn't want which makes her anxious Unhappiness at not getting what she wants</p>	<p>Intentional or on purpose Unpredictable Not happy Wants to hurt Can't/won't tell us Behaviour doesn't make sense; I just don't know to be honest No regard for self or others, doesn't care Won't leave you alone ADHD Just autism which is not well understood General confusion. Sees autism as part of it but that</p>	<p>Child's lack of understanding Doesn't understand things will still be there when he comes back Can't communication/ lack of communication linked to severe ASD Stopping doing something he likes/ his obsessions Transitions Hates change, needs routine Attacks people he loves most Very controlling, trying to</p>	<p>Communication problems, can't express his needs linked to being severely autistic. Mentioned lots of times Can't say what he needs so environment needs to support this becoming a teenager Not wanting to do things Mum feels she is is to blame, doing too much for him, not being confident and being emotional CB because he is upset, stressed, doesn't like</p>

<p>Focus on attacking Mum, because she can overpower or knows Mum is frightened  lack of understandings  can't communicate what is wrong  Sees things on TV or Internet that upset her  Bored, lack of stimulation  Tired and expected to do something she doesn't want to do  Picked up loads of undesirable behaviours from other SLD children  Simply don't know what upset her sometimes maybe picks up on other's anxiety  Brother thinks she is spoilt, parents give in too much  When H younger pursued all sorts of explanations, eg. Gluten allergy, vaccine damage.</p>	<p>may not really fit and is not well understood</p>	<p>control the chaos I that is his life  Everything has to be on his terms  Sensory problems  Loss of self control  Hitting is a reflex action caused by discomfort.  Normal behaviour.  Something physical which can't be controlled (not his fault): Crossed wires in his brain leading to frustration. (Neurological?)  Frustration  Can't maintain ok behaviour in all settings. Its got to come out somewhere.  A bit bloody minded child (normal) most autism  Reason for the behaviour changes. Dog barking used to stop him, now barking seems to make him worse.  Sometimes makes sense, DVDs or flappers, sometimes don't know  Both parents agree  changes in routine are helpful. Dad feels this is</p>	<p>something  Mum feels doing everything for him is unhelpful  Doesn't get on with brother  Mum understands that her being emotional and feeling guilty means she is less consistent which is unhelpful  T picks up on Mum not being confident  Understanding is a minefield, but really important to try and understand  Maybe he needed more time from parents  Lack of communication seen as really important. Mum very concerned that he can't express himself.  Mum recognised the emotional impact of wanting T to be a happy part of the family and how this affects her recognised need to be consistent and not do everything for hi,  Really important to her to have the support of her</p>
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		<p>“why should I bother to try”. family.  Both agree F can show remorse.  Any little thing can precipitate CB eg train being late. Things which can't be controlled.  Dad describes child as vicious. Different from Mum being more understanding  Big class of 9 autistic boys likely to be problematic.  F might be upset by seeing people from old school after he has left</p> <p>Autism seen as very important but also normal child being “bloody minded” at times.  Child struggling to communicate, some sensory issues, neurological explanations, difficulty with transitions, has obsessions, hates change, needs routine.  Triggers are when asked to interrupt obsessions. Child as controlling as world so chaotic for him, everything on his terms. Gets frustrated. Large class at school seen as</p>	
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		<p>problematic for child. Attacks those he loves the most. Mum trying to normalise the behaviour; (how we would all act,) dad more likely to see child as awkward. Can't always control the environment so triggers will happen. Behaviour changes, not always understandable or predictable.</p>	
<p>Teacher's meaning making about the behaviours</p>			
<p>Triggers; like.. Objects which she fixated on and needed to finish. Visual cues Classic passive autism; found it hard to sustain work Pain, discomfort, feeling unwell under-stimulated, not stretch at first Occasionally disliked her space invaded Teacher agreed obsessions may be self soothing Autism seen as too simplistic a label to explain beh. Little CB seen at school.</p>	<p>Screaming expresses "Don't like or don't want to Temper Non compliance and doing it on her own terms Flailing was not intentional was temper Rigidity is down to autism Finds change difficult Screaming is wanting attention Likes negative attention Attention seeking No apparent reason for repetitive saying No. Autism Mix of ideas with some elements seen as autism,</p>	<p>Task avoidance Head squeezing may be comforting/ Sensory understanding? Controlling, stop telling me what to do; wants to be in control all of the time. Nothing will work as F needs to control everything and everyone. Lazy; doesn't want to work behaviour seen as a communication, indicates upset or not understanding Teacher trying to make sense of behaviour; is he being naughty and is spoilt or is the behaviour linked to</p>	<p>T: Teacher: Understanding</p> <ul style="list-style-type: none"> <li>• Main understanding is behaviour as communication</li> <li>• Behaviour result of getting e</li> <li>• Doesn't want to hurt</li> <li>• Responds to a particular stern tone of voice or someone being told "No".</li> <li>• Too much language makes</li> <li>• Change in medication has lead to more behaviour</li> <li>• New environment leads to fear and being shut down</li> <li>• Noise as involuntary and he needs to get it out in a safe place, makes him embarrassed.</li> </ul>

