FAMILY AND PROFESSIONAL PERSPECTIVES ON THE LIVED EXPERIENCE OF CHILDREN WITH A LEARNING DISABILITY AND BEHAVIOURAL NEEDS

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<u>Acknowledgements</u>

CONTENTS

Abstract

This thesis considers family and professional perspectives on the lived experience of children with a learning disability and behavioural needs. The literature suggests that this group of children experience an increased risk of exclusion from their peers and their community due to their complexity of need and lack of appropriate support.

Twenty semi- structured interviews were conducted to gather data from parents and professionals involved in the support of children with a learning disability and behavioural needs. A phenomenological approach was adopted to consider the lived experience of children through perspectives of the participants. Interviews were transcribed verbatim and analysed using Attride-Stirling's (2001) model of thematic analysis.

A total of eight global themes were deduced from the findings. The parents' data yielded four themes: finding our way; square services round needs; the price of behaviour; belonging. The four professional themes identified were: the behaviour of services; complexity of need; behavioural barriers; needing to know- knowing needs.

The child's experience of inclusion and exclusion ran through the findings as central tenets of the participant perspectives on lived experience. The study adds to the body of knowledge that considers the inclusion and integration of children with complex needs into mainstream and specialist provision. Perspectives on lived experience highlight current practice that can increase the vulnerability of children to the risk of exclusion from families, peers and ultimately their community.

Recommendations call for proactive support to identify children in their early years at risk of experiencing exclusion due to their behavioural needs. Appropriate and effective provision will avoid the increased burden placed on families, and ultimately the state, of supporting children who remain vulnerable and at increased risk of exclusion from their communities.

1 Chapter 1: Introduction to the Research

1.1 Introduction

This thesis explores a phenomenon that I have been involved with and witnessed for many years in clinical practice as a Registered Nurse for Learning Disabilities. As a practitioner I have had the privilege of meeting many people with learning disabilities and their families. I have been able to work across multiple service contexts and been involved in inter-agency support and provision. As a professional who has the ability to move in and out of people's lives I have found that some of the families I have met have 'stayed with me'. I do not mean that in a sentimental sense (although at times this has proved to be unavoidable), but in relation to my admiration for how they managed, moved forward and supported their child. The families that are foremost in my mind are those whose children have learning disabilities and behavioural needs (this term will be considered later, and has been chosen in preference to the more common term of challenging behaviour).

The association between learning disabilities and behavioural needs is not uncommon in the literature. There exists a high prevalence of behavioural needs within this population of people. This thesis will not seek to consider this relationship, but attempt to contextualise the impact of behavioural needs for children with a learning disability. This will be achieved through the exploration of literature and the contextualisation of the journey for children in this minority group. All children grow. However for this group of children their experiences of childhood are unique and disproportionately shaped by their interaction with multiple service providers. Despite a reported need for support and inter-agency provision, children go on to experience extreme levels of exclusion from their peers, their community and ultimately their future opportunities. This thesis will aim to contribute to our understanding of the child's lived experience through the perspectives of those involved in their support, family and professionals.

1.2 Origin of research question

In 1998 whilst practicing as a Learning Disability Nurse within an NHS behavioural team for children I was fortunate to be awarded a fellowship by Merseyside Health Action Zone (MHAZ, Kiernan 1998). The fellowship released me from my usual practice role and supported a year of development work within my clinical area. During this year in

consultation with my team and line managers I was able to develop an early intervention project that supported professionals and families with pre-school children identified as having enhanced behavioural needs. The children identified for the project, although often undiagnosed, were required to have additional behavioural needs that were considered to be above and beyond that of their chronological peers. The project focused on the early support of a child's behavioural needs, and the development of appropriate intervention strategies for use by parents and early years professionals involved with the family. The project was called 'Early Behaviour Advice for Families' - on reflection not the most imaginative or exciting title.

The project received positive feedback from the professionals and particularly the families involved, with positive evaluations received from both groups. Despite this initial impact the project was discontinued due to a lack of ongoing funding, and the reluctance of the trust to commission a new form of service provision. Consequently the team reverted to the established criteria for referral. Successful referral to the service entailed the diagnosis of a severe learning disability and the presence of severe challenging behaviour (based on Emerson's definition 1995).

In retrospect of the 24 pre-school children identified during the pilot year several of these children had demonstrated a high level of behavioural need that would require intensive support. Their situation was often compounded by their social environment, which could place them at a high risk of requiring long-term service intervention. The early signs of behavioural needs exhibited by a child have been correlated with the presentation of more severe behavioural needs in their later life (Baker et al 2003, Murphy et al 2005, Meyer and Evans 2006). Professionals and families associated with the project held similar views about the positive value of early intervention for this type of child. This opinion was often unfortunately expressed when it was realised that the support of a specialist behaviour nurse was to be withdrawn due to termination of the project. As a professional I had no doubt that a number of the children that had been part of the early intervention project would be re-referred to the team in the future. Unfortunately it was clear that most of the children would also fit the service criterion. Their behavioural needs would have indeed become more severe. This left me as a professional disillusioned and somewhat compromised. Mansell (DH 2007) clearly argued that 'the development and worsening of challenging behaviour is a priority because of the costs (to the individual, family and society) of problems escalating or becoming ingrained' (DH 2007, p9).

Having supported children with behavioural needs for some time the journey of the families and their children showed a level of predictability. As they progressed through services the child would experience exclusion that prevented them from being part of their community. My continued employment in the Trust enabled me to have professional contact with some of the children from the project in their later years (usually from an average age of eight and onwards), they were the children that had been identified in the initial project as the most vulnerable. The experiences of the children and their families could have potentially been predicted, and therefore they could have been supported to improve or create more positive outcomes. This, as a professional, left me with unanswered questions. What is it about this group of children and families that suggests we can predict their journey through services? How, if we know there is a likelihood that the children may have those experiences, can we prevent this happening? Most importantly why does it happen? Through an attempt to understand the lived experience of children with a learning disability and behavioural needs the research described within this thesis has been designed to consider these questions.

1.3   Thesis structure

The thesis is presented in seven chapters:

Chapter1 sets the parameters for the research. Following the brief introduction this chapter identifies the origins of the research question and the structure of the thesis. In order to support the remaining chapters and the reader, current terminology and a definition of terms used in the research will be considered.

Chapter 2 will consider some of the relevant literature and current knowledge associated with children with a learning disability and behavioural needs. How the current research is situated in relation to contemporary research in the area will be considered. The lived experience of children with behavioural needs is a difficult area to address due to the complexities associated with the inclusion of vulnerable groups in research. Literature associated with outcomes for children is more prevalent than the more sensitive area of lived experience. This research attempts to place children at the centre of academic debate associated with this minority group.

The third chapter considers the methodology for the research. Crotty's (1998) framework is used to consider the epistemological background of the research, the theoretical perspective, the methodology chosen for the study and the methods used for data collection. A brief

section considers some of the strengths and limitations identified within the methods chosen. A description of the model (Attride-Stirling's 2001) used to facilitate the data analysis is also presented.

Chapter 4 will present the findings from the research. Data was conducted in two phases. Chapter 4 reports the findings from interviews conducted with parents of children with a learning disability and behavioural needs. The findings are illustrated through the production of web-like thematic networks in accordance with Attride-Stirling's (2001) model of thematic analysis. Four thematic networks are presented.

Chapter 5 presents the findings from the second phase of data collection. This phase involved interviews with professional carers of children with a learning disability and behavioural needs. A multi-professional sample was accessed. Four thematic networks are presented in this chapter to illustrate the analysis of findings.

Chapter 6 is the penultimate chapter, and provides a discussion of the findings from both phases of the research. A diagrammatic representation of the global networks from both phases of the study focuses the discussion on the two central tenets of the study, inclusion and exclusion. The lived experience of children with a learning disability and behavioural needs is discussed and structured through the use of a significant event time line. This allows the child's experience to be considered with reference to the findings across both phases of the research, and in relation to contemporary evidence in the area.

The final chapter of the thesis concludes the study and examines its limitations. Implications of the findings for future practice and recommendations for further areas of research are highlighted.

The reader will be guided from the conception of the study, through collection and analysis of data, to the discussion of findings and the final conclusion and recommendations. It has been my wish throughout the study to present a transparent and logical decision trail. This, it is hoped, will allow consideration of the assertions made and support the research to stand as a credible and coherent representation of family and professional perspectives on the lived experience of children with a learning disability and behavioural needs.

Through undertaking the research my understanding has been strengthened, enlightened and further reinforced. It is hoped that the findings, disseminated to families, and through

professional forums will provoke and promote further study in the area of children with a learning disability and behavioural needs. This should support practitioners and services to be evidence-based in their approaches to children with a learning disability whose life experiences are affected by their behavioural needs.

1.4   Terminology/language

Terminology in the field of learning disabilities is a complicated arena. Before embarking on consideration of the literature it is necessary to consider current definitions, terminology and prevalence in the area of learning disabilities. This will contextualise the research and clarify the language chosen for use within the thesis.

Within the field of learning disabilities the number and diversity of available definitions can create confusion. Terminology can vary widely between services, contexts and countries (Gates 1996, Lowe et al 2007, Hemmings 2007). At a practical level terminology and definition can depend on many factors which may include the type of service provision, current and acceptable language and the location (geographically, for example the country) of the research.

Terminology considered relevant to the current research both in relation to the literature review and in consideration of current knowledge in the field reflected the inclusion of international perspectives. Terminology encountered has therefore varied widely from examples such as 'mental retardation' (America), to 'intellectual disabilities' (Europe) and learning disabilities (UK). The term 'learning difficulties' has been reported to be the one that most people with a learning disability in the United Kingdom would prefer (The British Institute of Learning Disabilities (BILD) 2011), and has been adopted as the term of preference by 'People First', an international advocacy organisation. It was the Warnock Committee (1978) that originally suggested the term 'learning difficulties' to describe children with problems associated with learning, medical and emotional problems or language impairment. The term remains widely used in this country within educational practice and the literature. The children in the study will have been described and labelled with this terminology in the context of their education. The term learning disability was however chosen for the research to represent current language in the United Kingdom (UK) and the country in which the children, considered in the research, were based and received services (DH 2001). Although a minority term in a global context (North East Public Health

Observatory (NEPHO) 2011) the term learning disability held a fit with the location of the study.

The study was designed to consider the lived experience of children with a learning disability and behavioural needs, through the perspective of the families and professionals who supported them. No operational definition of terms was given to parents or professionals included in the research. The participant information sheet (appendix 1) used the terminology 'learning disability' and 'behavioural need'. I have adopted the term 'behavioural need' in an attempt to apply a neutral tone to the behaviour of individuals. The use of the word 'need' was intended to emphasise a desire for support rather than management. The term was used to remove the subjective nature of behavioural discourse, less judgemental or discriminative than terms such as 'challenging' or 'complex'.

The terms used in the study were not questioned by participants during either phase of data collection. Participants self selected and volunteered for the research as they believed that they had experience of parenting or supporting this group of children. Unreserved acceptance was given to the participant's description of a child's lived experience as is consistent with this form of research enquiry (Dickson-Swift et al 2007).

1.4.1   Definition of 'the child'

First and foremost the research was constructed to consider the needs of children. As emphasised within the Children Act (1989), children with a disability should be considered as 'children' first. However the provision of services for children with a learning disability is different from their peer group. A child with a learning disability can remain in children's services for longer periods of time than their peers. This is a unique problem for the learning disabled population as individuals can continue to access children's services until they are 19 (Slevin 2004). This may reinforce, both within services and society, that children with a learning disability are, or can be treated as, 'children' far longer than their peers (Slevin 2004). For the current study an age limit for the children discussed was not applied (see appendix 1); to this end some of the children discussed had moved, or were about to move, into adult services. Their discussion was therefore a retrospective account, which remained highly relevant to the research. A similarly flexible approach to the inclusion of literature and research about children was also adopted. Studies and literature pertaining to pre-school children through to adulthood were considered for inclusion in the literature review.

1.4.2 Definition of learning disability

For the current research the term 'learning disability' was adopted as all participants resided and worked in England. It is acknowledged however that it is only the United Kingdom that has adopted this term (NEPHO 2011). Scope (2012), defined the term learning disability as related to brain development. Identified as a lifelong condition a learning disability was described as having a significant impact on a person's life. Scope clarified that a learning disability was not related to mental illness or part of an educational specific need as suggested in the term learning difficulty. This distinction was also noted in the Department of Health White Paper 'Valuing People' (2001) which stated that a learning disability did not include individuals described within educational language as having a learning difficulty. The distinction is an important one.

As the official term for intellectual disability in England the White Paper DH (2001, p14) clarified a 'learning disability' as the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

More recently the World Health Organisation (WHO 2007) defined a learning disability as 'a state of arrested or incomplete development of mind'. BILD (2011) clarified the term as a diagnosis, and therefore not a disease, physical or mental illness that could be treated. The term 'learning disability' has been adopted for the study due to its relevance as the current terminology in the country in which the study was conducted but also related to its philosophical fit with the ethos of the study.

1.4.3 Definition of intellectual disability

Increasing numbers of international organisations and countries (for example, USA, Canada, Ireland and Australia) use the term 'intellectual disability' or 'impairment'. The term has been considered to be interchangeable with the UK term 'learning disability' (NEPHO 2011). Indeed the recent DH (2010) report about services for people with severe and profound learning disabilities used the term 'intellectual disability' throughout. As a term, 'intellectual disability' can be characterised by the presence of significant limitations both in intellectual

functioning and also adaptive behaviour (The American Association on Intellectual and Developmental Disabilities, (AAIDD) 2011). Intellectual functioning in this context relates to intelligence and general mental capacity, such as learning, reasoning and problem solving. An individual would need to have an IQ score below 70 -75 to indicate limitation in intellectual functioning. The AAIDD's definition also refers to difficulties in adaptive behaviour, split into areas of conceptual skills such as: language and literacy, money awareness and self-direction. Practical skills were also considered such as: activities of daily living such as personal care, occupational skills and use of the telephone. Finally, social skills were defined as: interpersonal skills, social problem solving, and the ability to avoid being victimised. The final skill suggesting that 'normal' levels of cognition may reduce the risk of victimisation. This research may reinforce an interpretation of this statement in the later discussion of discrimination and stigma.

Difficulties associated with terminology appear to be managed in the literature through the application of clear operational definitions. For example, Emerson (2003) used the term 'intellectual disability' in a study with children, and used several criteria to establish eligibility for inclusion. Such criteria included; parental reports of their child having 'learning difficulties' associated with serious concern about language development during the child's early years, the child's attendance at a school for children with 'learning difficulties'. To clarify, Emerson included exclusion criteria based on teacher reports related to average ability in reading, mathematics or spelling; developmental age compared to chronological age, age and failure to progress beyond Stage 2 of the Special Educational Needs (SEN) assessment process (DfE 1994). Emerson's study highlights the difficulties associated with definitions when attempting to consider the needs of children included in the current research.

1.4.4   Definition of complex needs

All of the children discussed within the study could be described as having complex needs. The term is often used to describe people with learning disabilities in a generic all-encompassing sense. By definition within the Children Act (1989) a child with a disability is a 'child in need'. This instantly places children within a class of people that require service level provision and support. The term is also synonymous with a medical model of diagnosis. In this context the term would be used to illustrate the complexity of an individual's medical diagnosis and care requirements (Rankin and Reagan 2004, Limbrick 2007). The term is

often used to describe technologically dependent children such as those who require mechanical ventilation, and who are now increasingly able to be supported at home.

In the context of this research the term 'complex needs' has been linked to children with behaviour problems (Gross 2002). The diversity of the term was reflected in the Scottish Government's (2007) review of multiple and complex needs. The review concluded that it was the presence of multiple interventions that created 'complexity' for a child, their family and the practitioners involved. The stigma associated with 'complex needs' and the difficulty associated with the interpretation of the term for services and indeed families has led commentators to call for a nationally agreed definition (Limbrick 2007, Scottish Government 2007).

Currently the constructs associated with the definition of 'complex needs' fit with the concept of behavioural needs. For people with behavioural needs the challenge is often related to the complexity of meeting those needs rather than a description of the behaviour itself (Emerson 1995).

1.4.5   Definition of disability

The term disability is widely used throughout the literature across multiple contexts. The World Health Organisation's (WHO 2011) revised definition includes: impairment, activity limitations and participation restrictions. Whilst attempting to support the inclusion agenda this definition retained the original characteristics of the WHO 1993 classifications, impairment, disability and handicap. The 2011 definition however has placed an emphasis on the social model of disability through the acknowledgement of societal factors on the experience of disability rather than individual 'causal' factors. The revised definition suggests that disability is complex and reflected through the interaction of society and the individual. The WHO definitions are not widely applied or used in contemporary practice, but do support a level of clarity particularly in the application of research and literature. The current study utilises the WHO's 2011 definition of disability, as it attempts to consider the wider context of lived experience for children at personal and societal levels.

1.5   The terminology of behaviour

The concept, definition and prevalence of behavioural needs can vary greatly within the area of learning disabilities, in practice but also within the literature. This situation has exacerbated disparity in the representation of challenging behaviour in the literature, and is particularly evident in the effect it has on the inclusion and exclusion criteria for research within this area (Whitaker and Read 2006). The term 'behavioural needs ' has been chosen as the term of preference for the research. This is not a term widely used in the field of learning disabilities and therefore not congruous with literature in the area. Terms currently used in the field include: challenging behaviour, severe behaviour, behaviour problems, problem behaviour, maladaptive/maladjusted behaviour, complex behaviour/needs, deviant behaviour and emotional and behavioural disorders (EBD). Although these terms are prevalent in services and across the literature, they do not in themselves indicate the needs of an individual. They are, in their application, used to label people at a basic and descriptive level. It is not unusual, for example, for a child to be referred to a specialist service with a diagnostic label of autism and challenging behaviour. It is useful to consider the more prevalent terms associated with behavioural needs such as: challenging behaviour, complex needs, EBD. These terms have been avoided within the thesis as they do not fit with the ethos of the study; they do however represent contemporary language in relation to individuals with a learning disability.

1.5.1   Challenging behaviour

One of the most commonly applied terms used to describe behavioural needs for an individual with a learning disability is 'challenging behaviour'. The literature in relation to behaviour continues to reinforce the complexity and difficulty associated with terminology, as it is essentially used to 'label' individuals with a learning disability in a diagnostic fashion (DH 2007, Hemmings 2007). The term 'challenging behaviour' has been used across contexts, professions and areas of research. As a 'catch all' phrase the words can be used loosely in everyday practice, without appropriate understanding or appreciation of the ramifications of such a label.

The term originated in America where behaviour was viewed as an interaction between an individual and their environment (Blundell and Allen 1987). This view has reinforced contemporary definitions which consider that '…. behaviours represent challenges to services rather than problems which individuals with learning disabilities somehow carry

around with them.' (Blundell and Allen 1987, p14). An individual's behavioural needs appears to present problems when services are unable to meet or rise to this challenge, with behaviour described as challenging considered to be a social construct rather than a personal attribution (Meyer and Evans 2006, Emerson et al 1994).

Within clinical practice the term is used interchangeably as diagnostic and descriptive, and also to 'label' individuals and the services provided to support them. Indeed the process of labelling individuals is reinforced by services that use this terminology. For example, 'Challenging Behaviour Teams' and 'Behaviour Specialists'. Mansell (DH 2007) highlighted the need for specialist provision to support people with behavioural needs. However the inappropriate labelling of services can lead to provision that is so specialised it may become restricted and exclusive in its ability to meet local needs. Delay or reluctance in the recognition of behavioural needs may be related to the impact of such a label on the inclusion agenda (Lowe et al 2007). Early intervention to support behavioural needs however is considered to be vital, related to the pervasive nature of behaviour (Murphy 2005) and the increased pressure it places on a child's family (McGill et al 2006).

There are multiple definitions of challenging behaviour; two of the most popular UK definitions will be considered. Qureshi and Alborz (1992 p132) defined it as behaviour which

> ...has caused more than minor injury to self or others, or destroyed the immediate living or working environment, or occurs at least weekly at either, and places the person in danger or requires intervention by more than one carer, or causes damage that cannot be rectified by care staff, or causes at least an hour of disruption.

This definition concentrates on the observable externality of behavioural needs. Although potentially useful at service level it holds little regard for an individual's support needs or the impact of their behaviour.

A preferred and frequently used definition in the UK has been Eric Emerson's view that, 'Challenging behaviour is culturally abnormal behaviour(s) of such an intensity, frequency, or duration that physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit the use of, or result in the person being denied access to, ordinary community facilities' (Emerson 1995 p4). The definition remains widely applied in clinical practice, with it frequently being embedded within

specialist service referral criteria. Emerson's definition is useful and supports assessment of need based on criteria that not only encapsulates the immediate, observable 'danger' or impact of an individual's behaviour, but also facilitates consideration of wider issues for the individual. The impact of an individual's challenging behaviour was also considered related to 'access' and community presence, facilitating a wide and holistic view of intervention and support. The definition removed the focus from behaviour perceived as dangerous and allowed services to respond to the 'impact' of the behaviour rather than the behaviour itself.

There exist multiple definitions of challenging behaviour, the discussion of which is beyond the scope of this thesis. There are however some commonalities across the literature that include: behaviour that is severe or deemed inappropriate based on the individual's chronological age and level of development, behaviour considered to be dangerous, behaviours that impact negatively on the acquisition of new skills or create additional problems for a person through their exclusion from learning opportunities, behaviours that place an individual at risk from exclusion to services, behaviour that causes significant stress for carers, behaviour which negatively affects the quality of a person's life, behaviours which do not meet and are unacceptable within society and behaviours which have an impact due to their intensity, frequency or duration (Emerson 1995, Zarkowska and Clements 1996, Emerson 2001, Sigafoos et al 2003, Allen 2008).

1.5.2   Emotional and behavioural disorders (EBD)

Emotional and behavioural disorders (EBD) is a term that is used within education to describe children who have behavioural needs. The term is descriptive and is used similarly to the term challenging behaviour to identify particular types of education provision, for example an EBD school. Some of the children discussed in the research attended educational provision that used this label. In 1994 the Department for Education defined EBD as '... social mal-adaption to abnormal emotional stresses .... were persistent and constitute learning difficulties ... involve emotional factors and/or externalised disruptive behaviours; and general difficulties in forming normal relationships ' (DfE 1994 p7). The definition suggested that children with EBD can be placed on a 'continuum' of need. 'Their problems are clearer and greater than sporadic naughtiness or moodiness and yet not too great as to be classed as mental illness' (DfE 1994 p7), with behaviour considered to be pervasive across settings and with all people. As a working definition EBD is used extensively in educational settings to describe service settings, identify children's needs and highlight their complexity.

It is an example of yet another discriminatory label that has been used to describe children with behavioural needs. As described in the introduction to a book entitled 'Emotional and Behavioural Difficulties' children with EBD are likely to be considered by their teachers to be 'unlikeable' and further disruptive to their peers (Howarth and Fisher 2005, p10)

1.5.3   Behavioural needs and mental health

The terms associated with behavioural needs for people with a learning disability have often been linked to the literature associated with mental health issues. The relationship therefore requires brief clarification associated with the remit of the current research.

Behavioural needs and mental health issues are not synonymous. Multiple psychiatric conditions exist that do not fulfill the criteria or available definitions for challenging behaviour, or behavioural needs (Emerson 1995). There are however links between challenging behaviour and definitions of mental ill- health within the Diagnostic and Statistical Manual of Psychiatric Disorders (DSM-IV 1994, Allen 2008). Further challenging behaviour has been included in the manual as a form of psychiatric disorder.

The Mental Health Act (1983) refers to the term challenging behaviour, and defines it as 'seriously irresponsible or abnormally aggressive behaviour' (MHA 1983, ch 20, p1). The links between mental health and challenging behaviour have therefore been reinforced by contemporary diagnostic and legislative contexts (Xeniditis et al 2001). The term challenging behaviour has been traditionally used to describe behaviour that is usually attributed to mental health issues (DH 2007). This situation has reinforced the medicalisation of behavioural needs and exacerbated problems associated with 'diagnostic overshadowing' within the learning disabled population (Allen 2008), further contributing to a reported increase in the prevalence of mental ill- health within the learning disabled population (Emerson 2003, Simonoff 2005, DH 2007, Allen 2008, Turner 2011).

The number of admissions to psychiatric units and hospitals of people with a learning disability based on their behavioural needs in England has been recently reported (Emerson et al 2012). Although the figures are relatively low in relation to the overall population, admissions for psychiatric care related to behaviour needs accounted for 2.67% of the admissions for people with a learning disability who were known to their GP.

The relationship between learning disabilities and mental health appears to be supported in the literature particularly related to the prevalence of mental health issues in the learning disabled population (Emerson and Hatton 2008 b). In relation to the current research, the links made between behavioural needs and the mental health of individuals must be considered significant as effective models of support will be potentially lead by a medical model of intervention. This is illustrated through evidence associated with diagnostic overshadowing and the increased use of psychotropic medication for people with a learning disability (Marshall 2004, Xeniditis et al 2001).

The link to mental health issues may be considered to be unhelpful for people with learning disabilities and enduring behavioural needs. There are however important parallels to be considered between the two groups, including the effect of mental health difficulties for an individual which can lead to stigma, issues with access, vulnerability and social exclusion (Morgan 2007).

1.6   Prevalence

Having considered pertinent terminology associated with the research area the prevalence of behavioural needs amongst children with a learning disability will be clarified. Definition and prevalence are closely associated. The application of a definition will directly affect the inclusion or exclusion of individuals within a study, and ultimately representation of the client group (Whitaker and Read 2006). Prevalence will be considered in several ways: the prevalence of learning disability in the United Kingdom (UK), in England (all participants lived and worked in England), the reported prevalence of behavioural needs in the learning disabled population and finally specifically for children.

1.6.1   Learning disability in the United Kingdom

The estimated number of people in the United Kingdom with a learning disability differs within studies and population surveys, with no official statistics available to consider the number of people with learning disabilities in the UK (BILD 2011). An estimated prevalence of 1.5 million people with a learning disability in the UK was reported by Scope (2012), whilst BILD (2011) reported that 2.5% of the population had a learning disability, with an estimated actual prevalence of 1-2%. Translated, this results in a total of between 602,000 and 1,204,000 individuals in a UK population of 60.2 million (World Bank 2012).

The variation in figures between reported and actual numbers continues to exacerbate the problem associated with providing support to people with a learning disability in the UK (BILD 2011). Individuals with a mild learning disability are not always identified and therefore not included within calculations. A more accurate prevalence can be established for people with moderate to profound learning disabilities, associated with their need for service support. It has been estimated that this group of people represent 0.35% of the total UK population, approximately 210,700 individuals (BILD 2011).

The population of people with a learning disability has been considered in the recent 'Strengthening the Commitment' report (Scottish Government 2012). The report recommends a renewed focus on the needs of people with a learning disability, and refers to evidence of a 14% rise in the number of people with a learning disability in the UK between 2001 and 2021 (Emerson and Hatton 2008a). The predicted rise in the numbers of people with a learning disability will of course be initially experienced within the child care sector and will have a major impact on the ability of services and professionals to meet the needs of children who present with complex issues such as behavioural needs.

1.6.2   Learning disability in England

In 2001 the White Paper 'Valuing People' (DH 2001) estimated that 65,000 children and 145,000 adults in England had a severe or profound learning disability, and 1.2 million individuals had a mild or moderate learning disability. The increase in the number of people diagnosed with a learning disability was predicted to be 1.2%. However this has since been revised to a 14% increase between 2001 and 2021 (Emerson and Hatton 2008a).

A variation in prevalence rates is also reflected in the English figures. The Centre for Disability Research (CeDR 2008) reported that the Department of Health (DH 2001) estimate for children with severe or profound learning disabilities was 67% higher than the Department for Education (DfE 2006) data, which was collated based on the number of children registered in England with special educational needs (SEN). Issues associated with terminology and definitions appear to have exacerbated prevalence issues. The DCSF consider a child to have a 'SEN' if they have 'learning difficulties or disabilities that make it harder for them to learn or access education than most children of the same age' (DCSF 2009, p6). Not 'behaving properly in school' was also clearly associated with the presence of

a 'SEN' (DCSF 2009, p7). Variations in prevalence may be attributed to the exclusion of children waiting for, or in the process of assessment for SEN (CeDR 2008), the unidentified children within mainstream schools and the effect of terminology and definitions across organisations.

One of the most recent sources of prevalence has been the 'People with Learning Disabilities in England 2011 Report' published by the Learning Disabilities Observatory (Emerson et al 2012). The report states that the total incidence of learning disabilities in England is 1,191,000. The figure included 286,000 children of whom 106,000 were girls, and 180,000 were boys aged from 0-17. 905,000 people were adults aged 18+, 530,000 men and 375,000 women.

1.6.3   The prevalence of behavioural needs

The prevalence of behavioural needs amongst the learning disabled population is difficult to calculate as it is entirely related to the interpretation and application of definitions (Gates 1996, Tustin et al 1991). Meyer and Evans (2006) suggested that the prevalence of behavioural needs for children was reliant on the ability and skill of individuals and services to apply criterion that is variable across services. Individuals should be able to consider behaviours that may be typical and developmentally appropriate in children that do not have developmental disabilities, and are therefore consistent with their peers, rather than related to their learning disability.

Due to the complexity of definitions studies often explicitly discuss a definition of behavioural needs in order to contextualise their data. Qureshi and Alborz (1992) applied their own definition of challenging behaviour to their study of prevalence. The result was an estimated prevalence of 1.91 people per 10,000 of the general population, defined as 5.7% of the known learning disability population. In 1993 Kiernan and Qureshi estimated the prevalence of behavioural needs to be approximately 7% (across children and adults). Emerson and Bromley concurred in 1995 with an estimate of 7.8%, however Kiernan et al (1997) later adapted Qureshi and Alborz's (1992) definition and reported an incidence of 4.5 within 10,000 of the general population, 17% of the learning disability population. The study was replicated by Emerson et al (2001) who identified 5.9 people per 10,000 of the population and 12% of the learning disability population. Application of definitions are highlighted in the study conducted by Hassiotis and Hall (2004) who only considered

observable and outward directed aggressive behaviour in their study of behavioural needs and reported this to be between a prevalence of 3.3% to 36% of the learning disability population.

It must be noted that changes in attitude, values and service provision will affect the way behaviour is perceived and therefore recorded. Provision of support for people with a learning disability has altered significantly and therefore perceptions of people with a learning disability are likely to have changed. A study of behavioural needs within a mainstream environment may elicit very different information from one conducted within a specialist learning disability provision.

Many reports highlight the low level prevalence of behavioural needs, but also emphasise the impact of this type of need on services, children and families (Gray DfES 2006, DH 2007). The Mansell report (DH 2007) estimated that on average there would be 24 adults with a learning disability that could be described as 'challenging' per 100,000 people in the population. This figure did not include older children described as 'challenging', and those in transition from child to adult service provision. Significantly Mansell stressed that the number of individuals described as 'challenging' continued to increase in the population of people with a learning disability. In light of the reported 14% increase in the population overall the ramifications for individuals with a learning disability and behavioural needs appear to be clear (Emerson and Hatton 2008b).

1.6.4 Children and behavioural needs

Prevalence studies associated with the behavioural needs of children are numerous. Services involved with children with behavioural needs appear to be infinite, and the impact and interest associated with the subject has seen the popularity of programmes such as 'Super Nanny' and 'House of Tiny Tearaways' rise significantly (Channel 4 2004, BBC3 2005). The prevalence of behavioural needs within the general paediatric population has been reported extensively within the literature. Patterson et al (2002) suggested that 1 in 5 children, under the age of six in the United Kingdom, exhibited behaviours described as disruptive to their families. More recently the National Institute for Clinical Excellence (NICE) reported that 45% of community child health referrals were related to behaviour disturbances (www.nice.org.uk 2012). To compare peer groups, Baker et al (2003) studied 205 families with a three year old, both with and without a learning disability. Children with

a learning disability rated higher for behavioural needs than those without, on both internalised and externalised behaviours. Temperament appeared to be an indicator of behaviour problems from early childhood to adulthood. The literature concurs that the presence of behavioural needs within all groups of children is high, requires significant support from services and is identifiable within a child's early life (Murphy et al 2005, Meyer and Evans 2006, NICE 2012).

To concentrate specifically on children with a learning disability Quine (1986) reported a prevalence of behavioural needs amongst two thirds of pre-school children with severe intellectual disabilities. He noted that the severity of intellectual delay was directly related to the likelihood of the child having behaviour problems including self-injurious behaviour and aggression. Utilising the same population of children Kiernan and Kiernan (1994) conducted a postal survey across 68 schools in England and Wales. 8% of children in the study were considered to have very difficult or extremely difficult behaviour with 14% of children reported to have less extreme behavioural difficulties. Two thousand children in England and Wales were estimated to present with severe behaviour needs, 3400 with less severe difficulties. Later Einfeld and Tonge (1996) reported severe emotional and/or behavioural needs in four out of ten children with an intellectual disability within a total population.

Using the term emotional and behavioural difficulties (EBD) to consider the prevalence of behavioural needs in children, the Mental Health Foundation (MHF 2002) reported that between 20,000 and 25,000 children attended EBD schools or pupil referral units (PRUs) in England. The use of provision as an indicator of need reinforces the issues described in point 1.4.4 associated with the labelling and stigmatisation of children with behavioural needs. A rapid increase in the prevalence of behavioural needs within the learning disabled population was noted by the MHF later supported by Mansell in 2007 (DH 2007). The increase in the numbers of children with behavioural needs has been considered by Local Education Authorities to be related to a lack of appropriate provision to match need to the support required (MHF 2002). This factor is repeatedly linked to an increased risk of children with a learning disability being placed in out-of-area residential provision (Quine and Pahl 1989, Felce et al 1993, Qureshi 1995, McGill et al 2006).

The recent Children's Commissioner report (Connolly et al 2012) has once again reinforced the increased risk of exclusion that children with behavioural needs face within local

statutory provisions. Significantly the report highlighted the prevalence of the informal and illegal exclusions of children with special educational needs from schools.

Children and their behavioural needs appear to be an area of increasing interest, both within the literature and evidenced in the rise of popular television programmes associated with the subject. Although the evidence may suggest that services and systems can identify children with behavioural needs during their early childhood years, literature related to the management of such needs indicates that children are placed at a disproportionate level of risk from exclusion due to their identification within services. The following chapter will consider the literature and evidence associated with the needs of children with learning disabilities and behavioural needs. The support of children with behavioural needs from a family and service perspective will be discussed. Relevant literature will be highlighted to consider the impact of their needs on their experiences, their families' journey and the relevance of services.

2 Chapter 2: Literature Review

2.1 Introduction

The research question for the study was designed to consider perspectives of the lived experience of children with a learning disability and behavioural needs. This chapter will consider research and contemporary literature in the areas of learning disability, children and behavioural needs. Analysis and relevance to the current research will create discourse between what is already known, and the context of the study.

In order to structure the review and provide clarity for the reader the chapter has been divided into four areas: children with learning disabilities and behavioural needs and their families; professionals and service; education; and stigma. These areas have been further broken down to consider the most relevant and specific issues associated with the current research.

2.2 Children with learning disabilities and behavioural needs and their families

The prevalence of learning disabilities within the total population of the UK remains small (Scope 2012). However recent reports of a 14% increase in the learning disabled population overall will have a significant impact on the numbers of children and families that will require support from services in the future (Scottish Government 2012). The literature consistently highlights the difficulties that children with learning disabilities and their families experience. For the children at the centre of this study the impact of their needs are disproportionately associated with the prevalence (Gray 2006).

2.2.1 Children and behaviour

Numerous studies concur that behavioural needs are common in young children with severe disabilities, and appear to persist over time (Emerson et al 1999, Emerson 2003, Murphy et al 2005). Further early indication of behavioural needs amongst pre-school children have been associated with an elevated risk of more serious and persistent behaviour problems in later life (Hawkins-Walsh 2001, Keenan and Wakschlag 2002, Caspi et al 2003). The literature provides compelling evidence that behavioural needs can be identified during the early years of a child's life (Meyer and Evans 2006, Murphy et al 2005).

One of the most useful studies to consider the pervasive nature of behavioural needs was Murphy et al's (2005) research that utilised retrospective data from a large sample of a 160 children. Collected in the 1970s, the original data was intended to consider the prevalence of specific impairments observed in children with severe learning disabilities (Wing 1971, Wing and Hailey 1972, Wing and Gould 1979). The findings allowed researchers to identify the presence of social impairment, communication issues and a lack of imaginative play amongst this group of children. These three traits were later to become known as the 'triad of impairments', considered as diagnostic symptoms for children on the autistic continuum (Wing et al 1977). The data was later useful to Murphy and colleagues as it had considered the children at two discrete time periods. Information was collected twelve years apart, and allowed the presence of old and new behaviours (referred to as challenging behaviours) to be considered over time. Murphy et al's (2005) later analysis of the data allowed consideration of the chronicity of behaviour amongst children aged 15 years or younger with severe intellectual disabilities and/or autism. The later study also focused upon the impact of behavioural needs for a child, the family and their community, if not supported from an early stage. Murphy and colleagues concluded that children labelled as 'socially impaired' during the first phase of data collection were reported to have significantly greater issues with their behaviour when re- assessed in phase two of data collection. Further, children described as displaying the most challenging behaviour in the first period, were later observed to display the most difficult behaviours during the second period of assessment. The finding that 'the relationship between abnormal behaviours and language skills was really more impressive and pervasive than that with IQ' (Murphy at al 2005, p277) must further be considered significant when considering the need for early intervention for children with a learning disability.

The study clearly demonstrates that high levels of difficult behaviour in a child's later life can be associated with the presence of behavioural needs in the child's early years. At follow up the study noted issues for children which included; a diagnosis of autism/autistic spectrum disorders, social impairment, limited expressive language, and abnormal behaviour. Anecdotally practitioners appear able to identify children and families that may require intensive and long-term support associated with their child's early presentation. The pervasive impact of behavioural needs for both the child and family therefore indicates a need for proactive intervention at an early stage (Fox et al

2002). This type of provision may prove more effective and efficient than current traditional reactive strategies, and has been advocated within current policy (NSF, Children Young People and Maternity Services 2004).

Young people with learning disabilities who are perceived to challenge services cannot be described or labelled as a homogenous group (Meyer and Evans 2006). The term 'challenging behaviour', prevalent in the literature associated with the behavioural needs of people with a learning disability, has become a euphemism for describing behaviour considered to be difficult or socially unacceptable. Mansell (DH 2007) clarified that the term was originally intended to emphasise that behaviours could be caused through the systems that support an individual as much as through the individual's characteristics. The term is often used to label people and can have powerful connotations when used to describe the needs of a child. The term is frequently used to describe individuals within learning disability services and provision. It is language applied by individuals with an often limited understanding of the impact of the terminology, and the power of terms associated with behavioural needs. For a child the label may be one that stays with them throughout their journey within services and is used as a descriptor rather than an indicator of need. Inappropriate application of the phrase suggests homogeneity and can negate attempts to support children through individual and child centred approaches.

For a child, their behavioural needs can interfere with their education, limit opportunities for integration into mainstream schools and community environments, and also affect family life (Emerson et al 1999). External, or outwardly directed behaviours have been considered to cause the most problems for individuals. As well as creating management issues, injury and placement breakdown, individuals with physically directed behaviours are typically more likely to be referred for specialist treatment (Lowe et al 2007). Internally directed behaviours demonstrated by children, such as avoidance and withdrawal, are more likely to be ignored and accepted as an intrinsic part of the child. It is externally motivated behaviour that is perceived to be the most 'unacceptable' behaviour, as well as the most difficult to manage (Lowe et al 2007).

Consequently the evidence suggests that specialist provision and support may only be sought for a child if behaviour is externally directed and has become unacceptable to those involved in supporting the child. This precludes the merits of early intervention for

this group of children and can serve to reinforce a notion that the child's behaviour is beyond 'mainstream' capacity and therefore tolerance. The early signs of behavioural needs, considered to be less severe and observed at an individual level may not be perceived as a priority for intervention, negating the opportunity for early intervention. If a behavioural need is only perceived to affect an individual and their quality of life, then society may appear to accept and reinforce this situation through a lack of access to appropriate proactive support.

This type of situation can exacerbate the vulnerability of people with a learning disability. As a group of people, individuals with a learning disability and behavioural needs appear to particularly susceptible to increased levels of risk. These include the risk of abuse such as deprivation and neglect (Emerson et al 1994, Emerson 2001), and an increased prevalence of placement breakdown and institutionalisation (Lakin et al 1983 and Allen 1989). The associated risk factors suggest that behavioural needs should be viewed as a long-term, high-impact health problem, exacerbated for individuals by limited social networks, exclusion from services and an increased risk of being placed away from their families in placements out of their local area (Hassiotis and Chaytor 2011). These factors have been graphically illustrated through the high profile media coverage of the 'Winterbourne View Enquiry' (Local Government Chronicle 2011).   The level of abuse suffered by the vulnerable individuals captured by the documentary, illustrated the problem but was unlikely to be atypical in view of the history of such events at Cornwall Partnership NHS Trust 2006, and Sutton and Merton Primary Care Trust 2007(Health Care Commission 2007).

2.2.2   Families and carers

A wide range of research was available for the review, that considered the needs and experiences of families and carers who supported a child with a learning disability (Asen 1996, Anderson et al 2007, Beresford and Rhodes 2008). Evidence related to the families of children with a learning disability and behavioural needs appears to suggest that as a discrete group of carers, families face significant and unique challenges in caring for their child. Families have consistently reported feelings of powerlessness and stress associated with the lack of appropriate support available to them and their children (Quine and Pahl 1989, Felce et al 1993, Qureshi 1995, McGill et al 2006). This situation is exacerbated by parental feelings of guilt or blame that can be directly associated with

their child's behavioural needs (Paffrey 1995, Farrell and Polat 2003). Ultimately families experience feelings of disempowerment, they report an inability to challenge services as their children's placements are often considered to be at risk due to their behavioural needs (Goodman et al 2006). This situation reinforces a lack of effective and honest communication between service provision, service users and carers. The combination of a child and their family's desire to maintain local service provision and poor communication will affect the ability of services to deliver child and family-centred provision. This would appear to reinforce the breakdown of local provision to meet a child's needs and the potential reliance on out-of -area provision (McGill et al 2006). This situation can preclude families and children who can eventually begin to exist outside usual forms of provision and society (Emerson et al 1994), evoking feelings of isolation from situations and communities that they find unsupportive, intolerant and indeed impenetrable. It is this very situation that emphasises the impact of a child's behavioural needs through the challenges created for families, educational settings, and the ability of children and their families to experience meaningful community participation (Glasberg et al 2006).

The role of services in enabling families to support their children's needs was considered in the Audit Commission's review, 'Children in Mind: Child and Adolescent Mental Health Services' (CAMHS, Audit Commission 1999). The review reiterated a need to adopt a holistic approach to family centred support based on their findings associated with the vulnerability of children and their families referred for CAMHS provision. 40% of children referred lived with only one natural parent, compared to a national average of 21%, (Office for National Statistics 1998), with 55% of children found to have more than one 'disadvantaging factor' in their lives, such as poverty. These factors predispose children to levels of risk significantly higher than their peers (Clarke and Clarke 2000, Mental Health Foundation 1999).

To consider the health of carers of children with disabilities Murphy et al (2006) conducted a study in America utilising questionnaires and focus groups to gather data from forty carers. Five key themes were identified by the researchers: the stress of caregiving, the negative impact of caring on the care giver's health, the need to share the burden of caring, worries for the future and coping strategies of caregivers. The study

highlighted the importance of early intervention strategies to support the early years of a child's life, and to alleviate stress within the family.

Carer's stress in supporting their disabled child was considered by Murphy et al (2006). The study used Anthonya et al's (2005) definition of stress which reflects the difficulty experienced by individuals from the demands of being a parent. Participants identified that their levels of stress were exacerbated by a lack of control related to day-to-day events within the family, the need to continually advocate for their child and frequent and unpredictable requests from school for the child to be collected due to their behavioural needs.

The practice of sending children home from school due to their behaviour has been defined as a form of informal exclusion by the recent Children's Commissioner report (Connolly et al 2012), and appears to be common practice highlighted across both mainstream and specialist environments. The impact of this type of informal exclusion has been considered to contribute significantly to the complex situations reported by carers. Murphy et al (2006) reported that families experience high levels of stress associated with the need to develop and facilitate liaison skills between professional groups such as doctors and other health professions involved in supporting their child. Stress was also attributed to anger and frustration experienced by parents through a lack of sensitivity and understanding displayed by medical professionals. The development of liaison skills and empathetic responses to family situations would not appear to be beyond the role of professionals employed to support and work with families. The evidence appears to suggest that for some carers it is they who must adopt these roles, potentially managing professionals and services as well as their child and families needs.

The prevalence of poor health amongst parents has also been attributed to the physical challenge of caring for a child with a learning disability and behavioural needs (Murphy et al 2006). As a result of their caring role parents reported periods of recurrent anxiety, depression and guilt. These were directly associated with physical exhaustion, despair and feelings of hopelessness. The future for their child and family was also raised by carers as an area of concern, as well as the barriers they experienced in addressing their own health needs, the paucity of available respite hours, the lack of qualified alternative care givers and the low prioritisation of their needs.

Parenting stress must be considered amongst the multi-factorial components of the child, the parent and their situation (Webster-Stratton,1990, Abidin 1995, Ostberg and Hagekull 2000, Reitman et al 2002). Parents who described their children as moody and demanding, and reported 'difficult' interactions experienced elevated levels of stress associated with their parenting role (Jackson and Huang, 1998; Ostberg and Hagekull, 2000). The presence of behavioural needs in a child's early years can therefore exacerbate an already demanding situation for parents. The National Service Framework for Children Young People and Maternity Services (2004) directly referred to children with behavioural needs, and recommended within standard 2, that parents who experienced difficulties in their child's early years should be a priority for service intervention and support.

Access to local and statutory provision for children with disabilities has, and continues to raise, many concerns (Cook 2011). In 2005 a lack of access to appropriate support for families was reported by the Commission for Social Care Inspection (CSCI, 2005), and the Valuing People Support Team (DH, 2005). The Local Government Association found that 80% of local authorities had reviewed their eligibility criteria for the provision of support to families. Further 70% of local authorities were only providing support to those with the highest level of need (categorised as critical and substantial). The situation was highlighted more recently by the Learning Disability Coalition Report (2011) which quoted a local authority as stating that:

> *Traditional services are to close…it is not known if additional funding for individual budgets is to be available from service closures…traditional services not being available will put additional pressure upon carers' families. Without sufficient funding available it is very likely that some families will not be able to continue to support individuals. (LDC 2011, p9).*

As the presence of behavioural needs is the main predictor of residential care for this group of children (McGill 2008) the situation for the children at the centre of the current research, and their families appears to be worsening. Evidence suggests that the withdrawal and reduction of service provision presents major implications for children with behavioural needs and their families (Tausig 1985, Black et al 1990, Bromley & Blacher 1991, McIntyre et al 2002).

The ramifications associated with a lack of support for children and their families was considered in the 2006 Breaking Point Survey conducted by Mencap. A cohort of 353 families of children with a severe or profound learning disability across England and Northern Ireland were included in the survey. Seven out of 10 families were reported to have reached or come close to 'breaking point' due to a lack of access to appropriate short break provision, with 9 out of 10 families attributing their poor mental health status to the amount of care they provided to their child. Five out of 10 families had not received a carer's assessment; from those that had, 5 out of 10 families had not received services. Mencap, a strong advocate for the needs of families, stated that families of children with disabilities can become 'invisible in their communities' (Mencap 2006, p15), exacerbated by a paucity of, and limited information about, the services available to meet their needs.

There appears to be convincing evidence to support the social and environmental impact of behavioural needs in the early years of a child's life. Families experience increased levels of stress associated with their child's behaviour. The changing policy context suggests that support for families and their children may be more difficult to access. This exacerbates an already limited range of provision for children with behavioural needs. It further increases the level of risk associated with the provision of emergency placement due to a lack of proactive planning involving the child, the family and service providers.

2.3   Professionals and services

Having considered children with a learning disability and behavioural needs, their families and carers, this section of the review will consider the provision of services to this group of children and their families. The attribution of behaviour will be considered in relation to its effect on the support of people with behavioural needs, alongside evidence associated with staff training and the provision of services. The prevalence of residential provision for children with behavioural needs will also be discussed.

2.3.1   Staff attribution of behaviour

Numerous studies have reported on the impact that paid supporters can have on the care and support of individuals with behavioural needs. The term 'staff' will be used in the

following section to denote those individuals employed to support children and adults with behavioural needs.

Supporting people with behavioural needs has been the subject of several studies. The evidence suggests that caring for individuals with behavioural needs can cause elevated levels of stress amongst staff, particularly personnel who struggle to access appropriate training to support their understanding of behavioural needs (Hastings and Remington 1994a, Bromley and Emerson 1995, Meyers and Evans 2006, DH 2007). Numerous studies propose that a lack of understanding of an individual's behaviour may lead to the misunderstanding of the function of that behaviour and ultimately affect the intervention offered or made available to an individual (Swap 1991, Bromley and Emerson 1995, Hastings and Morgan 1998, Meyers and Evans 2006).

The belief systems of staff and the understanding of behavioural needs are known to shape the delivery of care to individuals, as well as the ability of staff to interpret and seek advice to support their practice (Watts et al 1997). Watts suggests that the reaction of staff to an individual's behaviour is predominantly rule governed. However rules within an environment are often implicit and constructed by an individual carer, staff team, consultant or other professional group (Hastings and Remington 1994a). Rules that are not explicit are difficult to challenge and may be very difficult for a person with a learning disability to interpret.

How staff understanding affects the management of behaviour has been reported in several studies (Hastings and Remington 1994b, Oliver et al 1996). Noone et al (2006) reported that care staff viewed behaviours as unique to an individual, originating from and controllable by the person. They concluded that attribution of behaviour by support staff could result in inadvertent reinforcement of an individual's behaviour. This could contribute to the long-term maintenance of inappropriate behaviour and demonstrates the impact that staff can have on an individual's behavioural needs.

Research methods associated with the study of staff attribution and attitudes have been the subject of much conjecture within the literature. The discussion has focused predominantly on the use and application of vignettes (Grey 1994, Guerin 1994, Noone et al 2006). Grey (1994) and Guerin (1994) argued that the use of vignettes, rather than

consideration of realistic situations, may exacerbate problems associated with the difference between what people report they would do, in comparison to what they may actually do. Variables that may affect staff responses to a situation may include: the staff member's role, responsibility, emotional state and perception of their own safety. Such variables must be considered in the study of attribution to ensure training and research is relevant to staff teams (Lord 1997, Noone et al 2006).

Bromley and Emerson's (1995) study used a questionnaire to consider the behavioural attributions of 70 staff in adult and children's services. The five most frequent responses included an individual's internal psychological state or mood (41% of staff), past environment (such as institutionalisation – 26%), current environment (such as reaction to change – 26%), self-stimulation (24%), and a form of communication or control of others (23%). The use of questionnaires suggests that staff would reply based on their knowledge and experience of individuals that they had supported. This may be more realistic than the use of vignettes where staff would be required to respond to fictional characters. However Bromley and Emerson's results suggest that staff view their ability to affect change relating to an individual's behaviour as limited.

In contrast to the literature that criticises the use of vignettes (Grey 1994, Guerin 1994, Noone et al 2006), several studies have supported their use particularly when a level of experimental control was required (Watts et al 1997 and Hastings et al 1995). Berryman et al (1994) used questionnaire vignettes with 83 staff and reported attributions such as: social reinforcement (90% of staff), emotions (74%), task environment (53%), communication (35%), medical pain (44%), and intrinsic reinforcement observed as self stimulatory behaviours (37%). Hastings et al's (1995) study considered 148 healthcare workers from a large institution. Staff attributions included: client needs (wanting something, communication), stimulation, personal and environmental factors, social factors, biological factors, environmental contaminates (noise, overcrowding), and natural factors (a normal thing to do).

The breadth of evidence associated with the impact of staff attribution of behaviour should be utilised and applied to provide effective and targeted training of staff within services. Hastings and Morgan's (1998) study considered the impact of 'behaviour' training for service providers. They suggested that staff were significantly more likely to

identify different forms of reinforcement for an individual's behaviour having received training, than before the training. As suggested by Meyers and Evans (2006) and highlighted in the Mansell report (DH 2007) effective intervention for people with behavioural needs should involve a multi-element approach, implemented by personnel with the required knowledge, skill base and competence. The study of staff attribution as a baseline within training for staff teams may support the longitudinal effectiveness of training and further support appropriate interventions that will enhance individual lives.

Without an understanding of the functional value of behaviour for an individual, staff teams are unlikely to be able to intervene effectively in appropriate behaviour support plans, and may further be more likely to contribute to the informal exclusion of children from services (Hastings and Remington 1994, Connolly et al 2012). Effective inclusion of individuals within services appears to be therefore contingent on the ability and motivation of staff to support children's needs. For the children in the study their opportunities and experience of integration and inclusion can be directly affected by the people who support them.

2.3.2 Training

The evidence associated with the impact of staff suggests that knowledge and training can be crucial in the provision of effective behavioural support for people with a learning disability. The Winterbourne View exposé and subsequent enquiry highlighted the risks associated with placing vulnerable individuals in the care of staff that are unsupported and unskilled in their roles as paid carers (CQC 2012, LDC 2011).

Despite the recent events highlighted the need for staff to be trained when working with people with a learning disability was discussed in the Valuing People White Paper (DH 2001), and resulted in the 'Learning Disability Award Framework' (LDAF). The scheme commenced in April 2001 with an objective that new entrants to learning disability care services would be registered for a qualification on LDAF by April 2002, with a target of 50% of front line staff to have achieved at least an NVQ (National Vocational Qualification) Level 2 by 2005. However Campbell (2007) reported that training targets had not been achieved. He highlighted several factors associated with the training deficit including evidence related to high staff turnover within learning disability services (20–30% per year according to Allen et al 1990), cuts in service training budgets and the

multiple reconfiguration of community services (Felce et al 1993, Hatton et al 1995). These are all factors that affect the continuity of service provision and further exacerbate the vulnerability of service users.

The Mansell report (DH 2007) argued that appropriate training for services associated with the support of people with behavioural needs was vital. The report suggested that a lack of investment in training would create a situation in which the comparatively small numbers of people who required specialist support would increase substantially, and further increase the demand on services. In light of current evidence associated with the 14% rise in the learning disabled population up to 2021 (Scottish Government 2012), the need to provide early intervention and proactive strategies to support individual behavioural needs from becoming complex and enduring appears to be even more important.

The effectiveness of training for staff in supporting people with behavioural needs has however been debated within the literature. Cullen (1988) argued that staff training was not directly able to affect changes in staff behaviour. More recent studies have reported that the maintenance of an individual's behaviour over time had not been affected by carer training (Campbell 2007). Many studies concur that working practice may not be changed significantly as a result of training alone (Cullen 1988,1992, Foxx 1996, McBrien and Candy, 1998, Campbell 2007). Conversely positive outcomes for services users such as increased access to leisure opportunities have been reported as a direct result of service training programmes (Allen et al 1997, Allen and Tynan 2000, McGill et al 2007). The McGill et al (2007) study however also associated the introduction of active support for service users, with a rise in the incidence of lower level behavioural needs. Variations within the studies cited were largely associated with the use of outcome measures and indicators of successful training. This may account for the variation in opinion related to the efficacy of training staff to support people with behavioural needs. Ultimately, measurable quality of life outcomes for services users must be used as the benchmark to evaluate the effect of training staff, rather than engagement and compliance of staff to training programmes.

To this end Hieneman and Dunlap (2000a, 2000b) published a review and follow-up study that considered the outcome of community based programmes for people with

learning disabilities and behavioural needs. The researchers interviewed family members, service providers and experienced consultants. They reported that the ability of staff to appropriately analyse an individual's behavioural needs and further implement effective interventions were contingent on the knowledge and skill of staff as well as their personal investment. As recommended by O'Brien and O'Brien (2002) a values-led approach can be the most appropriate in the support of people with a learning disability.

Studies report that staff within services often had inadequate training for their role (McVilly 1997, Smith et al 1996). This issue has not only been considered in relation to untrained support staff. As recommended by Mansell (DH 2007) the provision of effective support for people with behavioural needs requires an enhanced response from services. Traditional forms of training do not appear to adequately prepare individual professions to effectively meet the needs of this group of people. As an example of this situation Slevin (2004) considered several groups of learning disability nurses in one region of Ireland. He advocated that nurses were instrumental in the identification of risk factors associated with the presentation of behavioural needs in children with learning disabilities. Appropriate levels of skill were considered by Slevin to support the planning and implementation of effective and efficient intervention programmes for individuals. However Slevin found that very few respondents in the study had received specialist or accredited training in behavioural intervention, potentially affecting the clinical effectiveness of practitioners and exacerbating the complexity of provision required to support individuals with behavioural needs.

Access to, and motivation appear to be the key factors related to the effect of training staff to support people with behavioural needs. The literature associated with training appears to support Campbell's (2007) assertion that staff who have limited or no training continue to support people who have the most complex and difficult to manage behavioral needs. This may account for (although not excuse) the recent issues exposed at Winterbourne View (2011).

2.3.3 The provision of services

A large part of the discussion within the current study focuses on the provision of services for children with behavioural needs. Mansell (DH 2007) recommended that provision for this group of people would involve specialist support. He highlighted the pervasive and long term nature of behavioural needs, with people who presented the

most serious types of challenge requiring lifelong support. Potentially individuals in this position will experience increased risk from social exclusion (Hassiotis and Hall 2004).

The nature of support for children with disabilities has been highlighted by many governmental reports and reviews. The complexity of service provision and the vulnerability of children with disabilities was considered in the 'Every Disabled Child Matters' review published in May 2007 (EDCM, DCSF 2007), and was highlighted by standard 8 of the National Service Framework (NSF) for Children, Young People and Maternity Services (DH, DSE 2004). The NSF stated that services should ensure that 'Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.' The EDCM review was undertaken to build on, and potentially strengthen, the commitment and existing policy and guidance available for disabled children and young people, particularly 'Together from the Start', 'Every Child Matters' (DfES 2003) and the National Service Framework for Children, Young People and Maternity Services (DH, DSE 2004).

Within this context the provision of effective services that are able to provide on-going behavioural screening and assessment for children with behavioural needs, has been considered in the literature (Glasberg et al 2006, Magee and Roy 2008). How, and by whom, this form of service could be provided appears to focus on the debate between specialist and mainstream provision.

Lowe et al (2007, p30) argued that people with behavioural needs were unlikely to have their needs met through specialist service provision alone. The researchers called for a '...broader, multi-dimensional approach' that would be able to support mainstream services in the development of appropriate provision. Examples to facilitate a holistic approach to the care of children with learning disabilities and their families included the provision of specialist health visitors within secondary tier provision and the strengthening of community support teams (Lowe et al 2007). A coordinated multi-professional and multi-agency approach has also been advocated by Limbrick (2007), a long standing champion of child and family centred approaches. This type of approach

however can be complicated and lead to a situation in which children are subjected to multiple and uncoordinated interventions.

Lacey (2001) proffered the term 'benevolent chaos' to support Limbrick's concerns and to describe the way that services had traditionally interacted with children and families. Lacey suggested a 'matrix' of shared responsibility as the solution to the multiple intervention model adopted by services. The matrix would support professionals in their roles and provide the catalyst to improve liaison, co-operation, co-ordination and collaboration. Such an approach would facilitate the sharing of knowledge and best practice for the benefit of the child and family. This model of multi-disciplinary working has been described by Limbrick (2007), who has campaigned for a 'Team Around the Child' approach. This type of model was originally devised for children with complex needs who required long term multi-agency support. The principles of complex care fit well with the provision of child and family centred support to children with learning disabilities and behavioural needs. Although Limbrick is commonly associated with the 'Team Around the Child' model, this type of approach has been advocated in the literature in various guises, including the trans-disciplinary model (Chen 1999, Orelove and Sobsey 1991) and the key worker model (Barnardos 2001). All of the approaches feature the notion of key interventionists (individuals most involved with the child and family). These named individuals would be able to call on and receive support from specialist practitioners when required on a consultation type basis. This type of approach has been recommended to avoid the typical fragmented approach that is often associated with the care of children with complex needs. Child and family centred approaches that stop the reported isolation of families from decisions about their child's needs and development are more appropriate, cost effective and productive for all involved (Limbrick 2007).

The impact and complex nature of behavioural needs for the individual, carers and service providers has rendered effective intervention as essential (Hassiotis and Hall 2004). However despite the strong evidence base for the success of early behavioural intervention, few people with behavioural needs appear to be able to access effective behavioural support (Allen et al 2005).

The need to aid parents to effectively support and intervene with their child would appear to be an obvious place to begin. Gates et al (2001) conducted a comparative study of three forms of training offered to parents, and examined the impact of each on a child's behavioural needs. The study considered, Gentle Teaching, behaviour modification and control interventions. For the parents who were coached in Gentle Teaching or behaviour modification techniques the study reported a lower need for support services. Less respite care was also noted compared to families who had not been trained to use the interventions. The study suggested that provision of brief training to parents can result in an improvement in a child's behavioural needs, and further offer practical help to the family in their ability to support their child. Many studies have considered the positive impact of family centred interventions. Parents are reported to experience a reduction in their levels of stress and perceived burden through the improvement in their child's level of social competence and the related decrease in their behavioural needs (Yoshikawa 1994, Anthony et al 2005). Furthermore, appropriate support, education and psychological resources have been shown not only to be able to alleviate stress for parents but also to increase their levels of resilience (Belsky 1984, Koeske and Koeske 1990, McLoyd 1990, Webster-Stratton 1990, Stormshak et al 2002).

The literature associated with the provision of training to empower families to support their children suggests that it is highly effective. This is in contrast to an ongoing academic debate associated with the longitudinal impact of training staff within service provision. It is unsurprising that family members are highly motivated to support their children. However the literature suggests that staff motivation can hamper the effectiveness of the training they receive and affect the long term sustainability of positive intervention (Cullen 1988, Campbell 2007).

The complex area of the care and support of children with behavioural needs and their families will propel families into multiple areas of provision and services where they will meet a multitude of professionals (Limbrick 2007). A call for specialist service provision to meet the needs of children with a learning disability and behavioural needs has been clearly indicated within the literature (DH 2007). However the provision of specialist services suggests that they are able to provide a level of skill and expertise that is different and more relevant to the needs of the child and family than that available within

mainstream provision. Evidence associated with the capacity of professionals within such services warrants brief consideration within this review.