	<p>other more temper or wanting attention</p>	<p>autism; can't plan what to do until she understands          Seems to say he gets away with everything at home and on the unit.          Negative effect of other difficult children in the class          Consistency valued          possessive of his Mum won't share.          Physical interventions make him worse          Feeling lost with F. His behaviour and what to do is very complex.</p> <p>Main understanding seems to be about F wanting to be in control. Teacher at a loss, feels completely undermined by TAs and school management isn't supportive.          Isn't sure if he is spoilt and undisciplined or whether his autism is a big factor.          Intervening physically makes things worse.</p>	
<p>Team member's meaning making about the behaviours</p>			
<p>Entering teenage years          Parental conflict rubbing off</p>	<p>Bored          wants structure</p>	<p>Autism seen as key factor;          includes problems with</p>	<p>Family's ability to cope affected by their confidence</p>



<p>H's way of saying; something's not right for me.  I don't understand  Why can't I have what I want?  Mum seen as person who can put things right wants things to be put right straight away  Autism plays a part, lack of social constraints, can't put herself in other's shoes, rigid.  Not coping leads to anger  Behaviour gets her what she wants.  No more adaptive strategies  Poor self regulation  Venting makes her feel better  LD and autism combined  Ideas come from lots of sources</p>	<p>Attention seeking/ wants 1:1 time  Not malicious/intentional  Strong focus on autism and ADHD  recognises that Mum may not have a good grasp of autism</p>	<p>sensory issues (hypersensitivity to noise and dislikes some parts of body being touched).  No major differences in understanding in the network, team member believes that autism seen as key contributory factor by everyone  Anxiety seen to fuel problematic behaviour.  Trigger include: DVD malfunction and computer freezing, losing 'flap-a-doodle'  Transitions seen as difficult and problematic (major like going to 2ndary school and little day to day moves).  Poor communication between staff don't help.  Brother physical involvement makes things worse  Brother and dad not staying calm makes things worse  Seems hard to keep a handle on behaviours  Parents being fearful makes them back off</p>	<p>in dealing with the noise  Can't suppress tics in Tourettes but exert some control, involuntary tics  Mum's confidence affected by others having difficulties with T's behaviour  Autism seen to underlie difficulties  Functional understandings; seek attention, gain validation, to communicate discomfort (emotional)  Medication helps agitation typical of LD and autism but not tics as one would expect  Sees teacher as different from TAs. Teacher trying to understand communications, TAs think he needs to change behaviour.  Prof. thinks Teacher feels there is a sensory component; space invaded suddenly, raised voice  Targets a particular member of staff</p>
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			<p>Diagnosis of tics seemed a relief for parents Dad accepts long term nature of the difficulties. Mum varies but has more hope of change Psychology have offered a more functional explanation. Ashley still thinks that there is a Tourette type element</p>
<p>Residential unit staff's meaning making about the behaviours</p>			

Carer:

Autism

- Needs routine
- needing to be in control
- Sensory
- Sensitivity to noise
- Tiny changes lead to aggression