Within special educational provision studies have highlighted that staff within special school environments find the support of children with behavioural needs particularly difficult and stressful (Paffrey 1995, Male 2003). The studies cited report staff feelings of isolation, and a belief that the special educational school system existed on the periphery of mainstream education. Paffrey (1995) and Male (2003) concluded that professionals felt helpless within the education system, and believed that they were unable to advocate effectively for the children that they supported.

Professional attitudes towards existing outside usual systems can be equated with the concept of stigma commonly associated with people with a learning disability (Goffman 1963). Mitchell (2000) considered this issue in the context of learning disability nursing. He suggested that as a professional group this field of nursing can experience a form of 'parallel stigma' from their peers due to the value attached to people with a learning disability. This is exemplified through the misfit of the learning disability nurse with the traditional medical model of nursing. If those within specialist services and professions for people with a learning disability are not able to navigate a coherent and valued presence within services then concern must be raised for the people they attempt to support. The disempowerment of professionals within specialist and mainstream services is likely to reinforce the vulnerable nature of children with a learning disability.

2.3.4   Residential provision for children with behavioural needs

The type of support received by children with a learning disability and behavioural needs can differ from that available to their non learning disabled peers. For example the numbers of people placed in residential provision with behavioural needs has risen (Emerson and Hatton 1998, Beadle-Brown et al 2006), indicated by the disproportionate number of children placed away from their families in comparison to their non-disabled peers (Goodman et al 2006). Literature associated with the extent of and reason for residential provision for this group of children will be briefly considered within this section.

Residential support for people with a learning disability has been available for many years in varying configurations. In 2006 Beadle-Brown reported that 44,000 people with learning disabilities were living out of their local area in residential care settings in England (out-of-area placements), predominantly small residential homes for an average of 5-6 people. People with a learning disability and behavioural needs have been found to be more likely to require hospital admission (within learning disability and mental health services) when adequate support was not available for them in their community (Emerson et al 1996). The paucity of local support and provision for people with behavioural needs as a predisposing factor for the provision of out-of-area placements for people has been considered in many studies (Jenkins and Johnson 1991, Parahoo and Barr 1996, DH 2007), with underdeveloped local capacity considered to place a significant financial burden on the provision of services for people with a learning disability (Ryan 1998).

The effective support of people with behavioural needs requires a significant service response (DH 2007), whilst there appears to be an identified shortfall of appropriate support within community provision, and a growing shortage of placements for people with behavioural needs (Emerson and Hatton 1998, McGill 2008). These two factors may be directly correlated, as depleted community resources may be the result of increased demand for residential provision, which will continue to detract resources from local provision, with a decreasing circle of provision ensuing. The reduced number of appropriate placements for people with a learning disability and behavioural needs has been attributed to the increased life expectancy of people with a learning disability (DH 2004), a situation which will be exacerbated in the future in light of recent predictions of an increase of 14% in the learning disabled population (Scottish Government 2012).

The use of residential provision to support people with a learning disability is not new; its increased prevalence has been noted and considered to be the result of a lack of local community based support (Goodman et al 2006). Associated literature with this area has provided a lengthy debate focused on integration and inclusion. The concerns raised appear to focus on the re-institutionalisation of people with a learning disability, exacerbated by a reported resemblance of contemporary residential provision to original long-stay hospital based forms of support (Pritchard 2003, Goodman 2006). Historically commentators purported that the use of long-stay residential provision removed people

from their local communities (Morris 1969). Often located within rural settings, residential provision has been observed to alienate people from their communities and remove opportunities for their community participation (Simons 2002). The increased exclusion of people with complex and behavioural needs from their communities since the original 1992 Mansell report (DH 1992), has been perpetuated by the increased use of residential placements (Goodman et al 2006).

In 1993 the Department of Health suggested that the rise in the use of this type of provision reflected a shortage of local specialist residential provision, and a lack of alternative quality provision (DH 1993). This situation however does not appear to have altered as Beadle-Brown et al's study (2006) highlighted 51% of people who had been moved from one county in England to an 'out-of-area placement' were under the age of 40. Appropriate and significant responses to the original concern of people being placed away from their local communities had therefore not occurred. The study reported that placements were directly related to the inadequacy in local services (this was particularly relevant for individuals with behavioural needs), and the relocation of people from long-stay hospitals. Significantly a third of the families in the study reported that they had not been able to choose a placement for their son or daughter and experienced anxiety related to criticism of their relative's care. This included issues associated with their relative's basic care, as families believed that the placement could be withdrawn or jeopardised if they were to complain.

The evidence suggests that out-of-area provision for people with a learning disability and behavioural needs is often a response to emergency and crisis type events. Emergency care can be the only option available to families following protracted system delays that can involve boundary and funding disputes (Abbott et al 1991). The process of placement for people with a learning disability can therefore often be the result of a 'crisis' situation when, it could be argued, a family may not feel able to advocate effectively for their child (Abbott et al 1991, Goodman et al 2006).

In 2006 Goodman et al highlighted that four times the number of people had been placed out of their local area than in the previous 10 years, noting an increase in the number of children with 'complex needs' that had been placed in adult service provision. From a total of 111 individuals placed, only 18 individuals were reported to have moved for

positive reasons such as to be closer to their family. Placed individuals were predominantly found to have behavioural needs with autism as a secondary diagnosis and 43% of individuals were described as having a severe learning disability. A lack of local capacity, lack of specialist services and families unable to cope were cited as reasons for placement.

The support of people with behavioural needs is complex. Slevin's (2004) study based in Ireland, reflected that the resettlement of people with learning disabilities and behavioural needs from institutional provision to community provision had been the most difficult. Slevin attributed the problems to the beliefs of service commissioners that provision within local communities would effectively be able to meet people's behavioural needs. The role of the learning disability nurse in the successful relocation of individuals was deemed to be pivotal. However this assumption does not correlate with evidence that suggests that staff in learning disability services have limited access to appropriate training in the management of behavioural needs (Lowe et al 1996).

Issues associated with the quality and monitoring of out-of-area placement for individuals with a learning disability have intensified, associated with recent media exposure of the abuse of people with learning disabilities whilst in residential care (Winterbourn View, BBC 2011). The effective monitoring and quality of out-of-area placement provision was considered by Beadle-Brown (2006). The study reported that professionals on local learning disability community teams expressed concern over a lack of regular reviews by care managers which was exacerbated by issues such as distance, travel and communication. Barriers to the review of out-of-area provision have been raised in studies (Price 2004, Goodman et al 2006). Whilst the quality of guidance available for the commissioning of learning disability services was raised by Mansell in 2007 (DH 2007), he concluded that the guidance was incomplete and inconsistent, and not conducive to the purchase of appropriate provision for people with a learning disability. The guidance, he suggested, actually reinforced incentives that would have a long term detrimental effect on service users and their families. The situation therefore has not improved despite the consistent evidence associated with the predisposing factors for the admission of people with behavioural needs into residential provision. The vulnerability of individuals who are away from their families and carers must be considered in light of recent media coverage (Winterbourne View BBC 2011).

More recently there have been positive moves toward increasing the support available for families. The White Paper 'Our Health. Our Care. Our Say.' (DH 2006) is committed to the revision of the 1999 National Carer's Strategy and the provision of emergency beds to support carers. Although the strategy was welcomed by family organisations such as Mencap (2006), the danger of moving towards a unilateral strategy of provision designed to meet all needs must be considered. Indeed families have raised concerns that a single focus of provision and support may lead services back towards residential and congregate living (Mencap 2006). A one-size-fits-all approach is unlikely to be successful option for children with behavioural needs and their families.

The placement of a child away from their family and community must be considered as a drastic measure to support a child's needs. However a lack of adequate local service provision to meet the needs of the family and child exacerbates the risk of out-of-area placements for this group of children. Recent evidence highlights that expenditure on support for people with learning disabilities has continued to grow faster than for any other client group, 24% from 2004-5 to 2009-10 (www.communitycare.co.uk. 2011). However the quality of support provided, particularly residential provision, appears to be the subject of numerous enquiries both within the NHS and across independent healthcare providers: Winterbourne View 2011, Sutton and Merton Primary Care Trust 2007 and Cornwall Partnership NHS Trust (2006). People placed away from their family home for support are undoubtedly more vulnerable to abuse. The literature has identified that periods of crisis and breakdown often pre-empted by poor provision appear to be the main factor in the placement of children. Clearly recognised as a vulnerable group, inappropriate placement places them at an unacceptable level of risk from exclusion and abuse.

2.4   Education

The literature associated with educational provision for children with a learning disability is abundant. Particularly significant for children with behavioural needs and a learning disability the move towards inclusion and integration within an educational context has been extremely important. The educational inclusion of all children was created through legislative changes that affected the way children were viewed and supported. In June 1994 the Salamanca Agreement urged nations to 'adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular

schools, unless there are compelling reasons for doing otherwise' (Salamanca Agreement 1994, p ix). The much earlier Warnock Report (1978) however had considered the practicalities of supporting children with disabilities and behavioural needs within mainstream education and stated that:

> *…the emotional needs of some children may be incompatible with those of others. Thus very careful arrangements will be needed, if children whose maladjustment takes the form of seriously disruptive behaviour are to be educated in ordinary schools. For many of these children separate provision in special schools may be essential… (Warnock Report 1978, p117).*

As an early start to the concept of inclusion the Warnock Report was fundamental in a shift towards inclusive practice in the United Kingdom. The report recognised that children described as handicapped had historically not been supported or considered in relation to educational legislation and provision. At the time of the report education for this group of children was often adopted by charitable organisations and tended to focus upon the needs of specific groups of children such as those with sensory impairments, the deaf and blind. Prior to this children considered to have special educational needs often did not attend formal educational settings but were supported in activity type centres, usually attached to forms of institutional provision (Paffrey 1995).

In England it was the Education Act (DES 1993) that reinforced the need for inclusive practices within schools. The act introduced the Special Educational Needs Tribunal which removed the power of Local Education Authorities to oversee their own appeal systems. Significantly the change allowed families to consider their child's inclusion into mainstream services with an option to appeal if the child's needs were stated as an obstacle to placement. The act appeared to prepare for the change and implementation in policy in a somewhat defensive style. Although not necessarily predicting that inclusion may be difficult to achieve for some children, it empowered parents with the right to independently challenge decisions that could affect their child's local inclusion in educational provision. The act did however assume that families would be willing and able to challenge services in this way. To this end Local Education Authorities were advised to provide parents with access to parent partnership schemes not only to support families but also to minimise the need for parents to resort to the official appeals process (DES 1993).

The importance of the educational environment and educational experiences for children with a learning disability and behavioural needs cannot be considered at length within this review. However the group of children who are the focus of this research have discrete and individual needs. It is those needs that appear to have reinforced an educational system that has created 'labels' not only applied to children, but also attached to forms of provision that children with behavioural needs may attend. Labels are formed from language that usually reflects current terminology, an example would be emotional and behavioural difficulties (EBD). This term may be used to describe a type of provision, an 'EBD school', or used within a statement of Special Educational Needs to describe a child's behaviour. The Mental Health Foundation (2002) emphasised how a label of EBD can reflect 'attitudes and practices' within mainstream schools. A school may use the terminology to describe pupils who they felt were difficult to manage; furthermore if an education authority has an EBD provision within their area pupils may be more likely to receive that label. These elements may promote the application of a label to an individual child but not always represent their true needs (Galloway et al 1994, Daniels et al 1998). Educational policy and legislation for children with a learning disability and behavioural needs will be considered within this section of the review, followed by a section on types of educational provision for this group of children.

2.4.1   Legislation and policy

It was a French philosopher Michael Foucault (1979) who discussed the concept of 'dividing practice'. He argued that it could be used to create differentiation, hierarchies and categories to exclude students and create 'normality' within a mainstream system. Recent research has focused on the process of inclusion, whilst Foucault's theories would appear to apply across specialist as well as mainstream educational provision.

To consider policy and practice associated with inclusion, the United Nations Educational Scientific and Cultural Organisation (UNESCO) promoted the principle of inclusive education for children with special needs within the Salamanca statement (UNESCO, 1994, 1996/1997, 1999). The statement advocated that children with a learning disability should be able to attend school classes and activities with their peers (WHO 2007).

The 1981 Education Act was fundamental in the promotion of integration in educational provision (DE 1981, Paffrey 1995). It was the later 1986 Education Act and the Elton report (Education Act 1986, DES 1989) that reiterated the need for integration and an ethos of common responsibility for all children within the education system. At this time the inclusion of children with a learning disability was delivered through the provision of special units that were designed to integrate children into mainstream schools (Farrell 1995).

As considered by many commentators it was the 1988 Education Act that introduced a 'market driven' agenda to education. The move towards national testing and the publication of school results has been perceived as negatively affecting the inclusion of children with special educational needs (Paffrey 1995). The providers of education began to be externally judged on their performance, rated through the publication of their academic achievements and compared against their national peers. For children with a learning disability (and by definition special educational needs) and behavioural needs the competitive agenda placed them into a vulnerable position (Gray 2006, Paffrey 1995). Incentives to support children with additional needs within mainstream educational establishments were limited. Policy had driven the needs of children into a situation that did not support their integration and may have led to the more recent situation described by the Children's Commissioner of informal exclusion (Connolly et al 2012). An agenda of competition and a results-led focus has challenged the positive integration and inclusion of children who cannot be regarded as academically successful.

Education however has many roles in the delivery of support to children. It has been linked in the literature with many facets of community cohesion, and has been advocated by many as a way of combating discriminatory attitudes as well as supporting an inclusive society (Eleweke & Rodda 2002, Jupp 2002). The Montreal Declaration on Intellectual Disabilities (Mental Disability Rights International 2004, article 4) stated that 'For persons with intellectual disabilities, as for other persons, the exercise of the right to health requires full social inclusion, an adequate standard of living, access to inclusive education, access to work justly compensated and access to community services.' Education as a catalyst for inclusion was further reinforced by the Centre for Studies on Inclusive Education (CSIE, 2011), which proposed that the removal of children from local schools would deprive communities and children of mutually

beneficial experiences. Inclusion within educational environments should not be separated from inclusion in the community. Indeed the educational experience of a child should be viewed as a holistic experience for the child the family and their community. It is the appropriate provision of multi-dimensional support designed to meet the individual needs of children that can, and should be, able to facilitate the inclusion of children with behavioural needs and learning disabilities within mainstream education (Emerson 2003).

2.4.2 Educational provision for children with learning disabilities and behavioural needs

The education system was socially constructed for the 'normally' developing child. This has led to what Holt (2003) described as the development of 'geographies' of inclusion and exclusion within primary school education. Indeed exclusion and exclusive practice have been considered to have been facilitated through the development of policy and practice that have reinforced this approach for children considered outside the 'norm' (Holt 2003), with the Special Educational Needs and Discrimination Act (SENDA 2001) perceived to further support a 'disabling' approach to disability applied within education (Holt 2003). Legislation plus a flawed philosophy of inclusion has resulted in an approach to inclusion that has been pursued 'irresponsibly' (Garner and Gains 2001).

To consider outcomes for children who had attended special schools and pupil referral units the Mental Health Foundation (2002) reported that children exhibited a lack of self-confidence, resilience and emotional intelligence. The foundation concluded that a child's behaviour, if described as aggressive or disruptive in education, was reported to indicate the presence of emotional difficulties, whilst children from specialist provision were considered to have social difficulties that extended outside their educational experiences. The impact of special education for children may therefore indicate that their needs had not been considered holistically but had been attributed to the child or their environment. This approach concurs with recent findings associated with the reluctance of schools to support children with behavioural needs published by the Children's Commissioner (Connolly et al 2012).

The most recent Education Bill (DE 2011) and Education Act (DE 2011) could however be considered to have made an attempt to further inclusive practice through renewed focus on the child as an individual, and their progress in relation to their special

educational needs (SEN). The act introduced an 'Equalities Impact Assessment' for schools. The Education Bill considered the disadvantage that children with SEN faced and highlighted that in 2009-10 pupils with SEN accounted for 74% of the total exclusions from schools. These statistics have led to a change in the review process for the exclusion of children from school, allowing parents to request the presence of an independent SEN expert at their child's review.

The ability of parents to advocate on behalf of their children associated with the educational process was considered by Gray (2006) in an audit of 'Support Services and Provision for Children with Low Incidence Needs'. Gray proposed that special school provision disempowered children and families as parents were unable to lobby as a cohesive group on behalf of their children. Exclusion of children with behavioural needs from schools was perceived in the audit as a symptom of the inability of schools to react effectively to pupils with behavioural difficulties (Gray 2006), with inclusive schools more likely to retain pupils with additional needs. Factors considered to successfully support the integration of children within a school include, the number of children with extra support needs, the catchment area and the resources available. The attitudes and values of a school, as well as policies related to the management of behaviour were described as crucial in supporting staff to manage pupils effectively (Gray 2006, Connolly et al 2012).

How educational staff viewed their role for children with SEN was also considered in Gray's (2006) audit. Within educational exclusion facilities teachers were reported to experience low self-esteem. Further they expressed their empathy with children in relation to the limited support that they received from the local education authority. Studies identified that staff within education systems report a struggle to advocate for children, exacerbated by a belief that they were unable to effect change or negotiate appropriate solutions for the children they supported (Paffrey 1995, Gray 2006). This situation equates to the concept of 'parallel stigma' (Mitchell 2000) as applied to the experience of learning disability nurses who considered themselves as practicing outside the norms of their professional peers.

2.5   Exclusion

The current study is concerned with the lived experience of children with a learning disability and behavioural needs. Children with a learning disability differ greatly from their non-disabled peers. Although they should be considered as children first (Children Act 1989), the evidence suggests that within society and services their experiences are often dominated by their needs, and the perception of others. The review has considered the provision of services and education, within which issues associated with the exclusion of children with a learning disability and behavioural needs have been identified. This section will briefly consider the concept of stigma, discrimination, social exclusion and inclusion as applied to this population of children.

2.5.1   Stigma

Within the literature associated with learning disabilities it is impossible to ignore the connections between labelling, stigma and discrimination that are both explicit and implicit. Stigma has been readily associated and applied to the experiences of people with a learning disability (Goffman 1963).

Goffman (1990, p11) attempted to define the concept of stigma:

> *While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind, in the extreme a person who is quite thoroughly bad, or dangerous, or weak. He is thus reduced in our minds from a whole and usual person to a tainted discounted one. Such an attribute is a stigma.*

Goffman suggested that stigma could lead to prejudice and the marginalisation of individuals within society. The process of stigmatisation is characterised through the use of derogatory language and terms such as 'deviance' applied by a society to individuals. Deviance has been linked to the existence of social norms within a culture or society. Behaviour considered out of context within those social groups can be considered to be 'deviant'. The label of 'deviant' can be applied to individuals by a social group, usually in the guise of a sanction or rule. Such conditions create the experience of 'stigma' manifested through discrimination and prejudice (Becker 1963, Jones et al 1984, Hubert 2000). Related to the behavioural needs of children with a learning disability, observed behaviours are considered to be outside the social norm, resulting in a predisposition to

stigmatisation. People with a learning disability use behaviours to communicate their needs and feelings (Emerson 1995), however the manifestation of behavioural needs is a powerful medium in a society that is concerned with social norms. An individual's behavioural needs therefore fit with Goffman's (1963) concept of deviance.

The 'labelling' of children within services is unavoidable. It is usually related to the matching of needs to service provision. Services however can use an individual's behavioural needs as a diagnosis or 'label'. This may 'stereotype' an individual who is then able to fit into available resources or support systems. Consequently people labelled as deviant, or stereotyped by their need, may often be placed in similar forms of provision, for instance special schools or EBD provisions.

For children with behavioural needs within mainstream provision their presence is often marred by the pressure on services to support the diversity of children who attend, the role of the service related to community cohesion and the need in relation to schools to compete within an educational market place (Paffrey 1995, Gray 2006). Such pressures may reinforce the desire to 'remove' children with complex needs from provision in order to create uniformity and to comply with external pressures for educational results (Connolly et al 2012). This will have an effect on the way a child's needs are described and perceived as they move through educational establishments. This can only serve to exacerbate the process of 'labelling and stereotyping' for a child, as exclusion from an educational placement is perceived as a failure of the child to fit in, rather than failure of provision to meet a child's needs (Gray 2006).

However an increasing number of studies have begun to consider that children may prefer to exclude themselves from 'normal' provision in order to preclude themselves from potentially exclusive experiences (Lloyd et al 2003, Farrell and Polat 2003). The recent Children's Commissioners report highlighted a level of collusion between school staff and children, to circumvent systems of attendance through informally agreed periods of non-attendance and exclusion (Connolly et al 2012). This type of practice was most prevalent associated with pupils considered disruptive due to their behaviour and was particularly evident for children with special educational needs.

2.5.2 Discrimination

The WHO (2007) suggested that people with a learning disability experience some of the most difficult living conditions in the world, compounded by universal discrimination and an absence of legal protection (Despouy 1991, Rosenthal and Sundram 2003, Quinn and Degener 2002).

Disability was historically perceived as a 'harmed condition' (Harris 2000, Holt 2003), with clear division made between the 'harmed' and the 'not harmed' groups within society. For those individuals within the 'non-harmed' group, a desire to avoid becoming part of the 'harmed' group was clearly expressed in the form of discrimination. People have feared that association with the harmed group may render them as not 'normal' or result in a lesser mental or physical state (Gilman 1998). Society has aspired to create a unilateral or 'normal' group of people through the removal of, or reduction of difference displayed by individuals (Hollins 1997). The exclusion of individuals from 'normal' society was evident within institutions, where people with disabilities were housed in remote congregate hospitals, behind walls, away from local communities. Individuals were 'de-humanised' and perceived to be less than human. The de-personalisation of individuals led to situations in which exploitation and exclusion could be considered legitimate (Wolfensberger 1972, Sibley 1998).

For children with behavioural needs their ability to be part of their peer group is affected by the discrimination that they experience. Ericson (2006) highlighted that children with emotional and behavioural difficulties experience difficulty with the formation and maintenance of interpersonal relationships with their peers and also professionals. Due to their special educational needs the evidence suggests that that are more likely to be excluded from educational provision (Gray 2006, DFE 2011, Connolly et al 2012). Their needs create discrimination. Children with behavioural needs must therefore be considered as vulnerable within social groups and at risk of stigmatisation, discrimination and consequently exclusion.

2.5.3 Social exclusion

The result of stigma can be exclusion. The concept of social exclusion originated in France in the 1970s (Pierson 2002), and was originally used to describe people with no

regular employment or income that were not considered to be part of mainstream society. The term was used in the Maastricht Treaty of 1996, and adopted by the Labour party in 1997. Pierson (2002) noted that heightened political interest in excluded groups was based on a notion that they may threaten social cohesion, mainstream society and potentially political power.

The political backdrop and philosophy of care for people with learning disabilities was considered by Hall (2005), who suggested that the marginalisation of people with a learning disability was a direct result of the closure of institutions, and an attempt to include people within mainstream society. Hall's view challenges the traditional philosophy that the institutionalisation of people caused exclusion. Kozma et al's (2009) review of literature associated with the resettlement of individuals however concluded that significant positive change had been reported for individuals related to their move to community provision. Significantly Kozma et al also noted that the frequency of behavioural needs observed in individuals had significantly increased following the change in provision. This may suggest that the move for people with behavioural needs had been difficult, and supports Slevin's (2004) assertion that people with a learning disability and behavioural needs can be the most difficult individuals to resettle within a community. The evidence supports the notion that this group of individuals have different needs from the rest of the learning disabled population, needs that require a level of specialist support above and beyond that available within mainstream and specialist provision (Slevin 2004, DH 2007). The literature suggests that aside from the political backdrop of inclusion, individuals with a learning disability remain stigmatised and marginalised within society (Paffrey 1995, Metzel 1998, DH 2001).

Commentators have proposed that 'social exclusion' may be a result of an expectation within society that individuals with a learning disability hold responsibility for integration into their community (Sibley 1998, Colley and Hodkinson 2001). This view may perpetuate the belief that non-participation of people with a learning disability in society is related to choice. The perceived choice of an individual would therefore negate a community from its role in the process of social integration and inclusion. Individuals not included within their community have been described as existing on the 'outside' of social groups, excluded as individuals (Emerson et al 1994). Sibley (1998) reported that people with a learning disability had to deal with the geography or physical sense of

being 'out of place'. Those that had adapted to social exclusion were able to exist within clear social and geographical networks of 'safe' spaces (Hall 2004), or as described by Dyck (1995) life in a 'shrinking' world. This situation may be ultimately more acceptable to a person than living on the outside of their community.

Social exclusion is characterised by, poverty, low income, unemployment, lack of access to social support and networks, exclusion from services and physical location issues (Pierson 2002). All the factors highlighted have been considered to affect people with a learning disability, and therefore places this group of individuals at a high risk of social exclusion (DH 2001). The implication for a practitioner when considering the design of interventions to support an individual's presence within their community, must be to consider the pre-disposition of people with a learning disability to exclusion (Madanipour et al 1998). An over-protective stance in support of inclusion may serve to deskill and alienate people. The premise of inclusion may be overridden and place people within an 'asylum without walls' (Wolch 1981, pg 225, Parr and Butler 1999, Hall 2004). The discourse can assume that people with a learning disability wish to be included. As discussed by Sibley (1998) people with a learning disability are able to develop their own sense of collective identity, one which can support resistance and survival. This can create a life and presence within communities that can co-exist with an absence from mainstream networks (Pinfold 2000).

2.5.4   Inclusion

Exclusion and inclusion cannot be considered as separate entities in the context of learning disabilities. The two issues are inextricably linked and may be experienced simultaneously by this group of individuals. The discussion of social exclusion has highlighted that exclusion can be an individual's choice, often based on their experience of inclusion (Sibley 1998, Hall 2004). Inclusion has many interpretations within the literature and also in practice. Inclusion related to citizenship and community participation will be the focus of this section.   Miller and Katz (2002, p9) defined inclusion as: '... a sense of belonging: feeling respected, valued for who you are; feeling a level of supportive energy and commitment from others so that you can do your best.' People with a learning disability may have achieved community integration, but in the absence of social integration (Gilbert et al 2005). Foucault (1973) originally discussed the concept of 'active citizenship', which has developed into a discourse associated with

normalisation and later citizenship. It is citizenship that can enable individuals to exercise their liberty (Gilbert et al 2005). To this end it could be argued that the notion of inclusion may involve criteria that people with a learning disability may not be able to achieve, particularly in light of their limited political and public presence (Hall 2004).

It is argued that the lack of understanding of citizenship within service provision has resulted in traditional delivery of support which has fostered inclusion and dependence, or resulted in the opposite, a position of independence and isolation for individuals (O'Brien and O'Brien 2002, Gilbert et al 2005). This situation can be seen in the educational context when children who receive 1:1 supervision discuss their feelings of isolation from their peers who do not have or need support. The provision of support itself can signify difference. Current provision and inclusive practice has been considered to focus on specialised spaces in the community (Hall 2004, Gilbert et al 2005). Such spaces are usually managed by professionals whose role should be to support and empower individuals towards self-management, inclusion and independence.

One of the areas associated with children in the current study and within the literature pertaining to people with a learning disability has been the issue of safety and risk. The literature suggests that the two elements can inhibit the ability of services to meaningfully support individuals to take advantage of opportunities and reach their potential. Whilst O'Brien and O'Brien (2002) propose that an individual's safety can be related to the extent and quality of their relationships, provision has often been criticised for focusing on the safeguarding of individuals. This approach can prevent people from experiencing meaningful experiences in their everyday lives (O'Brien and O'Brien 2002). For children to be able to gain positive life experiences, judgements related to the level of risk associated with their inclusion or indeed exclusion from environments or activities should be made in relation to values, and in the context of a person-centred risk assessment (Alaszewski and Alaszewski, 2005).

To this end it is argued that people with a learning disability do not always experience positive gains through the process of inclusion and social integration, with individuals with a learning disability reporting experiences of exclusion and rejection from their communities (Laws and Radford 1998). Loneliness has been described by Pitonyak (2007) as a symptom of 'isolation' rather than a product of disability. The formation of

positive social networks can create meaningful relationships. How this can be facilitated has been considered by some to be dependent on a process of meaningful integration and inclusion, ultimately promoting happier, healthier and more resilient individuals (Jupp 2002, O'Brien and O'Brien 2002, Pitonyak 2007).

However current professional working practices can erode natural relationships for people with a learning disability (O'Brien and O'Brien 2002, Pitonyak 2007). Professional roles are often detached and objective and delivered within adapted or special environments such as treatment centres, special educational areas, sheltered workshops or homes for people designed for those with a learning disability. This situation does not support or reinforce the delivery of a co-ordinated community approach to the management of people's needs. Services should be designed to promote the ordinary and everyday life experiences of people with a learning disability (Hall 2004, Pitonyak 2007). It has been proposed that individuals can often be in receipt of services they neither need nor want (Pitonyak 2007), a situation which suggests a service-focused agenda rather than a person-centred approach.

Most importantly for children, their ability to interact with their peers is paramount (The Children Act 1989). Children's behavioural needs can affect their ability to sustain relationships whilst studies conclude that children interact differently with peers who have behavioural needs (Byrne and Hennessy 2009, Marsden and Kalter 1976, Giles and Heyman 2004). Children have also been shown to have a stronger preference to befriend or help a peer without behavioural needs (Siperstein 1980, Graham and Hoehn 1995), although aggressive or difficult behaviour was described as the primary cause of exclusion of children from their peers (Deater-Deckard 2001, La Fontana and Cillessen 2002). For children with behavioural needs exclusion has been associated with an increased risk of psychological difficulties in later life (Byrne and Hennessy 2009). For this group of children the evidence suggests that their level of exclusion and vulnerability is exacerbated through the inappropriate application of inclusive practice and ineffective support and interventions to manage their behavioural needs.

2.6   Conclusion of literature review

The literature review has considered salient evidence related to children with behavioural needs, their experience of inclusion and exclusion, their families, professionals and the

provision of services. The relevance of existing research has provided a baseline of contemporary and historical information to contextualise the current study. The literature discussed pertains to the original aim of acquiring family and professional perspectives on the lived experience of children with a learning disability and behavioural needs. As well as providing a back drop for the study it has allowed consideration of how the research question is related to existing knowledge in the field. The needs of children with a learning disability and behavioural needs are reported as complex. Recent policy and practice appears to support the exclusion of this group of children. Appropriate training and skill within services to support the needs of children with behavioural needs appears to be limited. This may explain evidence that suggests that it is not only families that feel disempowered within services but also staff within specialist provision (Paffrey 1995, Male 2003).

The literature review has highlighted the complexities associated with the provision of effective support for children with a learning disability and behavioural needs. This study considers the impact that such complexity has on the experiences of the children discussed within the research. No children were directly involved in the study. The information was gathered from individuals involved in the day-to-day support of this group of children - parents and professionals. The study cannot therefore be considered to address the truth of the situation for the children, but will support the understanding of their lived experience through the perspectives of those most closely involved in their lives.