Controlling important

Personality; being stubborn,  
liking his own way

Regretful of aggression

Release of frustration

Response to distress

Response to lose of KW and  
one person pregnant

Occurs because Mum  
doesn't stand firm, learnt  
behaviour

Mum gets more probs as  
main carer at home

Changing class, during the  
day and at start of the year  
is problematic

people having different  
approaches

## Appendix 13a: Initial superordinate themes.

Appendix 13

### Themes (initial)

- understanding the behaviour seems to help people feel some sense of agency  
[What understandings do people have]  
- make meaning
- Strain on normal family life  
- effect on sibs  
- parental rels etc.
- lack of normal family life / normal classroom?
- Frustration with services (in gen. & specifically)
- passing responsibility / blame
- Mum's being the main burden.  
+ the importance of Dad
- child described as alien / different / other  
but loved ~~but~~ clever
- protection of child
- concern with the future.

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Behs can be grouped under  
descrip. of each child

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Impact of wider service /  
institutional / societal factors.  
(class / school / unit)

Ticky rels. have a -ve impact  
of the child.

**Appendix 13b** Table of Initial Superordinate and Subordinate Themes:

A:	Life is difficult with a challenging child		
	a:	The children behaves in overpowering and terrifying ways	
		i:	So many difficult behaviours
		ii:	The importance of understanding and consistency
		iii:	Not understanding is hard
		iv:	To blame or not to blame
	b:	Loving and affectionate descriptions of the children	
	c:	Strain on family life and family relationships	
		i:	Guilt and concern for siblings
		ii:	Marital tensions
		iii:	Trying to do the best for the children
		iv:	Burden of care falls on women; emotional and practical
	d:	Acceptance is a journey	
	e:	Worry about the future will bring	
B:	Life is so different with a challenging child:		
	a:	Treating the children in odd and unfamiliar ways	
	b:	Services help us keep going	
	c:	Services can really frustrate and let families down	
	d:	The world can seems an unpredictable and hostile place	
C:	Autism underlies the challenging behaviour/ Autism as an explanatory category		
	a:	Child doesn't have any consideration for others	
	b:	Unusual and idiosyncratic ways of communicating	
	c:	Child wants their own way all of the time	
	d:	Child is very rigid and inflexible	
	e:	Child is very anxious	
	f:	Child struggles with changes	
	g.	Sensory issues	
D:	Tense relationships within systems		
E:	The MMR Vaccine ruined our lives		

Appendix 14: Post-its used to re-organise themes



## Appendix 15: Summary of Themes:

A:	Loving and affectionate descriptions of the children	
B:	Life can be difficult with a challenging child	
	a:	The children behave in frightening and worrying ways
	b:	The effect of blaming or not blaming on relationships
	c:	Strain on family life and family relationships
	i:	Guilt and concern for siblings
	ii:	Marital tensions
	d:	Worry about what the future will bring
C:	Life can be different with a challenging child:	
	a:	The children and their families as special and different
	b:	Services help us keep going
	c:	Services can really frustrate and let families down
	d:	The world can seem an unpredictable and hostile place
D:	Making sense of the challenges is important to people	
	a:	Behavioural Narratives
	b:	Diagnostic Narratives: Autism
E:	The value of good relationships in the 'network of concern'	

**Appendix 16: Locating blame/responsibility for child's challenging behaviour.**

Who is blamed	For what	By whom
Child	Naughtiness	Parents and teacher
Husband	Inconsistency	Mothers and teacher
Husband	Gets angry/not staying calm	Mothers
Parents	Give in too much	Teacher
Parents	Parental conflict	Team members
Teaching Assistants	Being too harsh	Teacher
Teaching Assistant	Loud tone of voice	Teacher
School	Don't do enough for autism	Parent



**Appendix 17: Issues for parents concerning their sons and daughter; siblings of the child with a disability.**

Difficulties	Examples
Negative effect on siblings	Lack of confidence, being over sensitive. Problems at school Sleep disturbance Child witnessing violence towards mother
Siblings fighting	Sibling rivalry and falling out
Embarrassment	Won't bring friends round to the house
Resentment	Feel their brother or sister is treated differently and gets away with more. Possessions being destroyed
Parental guilt	Child witnessing violence towards mother Brothers and sisters lacking attention Siblings getting hurt or their stuff trashed Children getting involved to protect mum. This can make the situation worse
Being different from other families	The family not playing in the park together Parents spending time fighting for services or justice not focussing on the family Not being able to go out for a meal together
Defining identity	Seeing self as the sibling of an autistic child. This is used as an excuse for problems.