The following methodology chapter will explain the process undertaken to gather evidence for the study. The chapter will define the epistemological stance adopted, consider the underpinning theoretical perspective, the methodology chosen for the study and methods used for the collection of data. The model chosen for the analysis of data will be described and considered in light of its relevance to the current research.

3   Chapter 3: Methodology

3.1   Introduction

The research was designed to consider family and professional perspectives on the lived experience of children with a learning disability and behavioural needs. This chapter will consider the phenomenological approach adopted for the study. The research area will be outlined briefly, followed by a section related to my theoretical perspective and experience related to the research. Crotty's (1998) framework for research will be used to consider the epistemological background of the research, the theoretical stance for the study, and the relevance of the methodology and methods used for the collection of data. The model adopted for the analysis of data will be highlighted, and allow the reader to consider relevance and application of the chosen analytical tool to the research.

Although the area for study was clear at the start of this process the research question was less so. The literature evidenced the complexity of need associated with people with a learning disability and behavioural needs. To consider how this complexity affected children I sought support from a local parent support group. Following confirmation from parents that the area of research was considered to be of significance, worthy of exploration and most importantly could be of use to children and their families, the research question was developed. The study aim was to support children and their families through the discovery of useful, relevant and applicable findings. It was a child's 'lived experience' of a learning disability and behavioural needs that was to be the focus of the study.

An initial contact was made with an individual from 'Partners in Policymaking' (PIP). The organisation is a national parent and carer led action group whose goal is '... the development of a national network of people-champions who believe that all people should have the right to live the life they choose' (**www.partnersinpolicymaking.co.uk** 2011). Initial contact led to an informal meeting where the research area was discussed at length with representatives from the organisation. The question formulated as a result of the discussions was, 'what are the lived experiences of children with learning disabilities and behavioural needs, through the perspectives of families and professionals?'

3.2   The research area

The focus for the study was to gain an understanding of the lived experience of children with learning disabilities and behavioural needs, through the perspective of families and professionals involved in their lives. As a group of individuals, people with a learning disability have been described as one of the most vulnerable groups within society (DH, 2001). Central to the development of the study was a methodology that would support the empowerment of participants through their contribution. Although children with learning disabilities and behavioural needs did not, themselves, take part in the research they were the clear focus of the study. Parent participants spoke about their own children, and professional participants discussed children that they had supported in their professional roles.

A qualitative design was chosen for the study. This form of research has been considered appropriate in the quest to obtain information pertaining to, and involving, vulnerable groups (Becker 1992). Qualitative studies can support research designed to consider meaning and how individuals make 'sense of their world' (Willig 2001). The process of qualitative research involves learning from people rather than studying them, through the opportunity to interact utilising open and unstructured forms of communication (Spradley 1979). The emphasis of the research was on participants as active contributors rather than passive recipients. A methodology was required for the current study that would facilitate an understanding of the lived experience of children with learning disabilities and behavioural needs. Personal experience of a phenomenon has been highlighted as a way in which to consider the enlightened and coherent understanding of an issue (Bryman 1998, Ward-Schofield 1993).

Children with learning disabilities have been the subject of research in many areas, for example behavioural needs, education and social care. The study will be able to supplement and contribute to the knowledge in the area, while the findings can support future developments in the field (Field and Morse 1992). Although the concepts of inclusion and exclusion were not part of the original research question they clearly emerged from the literature considered within the review. As central tenets to the current study they will be frequently revisited within the research. The findings associated with the 'lived' experience of children as described by families and professionals will allow the reader to contextualise the salient issues for the children at the centre of the research.

3.3   The researcher

As noted in chapter 1 as a Registered Nurse for Learning Disabilities (RNLD) I have been involved with individuals with learning disabilities and their families for many years. Without doubt the study was influenced by my experience and perspective. Consistent with a qualitative approach a neutral, impersonal and objective view of a subject is not the goal of a qualitative researcher (Carter and Henderson 2005). The literature however suggests that nurses can be drawn to qualitative methodologies as they value an individual's holistic experience, and allow nurse researchers to utilise their familiar and everyday skills (Oiler 1982, Wimpenny and Gass 2000, Carter and Henderson 2005). Nurses are taught to be good listeners, to empathise and create rapport in a short period of time. Qualitative methodologies allow participants to use their own words, and support an interpretative approach to data that can lead researchers to 'new' or unexpected findings (Bryman 2008).

There are however issues associated with prior knowledge and familiarity. These include the temptation to make assumptions that may be based on personal motivation and prior experience (Carter and Henderson 2005). Husserl (1931) addressed this issue in his original form of phenomenology. He argued that attempts should be made to remove pre-conceived ideas from the research process and the interpretation of data. The concept is known as bracketing, and has been described as an attempt to ignore what is known about a subject to avoid the influence of preconceived ideas (Dowling 2004, Lopez and Willis 2004). This approach was not commensurate with the current study as the research question was borne out of experience in the area, which later supported the collection of data from interviews and methods of analysis. Although unable to predict the information given by participants, to deny my background in an attempt to 'bracket' out bias was not achievable or consistent with the aims of the study (Husserl 1931).

The value and relevance of a researcher's experience has been supported by several writers. Thompson (1990) argued that experience was inextricably linked to interpretation which could support the sensitive and insightful analysis of data. Heidegger (1962) considered the concept of experience in research within the hermeneutic phenomenological approach. He cautioned that 'Understanding is never without presuppositions. We cannot, understand anything from a purely objective position. We always understand from within the context of our disposition and involvement in the world' (Johnson 2000 p23). Sound understanding therefore can be achieved through a dialogue of interaction, where the researcher stays open

to the opinions of other. This would be impossible to achieve through objectivity or a bracketed approach (Gadamer 1975, McManus and Holroyd 2005). Heidegger contended that the only real way to conduct hermeneutic inquiry was for the researcher to have prior knowledge. Unlike Husserl's quest for 'objective' phenomenology, my acceptance that I, as the researcher, could be an active part of the study within a hermeneutic phenomenological framework was a central tenet of the study (McConnell-Henry et al 2009).

Heidegger's hermeneutic phenomenology asserted that prior understanding of an issue supported interpretation and understanding. He suggested that the researcher was a legitimate part of the research world of the participant (Heidegger 1962, McConnell-Henry et al 2009). He proposed that time, being, and context shaped the understanding of phenomena, with interpretation and understanding related to previous knowledge (Gelven 1989, Dowling 2004). A researcher is involved in the interpretation of something in which they already exist, and is consequently unable to participate from a detached standpoint (Koch 1995). The hermeneutic tradition asserts that experience can be used to support the interpretation of another's experience. It is contextual experience that can facilitate the formulation of possible research options (Balls 2009), as was the case for the current research. Heidegger described the difficulty in achieving interpretation free from judgement or influence from a researcher. The researcher's ability to describe and interpret their own experience in relation to a phenomenon has been acknowledged as part of the hermeneutic phenomenological process (Guba and Lincoln 1989). The issues associated with preconceptions and bias will however be considered within the research during the discussion chapter.

The potential effect of a researcher on data was termed 'reactivity' by Hammersley (1990). To embrace this issue I kept a research journal to facilitate and support the development of 'self-awareness' and to provide a tool to reflect on such issues. Awareness of my personal values, perspectives and biases has increased throughout the duration of the study (Morse et al 2002, Koch 1994). Interactions considered during the collection of data and reflective points within the research journey have been used to inform and shape the study, and further supported the analytical process.

My background was discussed with the participants in the study. Information was presented orally and also within the participant information sheet (appendix 1). Indeed when I was

invited by the national parent forum of Partners in Policymaking to attend their annual conference to present the study, my personal and professional roles were clearly articulated within a formal presentation. I attended the conference as a parent, as a professional working in the area and as a researcher. This was highlighted to the audience to provide transparency and allow potential participants to make a judgement about the study based on as much information as possible. The format and tone of the original consultation with parents and carers set a level of transparency that has been maintained throughout the research.

The nursing profession has been considered to hold a unique position in the area of research (Walters 1994, Chapman 1994). Walters argued that the nurse is able to truly experience 'being in the world' of a participant. It was 'being in the world' of families and their children that led me to the current research question. As a clinician with years of experience of working with children and their families, the notion of 'ignoring' experience and achieving pure objectivity was one that was neither appealing nor indeed achievable. It is hoped that my assertions are sufficiently transparent throughout the study to allow the reader to judge the 'integrity' and 'trustworthiness' of the findings and subsequent analysis (Guba and Lincoln 1989).

3.4   The research design

Crotty (1998) suggested that the epistemological stance of a researcher would inform the theoretical perspective of a study and support the methodology. Explicit discussion of these areas has been included to provide a level of clarity throughout the discourse of the study (Koch 1994, Koch 1996, Morse et al 2002). Crotty's (1998) four key elements: the epistemological stance, the theoretical perspective, the methodology and the methods used for the current research will be used as a framework for the next section.

3.4.1   Epistemology

Epistemology is defined as the basis of a philosophy. It is a theory or set of beliefs about knowledge or social reality. It differs from belief about knowledge as it considers the nature of the external world (Crotty 1998, Blaikie 2000, Bryman 2008). Crotty (1998) highlighted three epistemological positions: objectivism, subjectivism and constructivism. Objectivism suggests that social phenomena and their meaning exist whether society is conscious of it or not. The position involves consideration of cause, effect, and explanation, a direct contrast to subjectivism and constructivism (Bryman 2008). Subjectivists hold the belief that everyone

has a different understanding of what is known. Research using this assumption would involve the understanding of a person's meaning of what they do, essentially to understand an individual in their own terms. The third epistemological position of constructivism, or the constructivist approach was adopted for the current research. This approach suggests that individuals construct their own reality with phenomena and meaning experienced at an individual level. The nature of individual reality will therefore prevent experiences between individuals from being the same (Bryman 2008). Constructivism is the uniquely constructed version of reality that people use to interpret their day-to-day experience. The position asserts that social phenomena are developed in particular social contexts, as a product of social interaction and are subject to continual revision (Bryman 2008).

Constructivism supports the participant's interpretation of meaning through their engagement with the world. For the current research it reinforced the ability of individuals to make sense of the world based on their own historical and social perspectives. The constructivist approach supported the understanding of context and interpretation based on a participant's experience and background.

3.4.2   Theoretical perspective

The theoretical perspective of interpretivism was supported by the epistemology of constructivism within the research. The perspective considers the existence of multiple realities, (unlike positivism which asserts there is a single reality) that differ across time and place.

Interpretivism was originally derived from Weber's (1947) notion of 'Verstehen', or understanding (Bryman 2008). The position requires the researcher to explore the subjective meaning of social action. Interpretivism moves from the explanation of human behaviour (the positivist approach) to the 'understanding' of human behaviour (Hughes 1990). The researcher is therefore engaged in the discovery of the subjective meaning of social action as perceived by an individual (Bryman 2008). Linked with interpretivism, Bryman (2008) considered the notion of 'naturalism'. In the context of the current study naturalism would relate to '…being true to the nature of the phenomenon being investigated' (Matza 1969 p5). Naturalism recognises that people are unable to be neutral within their environment. Individuals interact within society, ascribe meaning to their experiences and function as agents within their social world. An individual's beliefs and participation are consequently

highly valued within this type of methodology (Spradley 1979). Naturalism supports the social process of research and its openness to interpretation (Avis 2005, Bryman 2008).

3.4.3 Methodology

The study was designed to consider a phenomenon of which I was aware, and in which I had been clinically involved. Crotty (1998) suggested that the philosophical implications of a research question hold direct influence on the methodology chosen for a study. Phenomenology was the methodology chosen for this research, and was derived from a philosophical approach linked to constructivism (Caelli 2001, Crotty 1998). It was developed as an alternative to the positivist paradigm and involved the application of theories of natural science to the study of social reality (Spiegelberg 1982, Bryman 2008). Phenomenology was described by Walters (1995) as a way of considering how an individual was orientated within their lived experience. It was chosen for the study to support the understanding of experience from another person's point of view, whilst interpreting the evidence (Bogdan and Taylor 1975, Morgan 2007). A phenomenological approach can support the examination of an experience through the consideration of the qualities of that experience, and identification of its meaning (Balls 2009).

To explore the two main approaches to phenomenology: descriptive and interpretative, the former was attributed to Husserl (1963, original work 1931). As noted above he proposed a concept of bracketing to maintain objectivity within a study in an attempt to ignore previous knowledge and experience about a subject (Dowling 2004, Lopez and Willis 2004).

The interpretative or hermeneutic tradition was developed by Heidegger (1962), from Husserl's original theory. Interpretative phenomenologists proposed that it would be impossible to remove a person's experience and approach the world in a neutral way. Mulhall (1993) suggested that this form of phenomenology supported a move from description to interpretation, and the notion of deriving meaning from being. Heidegger (1962) argued that it was impossible to live and have experience without interpretation. Understanding is based within an individual's definition, and can support multiple truths based on an individual's interpretation of a situation (Taylor 1987). Ultimately there can be no definitive truth, as it will always be the truth as experienced by the recipient (McConnell-Henry et al 2009).

The importance of context was highlighted by Heidegger (1962). He suggested that an individual's experience could be affected by the context in which it occurred. That is, the mood in which an experience was lived would affect the understanding of that experience. This view is fundamental to the current research as it is the situation that participants find themselves in that will affect their experiences. Further although individuals are rarely able to control the context of their experience (the situation that they find themselves in), they are able to make 'sense' of a situation within that context (Johnson 2000).

Smith and Osborne (2009, p66) suggest that knowledge of an experience can be '…obtained through a sustained engagement with the text and a process of interpretation.' The process of moving between prior knowledge and the experience of participants was described by McConnell-Henry et al (2009), and forms the basis of the 'hermeneutic circle' (Annells 1996). The process has been described as difficult to avoid, even when a researcher did not set out to engage in the hermeneutic process (Bleicher 1980). Koch (1995) asserted that every time a researcher engages in text for the purpose of data collection further possibilities can be identified. The hermeneutic circle allows the researcher to move from the whole to the parts, through the deconstruction and reconstruction of data (McConnell- Henry et al 2009). The researcher attempts to read between the lines of data; this involves prolonged periods of reflection to discover the essence of an experience as described by participants (McConnell-Henry et al 2009,Whitehead 2004). Hermeneutics supports the construction of temporal understanding; it is the science of interpretation, developed from the temporal constructs of a phenomena (Whitehead 2004). The nature of the hermeneutic circle suggests that the researcher can never achieve a finite understanding of data, interpretation can never be exhausted (Ormiston and Schrify 1984).

3.4.4   Methodological strengths and limitations

One of the limitations associated with qualitative methodologies has been the establishment of credibility. Unlike quantitative research the concepts of reliability and validity are not applicable. However an explicit review of the strengths and limitations of a chosen methodology can allow a judgement to be made about dependability and the choices made within a study (Whitehead 2004). Guba and Lincoln (1981) suggested that the quest for reliability in qualitative research was related to the notion of trustworthiness. This can be established through the consideration of four key areas: credibility, transferability,

dependability and confirmability. Tools that could support the demonstration of the above tenets and establish 'rigour' could include an audit trail, categorisation and the confirmation of results (Morse et al 2002).

Whitehead (2004) asserted that the process of qualitative enquiry could be described as time consuming and expensive in relation to resources. Emotional investment in data collection and analysis can also form a significant and fundamental part of this type of study. This in itself held several positive aspects for the researcher, which included the time to engage with participants to ensure they felt listened to and valued. My previous experience as a clinician allowed me to consider the needs of parents beyond that of an interview, whilst retaining the role of a researcher. The information they discussed was personal and sensitive. I wanted to ensure that the interview allowed parents to express their thoughts within an open, trusting and supportive environment. True engagement in the research can facilitate a meaningful relationship and strengthen a partnership approach to a study (Eggenberger and Nelms 2007).

'Confirmability' of interpretation during inquiry and the process undertaken to ensure that findings are informed through the process of prolonged reflection (reflexivity) and praxis are considered to be central to the validity of a study (Johnson 2000, Morse et al 2002). Guba and Lincoln (1981) argued that ambiguity associated with the decisions made during analysis of data, would diminish a notion of 'trustworthiness', considered central to the establishment of reliability. The framework chosen for analysis was selected to support transparency within the study. However Morse et al (2002) cautioned against the pursuit of confirmability within a phenomenological framework. They suggested that the author's experience can become an integral part of the data through interpretation. The premise that reality is dynamic and therefore changeable within the stance of constructivism would negate the relevance of confirmability. Todres (2005) however warned that the nature of true experience will mean that there will always be unique as well as common features in the experience of participants.

A flexible plan of inquiry facilitated interaction that engaged participants in an open and responsive manner. This allowed a constructive and responsive approach to the views expressed by participants. Participant's words were used in the study in an attempt to contextualise the data. However it is clear that although quotations allow reference to the original intention of the participant they, by their nature, are utilised out of context.

Whitehead (2004) made a valuable point when he highlighted that analysis and discussion within an academic study can be affected by the parameters of the academic criteria and guidelines. This may restrict and confine a researcher's ability to stay true to the data. As the current study is part of a doctoral award this will be considered within the discussion chapter.

Reflection on the decisions made as the study progressed was an integral part of the research. Mason (2002) supported the role of 'reflexivity' within a study as it allows an individual to reflect and adapt their role in the process of producing data (Johnson 2000). My research journal supported this process. Transparency of approach throughout was vital to the research as the very nature of the approach determined the individuality of the project. This may ultimately mean that while the study cannot be replicated, transparency can be achieved through a process of 'reflexivity', interpretation and a clear audit trail of the decisions made.

3.4.5   Methods

Interviews

The method chosen for data collection was semi-structured interviews. The primary function of an interview is to generate information to gain an insight into people's experiences (Silverman 2001). Open-ended, in-depth interviews have been considered an effective means of gathering data (Patton 2002, Van Manen 1990). Although interviews are commonly used in the collection of data for qualitative methodologies such as ethnography, phenomenological interviews have been described as distinct from other forms of in-depth interviewing. The focus of the phenomenological interview is to analyse the narrative of an interview, to understand a ''personal life story'' and the meaning attached to that experience by the participant (Patton 2002, Van Manen 1990).

The interview has been described as a method to reflect on, and uncover beliefs, understanding, emotion and the action of participants (Seidman 1998, Hutchinson and Wilson 1994). Consistent with this research is the view of an interview as a social encounter, where knowledge and understanding can be discovered, constructed and clarified between the researcher and participant (Holstein and Gubrium 2003). This type of exchange will help to construct a picture of meanings (Britten 1995). The researcher should refrain from making judgments about a participant's narrative, and try to understand how the views make sense in the participant's context (Potter and Wetherell 1994, Johnson 2000).

However the search for pure authenticity can be difficult. Baker (1984) highlighted that there could be an unseen relationship between participants and the world that they describe in a research interview. The reader of a study would therefore need to consider the authenticity of the accounts and the trustworthiness of the data. Each participant in this form of enquiry is describing their 'lived experience ' for them alone. This may challenge Heidegger 's view of the researcher's influence or bias on the data collected (Oiler 1982, Omery 1983, Paley 2005).

Silverman (2001) referred to the concept of 'emotionalism' as interviewees are valued within the research process as experienced subjects who actively construct their social world. Emotionalism is not concerned with objective facts but obtaining authentic accounts of subjective experiences. This supports the hermeneutic phenomenological focus of the study. Several authors have proposed the use of different terminology to reflect the value and importance placed on a participants' knowledge and experience, Van Manen (1990) proposed the term 'co-researcher' and Gilchrist (1992) suggested 'key informants'. The terms reflect the degree of insight, knowledge or experience participants possess in relation to the research area. Either of these phrases could have been applied to the participants in the current research; it was their experiences, and analysed information that provided the data for the research.

As discussed by Thomas and Smucker (1998) and consistent with the ethos of phenomenological research all participants were required to have had experience of the phenomenon and a willingness to be interviewed about that own experience. The phenomenon to be studied was the lived experience of children with learning disabilities and behavioural needs. The first phase involved interviewing parents and carers of children with learning disabilities and behavioural needs. The second phase involved interviewing paid professionals who had worked with this group of children and their families.

Semi structured and open-ended interviews based on prior and in-depth knowledge of the research area were regarded by Silverman as conducive to an effective interview. Silverman (2001) suggested that a researcher should create an atmosphere conducive to open and undistorted communication through the formulation of appropriate questions. The interview method held a 'contextual fit' with my clinical background. As a community practitioner my job involved visiting families and children in their homes to provide support. The forming of

relationships, acquiring knowledge, information and gaining trust was central to my role. An ability to construct appropriate questions considered pertinent and significant to the phenomena can support the hermeneutic researcher's attempt to understand the 'lived world' of the participant (Thomson 1990). As described by McConnell-Henry et al (2009, p3) 'People, their interactions and their lived experiences are the core of nursing.' As a transferable skill the nurse researcher should aim to effectively converse during an interview, intervene, guide and ask the same broad questions of all participants (Carter and Henderson 2005).

A semi structured topic guide was given to all participants to support the interview and allow the interviewees time to explain their responses (appendix 2). A 'safe' space was identified as important to allow participants to express their own views and opinions in comfort and privacy. All interview locations in both phases of the research were selected by the participant. This avoided the inconvenience of travel and supported a comfortable environment for the individual.

Twenty interviews were conducted for the study: ten family or carer interviews and ten with professionals. Although saturation can be achieved within a small number of interviews this was not the focus (Boyd 2001, Whitehead 2004), as a phenomenological study would not seek to ascertain an 'average response' (Morse 1998). The number of interviews undertaken reflected Creswell's (1998) view that in depth interviews of up to ten participants was appropriate within a phenomenological study. To this end ten interviews were conducted within each phase.

When meeting participants it was important for the researcher to establish an initial rapport and attempt to put the participant at ease (Wright and Leahey 2005). Eggenberger and Nelms (2007) suggested that the initial meeting can allow a researcher to begin the process of transparency through the discussion of the researcher's background and the motivation for the study. Silverman (2001) stressed the importance of gaining a rapport with participants who have actively constructed the features of their cognitive world. The aim of the researcher should be to obtain a deep mutual understanding with the participant. Participants volunteered to share their experiences. I was able to utilise my clinical experience of working with families and professionals within different environments to engage in active listening and support discussion during the interviews (Eggenberger and

Nelms 2007, Dickson-Swift et al 2007). Responsive interview techniques were used during the study to ensure the participant was able to express themselves without time limitations or stringent interview schedules. Clarification was sought to ensure that meaning was clearly understood. Phrases were used such as 'could you tell me more about that?', and 'how was that?', as well as affirmation of interviewee accounts, 'that sounds as if it was difficult for you' during the discourse (Ray 1994). It was important to create an environment in which participants felt listened to and heard. Colazzi (1978, p64) asserted "The researcher must realise that his participant is more than merely a source of data...he must listen with the totality of his being and the entirety of his personality".

The need to relax the participant and utilise the skills of active listening was paramount. Listening can be a difficult skill as the intuitive reaction of a listener may be to interject. However the role of the interviewer should be to stay quiet and listen actively (Seidman 2005). No comment was made about the quality of the participant discourse as the spoken 'lived experience' of the phenomenon was the criterion for inclusion in the study. The management of an interview can influence the data collected (Whitehead 2004). Open ended or non- directive questions can still exert a level of control over a situation, whilst the minimal presence and interruption of a researcher can affect the information received (Silverman 2001). To avoid this situation interview guides were used (appendix 2.3). I guided the participant through key topic areas if and when it was required. Often participants discussed the areas as part of their general conversation. Prompts were only used to guide the conversation towards topic areas. Re-iteration enabled the clarification of points raised and ensured the researcher had understood the participant correctly. During both phases of the study participants appeared to be honest and open in relation to the views and experiences they expressed. The therapeutic value of discussion of what had often been very difficult experiences for the child and family was often noted by the participant during the interview, and will be considered during the discussion chapter (Eggenberger and Nelms 2007, Dickson-Swift et al 2007).

3.5 The research process

This section of the methodology chapter will consider the process of research undertaken. The research question, ethics and recruitment will be discussed. The interviews, recording,

transcribing and analysis will be described with final consideration given to the process of analysis.

3.5.1 The research question

It was important to ensure that the research area chosen was appropriate and of value to the field. The formulation of a research question can come from a number of sources. The current study was born of personal experience, a social problem and the 'Gaps between official versions of reality and the facts on the ground' (Marx 1997 p113). Having consulted with 'Partners in Policymaking' the research question that emerged was ' what are the family and professional perspectives on the lived experience of children with a learning disability and behavioural needs?'

The study was conducted in two phases. Phase one involved parents and carers, phase two, professionals.

3.5.2 Participants

Table 1 provides the parental pseudonyms, the age of their child or children and a description (as identified by the parent) of their child's learning disability. Table 2 provides the role of the professionals interviewed and the interview pseudonym.

Table 1: Family participants

Parent Pseudonym	Age of child, type of learning disability
Jane	Girl 17, learning disability and cerebral palsy
Mary	Boy 15, severe learning disability
Angela	Boy 15, profound and multiple learning disability
Cathy	Boy 14, autism
Denise	Boy 13, rare disorder, severe learning disability
Kate	Girl 16, autism
Gill	Boy 11, autism
Susan	Boy 18, moderate learning disability
Lynn	2 boys, 7 and 10, autism
Emma	2 boys, 13 and 15, Attention Deficit and Hyperactivity Disorder, Attention Deficit Disorder and Oppositional Defiance Disorder

Table 2: Professional participants

Pseudonym	Role/ profession
Karen	CAMHS co-ordinator – PCT
Bob	Learning Disability nurse- social services respite area
Alison	Occupational therapist- social services
Julie	Speech and language therapist- independent sector
Lisa	Social worker- children and families disability team
Jenny	Speech and language therapist- independent autism service
Debra	Family liaison co-ordinator- special school- education
Helen	Behaviour analyst- independent-school based
Wendy	Integration support assistant- special school
Janet	Behaviour analyst- independent- community

Data for each phase of the study was collected using semi-structured interviews. The research process will be discussed in relation to each phase of the study.

3.5.3   Ethical approval

The data was collected in two phases. Ethical approval for each phase was gained separately from the Research Ethics Committee at Manchester Metropolitan University.

Participants were recruited through local and national organisations. My contact details were advertised via a national conference and newsletter for phase one of the study and via a local professional network group for phase two. All participants contacted me to express an interest in the study. Following the initial contact, the participant information sheet and consent form were sent to individuals electronically or by post (see appendix 1.6). Once an individual made contact after receiving the information, the study was explained in more detail and an interview arranged.

Following a verbal introduction to the study and an opportunity for potential participants to ask questions, a consent form was signed for each interview. Participants were reassured that they were able to withdraw from the study at any time during or following the interview. The participant information sheet contained my contact details and those of the Director of Professional Studies from Manchester Metropolitan University. The information was revisited before the start of the interview to ensure participants understood how to report issues if required.

Respect for participants was an important part of the study. Participants needed to feel comfortable and valued. To this end interview venues were chosen by the participant. Confidentiality was explained to participants in relation to recording and transcribing of data, and arrangements to ensure its safe storage and confidentiality. The recording equipment was demonstrated to each participant and the process of anonymity through the removal of names from recordings and transcriptions explained.

During the interviews participants were listened to unconditionally. Active listening skills were used to support the flow of conversation. Although there were no immediate risks identified to the participant or me, the potential for emotional distress was considered. All participants were encouraged to make contact with myself or the study supervisor if they had a question or concern following the interview. No issues were reported from participants. Emotional engagement with participants during the interview process will be considered in the discussion chapter of the study.

As a community practitioner I was aware of lone worker policies and principles and applied them in the interview situation. No issues related to safety or duress were identified during either phase of the study.

3.5.4   Participant recruitment

Phase 1- Families and Carers

During the first phase of the study, interviews took place with family carers of children with learning disabilities and behavioural needs. Ten interviews were conducted. A combination of strategies was utilised to recruit potential participants for the first phase of the study. The strategies utilised included snowball sampling and self selection (Bryman 2008). No direct one-to-one personal contact was made with potential participants before they had directly expressed an interest in the study.

Following the meeting to consider the formulation of the original research question with representatives of the parent support group, I was invited to advertise the study through their parent newsletter. The advertisement was distributed following successful ethical approval of phase one of the study. At this point I was also invited to present the study at a national parent's conference in Loughborough in March 2009 (National Partners In Policymaking (NPIP) Course 2009).

The experience of presenting to an invested parent led group was one which fundamentally shaped the course and momentum of the research. This will be considered in more depth in the discussion chapter. The presentation at the parent and carer led conference set the scene for the transparency of the study. I was invited to present and attend a two-day weekend conference. I attended as a researcher but the decision was taken to ensure that information was given in relation to my background and intentions at this initial stage. The presentation involved a brief history of my career and a picture of my family. As discussed by Dickson-Swift et al (2006), a researcher that chooses to disclose some of their own information is involved in an attempt to create equity and facilitate the building of rapport. The open and transparent approach I adopted supported the reciprocal sharing of information between study participants and later with myself as an interviewer (Liamputtong and Ezzy 2005). The generosity of the parent's group in their facilitation of the study, and the ethos of the organisation necessitated a level of openness and honesty which reinforced the quest for 'transparency' in the research.

The first phase of interviews was conducted from March 2009 – to October 2009. Participants were all mothers of the children they discussed during the interview. No men came forward; several fathers were present at the interview location but did not take part in the interview. All participants were clearly immersed within the 'phenomena' for study (Sim and Wright 2000). The terminology and language chosen for the study, as considered in the literature review, 'learning disability' and 'behavioural needs' was consistent throughout the information given to all participants. It was consequently left to participants to consider if the terms utilised applied to their 'experience'.

Access to the family participants resulted from snowball sampling and/or self- selection, via a chain referral system (Carter and Henderson 1995, Sim and Wright 2000). Snowball sampling can be a useful way to access participants when the study is related to a group or social activity (Faugier and Sargeant 1997). A process of chain referrals also took place amongst families who were recruited through people who knew one another (Berg 1988). Several parents interviewed had not attended the conference or read the newsletter but had made contact following discussion with a friend who had attended the conference or participated in the study.

All the parents who took part in phase one of the study were accessed directly through contact with the Partners in Policymaking organisation or its members. Access to participants can be difficult; the parent led organisation facilitated the opportunity to meet people who it may have been difficult to approach due to the sensitive nature of the issues discussed (Faugier and Sargeant 1997, Hendricks and Blanken 1992).

Phase 2- Professionals

During phase two of the study ten professionals involved in supporting children who had a learning disability and behavioural needs and their families were interviewed. Professionals were recruited through a local special interest group of multi-agency professionals. Supporting individuals with behavioural needs can be difficult (Allen and Tynan 2000, Grey et al 2002). The need for individuals to share best practice and network to support this group of children has resulted in professional groups establishing their own networks. This type of group is more likely to be multi-agency and reflect contemporary practice in the field of learning disabilities.

The study was presented briefly at a local network meeting to a small group of professionals in September 2009. Agreement was gained for the study to be added to the minutes of the meeting with contact details attached for interested members. Participants self selected and requested the research information via e-mail. One individual was interviewed following a chain referral (Sim and Wright 2000). The first ten professionals who contacted the researcher were interviewed.

As with the parents recruited in phase one of the study, professionals were those who attended a network group with a special interest in supporting children with a learning disability. This would therefore represent a motivated and committed group of individuals. Professionals who volunteered for the research would be more likely to be interested in the area for study than their peers, who did not belong to the interest group or who did not have an interest in behavioural needs (Sim and Wright 2000).

The participant information sheet and consent form were sent to professionals via e-mail. It mirrored the information sent to families (appendix 1.6). All participants in the research were treated equally and received the same information to ensure consistency, transparency and equal value in the research process. Recruitment and interviews took place between

Sept 2009 and November 2010. The study information and consent forms were sent electronically. Professionals contacted me directly if they wanted to be involved in the study.

Nine participants in the study were female and one male. As consistent with the aims of the research a representative sample was not the aim of the study. The inclusion criterion for participants in phase two was the experience of supporting children with learning disabilities and behavioural needs and their families. All participants self selected and met the criteria for inclusion in the research.

3.5.5   Procedure

Phase 1

A semi structured interview topic guide was designed for use with parents in phase one of the study (appendix 2). Participants were able to read the guide before the start of the interview to ensure that they were happy to cover the broad areas considered. All participants agreed that they would be able to discuss the areas covered in the guide without duress or concern. Participants were encouraged to talk freely and interview guides were only used when required.

Phase 2

Following the completion of phase one the interview guide was devised for professionals in phase two of the study. The guide was constructed to support and inform the study based on the data collected during phase one (see appendix 3). Participants were able to read the guide and ask questions if required. Participants were supported to talk freely and prompted during the interview if required towards the interview guide.

3.5.6   The interviews

Phase 1

The location for interview was chosen by the participants in both phases of the study. During phase one with families, three interviews were conducted at the location of the PIP National Parent Conference in Loughborough at the request of the participants. A room was arranged at the conference facility. The remaining interviews took place at parents' homes. Two parents met at one home to avoid travel between houses. All interviews were conducted with the mother of the child/children discussed. Fathers were present at some of the locations but did not choose to take part in the interviews.

In all cases I introduced myself in relation to the research, my professional background and present role. The study was explained with reference to the participant information sheet and questions answered. The interview guide was given to parents and discussed to ensure they were able to access the questions, were able to clarify or identify areas of difficulty and were happy to proceed. The participants' right to withdraw from the research during or at anytime following the interview was explained. Contact details from the information sheet were highlighted to reinforce their right to withdraw from the research at any point, and to provide a further opportunity to discuss the research process or progress if required following completion of the interview.

Consent to take part in the research and to use the information provided by parents was taken through signatures obtained on two study consent forms. One was returned to the participant and one retained by myself.

Phase 2

The location for interviews during phase two of the study were also selected by the participant. Four interviews were conducted at my place of employment, four in the professional's place of employment, one at a local university and one in a professional's own home.

On arrival at the specified venue I introduced myself to the participant, explained my current role and my relation to the research. The professionals usually discussed their experience, their role and interest in the research. The interview guide, consent forms and participant information sheets were given to professionals to ensure they were informed and aware of their right to withdraw from the study at any time. Two consent forms were completed to ensure that professionals had a copy for their records.

3.5.7   Recording and transcription

Phase 1 and Phase 2

A digital recorder was used to record the interviews. The potential distraction of the recorder was negated by the quality of the data gained and my desire to ensure that participants felt 'listened to' rather than recorded. To this end note taking and observation were not included in the interviews.

All the interviews were recorded and lasted between 35 and 80 minutes. Each interview was allocated a code and transcribed verbatim into a Microsoft Word document. Each line of text was numbered to support later coding and analysis. All place and individual names used by participants in both phases of the research were removed from the audio and transcript records. This supported confidentiality and maintained participant anonymity (NMC 2008).

3.5.8 Analysis

The analysis of data can be a problem for the qualitative researcher (Bryman 2008, Attride-Stirling 2001). The need for increased levels of disclosure and transparency in the analysis of qualitative data has required the increased formulation of sophisticated tools and rigorous methodologies (Huberman and Miles 1994, Attride-Stirling 2001, Bryman 2008). Several 'layers' of interpretation exist within a qualitative study. The research participant's experience and interpretation as well as the researcher's interpretation of that information may constitute an initial layer. Further interpretation takes place during the coding of data. Finally the findings are interpreted by the reader, where a judgement is made in relation to the data and links made within the discussion (Benner 1994, Bryman 2008). To this end interpretative work has been criticised for allowing bias, and not remaining true to a participants' lived experience (Tripp-Reimer and Cohen 1987). To avoid a situation of bias, Whitehead (2004) suggested that the researcher should attempt to remain within the hermeneutic cycle throughout the process of analysis. This is to avoid data becoming de-contextualised from its original meaning. During the analysis of the current research the coding framework and original transcripts were continually revisited. This ensured that interpretation was representative of, and faithful to, the true accounts of the participants.

The use of tools for the process of qualitative analysis has been considered extensively in the literature (Huberman and Miles 1994, Bryman 2008). Unclear analytical processes have been heavily criticised (Baker et al 1992, Koch 1996, Clarke 1998, Crist and Tanner 2003, Whitehead 2004). Whitehead (2004) proposed three areas for consideration in the attempt to establish credibility: the researcher's presence on the account, the nature of the phenomena described and the reporting process. Credibility and rigour within analysis were considered by Attride-Stirling (2001). She proposed that the disclosure of the analytic tool and the transparent illustration of recording and systematisation could support this process.

The notion of rigour for the current research was incorporated within the design and implementation of a transparent and visual analytic tool. The illustration of data was designed to support the interpretative process, and reinforce a level of trust and confidence in the concluding findings and assertions (McConnell-Henry et al 2009). It was resonance rather than truth that was the aim of the study, and is considered to be the focus of the hermeneutic phenomenologist (McConnell-Henry et al 2009). To establish resonance, identification of the analytical decisions made in the research were required. Transparency can serve as trustworthiness, in the endeavour to establish credibility (Lincoln and Guba 1985, Clayton and Thorne 2000). It can be achieved through a visible journey of '…recording, systematising and disclosing….' the methods of analysis (Attride-Stirling 2001, p386) or illustrated '...by showing the author's authentic search for what makes most sense rather than marshalling all the data toward a single conclusion' (Patton 2002, p543). Transparency within a study can avoid a situation in which researchers are able to manipulate a study's findings to ultimately support their own agenda (Byrne 2001). For this research the personal integrity required by a phenomenological researcher within thematic analysis appears fundamental, and links closely to the philosophy of hermeneutic phenomenology. The researcher's experience is valued and visible, but importantly transparent and accountable.

The level of engagement with the data facilitated an iterative process between the data and the theory (Bryman 2008). The principles of hermeneutic phenomenology guided analysis of the data, with the language and interpretation of human relationships as a focus of the study (Van Manen 1990, Gubrium and Holstein 1993). Resonance associated with the presence and meaning of words used by participants formed part of the analytic process (Todres 2005). Although the hermeneutic process can support interpretation it cannot, and indeed should not be able to, ensure that the reader will agree with the researcher's interpretation. The strength of the interpretative process however lies in the clarity and demonstration of the analytical process from which assertions are made (Koch 1994, Morse et al 2002).

It was a dynamic and interactive process that was sought for the research. An analytical tool was required that would allow the experience of the participant, the researcher and the reader to strengthen their understanding of the phenomenon and facilitate true depth of interpretation. A high level of transparency was required to support the analytic process and to evidence originality from the data.

3.5.9   Thematic analysis

The interpretation of the interview data was accomplished through the hermeneutic process of thematic analysis. Transcribed interviews were dissected but later related back to the whole (Pollio et al 1997, Thomas et al 1998). Each line of text was considered for key words or important statements significant to the research question. Shared experience and common meanings were identified and examined (Eggenberger and Nelms 2007). Themes evolved that were interconnected and reflected interpretation of meaning and the participant experience. A systematic search of themes, divergent patterns and explanations of material collected was conducted, as hermeneutic interpretation involves the initial identification of terms that can be assigned to significant meanings (Thomas et al 1998). Later the identification of relationships and patterns within the data allow the categorisation of participant experience into themes (Byrne 2001). Disproving the data was not the object of the analytic process, however the exploration of various and often differing themes was central. Any patterns identified were considered in relation to what supported or expanded upon emergent themes.

The hermeneutic circle was useful to consider the interview data as a whole, but the need for a framework to support the de-construction of text became evident. The volume and wealth of data gathered from participants was at times daunting and required a system that could transparently, systematically and logically represent the research findings. For these reasons Attride-Stirling's (2001) model of thematic analysis was chosen. Toulmin's (1958) 'argumentation theory' was originally involved in the construction of analytic techniques (Attride-Stirling 2001). Toulmin devised a structured format specifically for the analysis of negotiation processes. He suggested that the dissection of information could lead to a 'warrant' and further onto a 'claim'. Some similarity can be seen between Toulmin's theory and the basic elements of grounded theory; concepts, categories and propositions (Corbin and Strauss 1990). Essentially for this study Attride-Stirling's (2001) model of thematic analysis appealed as an accessible, transparent and logical form of analysis. The strength of the model lay in the systematic ordering of themes and the visual development of web-like structures. The visual illustration of data supported my desire for the research to be transparent and open. It further supported the dissemination of the research information and results by different formats, which could support clarity and understanding for the reader and future audiences.

Attride-Stirling (2001) suggested that thematic networks facilitate the methodical analysis of data. The model can facilitate the organisation of data through the systematisation of text and the visible ordering of the steps in the analytic process. Networks are used to visually represent the steps, and to illustrate the organisation of data through levels of hermeneutic analysis to clear and transparent assertions. Attride-Stirling (2001, p386) proposed that '…thematic analyses can be usefully aided by and presented as thematic networks: web-like illustrations (networks) that summarize the main themes constituting a piece of text.'

Three levels of thematic analysis are typically depicted within Attride-Stirling's thematic networks. Basic themes are described by Attride-Stirling as lower-order premises, whilst organisational themes constitute the grouping of basic themes into more abstract principles. The final global theme is described as a 'super-ordinate' theme which depicts the overarching and principal messages from the data. To clarify, a thematic network is created through the construction of basic themes derived from a coding framework. Basic themes are translated into organisational themes and further into global themes. 'The objective is to summarise particular themes in order to create larger, unifying themes that condense the concepts and ideas mentioned at a lower level' (Attride-Stirling 2001, p393). The model allows this complex process to be visually represented.

3.6   Thematic analysis (Attride-Stirling 2001)

Attride Stirling's model of thematic analysis was chosen to support the analysis of the interview data for the research. The process involves six stages, from coding through to the interpretation of patterns within data. The stages will be briefly considered in the context of the research.

3.6.1   Step 1 - The coding framework/dissection of text

a) The coding framework

A coding framework was devised for each phase of the study. The codes were devised from prolonged interaction with the audio recordings and the transcripts from the 20 interviews undertaken. Each line of text was considered for key concepts in a participant's account. The coding framework was comprehensive and directly deduced from initial meanings interpreted from the text.

Data from phase one of the study contained 58 codes that were indicative of issues described by families in the study. Issues identified broadly focused on the child, the family and support needs. Complex issues were reduced to ensure that each and all areas identified were represented by an initial code.

The data collated during phase two of the study with professionals resulted in 54 codes. These were deduced from prolonged engagement with the audio recordings and the transcribed interviews from the professional participants. Professionals focused on the needs of the child and family, resources and communities. Initial preliminary examination of the texts resulted in the identification of key issues within the discourse. Across both phases of the research the initial identification of codes allowed the extrapolation of broad issues but further supported the inclusion of data within the individual narratives of perspectives on the lived experience of children.

b) Dissection of text

The second phase of the analysis involved the dissection of each transcript into meaningful text segments. This process was conducted across each phase of the study.

Using the coding framework each segment of text was coded and placed within the framework. Each text segment contained multiple codes as all relevant codes were attributed to each and every section. This resulted in multiple coded segments of text. The family results yielded 5685 individual coded text segments. The professional results contained 4441 coded text segments. All the research codes for each phase of the research were used to create two Microsoft Excel spreadsheets designed to organise the data into accessible segments. This system allowed data from the transcripts to be directly inserted into the coding framework. The use of an Excel spreadsheet facilitated ease of access to text segments with singular or multiple codes within the framework.

3.6.2   Step 2 - The identification of themes

For each phase of the study, themes were extracted from the coded sections of text. This involved the identification of common or significant themes, related to the original research question, within the text segments. The process involved the re-visiting of text segments under their specific code. This process allowed a realignment of the data and identification of emergent commonalities.

Refinement of the themes identified formed the second part of step two. At this stage an attempt was made to identify themes that were individual to participants, not repeated in the data, or themes that were broad and able to include numerous related ideas within the text.

The identification of themes within the data is the result of an interpretative process. Original interpretation is shaped to encompass new pieces of text that match the data and fit with the original meaning. A theme therefore is required to be specific whilst also applicable to those pieces of text that emerge in different forms throughout the ongoing process of analysis (Attride-Stirling 2001).

3.6.3   Step 3 - The construction of thematic networks

This stage of analysis involved six discrete processes: grouping themes, selecting basic themes ('lower-order premises' Attride-Stirling 2001, p388), deducing organising themes ('categories of basic themes grouped together to summarize more abstract principles' Attride-Stirling 2001, p388), formulating global themes ('super-ordinate themes encapsulating the principal metaphors in the text as a whole' Attride-Stirling 2001 p388), the visual illustration of the process within a thematic network and the final verification and refinement of the networks constructed.

a) Grouping themes

The themes that had been deduced from the data were grouped into areas that presented as similar in the text. The process of deciding how themes could be grouped was considered at this point. Through the iterative process of revisiting original audio recordings and transcripts the context of the data was considered. This ensured that the grouping of codes reflected the intention and meaning of the participants' words. The groupings resulted in the formation of global themes, underpinned by organising themes and the initial basic themes identified within the thematic networks.

Attride-Stirling (2001) suggested there was no limit to the number of themes that could construct a network. This however was not an issue in analysis for the current research as codes were 're-contextualised' within the transcripts to ensure themes were inclusive of all the codes. This reinforced and strengthened the subtle difference in meanings between the codes which were clarified against the original transcripts and recordings. The resulting global themes illustrate the transferability of the findings between the phases of the research

and reflect the content of the supporting network effectively. No attempt was made to 'fit' codes into particular networks. All codes were contextualised within the ongoing iterative process.

b) Selection of the basic themes

The themes identified and placed into groups became the 'basic themes'. Attride-Stirling (2001, p392) suggested that the re-labelling of the original groups can facilitate 'a conceptual division between the identification of themes, and the creation of the thematic network'.

c) Development of organising themes

The basic themes identified were then constructed into organising themes based on their wider commonalities. The basic themes were there to support this grouping, to provide the back drop for the formulation. For example, in the family data the organising theme labelled the 'Child's Needs' was deduced from the basic themes of 'Realisation', 'Diagnosis' and 'Child Potential/Progress'. The basic themes were dissimilar but related to the emergent organising theme.

d) Development of global themes

This part of the process involved the identification of a main assertion from each network. This stage in relation to the labelling of the theme was complex as each global theme represented a host of information which was difficult to convey. However the visual representation of the thematic network allowed transparency of the decision trail for readers and supported the development of the resulting global themes.

e) Visual representation of thematic networks

This stage allowed the data to be represented in a '…non- hierarchical, web-like….' structure (Attride-Stirling 2001,p393). Although the grouping of themes and the terms used by Attride-Stirling may suggest a hierarchy, the visual representation suggests that each theme is the sum of its component parts and can be traced back to its original origin. Each global theme was represented by a thematic network related to the preceding organisational themes and related basic themes. Each stage in the development of themes was colour coded for ease of reference.

f) Confirm and revise the networks

After the formulation of the visual networks the text segments associated with each basic theme were revisited. This was to confirm that the data were reflected through the three-staged thematic process, basic, organising and global. Further it was important to ensure that the data supported the themes. Discrepancies or adjustments to the process were rectified at this stage.

3.6.4. Step 4 - Network description and exploration

According to Attride-Stirling (2001) thematic networks are tools utilised during the initial organisation and analysis of data. They represent the data visually but do not interpret or critically analyse the information they represent. Step 4 involved the description of each network and exploration of content. During this stage the themes were explored through a return to the original transcripts and consideration of them in the context of the networks. This process was conducted in two stages, description of the networks and later their exploration.

a) Network description

Each network was considered individually. The themes and original codes were described and supported with sections of text to support the understanding of meaning.

b) Exploration of the networks

During the description of each of the networks and during the return to the original text, exploration naturally occurred, and emergent patterns were noted. The text at this stage was considered through the context of the themes. The networks were able to demonstrate the process of analysis and interpretation for the researcher and hopefully the reader. This will be explored within the findings chapters, through the interpretation of networks and the support of segments of text from original transcripts. This centralises the voice of the participant in the research process and will allow the reader to judge the integrity of the assertions made during the analytical process.

3.6.5 Step 5 - Summary of thematic networks

Each network was summarised during stage 5 of Attride-Stirling's (2001) model of analysis. The key themes were highlighted and underlying patterns that supported them clarified. This was a useful stage in the analytic process as the succinct presentation of the networks facilitated a level of clarity, and supported the process of transparent and explicit assertions.

3.6.6   Step 6- Interpretation of patterns

During the process of interpreting patterns Attride-Stirling (2001) suggests that the researcher should return to the original research question. For the current study it was a useful stage. A summary and analysis of the networks was conducted at this point with contextual consideration of the 'lived experience of children with learning disabilities and behavioural needs'. The relationship between assertions made, current theories and significant areas of interest were considered. This was a complex but essential stage. As Attride-Stirling (2001) suggests, it involves the reframing of assertions developed, within the context of the research.

For the purpose of this thesis, the last three steps of Attride-Stirling's model; description and exploration of thematic networks, summarisation of the networks and interpretation of patterns within the data will be used to structure the findings and discussion chapters. Thematic networks, described as visual pictorial representations (Attride-Stirling 2001), will be included to illustrate and describe the findings from the interviews. Findings from both phases of the study will be presented in this format. The networks are not a hierarchical presentation of findings, but a visual transparent model of the analytical process undertaken. Each network will illustrate the construction of basic themes through to the development of organisational themes and the final global themes.

3.7   Conclusion

In conclusion a qualitative framework was chosen for the study. The focus of data collection was the thematic analysis of textual data. The design utilised an epistemological stance to consider perspectives of the lived experience of children with learning disabilities and behavioural needs. The study was constructed to extend our understanding of lived experience and social context for this group of children (Avis 2005). To consider Crotty's (1998) four key elements to the design, constructionism formed the epistemological backdrop and phenomenology the theoretical perspective. Phenomenological research was utilised for the methodology with interviews as the method of data collection. Attride-Stirling's (2001) model of thematic networks was used to structure the data and aid the interpretation and analysis of text.

The following chapter will consider the findings of the research illustrated through the use of thematic networks. Each stage of the study will be considered separately. Chapter 4 will report the results of the interviews with families of children with a learning disability and behavioural needs. Chapter 5 will highlight findings of the second stage of the study, interviews with professionals involved in supporting this group of children and their families.

4 Chapter 4: Family Findings

4.1 Introduction

The research question asks 'what are the family and professional perspectives on the lived experience of children with a learning disability and behavioural needs?' A qualitative methodology was chosen to generate the findings and analyse the data. The literature review and methodology explored the context of the study and provided information associated with the methodology and methods used to collect data from participants. The participants in the research provided rich information; interviews were often very personal and reflective interactions of which I am privileged to have been a part. The findings from each phase of the study will be reported in separate chapters.

This chapter identifies the results of interviews with ten mothers of children with a learning disability and behavioural needs. The initial coding framework is identified, and the emergent global networks considered individually. To briefly review, Attride-Stirling (2001) proposed six stages within her method of thematic analysis. Stages one to three: coding, identification of themes and construction of thematic networks were discussed in the preceding methodology chapter. Stages four and five of the model, description and exploration of the networks and also a summary of the networks, will be considered within the findings chapters. Stage six, the interpretation of patterns within the networks and across both phases of the research will be considered within the discussion chapter.

Four global themes were deduced from the family findings:

- Finding our way
- Square services, round needs
- Behaviour touches everything
- Belonging

Each global theme will be considered individually.

4.2 The family coding framework

58 initial codes were identified and numbered from the ten family transcripts. Multiple codes were applied to each text segment. The original 58 codes were identified 5685 times across the data. Table 1 illustrates the thematic networks, from original codes through to the formation of each global network.

4.3   Family thematic analysis

Table 3: Family thematic networks

ISSUES DISCUSSED	BASIC THEMES	ORGANISATIONAL THEMES	GLOBAL THEMES
Diagnosis	REALISATION	CHILD'S NEEDS	**A**
Needs	DIAGNOSIS		
Different- coming to terms	CHILD POTENTIAL/PROGRESS		FINDING OUR WAY
Family affect			
Struggle	FAMILY STRUGGLE		
Child's progress/ potential	PARENTING PROFESSIONALS	THE COMPLEX	No of codes identified
	HOPES AND DREAMS	JOURNEY	3146
Wait for help	SERVICE USEFULNESS		**B**
Inappropriate services	CO-ORDINATION	SERVICE FIT	
Medicalisation	TIMELINESS		
Co-ordinated services			SQUARE SERVICES,
SEN			ROUND NEEDS
Transitions	TRANSITIONS	PERSON CENTRED	
Person centred	THE FUTURE	SUPPORT	
Other agendas	SERVICE SILOS		No of codes identified
			1152
Understand behaviour	UNDERSTAND	FAMILY AND	**C**
Safety/vulnerability	BEING SAFE	BEHAVIOURAL NEEDS	
Manage life/needs	MANAGING BEHAVIOURAL		
around behaviour	NEEDS		BEHAVIOUR
Emergency/crisis	EMERGENCY/CRISIS		TOUCHES
School struggle			EVERYTHING
Specialist support	EXPECTATIONS	BEHAVIOURAL NEEDS	
	SPECIALIST SUPPORT	AND EDUCATION	
	EDUCATIONAL EXCLUSION		No of codes identified
			802
Group/social activities	CHILD FOCUSED INTEGRATION		**D**
Others reactions	INFORMAL SUPPORT	OUR COMMUNITY	
Child fits in			
Exclusion			BELONGING
Inclusion	INCLUSION	OUTSIDE IN	
Peers	EXCLUSION		
	CHOICE		No of codes identified
			5685

Four global themes were identified within the family data (Table 3). Each will be considered separately with examples given from the transcripts to support interpretation and to contextualise the issues raised. Each parent has been anonymised using a pseudonym (the

pseudonym and demographics of each parent and their child/children is provided in Table 1).
The reference preceding a quote refers to the parent's ascribed pseudonym, the page number
in the transcript in which it was located and the original number assigned to that code. For
example Kate.2.3 refers to Kate's interview, page 2 code no 3.

4.4   Global theme: Finding our way

Figure 1
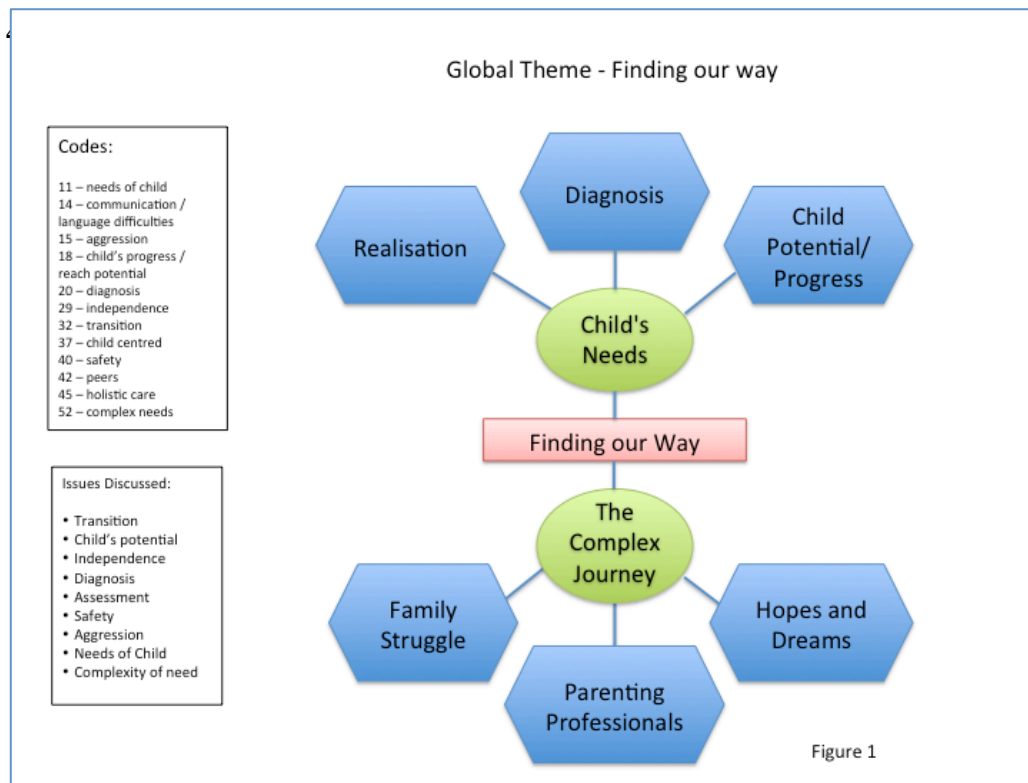
The theme of 'Finding our way" represented how families discussed their experience of
supporting their child, negotiating their way through their new situation and the services they
encountered. The network represented the families' realisation of their child's difference and
the subsequent journey they had undertaken.

The network represents the most prevalent themes within the family data. Initial codes
considered the child and parent journey from the realisation that there was something
different about their child to the point of a formal diagnosis. Parents discussed their struggle
to understand their child and their needs but also the emerging barriers they and their child
experienced in accessing services and support. The network was derived from six basic
themes: realisation; diagnosis; the child's potential and progress; the family struggle;
parenting professionals; hopes and dreams. These themes formed the two organisational

themes; child's needs, the complex journey. Each of the organisational themes will be considered in relation to the basic themes from which they were derived.

4.4.1 Organisational theme: Child's needs

Parents described how they came to realise over time that their child was different from their peers. The theme emerged from three of the six basic themes; realisation, diagnosis, child potential. These were developed from the original coding framework and will be considered in turn. Segments of interview data will be used to illustrate the themes.

Realisation

Most of the parents discussed a time when they became aware that their child's needs were different from other children. They described a process of realisation. This occurred at different times but their child's difference was also considered as a constant as it affected all of their encounters and experiences. Parents recounted numerous situations when their child's difference created barriers to opportunities, both formally and informally. The process of realisation was therefore an ongoing situation that affected the child's everyday life.

Kate described how her daughter did not develop in the same way as her other children, or similar to her peers. She was aware from a young age that her daughter's behaviour was different.

> *Kate.1.1*
>
> *When she was about two and a half roughly, what she was doing was not the norm. She was very hyperactive and couldn't sit still, always wanting to escape. ... boundaries didn't exist, so that's when I knew there was some difficulties ..*

Denise described how she knew that her son's development would be different from other children's. Following diagnosis of her son's rare syndrome she explained how they were encouraged to visit a parent support group where they could meet families and other children with the same condition. Denise however felt that her son developed very differently from the other children in the group.

> *Denise.1.3*
>
> *...there were children of two and three running round, talking, eating sandwiches but then we didn't see the worst case children with it, until he was a bit older and then we realised he wasn't going to be one of the ones doing all the running round.*

Diagnosis

Along with the difference recognised by parents, they also discussed the experience of their child's formal diagnosis. For the parents and child this point seemed to signify the beginning of a very different journey for them. Diagnosis was a pivotal and crucial moment for all the families interviewed. Families had clear and vivid memories of how their child's diagnosis was disclosed, and had differing opinions and experiences related to how useful the support offered at the time had been. Diagnosis was a very important part of the parent's quest to find out what was wrong with their child. This was often following lengthy periods of time and experiences which involved coming terms with their child's difference.

Mary described how her son's diagnosis was unhelpful. Her son's condition is rare and she reflected upon the level of uncertainty that the diagnosis yielded based on the information that was available to the family.

> *Mary.4.7*
>
> *No they weren't understanding because we were still going through tests and understanding you know, what his condition was and they said 'We don't really have an understanding, we don't know how it's going to develop, we don't know whether he's going to deteriorate or not. It was so rare what they'd seen because it was two genetic things that came together, that they never had any examples of, as they're growing up this may happen or that may happen, so it was like living every day wondering what was going to happen…..*

Mary reported that uncertainty in relation to her son's condition had continued from diagnosis to the time of the interview, and that they continued to live with this. She reflected on her family's resilience, and how they had managed to cope with and deal with their son's complex needs.

Lynn described the process of diagnosis as a route to enable access to support for her youngest son. Her older son had been diagnosed with autistic spectrum disorders and Lynn discussed the realisation that her youngest boy also displayed characteristics of the condition. Although she was clear that her youngest son had some similar needs the process of diagnosis remained painful. Lynn felt that the process of formal diagnosis would ensure that he would be able to receive the provision he required, through the provision of a necessary label. Lynn attributed feelings of guilt, anger and doubt to the experience of diagnosis, associated with her perceived abilities as a parent.

Lynn.1.1

It was a very personal thing and I decided not to share it with huge numbers of professionals. We did go and get a diagnosis because I did know that that was the only way to get services in my area. It was the only hope we had for getting a statement at the time…

Child potential/ progress

Parent's wanted their children to be able to reach their potential, have positive experiences and make progress, as indicated in the coding framework. Parents reflected on feelings of pride associated with their child's experiences and achievements.

Jane discussed how despite an initial poor prognosis her daughter continued to defy all expectations. She had made significant progress in all areas considered difficult for her, often beyond expectations based on her physical disabilities and ill health. The acquisition of everyday skills and experiences were considered as a triumph for this child and family.

Jane.8.48

…she still continues to surprise us all the time. I mean she's still doing things, her speech is coming on more and more and she'll get up now… whereas before food's never been a big thing for her, she'll go and get something out of the cupboard so that's like a big thing…

How parents fought to have their child's progress recognised was also contained within this theme. Parents felt that they had to advocate for their children to ensure that they received appropriate opportunities and support to aid their development. Frustration associated with the value base of services was expressed by Cathy, who felt that her son's school did not develop his skills and potential.

Cathy.9.48

*…they don't care the school. They think in those schools (*the children*) are animals and we just treat them as animal. The school is just a day care for them and when it's time for them to go home, let them go home. I mean ….they don't care what they can be tomorrow or not.*

Cathy felt that her son's progress was not considered important by the school. She suggested that his support focused on basic needs and that staff did not support his development. Indeed her views were echoed by a number of parents who felt that services saw their role as caring for the child rather than encouraging them to develop. Parents believed that staff

within service provision reflected a typical view of the value of people with a learning disability within society.

Angela described her son's experience of support from a service designed to support his visual impairment. She described her own and her son's frustration at the perceived lack of interest the service displayed in stimulating her son.

> *Angela.9.24*
>
> *The guy comes in and he has a rattle here and a torch thing that he points there….. my son enjoyed it but after a while he thought, you know what, I'm not a bloody monkey nor am I a performing dog so don't show me these things and he said 'oh well he's not interested'…. then you'd think forget it .*

4.4.2   Organisational theme: The complex journey

This theme was derived from the coding framework that formed three basic themes; our family struggle, professional parenting, hopes and dreams. Parents described how their experience of supporting their children's needs were very different from what they considered to be the 'usual' parenting experience. Eight of the parents in the study had more than one child and so felt able to compare their children's experiences directly. The three basic themes reflected how parents considered the experience of parenting their child and supporting their needs.