## Appendix 18: Marital tensions and women's roles:

Issues	Examples
Women worrying about the toll on their husbands	Men seen as pushing themselves too hard Men seen as not as emotionally robust
The value of men being stronger physically	Men taking their sons or daughters out in public when women are unable to do this anymore, e.g. swimming or shopping Men managing physically aggressive situations at home and protecting the family.
The importance of agreeing	Agreeing on how the behaviour is understood and the strategies to be used: "Singing off the same hymn sheet". Frustration expressed when men not seen to manage in the same ways: parents not seeing eye to eye or men who can't stay calm.
Resentment at men's apparent freedoms	Men being able to leave either to go to work or to take a break Women seeing themselves as the main carer Lack of a career or job opportunities for women. Annoyance expressed about having to go to work and cook etc.
Barriers to enjoying each others company	Can't celebrate anniversaries as no one will babysit No social life
The child experienced as challenging places a strain on the marital relationship	This was more commonly mentioned by some of the teachers and team members, but was also directly addressed by some of the women. Stress seemed to be greater if women felt isolated and alone, either from friends or from the wider family

## Appendix 19: Summary: constructing meanings about behaviours experienced as challenging

### Parents:

	Constructions:	Examples of parent's words
Within child factors:	<p>Diagnoses including; Autism, ADHD, Tourette's syndrome.</p> <p>Experiencing pain.</p> <p>Feeling unwell.</p> <p>Tired and/or bored</p> <p>Various emotions: Unhappy, Anxiety, Anger, Stress, Frustration.</p> <p>Hitting as a reflex action.</p> <p>Becoming a teenager.</p> <p>Being "bloody minded" (personality).</p> <p>Can't or won't communicate what is wrong.</p>	<p>Becoming a teenager: Triad 4: Tahir's mum said, "I know that it will pass, because I believe it is part of his growing up, and he is 14" T:M154</p> <p>Can't or won't communicate: Triad 2: Shirley's Mum said, "Well we ask her and she won't say. Are you hurting? Are you hungry? She can't say, she won't say." S:M61</p>
Between child and family members:	<p>Not getting on with siblings.</p> <p>Being asked to do something the child doesn't want to do.</p> <p>Being stopped doing something they want to do or loved doing. This could be being asked to stop or the thing broke e.g. a DVD.</p> <p>Wanting to hurt someone.</p> <p>Child picks up on Mum being less confident or emotional.</p> <p>Targeting someone because the child knows they can overpower them.</p> <p>Parents giving in - seen as spoiling the child by siblings.</p>	<p>Being stopped doing something the child wanted to do: Quartet 3: Fraser's mum on asking him to have a bath, "And it was actually very aggressive, because you could see his face, purely because he didn't want to leave his DVDs and go to the bath". F:M61</p>
Between child and wider world: thought dominant discourses, outsider comments might feature here?	<p>Copying other children, trains not coming, things being moved in shops, police being called by the neighbours.</p> <p>Gluten allergy and vaccine damage understandings were particular to Hayleigh's mum and dad.</p>	<p>Copying other children: Triad 1: Hayleigh's mum: "She was put in the special education school with severely autistic children and we lost Hayleigh". H:M246</p> <p>Vaccine damage: Triad 1: Hayleigh's Mum:</p>

		"When she had the MMR literally the day after she looked like a totally different child" H:M641
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**Teacher:**

Types of understandings	Examples	Similarities or differences to parents
Within child factors:	Autism variously described as leading to sensory issues, rigidity, "has a mind of her own", and anxiety. Feeling unwell and a medical condition.	Parent's understandings were much more varied although included all the things mentioned by teachers.
Between child and class staff:	Not being stretched, (boredom?) Non-compliance. As a way of getting out of doing something. Being asked to do something the child doesn't want to do. Being stopped doing something they want to do or are obsessed with. Behaviour as a communication. Child being seen as spoilt. Staff using too many words. Tone of voice. Hearing the word 'No'. Personal space being invaded. Attention seeking.	Different types of language used e.g. non compliance, and the focus on task avoidance was different from parents. Being stopped doing things was in common. Communication was seen as key in both groups. Parents were at times more self critical and talked about the children targeting them.
Between child and wider world:	Noisy environment, bad mix of children in the class, class transitions.	Different ideas from the parent group as specific context of school was the concern.

**Team members:**

Types of understandings	Examples	Similarities or differences to parents
Within child factors:	Diagnoses: Autism including sensory issues, ADHD, Tourette's Syndrome (verbal tics)	Nursing and psychiatry used diagnostic labels while the psychologists used more psychologically informed

	<p>which are partially under control) and learning disability.  Moving into adolescence.  Anxiety.  Poor self-regulation.  Bored.  Seeking attention.</p>	<p>labels, e.g. poor self-regulation. These types of professional understanding were different from parents although there were some overlaps.</p>
<p>Between child and the family:</p>	<p>Gaining validation.  Getting what they want.  To communicate discomfort. Behaviour seen as a communication.  Parents backing off because they are scared.  The family's ability to cope is affected by their confidence.  Brother getting involved makes things worse.  Parental conflict rubbing off on the child,  Family members not staying calm makes things worse.</p>	<p>There was considerable overlap with parents' issues with a focus on life at home rather than life in the classroom. Parents did not mention parental conflict rubbing off on their child. Parents discussed siblings being involved, although more in terms of protection or concern rather than making things worse. Descriptions were less nuanced in general.</p>
<p>Between child and wider world:</p>	<p>Little data, however, one person commented that everyone in the network seemed to have the same understanding.</p>	<p>Different from parents and teachers as professional focus seemed to concentrate on home life.</p>

## **Appendix 20: Ways parents described managing the difficult behaviours.**

Hayleigh's Mum:

- Adapting service provision to address child's needs is helpful e.g. Shorter respite to lower anxiety
- Having strategies to work on. (Feeling more in control?)
- Distraction
- Mum escapes or lets herself be hit to stop the pattern
- Addressing H's pain (Hot water bottle, paracetamol)
- Mum being available to put things right
- Time with people and time on her own
- Mum putting herself in H's shoes
- Parents having regular breaks
- Patience (ie. not reacting angrily)
- Applied Behavioural Analysis: *"For the six years that H was taught at home we didn't have a home, our house was open to strangers and people working here constantly with H or me doing things for the people who were working here for H or me working with H. And we were just drained, absolutely drained."* H:M312
- Giving in to her sometimes to manage a really difficult situation e.g. attacks and noise in the night
- Structure and setting limits
- Listening from someone who knows H, suggestions.
- Help with problem solving
- Counselling

Very rich understandings and lots of things that can help but also some mentioned unhelpful things including lack of understanding from outside the home.

Shirley's Mum:

- Punishment; time out and fining
- Timeout mentioned a lot, may or may not work Seen as a punishment for Mum
- Stuck/lack of ideas
- Try and follow professionals suggestions, may or may not work
- Reward chart; not done right Mum has little hope
- Remove her and isolate her as punishment
- Send her outside
- Short sentences and simple language
- Consistency although Mum thinks dad isn't consistent
- Recording- onerous
- Things done or suggested elsewhere may not work
- Nothing works consistently

Focus on negative and punishing strategies. Knows of some other strategies but either doesn't apply correctly or hasn't tried yet. Ideas offered from outside are unlikely to work. Sees one of the difficulties as dad being inconsistent doing things differently from her. Feels pretty hopeless and burdened. Behaviours are poorly understood and make little sense.