Family struggle

Struggle was a word that was used frequently in the interviews with parents. It was used to convey difficulty in many areas. These areas included the struggle to access and communicate with services, the struggle to come to terms with their child's difference and the struggle they experienced in meeting the everyday needs of their child.

Angela discussed how she had battled to access provision for her son and described this as an ongoing and constant daily issue. She felt clearly that her son's needs were not considered as a priority in the area in which she lived. This was reflected in her discourse as she described her frustration with the situation.

Angela.9.22

It's been a terrible struggle because the authority I live in is, on paper, it's very affluent and it's very rich sort of thing but in reality it isn't. It's an authority that doesn't want to spend its money anywhere.

Cathy described a different type of struggle. The difficulty she had experienced in understanding her son's behaviour and meeting his needs. She was aware that his needs were different from his peers, and articulated feelings of regret that she had felt unable to support or interpret his communicative behaviour effectively during his early years.

Cathy.3.22

...I don't know this boy because he hasn't got communication he couldn't talk and tell me what he wants so that is why he doing these things...

All parents described how difficult they had found it to manage their child's needs. For some families the ongoing struggle had reached crisis points. In relation to one particular family the crisis was exacerbated by the response and inability of services to respond the child and family's needs. Denise recounted how her son exhibited extreme levels of behavioural need, and for significant periods of time. She described how this put the family under enormous strain. Her son was eventually given an emergency placement in a respite unit. Due to the severity of his behavioural needs Denise and her family were informed that the respite area would be unable to continue with the emergency placement. The suggestion from the manager of the respite provision was that he needed to return home to the family. She discussed the family's desperation at the situation and the realisation that they would be unable to cope with their son's return. She reflected on the phone call from the service manager and how they as a family had responded.

Denise.2.22

So she said 'No he is, he's your responsibility, he is he's coming home.' And we went and sat on the beach in case anybody brought him home. We just couldn't cope. The screaming, we didn't know why ...

Parenting Professionals

In the context of meeting their child's needs, the realisation of difference and their struggle to gain support, parents discussed how they negotiated their child's journey. Parents described how they realised that they had to advocate on their child's behalf. Parents moved from feelings of helplessness through to a belief that they knew what was best for their child.

Parents discussed how they asserted and advocated with professionals and services to ensure that their family and their child received what was required.

Parents developed support networks for themselves, their child and also other families. Emma described how she had started a support group for parents in her son's special school. She explained how isolated parents could feel in relation to their child's behaviour and believed that collectively they could support each other through the sharing of information and experiences. As an example of the group's impact on her as an individual parent, Emma reflected on a situation she had experienced with her son. She described how she was frequently called by her son's school to collect him because of his behaviour. She reflected that the parent group had enabled her to explore the situation and become more assertive in her response to the school's requests.

Emma.3.25

But it's only now since I've started the support group that we've had people coming in talking and I know my rights and didn't have to take him home unless he was a danger to himself or another child so I could have just said on the phone, 'I'll be there at three o'clock'.

Gill reflected that in order to obtain support to meet her son's needs she had become skilled at finding out how to access services. She likened this ability to becoming a professional.

Gill.5.25

But I've realised to be a mum with a child like him you've got to go out and do your own research because someone's not going to come knocking on my door and telling me everything and giving it to me on a plate. So I think you've got to become a professional in yourself, and go out there.

Determination, resilience and persistence were a large part of the discussion within this theme. Mary described her experience of being 'fobbed off' by services. She discussed how she now felt able to persist in her dealings with services and professionals in order to get her son's needs met.

Mary.10.25

I tend to be one of those Mums that sort of picket, you know if I believe something can be done or should be done, I'll picket the line for it and say 'Look this is affecting my life, I need help now!   I'm not going until you've sorted something.'

Parents discussed the strategies they employed to get their family and children's needs met. This involved them being able to advocate on behalf of their children and family, but also being articulate and assertive with services and professionals. This level of skill was discussed by most of the parents in the research, and was attributed to the level of frustration with services and professionals that they had encountered. Confidence in the knowledge of their child's needs, their negotiation skills and their need to move forward was a direct result of their experiences. Parents described how they considered themselves proficient in dealing with others, often having to behave as, or take on the role of a professional.

Hopes and dreams

This basic theme reflected how parents perceived their children's futures. It emerged from initial codes such as reflection on their journey, change of expectations, letting go and independence. Although families discussed the difficult situations they had experienced with their children, they all expressed positive hopes and dreams for their child's future. The aspirations of parents however had changed because of their child's needs. Hopes and dreams had been re-visited or revised and were often expressed in relation to their child's strengths and abilities. This point in the interview was a very enjoyable and positive part of the discourse with parents. They revelled in their child's successes and I felt privileged to listen their aspirations for their children.

Kate's daughter had physical health issues and autism. Kate's understanding of her daughter's difficulty in accepting change created a sense of pride in what she had been able to achieve.

> *Kate.8.47*
>
> *Big jumps for her because they are different, for the normal, I shouldn't say that, but for us we accept it, but for her, I didn't realise just how tough it would be for her to cope with all these changes because she doesn't like changes, she likes things to be the same, she knows where she's going …*

Gill discussed how she wanted her son to be part of the everyday normal activities of being a young boy. She described her desire for him to attend a mainstream school which she felt would provide her son with appropriate role models and mainstream experiences. Her son's wish to walk to school stemmed from his dislike of the escorted taxi that had been arranged for him to attend his special school. The taxi had been an initial compromise due to his

refusal to get on the 'special yellow bus' that he believed identified and separated him from his peers.

> *Gill.8.53*
>
> *I want him to be able to access what other children take for granted. He does too. At the end of the day he wants to be able to walk to school in the rain because he can't do it.*

Lynn has two sons with autism. She was keen to celebrate her youngest boy's abilities and discussed how he could apply his talents to future employment. Although Lynn spoke light heartedly about her son's future she was certain that he had a valued place in society. She conveyed her determination to ensure that he could fit in to a role that would allow him to be valued.

> *Lynn.6.47*
>
> *…I think he could probably do that job without measuring distances because he's got that way of working things out. Fencing contractor - he's got the strength, he likes standing things up sort of yeah so that's one of the first things I thought about, so now I need someone to apprentice him, but it's early days he's nine. But at the moment what I could see it's never really negative with him, he doesn't really need to work as a fencing contractor. As long as he's working with someone he's happy.*

The diversity of issues discussed within the basic theme of 'hopes and dreams' emphasised the complexity of the journey families described during their interviews. For some families the opportunity for their child to experience normal and everyday life events would be a welcomed achievement. Other parents expressed their level of pride at what their child had been able to achieve and relayed their hopes for the child's future. The need for their child to have a fulfilled and happy life was common to all the interviews but constituted different elements dependent on the child, their needs and their families' aspirations for their future.

4.4.3   Summary of global theme finding our way

The global thematic network of 'finding our way' contained two key organisational themes, the child's needs and the complex journey. The network identified the inextricable link between the two aspects. The network considers experiences described by families associated with the realisation of difference, the difficulty of diagnosis, the need for the child to reach their potential and progress, the struggle of the family, the professionalisation of the parenting role and the hopes and dreams of children and their families.

The realisation of difference and the experience of the complex journey with their children led families to express their disappointment with service provision. They had waited for help that did not arrive. When it was offered it was not child and family centred or appropriate to support their child. Extreme circumstances led families to require reactive and emergency support. As a result of such experiences, families described how they developed in their skills and ability to trust their own judgement, often contrary to the advice of professionals. Families described their children's gifts and skills. They discussed how they would need to continue to support their children to ensure that they were able to lead fulfilled and meaningful lives.

4.5   Global theme: Square services, round needs

Figure 2
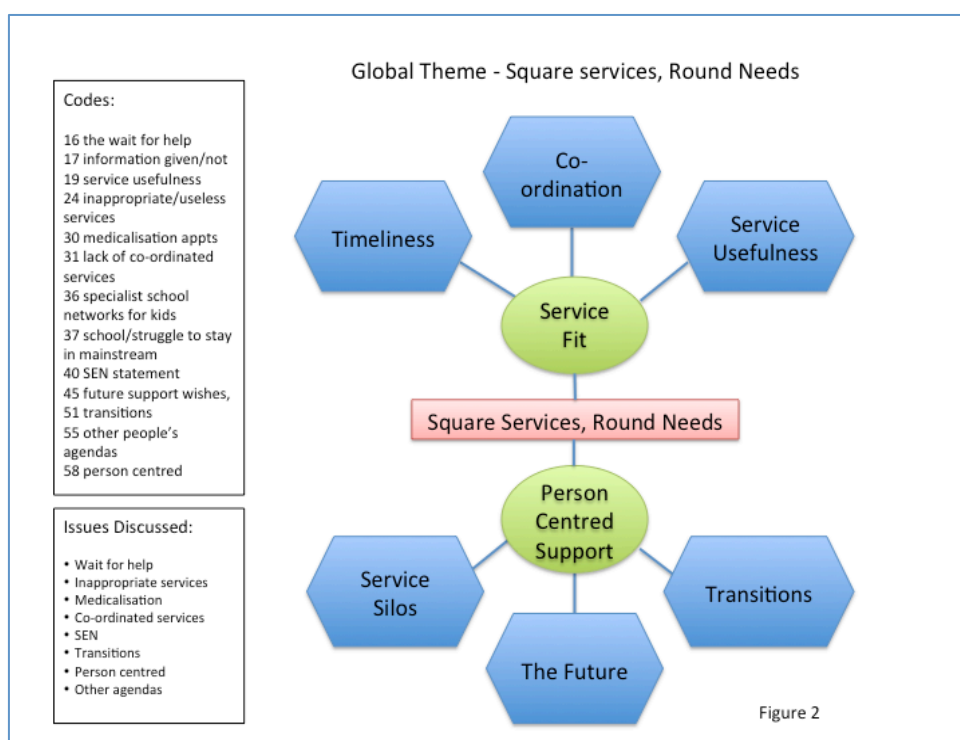
The second global theme identified within the data showed how children had experienced services and the level of support they had received as reported by parents. Thirteen codes from the framework are contained within the global theme, with 1152 coded segments identified in the formation of the network. Basic themes came from issues associated with the extent to which services had supported the child's journey, and how families viewed the future needs of their child.

The network emerged from the discussion with families that centred on how they had been supported by services and professionals. The codes identified within this theme considered

issues such as the wait for help, the appropriateness of service provision, the dominance of the medical model in their child's lives, the co-ordination of services and special educational provision.

From the original codes six basic themes emerged; service usefulness, co-ordination, timeliness, transitions, the future, service silos. The basic themes formed two organisational themes of service fit and person centred support. It was the complexity of provision and experience that led to the development of the overarching global theme of square services round needs.

4.5.1 Organisational theme: Service fit

Service fit was an organisational theme constructed from the three basic themes of useful services, co-ordination and timeliness. Parents considered how their child's needs had been supported or impeded by services. At times the child had experienced an inability to be part of provision that was often unable to meet their behavioural needs. The child had consequently been excluded from support that placed further pressure on families that felt unable to cope with the specialist nature of their child's support needs.

Service usefulness

Parents were asked to consider their own and their child's interaction with services; what in their opinion, had been useful and what had not. Some parents described how they had been offered services or received services that were not appropriate for their needs. This was felt to be related to what was available rather than what was required to support the child and family.

Jane described how her daughter's medical needs had meant that she spent a significant amount of her early years attending medical appointments. She felt that her daughter's holistic needs were not considered during these times. Jane described how the negative situations her daughter experienced often affected the true assessment of her needs. Although the experience may feel common to many families, for Jane the understanding of her daughter's needs was vital in their ability to access appropriate provision.

Jane.10.19

... it was the same every time. I would wait about an hour in a tiny little corridor with nothing to keep her amused and then she was like really frustrated and uptight and by the time you went in there was no way she was going to comply to a hearing test....

Gill described how she had requested respite provision for her son due to their family situation. She was asked to consider a local respite unit that offered support to children with a learning disability. She explained how the provision was unsuitable and inappropriate to meet her son's needs. As a result of her refusal to use the service she was consequently unable to access any respite support

Gill.6.19

...children of this generation want Nintendo, Wiis, DSs, some comfy loungers, I just think the provision is appalling. I mean, but you've got like a broken Wendy House in the corner with some brightly coloured cushions thrown on the floor and some colouring books. Now how is an eleven year old boy going to be entertained with that?

Most parents expressed the view that the provision available to their child was not able to effectively meet their needs. Parents felt that they had been offered what was available, rather than what was appropriate for their child. Most parents were able to articulate the support needs of their child and felt that they could clearly pinpoint the level and type of support that they required. The inappropriate use of resources angered some parents. Angela described this situation in relation to provision for her son who has profound and multiple disabilities.

Angela.14.24

...services that are useless, which cost them a lot of money and there's some things which could be done cheap (simply) and it's cost them an arm and a leg for nothing.

All the parents interviewed clearly articulated their frustration at services which were neither fit for purpose nor child and family centred.

Co-ordination

Families reported that their experience of services had been that they were often disorganised and uncoordinated. This had led to communication issues with services that

were considered to lead to avoidable delays in provision. Parents felt that access to support was often hindered by unnecessary bureaucracy.

Mary explained how the service that she required for her son was not provided in her local area. Fortunately the service made an exception to their referral criteria due to the severity of her son's needs and the impact of those on his and the family's life. Mary was aware, however, that the professional involved was working in isolation, resulting in a fragmented approach to her son's care.

> *Mary.2.31*
>
> *...he was working completely isolated from children's social services. You know what I mean, it wasn't joined up or anything. So anything we were doing or anything he was saying 'This is the kind of support you need.' and they were saying, 'Well we can't do anything about that because we don't provide that service.' So it was very, very, very disjointed but very successful.*

Mary described a successful behavioural intervention programme. She felt the support had played a major part in her son's progress and allowed her family to successfully manage and understand his behavioural needs. She was however aware that access to this type of specialist provision was related to her tenacity in effectively accessing the specialist service that her son required. She was clear that not all families would be able to exert enough pressure to facilitate their own child's needs. Mary reported major unmet needs in her area due to the paucity of service provision for children with behavioural needs and their families.

Mary's experience in accessing appropriate services for her son could not be considered to be consistent across all the families interviewed. However the parental awareness of a mismatch between what was available and what their children required was clear and was asserted across all the interviews conducted.

Kate described how when her family moved her daughter did not receive the services she required. Kate reported that she was told it was her responsibility to co-ordinate her daughter's support needs.

Kate.1.31

Then when I moved here and tried to access services, and they were non- existent. I was told by the GP that I needed to get in touch with all her consultants, right, to get the service I needed.

Families reported how they, as parents, had needed to ensure that their child's needs were met. Services appeared to be fragmented to some parents, un-coordinated and difficult to access. The ability of services to respond appropriately to the changing needs of children and their families was consistently described as poor.

Timeliness

When and how support was offered to families was also prevalent in the data through codes such as the wait for help, and the provision of information. Denise described how her family had requested support. The family had found themselves in a situation of crisis that resulted in the need for emergency respite provision. Denise was clear how the situation could have been avoided.

Denise.5.16

We asked all along for this thing, it's called 'Share Care' and it's just for two nights once a month and that's all we were asking at the time and we couldn't get anybody.

Emma described how families struggled to access the support they required. She felt the situation was exacerbated by poor information, lack of parental knowledge of what was available and a paucity of appropriate referrals from professionals.

Emma.10.16

Yes but you see you have to be referred to these and you have to meet certain criteria to get this help where other families are struggling as well. Not everybody can get referred to certain organisations.

Parents were clear that access to appropriate service provision was an issue for most families. They described a lack of power and a perceived level of invisibility within their communities and their dealings with services. All parents reported their frustration with the wait for help and the availability of appropriate support which at times felt exclusive rather than inclusive of their children.

4.5.2   Organisational theme: Person centred support

Person centred support was derived from the basic themes of transitions, the future and service silos. Families discussed how services supported the individual needs of their children and their family. Key times of difficulty were noted by families to be related to transition for their children. The move between services was disjointed and uncoordinated. Families discussed how provision appeared to be led by service agendas rather than by the needs of the child and family. This situation left families concerned for the future support of their children.

Mary described how her son's move from children's to adult services had illustrated the paucity of child centred provision he had received. She reflected on the price, both financially and personally, to her son and her family, of poor support.

> *Mary.8.55*
>
> *...the way I see it, it saved services money, if it had been done earlier ....trying to say to children's social services, look the impact of what's happened and happening, is going to cost more than if you'd put support in, in the first place – proper support into the home that made sense for us as a family. Yes it would have saved so much more money in the long run....*

Transitions

The basic theme of transitions was derived from the coding in relation to the move between services and the struggle that children experienced between special and mainstream provision. This theme was largely discussed at a service level, education was a dominant area of conversation related to services across all the parent interviews. The transition between junior and secondary school, and school and college were considered as extremely difficult for children with behavioural needs by parents.

Jane explained how she felt when her daughter left a special school to move to a college. She reflected on how the process had been a very different experience for her other children. She expressed the uncertainty that she felt for her daughter when trying to plan for the move.

> *Jane.9.51*
>
> *I think that leaving school was the scariest because for a long time we just didn't know what was going to happen and the options seemed to be getting less and less and I remember at that time feeling really quite down.*

Mary felt that her son's move from junior school was poorly managed. The transition coincided with an increase in the intensity and frequency of her son's behavioural needs. Mary described how his behaviour became apparent across all his environments and attributed the changes in his behaviour to the situation.

> *Mary.12.37*
>
> *No transition across, so you've got a young lad whose got hormones that's kicked in earlier, who hasn't been skilled up at the junior school to start thinking about how he's going to start doing that himself, ready for when he goes over into high school, so there were key things that were triggers, not just at home, but it was also the environment, the school and everything.*

Transition between services and types of provision were a key area for discussion in the interviews. Families reported the struggle that their children had experienced during these difficult but often predictable periods of change. The professional role in transition was not as evident in their discussion as the service role. Families were able to pinpoint major times of difficulty for families, but reported a lack of provision or capacity amongst services to meet their needs.

The future

All interviews with parents included a discussion about the future needs of the children. The basic theme was derived from the coding framework associated with 'future support wishes'. It was however closely associated with transitions and information. Families were clear about how their children could continue to progress and how this could be achieved.

Angela described her concern for her son who had profound and multiple disabilities. She believed that his provision would stop at twenty one and feared for his and her family's future.

> *Angela.8.45*
>
> *School or college until he's twenty-one, after that there's no provision there, everybody, all services, are cutting down and then when they come to that age twenty-one, they then become a burden to the family or, if they go somewhere, to that society.*

Related to educational provision, although families were not always happy with their child remaining in special educational provision until they were older, they were aware that it

provided some security for the child. The absence of planning for the child post education however was discussed as a major concern as their child's behavioural needs were considered to affect the opportunities available to them.

Denise and her family had been actively involved in the consideration of their son's move into residential provision. Denise however described the response they received when the service they were offered was inadequate and inflexible in meeting what she considered to be a basic but fundamental need.

> *Denise.9.45*
>
> *And we looked at supported living and there wasn't a bath, he loves a bath, he loves water, and said you know that will be no good and then they said to us if we didn't decide they could make the decision and take us to court for best interest. So now we're going through the courts….*

Parents discussed how they often felt compromised as they usually had to accept support that was not entirely suitable for their child. Parents felt that services were unable to change or be responsive to their child's needs due to external factors such as resources. Although families described their anxiety at a lack of suitable provision, they also alluded to a lack of choice and viable options for their children. Parents felt that they had little choice or power over what should be provided and available. A conflict of agendas was noted as services were not perceived to be child and family centred, while the individual needs of their children were paramount for all the parents in the study.

Service Silos

Within the organisational theme of person centred care parents discussed how other people's opinions and agendas were able to affect the support offered to their child.

Angela described how she felt her son had been labelled so that he could be fitted into discrete types of service provision. This resulted in her opinion that her son was considered by professionals to be a collection of needs rather than an individual person. Angela was clear that this type of needs-led approach had prevented her son from being considered in an holistic, child-centred way.

Angela.2.24

Unfortunately the professionals want to put you in boxes and they label you. This person's got this, this, this, this, so it makes them feel comfortable and if something goes wrong they can say, 'Oh we did say he had behavioural needs or he's got mental health problems, he's got this and that, it's a way of life unfortunately'.

Mary discussed how her family had reached crisis point in relation to her son's behavioural needs. When she approached the school for support they refused to help as his behavioural needs were not apparent within the school environment. Mary was clear that their focus was on education and not his overall progression and wellbeing**.**

Mary.9.24

School very clearly said that unless they saw the behaviour at school they couldn't intervene, erm so basically they did nothing because there's almost like that barrier between believing what's happening and we're not seeing it at school. And they said to me that's a positive because if he's only doing that at home at least it's not interrupting his education.

Families discussed within this theme how they fought to get their child's needs met, often against the agenda of services or professionals. Families experienced a compartmentalised approach to the needs of their child with services unwilling or unable to work together for the needs of the child and family. This was considered as unhelpful and obstructive to families who often sought support due to the very difficult situations the family and children were experiencing.

4.5.3   Summary of global theme square services, round needs

This theme emerged from the two organisational themes of service fit and person centred support. Service fit focused on how families considered that their family and their child's needs remained unmet. This was related to provision that was service-led, rather than child and family centred. The person-centred global theme reflected the extent to which services were generally perceived as inappropriate and unsupportive in meeting the needs of children with learning disabilities and behavioural needs and their families.

The six basic themes: service usefulness; co-ordination; timeliness; transitions; the future and service silos, emerged from the coding framework. Essentially this global theme represented the mismatch between a service-led approach and a person-centred approach. Families were aware that provision was led by service agendas. Some parents discussed how

they had tried to challenge this perspective but took the view that service-led provision was inevitable. Experience had illustrated to the families that their child would need to make do with provision that was scarce and inflexible.

Periods of crisis and difficulty associated with the child and their behavioural needs were described at length by families. These experiences were relayed to illustrate how they had accepted the available (often unsuitable) provision, in the absence of appropriate alternatives. With this in mind families viewed the support available to their children in the future to be of major concern.

4.6   Global theme: Behaviour touches everything

Figure 3
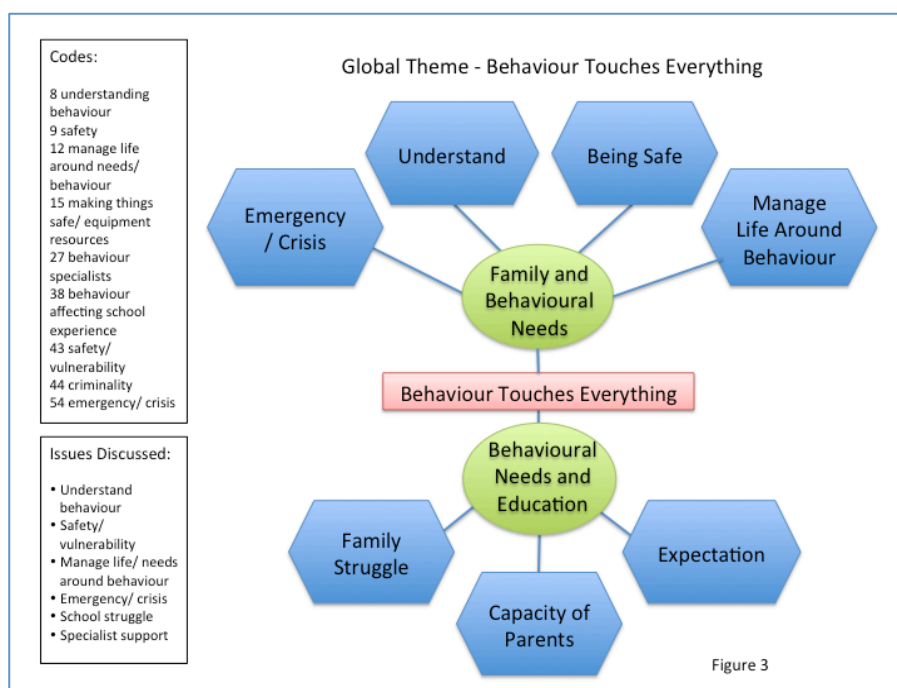
The thematic network that considers behaviour and its impact was derived from nine codes within the framework for analysis and represented the identification of 802 coded segments. The codes reflected how behaviour had impacted on the child's life, the family and also their education. The network contains seven basic themes: understanding; safety; managing behavioural needs; emergency/crisis; impact on education; specialist support; educational exclusion. The basic themes became two organisational themes of: family and behavioural needs; behavioural needs and educational. Each organisational theme will be considered through discussion of the basic themes contained within.

4.6.1 Organisational theme: Family and behavioural needs

This theme represented four of the original basic themes. Parents discussed how their child's behaviour had affected their family life. The management of the behaviours had been a difficult area and parents reflected on their lack of understanding or knowledge to effectively support their child. Parents described how they had come to adapt to their child's behavioural needs following times of crisis and breakdown.

Understand

Parents expressed levels of frustration and regret in relation to how they had initially managed their child's behavioural needs. On reflection, having learnt to understand their child's behaviour, parents were clear that their child's early experiences were affected negatively by the lack of understanding they received in services and within the family.

Mary described how they had come to understand her son's behaviour. He would be physically aggressive in the home but not in other environments. She described how difficult it was for her to manage her son when his behaviour deteriorated.

> *Mary.3.8*
>
> *... I mean at first I didn't understand triggers, I didn't understand the escalation period and the fact that if you didn't nip it, catch it straight away and understand what the trigger was, then you actually stop it. But once he got past a certain point there was no stopping it and there was no controlling it and he had no idea what was happening until he started to come back down the other side.*

Cathy described how she had eventually developed a system that enabled her to communicate and interact with her son. She reflected on times when she had been very frustrated with his behaviour, as in his early years he had displayed coprophagia (smearing of faeces). She discussed how difficult she had found this particular behaviour to manage and expressed regret at how she had dealt with the situation in the past. Cathy reported that it was her lack of knowledge of the communicative intent of his behaviour that had affected his early years and experiences.

> *Cathy.2.8*
>
> *.. poohing all over its difficult because I don't understand him. I was smacking him because I was distressed so by that time I think of that I just want to throw him in the water. Because erm I don't know.*

All parents reported their desire to support and understand their child. They spoke positively about their children's skills, but also reflected on the initial struggle they had undergone to find a way to understand and manage their behavioural needs.

Being Safe

The need to consider the safety of their family and child was prevalent across the data. Families described times when their family life was dominated by their child's behaviour. The basic theme was derived from codes which reflected the need to keep their child safe from external factors, and also their child and family's safety due to their child's level of behavioural need.

Mary's son had demonstrated some extreme behavioural needs and she described how the management of it completely dominated their lives as a family. The safety issues involved for the family were extreme and clearly articulated by Mary.

> *Mary.6.9*
>
> *...your whole life revolved around his behaviour, what you could and couldn't do. How you could function as a family revolved around his needs. And while he was going through that really bad period for the four years, it took two of us to actually maintain that stability, the behaviour, sometimes even two of us because it would get so violent you would have to try to restrain him you know because ... which made you feel awful as a parent, completely against my principles, restraining somebody, but it was about safety and nothing else.*

The other aspect of safety discussed by parents was related to the vulnerability of their child due to their level of cognition and their behaviour. Susan's son believed that he had made friends in the local area. Susan believed that he was targeted as a vulnerable person. She described how he was stealing for his friends and allowed them into the family home while she was at work. Her son had recently been placed in a youth offending institution at the time of the interview. Susan believed strongly that his behaviour was directly influenced by others and the lack of support that he had received from services.

> *Susan.4.43*
>
> *They know I am not there and he is vulnerable, as you call it, stupid. So they enjoy it, they abuse my home. No, he doesn't see it happening.*

Lynn's son had a very different relationship with the police than that described above. Lynn described how as a family they had adapted their home and life to ensure their son had limited opportunity to run away, and was safe. She discussed how she had made her son known to the local police in an attempt to ensure that he would be safe in the community when attempts at keeping him at home failed.

> *Lynn.1.15*
>
> *...life is very restricted because he's really prone to just disappearing off and he runs really fast. He's really incredibly fit and agile you know so that's affected, to a large extent the way that we live. I have to, you know, lock doors and windows just to slow him down, and the police have been fantastic, he's been brought back countless times; we have to phone the police and say 'he's gone again' and this time he was on his bike.*

Her son's behaviour required the family to make adaptations to the way that they lived. To have a child known by the police may be considered as negative for most families, however, for her son, Lynn believed it provided a necessary safety net to meet her son's behavioural needs.

Managing behavioural needs

The basic theme of managing behavioural needs was derived from the coding framework in relation to the complexity of the child's behaviours. As well as vulnerability, criminality and understanding of behaviour it was clear that management of the child's behavioural needs was paramount to the families. There would be no requirement for family adjustments, specialist support and provision if the child's behaviour was considered as typical. This theme reflected the impact that a child's behaviour had on their life.

Emma described how her son's impulsivity made him vulnerable and very difficult to manage. As a single parent she explained how she struggled to ensure that he was safe all the time, particularly when he was at home. She described how exhausting the worry and stress had become.

> *Emma.3.43*
>
> *The constant worry, you know I felt worn down. What next you know? He'd jump out of bedroom windows you know. I was in the living room or in the kitchen and I'd go up to him and Oh My God, the window's wide open, blinds pulled back –*

Mary described how her older son's volatile and extremely aggressive behavioural outbursts had affected his younger brother. She described situations when she found herself in the position of trying to physically protect her younger son. She was acutely aware of the vulnerable situations she and her family had found themselves in, and reported on the lack of support available to them during the episodes.

Mary.2.12

Very distressing for my other son who was six at that time because Social Services answer to that was 'Send him to his bedroom and tell him to lock himself in.' Well a six year old would be wondering what was happening to his Mum downstairs and that's no answer. And I used to have to physically protect him so he couldn't get to him, because he would try. He used to try to throw me around, once he'd reached that height there was no stopping him.

Emergency/crisis

During the interviews some of the families discussed their family and child's experiences of very difficult situations related to their behaviour. Most families were able to recount a time when they felt that their situation had reached a point of crisis. This was discussed often in relation to how they had unsuccessfully sought support (to discover this was often not available) due to the severity of their situation.

Denise described how she and her family had reached a point of crisis due to the complexity of her son's support needs. She discussed how they had consistently asked for respite provision due to the strain on the family. This was not provided for her son. Following an extremely difficult period of behaviour experienced by her son, Denise discussed how they felt unable to cope and asked for emergency care.

Denise.5.54

....we cried our eyes out when we took him – but we knew that he had to, and then when he'd gone, it felt like we were on holiday.

Gill described a similar situation of crisis. She discussed how she had only been able to gain respite when she had reached the point of despair. Gill felt that her son eventually received short-term emergency care, only once she had threatened to place him into long term care. She described how the situation had made her feel.

Gill.6.54

Yes it was heartbreaking because you just know at the end of the day you wouldn't hand your child over to the Local Authority.

Parents were able to describe very difficult situations that had resulted in the provision of emergency support. Even at this point, the care provided for their children was temporary, and parents felt it was only provided due to the crisis situations they had eventually reported to service provision. The examples shared by families were given to illustrate the impact that the child's behaviour had on their and their family's experience of family life.