#### Fraser's Mum and Dad:

- Anything which improves communication: reading, PECs, visual timetable, simple verbal instructions.
- Knowing what is going to happen in advance
- SaLT seen as important but unable to access
- People understanding the autism
- Staying calm
- Being consistent
- Dad being really involved and still around very important to Mum
- Size and implied physically managing seen as critical: Size matters
- After physical management time and space to calm down
- Practical solutions to risky situations
- Getting outside advice and acting on it
- Help seen as really important; support from the unit, respite etc
- Small caring school has been really helpful
- Fraser being happy with things seen as important.
- Fraser might not respond well to being pushed as he is so controlling
- Services being close is helpful.
- Mum escaping when Fraser is too difficult.
- Staying in the same routine, only one placement
- Good communication with all the places Fraser goes, respite, unit, school etc
- Mum feels she can cope if she knows Fraser is happy and OK
- Counselling for Mum
- Lack of uncertainty about move to secondary school seen as very unhelpful and the fault of the LEA. Mum feels this transition needs to be 'perfect'.

Having someone with Fraser all the time to manage difficult situations when out and about. Eg of public not understanding him.

#### Tahir's Mum:

7. Sent to a quiet place to calm down
  8. Getting back up from Dad
  9. Trying to understand
  10. Giving him an outlet for anger or upset
  11. Not always giving in to him
  12. Giving him something to bite onto
  13. Going for a drive
  14. Watching a DVD
  15. Try to understand, find the source, put intervention in place
  16. Treating brothers equally
  17. Chastising him might make things worse
  18. Need to have time to sort out behaviours, give in if in a hurry
  19. Suggestion from OT, give him a towel to bite down on
  20. Sit with him, not in his face, give him time to calm
  21. Sitting him in bathroom to calm down. This is hard for Mum as she wants him to be part of family, seen as being for them not T
  22. Mum has idea of involving wider family more, having a meeting
- Consistency seen as key to good parenting. Mum thinks she and dad have

different responses. Down to her emotional reaction. Consistency key to his well being but hard to do.



**Appendix 21: In what ways parents drew of different underlying models to respond to their children's challenges**

Developmental understandings - behaviour gets worse as children move into teenage years.	Not used as a way to help. Perhaps because one cannot delay growing up?
Medical model - diagnoses e.g. Tourette's, ADHD, autism etc.	An understanding of autism was used to determine strategies.
Psychological models - attachment, social learning theory and behavioural understandings.	Behavioural approaches were the most commonly used strategies. There were no strategies mentioned which might address the other models.
Mixed - autism and learning disabilities as an implied cause of communication difficulties and raised anxiety etc.	This was implied in some strategies, although primarily linked to ASD.
Social comparison - judgement of others, e.g. neighbours calling the police as a source of stress and - lack of understanding by others.	Not described as an approach, although how parents coped in the community is discussed above.
Sibling rivalry and family dynamics.	Perhaps implied but not discussed in detail by parents, although one family described family therapy as valuable.
Environmental understanding - coping with the wider world.	Not described as an approach, although how parents coped in the community is discussed in Theme C:c above.
Pragmatism and keeping safe were strategies that had no particular basis in the understanding of the behaviours but was seen as very important.	

**Appendix 22: Ideas of parents, teachers and team members about what helps in situations when the child is experienced as 'challenging.**

1. Parent's ideas of what helps:

Types of strategies	Examples	Parent's strategies
Direct interventions with the child ranged from positive, proactive strategies to aversive, reactive strategies:	Using behavioural approaches; e.g. using reward charts and making recordings. <i>Hayleigh's Mum mentioned a strong belief in behavioural approaches. Shirley's Mum seemed to be trying to apply behavioural ideas although without a good understanding of the underlying principles.</i>	Triad 2: Shirley's Mum; "Reward charts as well. I've only started that three weeks ago, however she hasn't gotten anything yet because she just didn't do the task or whatever. I don't know if I'm getting anywhere with that, it's just trial and error really." (S:M223)
	Putting things right: <i>this was linked to a belief that if the underlying problem could be sorted the behaviour would improve or cease.</i>	Triad 1: Hayleigh's Mum focussed on trying to work out what was wrong and putting it right. So if Hayleigh was in pain she gave her a hot water bottle or paracetamol. Quartet 3: Fraser's mother's described trying to fix a broken DVD player.
	Physical management. <i>This was not linked to any understanding of the behaviours, but was linked to staying safe.</i>	Triad 4: Tahir's parents talked about having to try and hold him at times although said this was very difficult, as he got older and bigger.
	Timeout: <i>The underlying model here is behavioural. Shirley's mum and dad had a 'naughty step' for this purpose, although remaining with her probably defeated to object of the exercise; perhaps Shirley liked her mum sitting with her.</i>	Triad 2: Shirley's Mum tried hard with timeout although she didn't seem to understand the underlying principles. "With me I do give her the timeout, but then again you have to sit there with her, so for me it's like I'm on timeout as well, that's how I feel." (S:M336)
Indirect strategies used by parents to manage difficult behaviour or	Staying calm/Place to calm down. <i>Tahir's mum and dad used the bathroom as a calm down space, Fraser's</i>	Quartet 3: Fraser's Mum commented on advice from the team member. "Mostly I try and stay as calm as I

difficult situations:	<i>mum and dad used his bedroom. This may be linked to ideas around the unhelpfulness of high arousal and autism.</i>	possibly can: which sometimes is really difficult." (F:MD571)
	Pragmatism and letting things go. <i>This included just giving in even when the parent knew this was not helping in the long term, i.e. the child might learn that the behaviour got them what they wanted. (Behavioural explanation?)</i>	Triad 1: Hayleigh's Mum said, "Sometimes it's well just let her give me a good beating (laughs) so that everything can settle down". H:M471
	Getting out of the situation/ staying safe.	Triad 1: Hayleigh's Mum talked about escaping to the shed
	Having activities outside the home. <i>This is perhaps based on the idea of distraction or more generally enrichment of the child's life, and is loosely included in an ABA approach.</i>	Shirley's dad took her swimming and Fraser's dad took him shopping on Saturdays.

## 2. Teacher's ideas of what helps:

Types of strategies	Examples	Similarities or differences to parents
Direct interventions with the child ranged from positive, proactive strategies to aversive, reactive strategies:	Behavioural approaches; making recording to identify patterns, using rewards and motivators and ignoring behaviours.	Similar approaches to the parents but more detailed for the teachers.
	Using a calm and reasoning approach; and avoiding negative language or a stern tone of voice. Don't say 'No'.	This was suggested by Fraser's mum particularly but mentioned by others
	Managing the risk by moving the child to a safe space and giving them something they like to do.	This was mentioned particularly by Hayleigh's mum but implied by all parents. e.g. Not taking the child out alone.
	Physical restraint. This was seen for one child as making things worse.	Described by parents but seen as impractical for some mothers.

	Medication	Not mentioned by parents
Indirect strategies used by the teachers to manage difficult behaviour or difficult situations:	Managing the risk by moving the other children away.	Risk to siblings was talked about in terms of trying to stop them getting involved rather than moving them away.
	Discussing strategies as a staff team to ensure understanding and consistency.	Parents did not seem to talk to each other much about ways of managing.
	Trying to understand what the behaviour was communicating.	Most mothers mentioned the importance of communication, although not specifically what the behaviour was saying.
	Making school work more challenging.	N/A

### 3. Team member's ideas of what helps:

Types of strategies	Examples	Similarities or differences to parents
Direct interventions with the child which ranged from positive, proactive strategies to reactive strategies:	Using behavioural approaches; e.g. rewards and making recordings.	Shirley's mum mentioned this, although found recording burdensome. Other behavioural approaches discussed included timeout, which is more aversive.
	Comprehensive/intensive applied behavioural analysis. E.g. Detailed approach to teaching Fraser to cope with the loss of a 'Flap-a-doodle'. (ABA)	Discussed by Hayleigh's mum who was very knowledgeable about this approach. She reflected on the overwhelming nature of the approach used when Hayleigh was little.
	Proactive strategies, for example a visual timetable, now and next chart, routines and using social stories (Autism-friendly).	This was discussed by teachers and less explicitly by parents.
	Medication: seen as helpful by psychiatry and nursing. Psychiatry was also very interested in reducing the amount of medication for Tahir. Shirley's dad was	Medication was not mentioned specifically by parents.