4.6.2   Organisational theme: Behavioural needs and education

As the research was related to children, education as a main provider of services to this population featured prominently in the parent interviews. In relation to the organisational theme, the child's education was significantly affected by the presence of behavioural needs. The coding framework revealed three basic themes: expectations; specialist support; educational exclusion. It appeared that a child's behavioural needs had a significant impact on their educational experiences and journey.

Expectations

How the child's behaviour affected their educational opportunities was discussed at length by parents in the study. Many examples were reported by parents and included, the school's ability to manage the child's behaviour, and the impact that the child's behaviour had on their journey through education.

Susan described how her son had attended numerous schools. She felt that schools had not wanted to support her son due to his behavioural needs. For this reason she had moved him several times in search of what she considered to be supportive environments. She reported how one school would frequently request her to collect her son when they were unable or unwilling to support his behaviour. Susan was clear that this had been detrimental to his educational progress and experiences.

Susan.6.38

They didn't do nothing. He's been there six months, maybe one year. Yes calling me – ' Mrs - there has been a problem. He has been doing this he has been doing that. Will you come and fetch him?'

Emma described how her son had struggled within mainstream educational provision. She reported that the situation was exacerbated by a lack of support for his behavioural needs. Her son had attended several schools and had experienced exclusion both formally and informally. Emma was able to discuss how his current school enabled him to effectively access his education, despite a delay in the provision of an educational statement of special educational needs.

Emma.10.38

School said, 'He's just naughty, just naughty.' And it wasn't until he was almost ten that he got assessed. You know so at the new school I was very lucky they actually took him before he was statemented because he would have been excluded so I was very, very lucky.

Emma was able to identify an educational experience that was able to provide the behavioural support that he required. The importance of an educational statement that recognised the child's behavioural needs was mentioned by several of the families. The prevalence of behavioural needs within education both mainstream and specialist was identified as a problem in relation to the children's progress and experiences. Emma's description of finding a school that was supportive of her son's behaviour as 'lucky' represented other families' views that the quality of a provision was related to the staff and professionals rather than the type of provision.

Parents clearly communicated that it was because of their child's behaviour that their educational experience was different. Despite individual preferences associated with the type of provision parents wanted for their children, it was behaviour that was viewed by parents to be the barrier that prevented a normal journey and experience through their school career.

Specialist support
The basic theme of specialist support was derived from the discussion of individuals or services that had been involved with a child and their family related to their behavioural needs. Parents discussed how schools were often a place where they sought support and advice in relation to their child's behaviour. The behavioural support received by children came from a range of professionals and services. The impact however that the support had on their child's education and progress was considered significant by the parents in the research. There appeared to be agreement amongst the parents that behavioural support was

difficult to access and often unavailable. The parents however appeared to agree that where it had been provided the effects had been positive for the child and their experience. Views expressed by parents were associated with the struggle they had experienced to gain specialist and appropriate support.

Mary described the impact that a behaviour specialist had on her son's behaviour. Mary had previously discussed how difficult her son's behaviour had become and the actions she had taken to secure a specialist to support him. The service she received was not typical in her area as it was usually only available within adult provision. Following a significant period of negotiation and tenacity on her behalf the intervention eventually implemented was very successful, even empowering her son to manage his own behaviours.

> *Mary.2.27*
>
> *The behaviour nurse was the best thing that ever happened. Hugely intensive I have to say but the advice and time and support that he spent with us as a family, trying to understand the triggers, trying to find the right kind of methods to work with him, was phenomenally beneficial. Hugely, and to the point now where we hardly see any behaviour from him and if he does, he can self-manage it.*

Lynn described how she had been referred for numerous interventions considered to be appropriate to meet her two boys' needs. She was able to pinpoint what had been the most useful but also identified numerous services that her boys had encountered that were ineffective. Lynn felt that the most relevant and useful intervention was received from behaviour specialists who had been able to support the family to understand and manage their son's behaviours, and further support her sons to maintain their places in mainstream schools.

> *Lynn.3.27*
>
> *....I've worked out my own strategies with him. I've had lots of people come and talk to me about what to do but when it comes down to it what I've learned from talking to behavioural support people like, people like that, they're the people who've really given me the... and now people are amazed at how kind he can be and how he can fit into the mainstream school.*

Educational exclusion

Exclusion was multi-faceted within the findings and will be discussed in depth within the discussion chapter. The issues identified from the original coding identified how a child's

education was affected by their behavioural needs. This had ultimately led to some children being excluded from education. Exclusive practice ran across many of the experiences parents discussed both in an informal and formal context. Several parents clearly identified that their child had experienced exclusion within school. However parents appeared to accept that due to the child's behavioural needs this situation was an unavoidable part of the educational journey.

Exclusion was apparent within the data in many guises. Parents described their child's experience of both formal and informal exclusion directly related to their behavioural needs. Some parents described how their children were aware that they were different from their peers and felt excluded because of their needs.

One child had discussed his experience of exclusion with his mother. Gill reported that her son felt excluded by the visibility of the support he received related to school transport. He felt different from his peers and wanted his support to be less obvious.

Gill.8.41

He says he feels different. Because it's not normal to go to school on the bus and it's not normal that someone comes to ring on your doorbell wearing a yellow jacket. I say it is normal because they go to a local school and you go to a school here and she's got to wear a yellow jacket because it's her uniform. Yes but it's not normal is it? It's not normal behaviour. He says people stop and look at us and stare if we're on a bus. So I had to move him from the bus because he was getting so agitated on this bus and people were staring at him, so we had to put him in a taxi.

Emma described how her son's school frequently requested that she take her son home due to his behaviour. She discussed how this prevented her working and meant that her son was informally excluded from receiving his education.

Emma.3.41

Well I can't go back to work because I had to leave my job through him, I was getting called to the school every day. Stupid little things to be honest. Throwing a brick into the railings and you know occasionally yes it could be something quite serious but most of the time it's silly little things, he won't listen, he's just shouting out in class - to be honest he spent most of time in junior school in the corridor. Yes they just couldn't cope in the classroom and (so if they called you what did they expect you to do?) Take him home.

The children discussed in the research experienced exclusion in many forms. Parents were very aware of the implications of removing their child from school when requested to by the school. They felt powerless to alter this situation for due to the perceived risk of formal exclusion of their child due to their behaviour.

4.6.3   Summary of global theme: Behaviour touches everything

The impact of behaviour was considered within this network. Families discussed how their child's behaviour affected the lives of their family and also the child's education. The two organisational themes: family and behavioural needs and behavioural needs and education were derived from the seven basic themes: understanding, being safe, managing behavioural needs, emergency/crisis, educational exclusion, specialist support and expectations.

The network identified that behavioural needs had a significant impact on a child's educational and family life experiences. Families struggled to understand their child's behaviour while attempting to advocate for them effectively within systems that families felt were often unsupportive and inflexible. Parents described how their family life was affected by their child's behaviour, but attributed the issues to the lack of appropriate specialist support for their child. The vulnerability and safety of the child as well as the physical safety of the family were also considered within this network. The network reflected the direct impact that a child's behavioural needs had on all aspects of the child and family's life.

Schools featured strongly in this network as a place families sought advice and support associated with the management of their child's behavioural needs. Parents however did not feel that their children's schools were experienced or supportive in helping their child's behaviour. Moreover how their child's behaviour was perceived and managed in schools actually created and perpetuated problems for families. Parents described numerous incidents when their child experienced both formal and informal exclusion from educational opportunities.

4.7   Global theme: Belonging

Figure 4
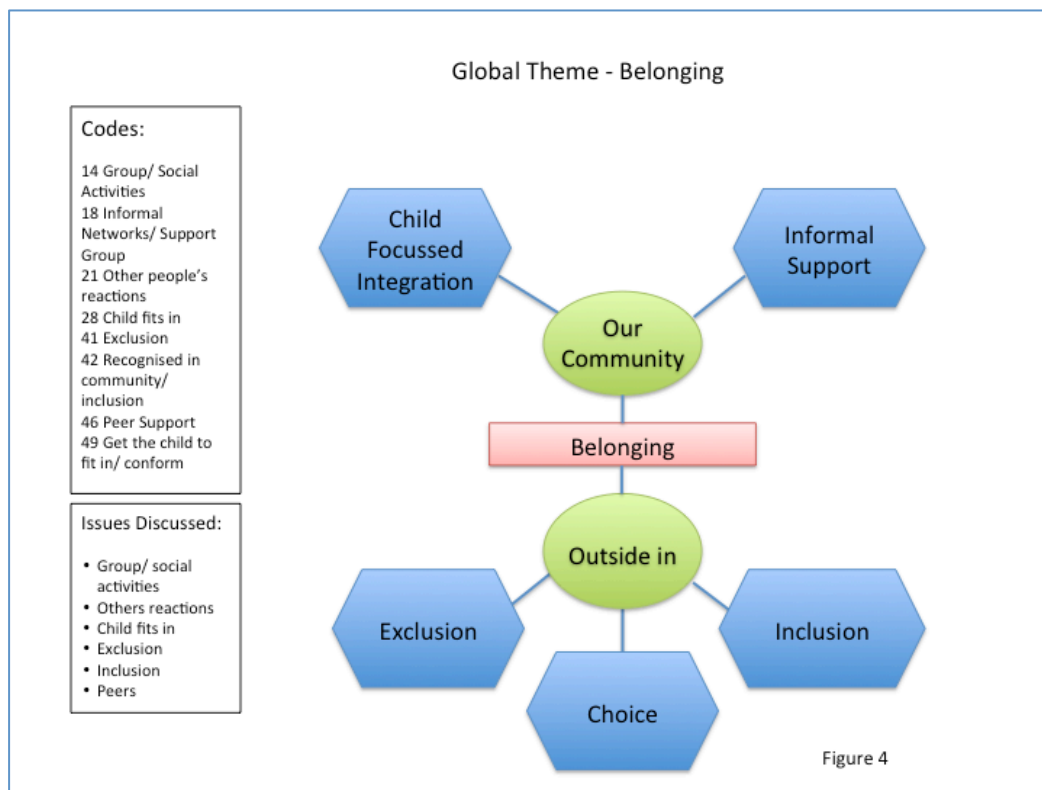
The global theme of belonging was derived from eight codes associated with how families viewed their level of community and social participation. Some of the discussion was affected by the choices families had made in relation to how they felt their children should be included in their local community. For some parents their child was seen as able to participate in mainstream activities. For other parents the type of activity they felt appropriate would involve a high level of support and specialist provision. How the child fitted into their community appeared to be very important for families on different levels from safety through to exclusion.

The global theme was derived from two organisational themes:
- our community
- outside in

Child-focused integration and informal support formed the organisational theme 'our community'. The organisational theme of 'outside in' was formed from three basic themes: inclusion; exclusion; choice.

4.7.1   Organisational theme: Our community

Families considered that their child's integration was dependent upon the networks that they were able to access within their community. Families differed on their view of integration. What was evident in the interviews was the child and family centred approach to integration. Decisions were made by families about their child's level of integration and inclusion based on their experiences.

Child focused integration

Jane discussed how her daughter preferred the local youth group to some of the specialist provision she had attended. Her daughter's enjoyment from being with her peers had shaped the type of provision that the family considered beneficial for her.

> *Jane.4.36*
>
> *She had a challenging behaviour when I tried to bring her out of it 'cos she just didn't want to come home. Some of the schemes I used to send her to which were just for children with special needs, I knew it wasn't right kind of thing whereas this, she couldn't wait to get there and I think it was just the chatter of all the other kids - she really loved that. That was a really positive experience.*

Denise reported her frustration at what was available for her son. She felt that he would not be able to access mainstream provision due to the complexity of his needs. However, with a group of parents who were in a similar position, Denise described how she formed and ran a play scheme for children with disabilities in their local area. The scheme was very successful, however Denise withdrew from the organisation due to the pressure of caring for her son.

> *Denise.6.14*
>
> *...so there was four of us set up a play scheme and we used to take thirty five kids a day, and we had charity status and it was great while it ran. (there was nothing available?) yes so we set one up.*

The school holidays were reported to be a particularly difficult time for the children and their families. Parents discussed how the services that were available to them were limited due to their child's needs. Indeed specialist provision was often not able to offer support to their child because of their behavioural needs. Most parents had repeatedly tried to access a number of provisions. For children who had a learning disability and behavioural needs their options were considered to be extremely limited.

Informal support

All families discussed how they and their child had interacted with informal levels of support. This form of help was described by the parents in different ways, as family situations and dynamics appeared to affect how supported they felt. Some children were considered to receive valuable support from extended relatives and family friends. Like Denise several other parents discussed how they had been part of, or instrumental in, the formation of informal networks, as an attempt to network individuals that could support each other.

Emma has two boys with behavioural needs. With other parents they formed a local group within her children's special school. The group was designed to support families and share information. Although the group was in its early stages Emma was proud of what the parents had achieved. As well as meeting her needs for information and support, she reported that the group could give her a focus and help her use her skills. Emma described her frustration at not being able to work due to her children's behavioural needs.

> *Emma.4.18*
>
> *Yes well I run the support group in the school, me and a couple of other girls, we only started it six months ago. Well we find it useful and we've got people very slowly to join in and it's still really getting off the ground but we've got loads of people wanting to come and do talks and therapy sessions and come September we'll be on the website and it's took time getting there. It keeps my life occupied because I want nothing more than to go back to work. I'm bored, fed up and until we started this group really I didn't talk to adults during the day. I'd be stuck in this house. I couldn't go anywhere or do anything because I'd get a phone call, I'd be in town shopping and 'You need to come and get them'.*

Emma's sense of usefulness had been restored through the formation of the group. She discussed her feelings of exclusion as a result of supporting her sons, and how she was unable to work or socialise with friends. To some extent Emma's approach to meeting her sons' needs had resulted in her being able to meet her needs also.

Jane described how talking to other parents whose children had learning disabilities and behavioural needs had proved to be useful. As well as practical advice Jane echoed how it prevented her from feeling isolated and allowed her to feel included within a supportive community of peers.

The need to feel included and how parents negotiated that for themselves and their children was obviously unique to each family. For all the families interviewed, their sense of inclusion was affected by how their child fitted in to their community, which ultimately impacted on how they were accepted as a family unit. The need for families to seek out and facilitate their own informal networks was therefore a way of gaining support and a sense of community that they needed.

> *Jane.4.18*
>
> *...talking to other parents as well, quite often, and they seem to have a feel of, you know, well this worked for me, give that a go and I think that helps, well it certainly helped me in feeling that it's not just me.*

4.7.2   Organisational theme: Outside in

The organisational theme of 'outside in' came from the three basic themes: inclusion, exclusion and choice. The name of the theme reflects the parental perspective that their children were often on the outside of activities and their community, often observing and hoping that they may be included.

Parents relayed how important a sense of belonging in their local community was to them and their families. They were able to express their disappointment at times when they felt that they and their children had been excluded. Families had their own terms of reference for what they felt were inclusive and exclusive experiences. The need to be part of, or withdraw from, their community was expressed by some families who had made a considered choice about how their child would or could integrate into their local community. This type of choice was usually based on the situations that their child had experienced.

Inclusion

The basic theme of inclusion was related to codes such as 'child fits in' and 'recognised in community'. The concept of inclusion and exclusion are inextricably linked and parents discussed the terms and experiences interchangeably.

Gill described how her son was due to attend a mainstream senior school. She explained the problems she had experienced accessing the correct support for him. However, whilst successfully gaining the appropriate support she had also made her son feel that he would be different and not included within his new environment. Essentially the support offered was

felt by her son to be counter-productive to his inclusion in a mainstream school and signified his difference to his peers.

Gill.9.49

...but he doesn't want his one-to-one so I'm slowly losing control. He's becoming an adult in his own right and he's got freedom of choice and I know that but he's saying to me 'I don't want someone with me round the school. That's strange. I'm going to tell her to go,' he said. 'I'm going to tell her to go away'...

The need to feel included was discussed by Emma who described how her sons had been treated differently by friends due to their behaviour. Her younger son was not invited to parties with his classmates. Although Emma could understand why this happened she also described how difficult it was for him to deal with.

Emma.5.49

...when he was seven, eight, he didn't get invited to parties; you know his brother would, but he wouldn't .....he would just sob and sob you know. 'Why can't I go?' because they were in the same class at one point and they had the same friends, but the parents had seen the way he had acted up and didn't want him at the party so it was heart breaking.

It was through attempts to be included in normal activities and experiences that families described how their child had experienced exclusion. Potentially the experiences formed the child's and parents view of how, and if, their child should be integrated. For some children the experience of inclusion was considered to be harmful and counter productive.

Gill's son was due to move to a mainstream secondary school, he was concerned about the impact that his support would have on his ability to integrate with his peers.

Gill.10.41

In the statement it said that she was going to be with him at lunch-time, at break-time, he doesn't want that…. If he doesn't want it, he doesn't want it. I think he's going to need her.

Exclusion

The concept of exclusion was multi-faceted for the children in the study. The experience of exclusion had shaped the way the family supported their child to integrate with their peers and the local community. Although choice will be discussed as a separate basic theme within this network, parents reflected on how in some situations they had chosen to remove themselves and their child from negative experiences associated with exclusion. Consequently exclusion was described at a negative level of experience but also as part of a coping or protective strategy to ensure the child was not subjected to external forms of exclusion. The codes of 'other people's reactions' and 'exclusion' formed part of this basic theme.

Gill described how she had decided to take her son out on her own due to other people's reactions to his behaviours. She felt it was easier to manage his behaviour when she was not with other people. This situation had resulted in Gill and her son feeling isolated as they had withdrawn from social activities with other people. Gill however described that this situation was preferable to her son experiencing the negative consequences of other people's reactions to his behavioural needs.

> *Gill.3.21*
>
> *...I tend to go on my own with him. Because people don't understand until they've lived with it. And I'm sick of people looking and they tut and I mean he can't read keep off the grass anyway for a start and erm and they just do it don't they, they don't think. I know. The times you tell him until you're blue in the face. And I didn't know how to deal with his behaviour in public. So I suppose I withdraw him and myself from outside community.*

Kate described how her daughter integrated in her mainstream school. Although she had some friends Kate believed that her daughter still experienced feelings of isolation from her peers. She was unsure about the value of the relationships she had formed due to her daughter's vulnerability.

> *Kate.2.21*
>
> *....she likes her own space but she's a very sociable girl, but she's not had much to do with children as such so she's got no friends. She can't make friends easily at all. The ones she's got can be very cruel to her.*

Exclusion of the family, and within the family was also considered within this basic theme. Mary described how her younger son, was referred to a sibling service due to the needs of his brother. He described to his mother feeling excluded from home and family.

Mary.6.41

And he only went once and said 'Why am I doing this Mum? I'm being sent away from the home.' And I went 'I fully agree with you, if you don't want to do it, don't do it.' And he said 'I don't. I want us to be a family and doing stuff together.' 'I fully agree with that but I can't get the services.'

The exclusion experienced by this family was considered to be the result of inappropriate provision and a lack of appropriate person and family-centred planning and support. The components of exclusion for this group of children and their families are multi-layered and will be considered further in Chapter 6.

Choice

How families experienced choice has been briefly considered within the basic themes discussed and the organisational themes of 'our community' and 'outside in'. Choice can be a difficult concept and parents discussed choice in various forms. Families discussed a clear choice in relation to provision for their child and how they wished them to be supported. Their child's choice of provision and how they had supported that choice was also reported. Families however suggested that they experienced a lack of choice due to the complexity of their child's needs. They often discussed how their choices were limited within the realms of what was provided or available. Some parents reported times when they felt completely disempowered related to what was happening for their children.

Lynn had made some very clear choices for her sons. She discussed how the choice to include her youngest son in a mainstream environment had enabled her to feel that he was safe.

Lynn.6.42

In a way it doesn't really matter what your child learns at school in terms of the academic side. If they are known and recognised in their community that gives something that school has to achieve. If it's going to be worth sending your child to any school they need to be known by a group of… people and recognised and not only when they're at school so … and that's the way to keep him safe and it's very often when he's disappeared from home and it's been people that know him from

school that have spotted him in town and say he went that way and….It's so important that people know him in the neighbourhood.

The positive choice that Lynn made to send her son to a mainstream environment was reinforced by the example she gave related to an incident in which he ran away.

Lynn.6.42

…for example he has actually gone over the back fence, got into someone's house, and the normal householders haven't been around. Their daughter who was staying with them, they'd gone out, actually found him in the kitchen going through the fridge probably looking for chocolate biscuits. Now she was obviously quite, now what's going on and then she kind of thought about it and remembered that her parents had said something about the little boy that lives over the back and she had a special needs daughter herself…..so she caught the fact that he was not, you know, sort of…

Lynn felt that her son had been recognised by someone in their local area because of his attendance at the local school and his resulting presence in the local community.

Emma described how she had not wanted a special school placement for her son but had limited choice because of his behaviour, which had resulted in numerous school exclusions. Her comments suggest that the special school had in fact been a positive move for her son.

Emma.12.28

There's all those children with so many problems in that school yet it's such a calm effect when you walk through the door and everyone's so polite and helpful – I just knew it was the right place for him.   And lucky enough three years down the line they've worked wonders with him.

4.7.3   Summary of global theme: Belonging

The network of 'belonging' was related to how families considered that they were included within their local community and services. Two organisational themes depicted the division in the findings related to how families interacted with their community and how the family felt about their sense of 'belonging' in their community. Five basic themes supported the network. These themes considered the level of integration, inclusion, exclusion, support and choice families and their children had experienced. Many of the themes within this network were interlinked and so the results have overlapped and supported each other. Families had made choices for their children based on the journey they had experienced associated with

provision of support, education and the reaction of their local community. Parents articulated their decisions and illustrated them with powerful examples that had shaped their lives and that of their children.

4.8   Summary of family findings

The family interviews provided data that reflected the parental perspective on the lived experience of children with a learning disability and behavioural needs. Four global themes emerged from the findings;

- Finding our way
- Square services, round needs
- Behaviour touches everything
- Belonging

The 'finding our way' global theme considered how the families managed the support of their son or daughter with a learning disability and behavioural needs. After initial realisation that their child was different from their peers, exacerbated by an often protracted journey through the diagnostic process, families discussed how they were able to move from a stage of realisation, to coming to terms with their child's difference. The parents described the struggle to meet their child's needs as complex. Discussion related to the effect that their child's needs had on the whole family unit dominated this theme. Parents reflected on how they had moved from a position of uncertainty about their child and difficulties with diagnosis, through to a situation where they felt more able to effectively advocate for and support their child. Indeed parents began to feel that they were the expert related to their child's needs, particularly in the absence of coherent responses from professionals and services. Along the journey described by parents their experience of how their child and family had been supported by services was central. Indeed part of the struggle described by families was directly related to how they were able to access services and the specialist support required for their children. This led the findings into the second global theme of 'square services, round needs'.

This network represented the parents' experience of accessing appropriate support for their child. Families had experienced difficulty in negotiating their way through services and described a wait for help that was not always provided. Parents described services as disjointed and unable to meet the complex needs of their child and family. The need to

advocate for their child that parents recognised in the first global theme of 'finding our way' was confirmed in this network. A lack of child and family centred provision was discussed at length with parents describing key transitions in their child's life that had created major issues for them as well as some of the services involved. It was clearly articulated by parents that their child did not 'fit' into provision traditionally provided for children with a learning disability. Consequently the child's needs were often left unmet which exacerbated an already complex situation for the child and family.

The problems discussed by families associated with a lack of support to meet their child and families' needs was central to the development of the third global theme, 'behaviour touches everything'. It was the child's behavioural needs that parents recognised as having the overriding impact on their own and their child's life. This theme identified the problems encountered by both the child and the family associated with the day-to-day management of their situation. The child's behaviour was often perceived as the cause of an inability to access services and facilities that were usually available to all children. Parents described how their child's needs affected their ability to work, as they were often expected to respond to requests to remove their child from a provision due to their behavioural needs. Parents reported that they struggled to find appropriate out-of-school provision for their child, such as specialist play schemes, as they were perceived to be a risk to other children due to their behaviours.

Education was an important area discussed by parents within this theme. Families described how their child's progress and potential was affected by a paucity of provision and training within specialist and mainstream educational provisions to support their child's behaviour. Education, as a key provider of a child's experience, was considered to be central to the child's ability to be part of their community and to achieve their potential. Parents described their disappointment at the support available from educational services. Reports of educational exclusion at both informal and formal levels were considered as a central tenet of the child's experience of school.

A further strand within this theme was associated with the provision of specialist support. Where this had been provided for children parents reported positive results. However access to this form of provision was considered to be poor, and directly linked to incidents of exclusion and poor service provision that their children had experienced. Ultimately parents

reported that services were not able to offer the holistic support that their child required, which resulted in a fragmented approach to meeting their needs.

The lack of support, and an inability to 'fit in' to services and their local community led to the development of the fourth global theme of 'belonging'. This represented how families felt about their experiences of integration for their children within society. This involved consideration of their community, their child's education and informal networks. The decision to not include their children in mainstream services and their local community activities was described by families as a choice based on experience. All parents were able to describe how they felt their child was integrated in their local community. This was, they were aware, directly affected by the decisions that they had made associated with the provision the child received (such as mainstream education or specialist provision). Family experiences varied but for some children mainstream provision allowed access to normal activities and services. For other children parents reported that attempts to access mainstream support had resulted in negative experiences and exclusion. Several parents expressed a preference for specialist provision for their child due to the complexity of their needs and their previous experiences of poor support.

Interpretation of the family networks will be considered in Chapter 6 and will complete the final stage of Attride-Stirling's (2001) model of thematic analysis, the interpretation of patterns within the networks (stage 6), across both phases of the research.

The following chapter will report the findings of the interviews conducted with professionals involved in the support of children with a learning disability and behavioural needs and their families.

5 Chapter 5: Professional Findings

5.1 Introduction

The previous chapters have outlined the reason for the study (chapter 1), literature associated with children with a learning disability and behavioural needs and their families (chapter 2), the theoretical framework and methods employed to gather information for the study (chapter 3) and the findings from the first stage of the study conducted with families (chapter 4). This chapter will consider the professional perspective on the lived experience of children with learning disabilities and behavioural needs. Ten interviews were conducted and constituted the second phase of the research study. To aid clarity the findings are reported separately before being discussed in Chapter 6 with the family findings.

Professionals were recruited through a special interest group for people involved in working with children with a learning disability. The first ten individuals who volunteered were interviewed. To support the consistency of information provided in each phase of the study no definition of terms was provided for the participants. Their willingness to be involved and relevance to the subject area were considered to satisfy the inclusion criteria for the research. Nine participants were female, one male, which may be reflective of the female nature of the caring professions (Simpson 2009). The professional participants' roles and pseudonyms are presented in table 2. Professionals were given the information provided to the participants in the first phase of the study (appendices 1,3,6).

As in the first phase of the study the Attride-Stirling (2001) model of thematic analysis was used to analyse the interview data. Stages four and five of Attride-Stirling's model, description and exploration of the networks and summary of the networks, will be considered within this chapter, with the final interpretation of the networks (stage six), completed in Chapter 6.

5.2 The professional coding framework

Fifty-four codes were identified and numbered within the ten transcripts. Multiple codes were applied to each text segment. The original 54 codes were identified 4441 times across the data. Table 4 identifies the frequency of codes used within the professional interviews.

As in the previous chapter each global theme will be considered separately with examples given from the text to support the interpretation from initial coding through to the generation of global themes.

5.3   Professional Thematic Analysis

Table 4:   Professional Thematic Analysis

ISSUES DISCUSSED	BASIC THEMES	ORGANISATIONAL THEMES	GLOBAL THEMES
Early support Behaviour knowledge Behaviour training Multi-disciplinary working Resources Specialist provision Service fit Service knowledge Professional roles	APPROPRIATE SERVICES TIMELY SUPPORT SPECIALIST TRAINING FAMILY CENTRED CARE PROFESSIONAL CAPACITY	APPROPRIATE FAMILY CENTRED SUPPORT SPECIALIST BEHAVIOUR SUPPORT	THE BEHAVIOUR OF SERVICES No of codes identified 1341
Transition Child's potential, independence Diagnosis, assessment, safety, aggression Needs of child, Complexity of need	CHILD'S PROGRESS AND JOURNEY CHILD CENTRED CARE IMPACT OF BEHAVIOUR CHILD NEED HOLISTIC SUPPORT	MOVING FORWARD COMPLEX HOLISTIC NEEDS	THE COMPLEXITY OF NEED No of codes identified 1193
Educational provision Impact of behaviour Opportunities Labelling and stigma Inclusion Exclusion	EDUCATIONAL PROVISION IMPACT OF BEHAVIOUR INCLUSION EXCLUSION STIGMA OPPORTUNITIES	EDUCATIONAL INCLUSION OPPORTUNITIES AND ACCESS	BEHAVIOURAL BARRIERS No of codes identified 961
Families needs Sibling impact Family support Parent capacity Informal support	HOLISTIC FAMILY SUPPORT IMPACT OF CHILD'S NEEDS PARENTAL WAIT EXPECTATION PARENTAL CAPACITY	AFFECTED FAMILIES PARENTAL EXPECTATION	NEEDING TO KNOW-KNOWING NEEDS No of codes identified 953 **Grand total 4441**

Four global themes were identified within the professional results (Table 4). As in the previous chapter each theme will be considered separately with examples given from the transcripts used to support interpretation and to contextualise the issues raised.

5.4   Global theme: The behaviour of services

Figure 5
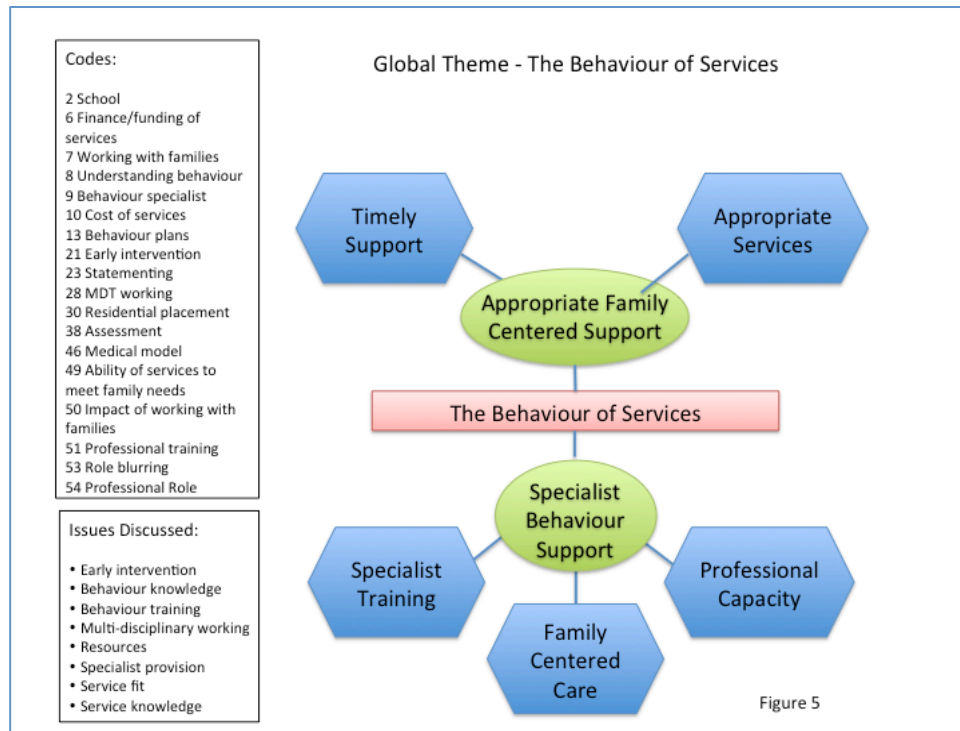
The global theme 'the behaviour of services' contained the highest number of codes within the professional data (1341). The global theme was deduced from two organisational themes: appropriate family centred support, specialist behaviour support.