	said to be opposed to medication but was talked into trying it. (Medical model)	
	Having one person manage the situation. This is possibly linked to low arousal approaches. (Autism).	Not mentioned by parents, in fact they often talked about the need to get help - from dad especially.
	Introducing sensory ideas was suggested for Fraser. (Autism)	Tahir's mum mentioned using a towel for him to bite on. The teacher also mentioned sensory ideas for Tahir.
	Timeout/place to calm down. This was mentioned by two team members. (Behavioural)	Mentioned by three parents.
	Stimulus change: a technique for doing something unexpected to disrupt the pattern of behaviour briefly. (Part of ABA) Only discussed by the psychologists.	Not mentioned by parents
	Restraint was not discussed	
Indirect strategies.	Staying calm. Reduction in high expressed emotion. (Autism friendly)	Discussed by most people.
	Doing lots of fun things outside the home to improve quality of life for the family. (Proactive ABA)	Dad being involved with taking the child out to swimming and shopping was valued was two of the mothers interviewed.
	Parents staying safe.	This was discussed by most parents.
	Making environmental changes, e.g. preventing access to food for one of the children who stole food and was overweight, or sitting near the exit in school assembly. (Behavioural/ABA)	Not mentioned by parents.
	Parents having a good	This was an aspiration for

	understanding of the child's needs. (Generic parenting)	most parents.
	Having a diagnosis was seen as helpful for Tahir's parents and mentioned as useful by the team member working with Shirley. (Medical model)	Diagnoses were mentioned by all parents. Shirley's mum felt that she didn't understand autism and that this was unhelpful.
	Hayleigh's sibling being warm and loving	Hayleigh's mum also appreciated this.
	Having a supportive network around the child.	This was really important to all of the parents, although Shirley's family wanted more as they felt isolated.
	Having respite services. (Supportive network around the child)	Mentioned by those parents who had respite.
What helped the team members	Clinical supervision Trying to learn from parents	These ideas were not mentioned by parents.

## **Appendix 23: The framework used to explore diagnostic accounts of autism:**

I quote Kanner's classic descriptors of autism, as these seemed to mostly closely fit the accounts of people and are most often applied to individuals with a high degree of learning disability (Kanner, 1943, Brookdale Care: What is Autism). I have added 'sensory issues', as it was a component of some interviews. Sensory issues are currently seen as an important understanding, which were not recognised in the past.

### **Kanner's Classification**

#### ***E:a Impairment of Social Communication***

'Impairment of social communication' is one of the key diagnostic indicators of autism. It is described as the person having difficulty understanding verbal and non-verbal communication, and can include little or no expressive language, repetitive speech, and difficulty in understanding that other people can see things from a different point of view.

#### ***E:b Impairment of Social Relationships***

The second diagnostic indicator of autism is people's inability to form social relationships. People seem unable to understand the rules of society and struggle to know what is expected of them in social situations. This inability to relate to other people is present from early life.

#### ***E:c Impairment of Imagination***

This refers to the person's tendency to have a strong preference for sameness, becoming distressed and anxious when even small details change. Thus routine and predictability are seen as helpful. The person lacks the ability to imagine what other people are thinking and feeling or to see how their actions might affect someone else. The person may also become fascinated with certain activities or objects.

#### ***E:d Good cognitive potential***

This implies a capacity to learn and develop which is impaired by the autism and is perhaps not expected in people who only have a diagnosis of severe learning disabilities.

#### ***E:e Sensory issues***

Many children with autism have sensory problems. Children can be intolerant of too much stimulation, for example loud noises or particular tastes. Or they can

be intolerant of too little stimulation, for example they seek out some particular stimuli, e.g. vibration or strong touch.