5.4.1   Organisational theme: Appropriate family centred support

This theme was derived from the basic themes: appropriate services and timely support. The codes deduced from the original data related to this network included; early intervention, access to services. Professionals discussed how families often waited for support or were given support at times that were not appropriate for families. The residential placement of children with behavioural needs was also considered within this network. It was felt by professionals to be a reflection on how services failed to meet the needs of families that ultimately resulted in crisis and emergency management situations. Services that were tailored to the individual needs of the family, and available when required, were therefore considered a priority.

Appropriate services

The basic theme of appropriate services was derived from the codes related to: service ability to meet family need, funding and cost of services and access to services. The codes identify how the professionals discussed their experiences of supporting children and their families when resources were often unavailable. Professionals discussed their frustration with the paucity of appropriate provision available to children with behavioural needs, and a service agenda which expected children to fit into provision that was not able to meet their needs.

Bob was employed as a learning disability nurse within a respite area for children with a learning disability. He stated that most of the children who used the unit had a level of behavioural need. He felt that the provision was useful for families, particularly those who required overnight respite support for their child. He was however aware of a lack of flexibility within the provision which meant that some families had to compromise their wishes for their child.

> *Bob.8.49*
>
> *Our service is quite static in a way, in a sense that we work out of the building, we're four bedded now, but not all young people are going to fit in to us so we might not be the best place for all young people but if parents want overnight breaks then they'll see us as probably the best place to come to but it doesn't mean that their child is going to fit in.*

Debra was employed as a teaching assistant whose role was to specifically support children with behavioural needs in a special school environment. She considered how children she had supported had been involved in lengthy waits for provision that had often resulted in emergency or crisis situations.

> *Debra.2.49*
>
> *The family gets to sort of crisis point before anything is done. I don't think it should get to that point before other services become involved, they should be trying to stop that person hitting the crisis point first.*

Timely support

Support at key stages for children and their families was identified within the professional findings. The basic theme was related to the original codes, service ability to meet family

needs and also early intervention. Professionals felt that some children did not receive the support they required when it was most needed. Professionals were clear that this often left families in very difficult situations that could have been avoided.

Wendy, a teaching assistant in a special school described the need for appropriate respite provision to be available for children with behavioural needs. She discussed how families needed to be supported early to enable them to see the long term and future needs of their child.

> *Wendy.5.49*
>
> *I think they should all be offered some respite and I think parents should be encouraged to take that respite, to look at the bigger picture because …they can manage them all right but these young people get bigger and get stronger and it's very difficult then to start feeding them into services…*

Janet was an independent behaviour analyst employed directly by parents to support their child. Support available to families in the child's early years was considered crucial by Janet in order to manage and support the child's behavioural needs. She referred to behaviours that can become entrenched if not managed early in the child's life.

> *Janet.8.21*
>
> *….early intervention definitely that just goes without saying,… 'we (statutory services) don't have an obligation until the child's four.' Well by that stage, depending on the level of the child, they've got a lot of quite embedded behaviours so access to early intervention, access to good speech therapy…*

5.4.2 Organisational Theme: Specialist behaviour support

Specialist training, family centred care and professional capacity were the basic themes that contributed to the formation of the organisational theme 'specialist behaviour support'. Professionals identified the need for skilled practitioners to support the needs of children and their behaviour. This type of knowledgeable practitioner was considered to be rare in services. The high cost of providing support to children with behavioural needs was acknowledged by professionals as a service issue. It was also suggested that services did not always consider family need as a priority, with issues identified related to communication across multiple and complex professional areas.

Specialist training

Professionals discussed the need for service staff to support children with behavioural needs effectively. There was some agreement that training in behavioural needs was essential to provide a workforce that was capable and competent. Some professionals in the study had been able to access training. There was however a level of concern raised during the interviews about the knowledge base of staff in services that supported children with behavioural needs.

Karen's role involved managing a Child and Adolescent Mental Health Service across a borough. She was keen to discuss the deficit of training within services and the impact this had on the children they supported.

> *Karen.3.8*
>
> *.....although they might record behaviours they didn't use evidence-based tools to really support their formulation of what behavioural support might be about, or support them in putting appropriate interventions into place. And from that one of the hypotheses is well if they couldn't do that, would they be able to meet the basic needs of children with a learning disability, and certainly if they couldn't even identify the basic needs of those children they wouldn't then be able to identify additional needs of children either.*

Debra was clear that current professional training did not prepare staff within services to support children with behavioural needs effectively. She believed that staff within the special school environment were not prepared adequately to work directly with children.

> *Debra.5.8*
>
> *I think the understanding of behaviour, the expertise in dealing with it, erm staff training. They don't discuss child development, they don't look at behaviour, they do placements but some of the assessments that's done isn't necessarily dealing with a young person or behaviour or sitting down and working with someone…*

Family centred care

The basic theme of family centred care came from coding related to how professionals perceived their role in working with children and families, and how services were able to meet the complex needs of the whole family. Professionals identified that supporting families and children with behavioural needs had an impact on their individual role and perceptions of services.

Lisa was employed as a social worker based in a 'children with disabilities' team. She discussed the strain families faced when meeting multiple professionals across agencies, and identified the need for consistency. Lisa felt that improved communication and coherent services would enable families to develop a trusting and valued relationship with individual professionals and service providers.

> *Lisa.10.50*
>
> *....these families need some sort of counselling, someone to talk to at that point, that needs to be someone who's maybe going to stay involved with them for a little bit of time..... if you're there and you're going out and you're talking to them about it then it becomes a little bit easier, because they're thinking you've been here right from the start....then when you think they're going to school and that's a new set of professionals and it's like 'Oh I've got to tell everybody again' ...*

Alison an occupational therapist within a local authority team for children with learning disabilities considered the progress that had been made within services to respond effectively to child and family need. She was clear that the situation had improved, but was still an area for development.

> *Alison.9.50*
>
> *...services are improving and there are targeted areas, I do see change.... I don't think it's stagnant, I don't think we're sitting back and thinking everything's OK. As professionals we can see pockets of areas but then we can also look at the positive areas as well so I don't think it's all doom and gloom I can see progression... I've still got a long way to go and things to learn and I think by making sure that we look at all the areas, you know and make it more coherent for the families then that will improve.*

Professional capacity

As well as considering the ability of services to be family centred, professionals also discussed their views on their role within provision, and the impact of supporting children with behavioural needs. Role blurring, multi-disciplinary working and complexity were all discussed in the interviews.

Alison described how her role was often blurred in relation to trying to meet the needs of families. Employed as an occupational therapist she felt that the situation was inevitable when supporting this group of children, and appeared confident to embrace this.

Alison.6.53

...working outside your role, I know there's a lot of role blurring and that but that's how we need to be as professionals. It shouldn't be something that's daunting if you're a highly skilled professional, you know, I work as a social worker, as a physio, as an OT, as a behavioural therapist...

Julie was employed as a speech and language therapist for an independent residential provider for children with learning disabilities and behavioural needs. In contrast to Alison's perspective she described an experience with a family when she felt compromised and unable to provide reassurance about the quality and skill of the services that the family required. Julie discussed the vulnerability of children with behavioural needs, and understood that families needed to feel confident in the ability of services to effectively support their child's behavioural needs.

Julie.6.50

I felt very inadequate at that time. I couldn't say hand on heart, yes all his support staff are being marvellous, because you've got all the issues of human error and inexperience and change and everything that compounds. I wanted her to feel that he was in safe hands if you like and that was really difficult.

Debra expressed her frustration at the way services responded to families. In her role as teaching assistant in a special school she discussed how professionals struggled to communicate effectively with families. She suggested that some professionals and services were reluctant to support children whose needs were considered to be long term and complex.

Debra.2.28

I think some of it is the lack of communication. I think some of it is the paperwork, I think some of it is that people don't want to get involved because it's too much work, or it's too hard or whatever and try and pass the buck to somebody else and I think that happens quite a lot.

5.4.3   Summary of global theme: The behaviour of services

The network of 'the behaviour of services' considered two organisational themes; appropriate family centred support, specialist behaviour support. The organisational themes were derived from five basic themes; appropriate services, timely support, specialist training, family centred care, professional capacity. Professionals felt that the needs of this group of children and their families were different and complex compared to the needs of other

families. Due to the vulnerability of children and the difficulties that families encountered directly associated with their child's behavioural needs, professionals suggested that an enhanced level of support was required from services. This level of skill and specialist knowledge was considered to be different from that generally required within learning disability provision. Associated with the child and families' complexity, professionals discussed issues of role blurring, behaviour training and the multi-disciplinary complexity of provision that they found themselves working within. Whist identifying the complexity of supporting families they also identified how difficult it was for families to access knowledgeable and specialist support when they needed it. Professionals were clear that services for this group of children were lacking in their ability to provide family centred specialist support.

5.5   Global theme: The complexity of need

Figure 6
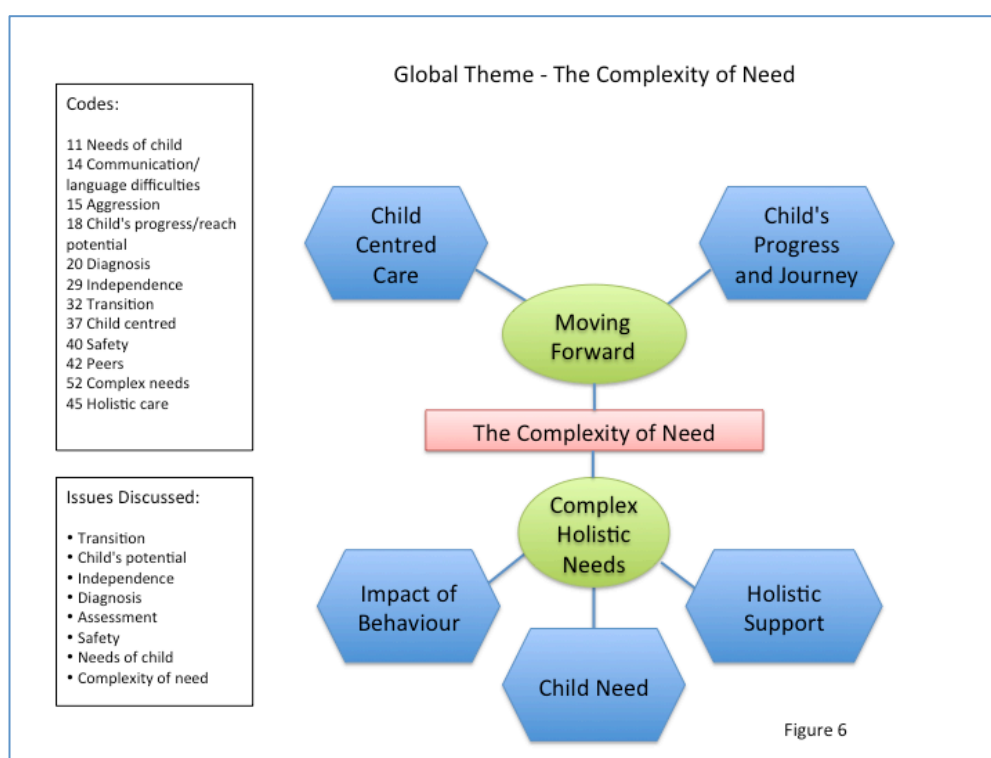
The global theme of complexity of need reflected findings that suggested that children with a learning disability and behavioural needs had a unique set of support issues different from their disabled and non-disabled peers. The theme was derived from two organisational themes; moving forward, and complex holistic needs. 'Moving forward' was derived from the basic themes that considered the child's progress and journey and child centred care. The

second organisational theme of complex holistic need contained three basic themes; the impact of behaviour, the child's needs, holistic support

5.5.1 Organisational theme: Moving forward

The organisational theme of moving forward encapsulated professional acknowledgement that children with learning disabilities and behaviour needs required significant support to meet their potential. How progress was facilitated and the journey that children experienced was hampered by their complexity of care and the lack of skilled support available to them. Support was required that was child centred rather than service led.

The child's progress and journey

Karen discussed her perspective on how the workforce for children with a learning disability had developed. She highlighted issues associated with the negative value base of individuals employed within services. She suggested that expectations for children with a learning disability and behavioural needs were different within society and services, than they were for non-disabled children.

> *Karen.6.18*
>
> *…people's perceptions of working with that population are often very different and their value base in kind of accepting those children and wanting to put in as much as they possibly can to help those children to reach their full potential, whatever that is, I think is often very different from the generic children's population.*

Jenny discussed a young man who had attended mainstream education and struggled. In her role as a speech and language therapist in an independent specialist school she had been involved in supporting the child's transitional journey through specialist provision. She described his needs but also how he managed to 'fit in' with his peers.

> *Jenny.4.18*
>
> *… he's still got very low self-esteem. Always going to be an issue, but he has friendships; he's developed relationships and he does regular assemblies at school. He has this theme of stick man and stick dude and he does these shows and that has really, really boosted his confidence….he sees his likeness in the other pupils.*

Julie, also a speech and language therapist in the independent sector, described how individuals could be supported to develop their skills and move towards independence. Julie

felt that services and staff did not always celebrate a child's potential and success. Particularly as progress was often non typical or very small in comparison to their peers.

> *Julie.8.29*
>
> *....he does this job, this job and this job and puts it in the pan and that lasts about three minutes and that's fantastic. I think we gloss stuff over and we don't..... actually we're not celebrating that young person's achievement then are we? That's something I've learned - he's a great chopper! Chops the meat!*

Child centred care

Professionals discussed how children moved between services. Change was recognised as a large part of any child's life, for example the move from junior school to secondary school. However for the children discussed by professionals in the study they had often experienced multiple moves between services. The frequency of change was attributed to the child's behavioural needs, whilst transitions were considered to be difficult and complex for children and their families. Professionals highlighted inadequate support as compounding problems in the transition process.

Jenny discussed how children were referred to the independent service in which she was employed. In her role she was involved in the assessment of children whom, she considered, had not been identified during their early educational years. Supporting children with autism Jenny described how the lack of early support had often exacerbated unnecessary transitions between services that were often unable to meet the child's needs. This led to a pattern of secondary age referrals for children whose behavioural needs had been exacerbated by this situation.

> *Jenny.2.32*
>
> *They tend to get picked up at secondary provision, primary level tend to be able to cater for their needs because there's one class teacher, it's a more nurturing environment. As soon as the transition to secondary then you've lost it on a number of counts and that's when a lot of the referrals come in.*

Bob discussed the children he supported within a respite centre. He considered their complexity of need and the situations that some of the children had experienced associated with their behaviour. He identified children who had experienced several moves between services and described the positive and negative experiences that children could encounter.

Bob.14.32

...one young man went on to a college of further education but then there were lots of problems there because he was less supervised because he was older, sixteen, and more was expected of him. There became a lot of behaviour issues and then they moved him from there back into specialist education at a school that would take young people on from nineteen. Now for that young man since he's been there he's done really well because he needs that more structured environment. Now obviously that might be the best thing for him but obviously you can't generalise.

5.5.2   Organisational theme: Complex holistic needs

The organisational theme of complex holistic needs was developed from three basic themes; impact of behaviour, child need, holistic support. 'The complexity of need' network described how children with a learning disability and behavioural needs experienced a very different journey from the norm. The professionals clearly discussed how a child's behavioural needs impacted on the child's progress and ability to access services. This served to increase the complexity of the child's needs and further excluded them from provision. The need for holistic support that could consider a child's holistic needs including their behaviour was central to this theme.

Impact of behaviour

Professionals discussed how a child's behaviour impacted on a family's ability to cope. The services identified by professionals that could support children with behavioural needs were specialist services. There was, however, a recognition that specialist provision could also experience difficulty meeting the needs of the child, and consequently refer children on to other forms of provision.

Helen, an independent behaviour analyst described how the school she worked in was not able to support children with behavioural needs in their home environment. As a practitioner she argued that she was able to support the behavioural needs of children across environments but she was aware that as a provision children were often referred to other agencies outside the school for home support. Helen believed that this type of support facilitated a disjointed and overly complex form of provision for children.

Helen.4.15

At home well it's all child dependent, some of the families we've had have struggled immensely with the behaviour of their children at home, especially the children who exhibit aggressive tantrum behaviours, especially families where there are other

siblings as well. I mean sometimes, on occasions, the challenging behaviour at home has been so severe it's actually been out of our remit because we would have needed to spend a more intense amount of time at home so we've referred onto the learning disability team or the behaviour support team

Bob described a situation associated with respite provision. Children he had supported had been withdrawn from the service due to family beliefs that the service could not meet the behavioural needs of their child. This he felt resulted in limiting the already reduced supply of support available to them and their child. It was the child's behavioural needs that were perceived to limit the child's access.

Bob.6.40

... We've had a number of parents who've withdrawn children from services because their child's got hurt there and also because parents have felt that services can't meet the behavioural needs of their child who exhibits challenging behaviour so yes I think it works both ways.

Child need

Professionals in the research were keen to stress that services were often unable to meet the needs of children, which invariably left them and their families unsupported. Meeting the individual child's needs were considered to be central to effective support but described as difficult for most services.

Julie reflected on her work with a young man whose behaviour was considered to be complex. His obsession with cameras and taking pictures of objects and people constantly proved difficult for his staff team to manage. The example Julie used highlighted the level of support required to ensure that his individual needs were met whilst ensuring he was safe.

Julie.2.11

He was potentially making himself and his support workers really, really vulnerable because he'd whip out the camera, having also wanted it to have its own seat on the bus... In his previous setting either in his family or residential school in the middle of Wales with no people, he genuinely hadn't come across it in the same way so he had to learn over time and he made progress but ... that's a really clear example.

Debra described how the needs of children within a special school were compounded by their behaviour. She described how even within a specialist environment children could

become isolated. This resulted in them being unable to access the full curriculum and reduced their opportunities to access the social skills support they required.

Debra.2.11

Well the child's not getting the social contact that they would need, they're not getting the experience of the social skills, the life skills, erm you know the key skills, the general skills that they need to move on as an adult.

Holistic support

The basic theme of holistic support for the child was deduced from the data that described the needs of the child, but considered how these needed to be considered holistically by services and staff.

Bob described how services had attempted to be child centred but highlighted some of the issues that he perceived had complicated the process. He explained how even when funding was available parents were unable to access support for their child due to the lack of available people with the appropriate skills.

Bob.9.45

....everything's supposed to be person centred round the child for instance, but the reality is that there's only so many services out there. Again services depend on availability and how good the staff are, because we've had lots of families who want direct payments, who've got funding for it, but can't find anybody to do it, that's another big issue.

Janet described how her role as a behaviour therapist involved working on a privately employed basis with individual children. Her work was usually funded by a child's family. She advocated for individualised and child centred holistic support that she believed would increase their opportunities for independence.

Janet.6.37

... it doesn't mean that every child is going to become a normalised child. If you can make them a child who's gone from being very reliant on an adult to somebody who maybe at sixteen can be semi independent or even living in supported communities...

5.5.3   Summary of global theme: The complexity of need

This thematic global network encapsulated the professional view of how children with a learning disability and behavioural needs were unable to progress and achieve. The two

organisational themes that supported the network described how difficult it was for children to move forward, and how complex meeting a child's holistic needs could be for services. A child's behavioural needs were considered by professionals to have a major impact on the services available to them. Provision was generally reported to be inflexible and unskilled. Professionals were candid and clear about their own services that were often considered to be unable to meet the needs of the child and family. Inadequate service provision was therefore considered as one area that made the child 's journey through services so difficult, often resulting in fragmented support or exclusion for the child.

5.6   Global theme: Behavioural barriers
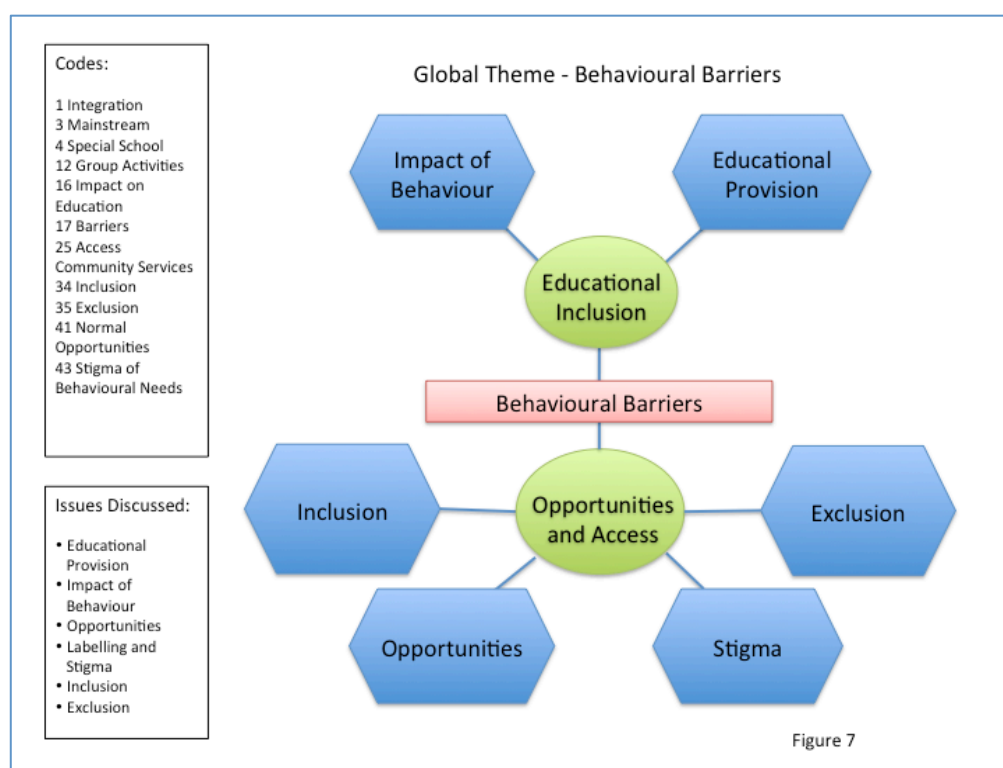
Figure 7

The global theme of behavioural barriers contained 961 of the coded segments. It is supported by two organisational themes (figure 7); educational exclusion, opportunities and access. Six basic themes were identified within the network; educational provision, impact of behaviour, inclusion, exclusion, stigma and opportunities.

The network considered how professionals viewed the impact of behaviour on the child's experiences. Particularly how it affected the ability of children to integrate and be included in their community.

5.6.1 Organisational theme: Educational inclusion

Educational inclusion was derived from two basic themes; educational provision and impact of behaviour. Professionals discussed how school was a major influence on a child's life and experiences. Four of the professionals who participated in the study were employed in educational environments. These professionals were keen to describe the issues faced by children in relation to how their behavioural needs were supported within an educational setting, and the impact this had on their experiences.

Educational provision

The basic theme of educational provision came from the coding framework associated with: special school, mainstream and integration.

Jenny, a speech and language therapist in an independent sector specialist school, discussed the lack of provision for children who had communication difficulties who attended state provision. Jenny described how only children who had the most significant needs could be supported due to a lack of therapists.

> *Jenny.2.4*
>
> *Although I'm a Speech & Language Therapist I think services within local provision, within mainstream schools and even Local Authority specialist provision is very limited. The caseloads are great and you usually get a therapist who may be going in one day a week so the priority needs are those who have significant communication needs.*

Bob felt that the children he supported and their families were largely satisfied with their child's educational provision. He did however consider that this may be related to a lack of alternatives for a child.

> *Bob.13.4*
>
> *....I think probably a lot of the families, as long as they're getting some sort of provision, don't actually mind where it comes from and that's a debate at national political level isn't it? About should children go to special schools or not and obviously more recently that's moved back in favour of that and so I've never come across a parent who's complained because the child's got some provision.*

Jenny recognised how difficult it was for schools to meet the diversity of children's needs both within mainstream and special educational settings. She suggested that staff within

education should be able to access, and encouraged to accept support from, specialist practitioners in order to meet the needs of pupils.

> *Jenny.8.3*
>
> *I think even within specialist provision, because the problem is with learning disabilities it's so wide ranging you know from global developmental delay is a whole different thing to Asperger's/autism, to specific learning disabilities of dyslexia and dyspraxia. They're just endless. And you can't expect staff in mainstream school to have a level of expertise in all areas. Erm, but you would expect them to be able to listen to other professionals who would give advice or just point out from a detailed assessment this is the child, this is what their needs are, take it from there.*

Impact of behaviour

The impact of a child's behaviour was associated with the codes: impact on education, barriers. This theme related to how behavioural needs affected a child's education, progress and experience of school.

Karen described how a child's behavioural needs could affect their whole school experience. She associated a child's behaviour with the skills and ability of the staff employed by schools to support them. Karen believed that a child's behaviour was often exacerbated by inappropriate support. She described a situation of a child's needs becoming more pronounced, and a service being less able to cope or meaningfully support the child. She suggested that the child's behaviour….

> *Karen.4.16*
>
> *…can exclude the child from everyday activities in the school so it affects every domain of their lives really but even if they are accessing school it doesn't necessarily mean they are accessing the whole curriculum with school. So if people don't understand their developmental needs, don't understand their behavioural needs then perhaps they're not even delivering information to them or making the lessons stimulating enough to meet their particular needs. That can often then lead to children.....having poor concentration, attention, you know looking for other things to do because they're not stimulated by the lessons they're given.*

Janet's role involved the re-integration of children with behavioural needs into educational environments. This often involved working with children who had been excluded or withdrawn from school due to their behaviour. She described how such situations arose, and

considered her role in re-integrating children once their behaviour had been effectively supported.

Janet.11.16

I think a child gets to a certain age where they have particular behaviours and it's almost like their route is destined then because they really wouldn't fit, whether that's by the parents' admission and they decide not to push the child down that route, or whether the school or the Authority or both would say 'well we don't think we can meet the child's needs.

5.6.2 Organisational theme: Opportunities and access

The organisational theme of 'opportunities and access' was developed from four basic themes that centred on the child's integration in their community. The organisational theme ran across the data as a whole but was explicit in some of the themes. Basic themes derived from the coding framework were: inclusion, exclusion, stigma and opportunities. Professionals discussed how the child experienced inclusion, exclusion and the stigma associated with their behavioural needs.

Inclusion

Alison described how children she had supported had experienced exclusion. She discussed her role in supporting their integration, particularly in the home environment with family and siblings. As an occupational therapist the opportunity for children to be able to play safely with their peers was considered a major priority.

Alison.1.34

It is important, you know, these children can feel very excluded from society, from schools, from education, from their peers. So within the home I've found that my role is really important to make sure they can do everything they want to do or have the opportunity to do those things that they want to do.

Bob discussed how children with behavioural needs often struggled to access opportunities outside those provided through specialist provision. He described how difficult it was for children to attend activities due to the level of support they required. If children he supported had not been able to access special school based activities he believed that they would not have able to take part in leisure opportunities. He described how this type of provision allowed children to take part in school leisure pursuits albeit in a segregated and specialist environment.

Bob.13.34

....because obviously the child' s going to need support to get there, get changed, they may need specialist swimming equipment, obviously one to one support in the pool generally. Obviously a lot of children couldn't be left at all, especially somewhere like swimming which has a potentially very dangerous outcome, and that's the problem it's again about resources and availability. That's what I'm saying, it's better than doing it as a group in the school, at least they're learning to swim.

Exclusion

The basic theme of exclusion came from a single code within the coding framework, but was pervasive across much of the professional data. Professionals were clear that children and their families faced exclusion in many guises across services and within their communities.

Bob described how children were more likely to experience exclusion if they had behavioural needs. He suggested that the child's needs eventually had an impact on all members of the family and resulted in the whole family experiencing forms of exclusion.

Bob.4.35

A lot of families say 'I won't take my child out with me because I know he or she will do this when we're in public' which means their siblings don't get to go out so much and so often the siblings will end up with behavioural problems themselves because they're obviously competing against the other child, especially the younger children, for attention so it's a lot of attention seeking behaviour from the siblings. Actually it can be quite a vicious circle for a lot of families and they get sort of trapped into it basically.

Lisa described one child whose support needs prevented him accessing normal activities. She discussed how services had struggled to manage his behavioural needs that resulted in his mother being frequently called to collect him from school. As well as the problems he experienced within his educational environment, the family had difficulty in accessing their local community due to his behaviour. Inevitably Lisa reflected that both the child and family had experienced levels of exclusion from their community.

Lisa.4.35

I can think of one family ....issue was about 'I can't get him out in the community' and it was simple stuff like you know he was three years of age and she was absolutely worn out, wasn't sleeping, his behaviour was really difficult in the home but when she took him into the community he'd just throw himself on the floor ... so one of the key issues for me was that this is a young mum that is totally segregated

and doesn't access anything…. School were constantly on their case saying 'the behaviour's really bad, can you go in and get him?' … So if you think about when we're not there, the barriers are there all the time for these families.

Jenny discussed the difficulty children experienced in feeling included due to the levels of support they required. She identified that in some environments the support available actually served to reinforce exclusion for the child as it isolated them from their peers.

Jenny.5.35

… I do think that children within the mainstream provision, particularly once they get to secondary are almost excluded by being included, because they are having to be taken out to access services, they're having to have quiet time...

Stigma

The stigma experienced by children with behavioural needs was considered by the professionals in the research. Although not always explicitly labeled as such by the participants, discussion of how behavioural needs impacted on the child and families' life clearly identified stigma as part of the problem that they faced.

Alison described a situation that a parent had discussed with her. She identified that some children and parents would be able to articulate their needs and frustrations at the social impact of behavioural needs. However she was also aware of children and parents who would find the situation more difficult to manage.

Alison.7.34

…I was speaking to one woman last week and she's very vocal and she's quite a live wire and she snapped the other day at someone who was muttering and saying how she clearly couldn't control her child, and turned round and said, you know, really gave it to her, and I think it was just bubbling up and bubbling up and then exploding but then she said that didn't help because it looked like she had behavioural problems ha, ha, ha,. But it's that pressure all the time and this particular mum was very vocal, where I've got lots of parents who are quite insular with it and quite withdrawn with it and so it's trying to support those.

Alison identified that she had observed the affect of stigma for children with behavioural needs when it was applied across service provision and within the local community. She acknowledged once again how families struggled to deal with this situation and often decided to exclude their child to avoid the community's reaction and to protect their child.

Alison.1.35

It's this unseen disability. The child who seems to be very mobile, who looks very normal in relation to society yet acts very differently, and unfortunately society's perception of those children, and that's within all different settings you know. Parents find it very difficult still to get them out in society, out in public because they don't go with the same norms and rules, unwritten rules that the rest of us do…. So they would prefer not to go out at all and so those children are really excluded.

Julie described the impact that stigma could have at an individual level. She identified the concept of labelling applied to children with behavioural needs. Julie discussed the negative impact that a child's label could have on the opportunities available to them to progress and move forward. She suggested that a child's reputation can provoke a negative reaction from people within services and the community, and can be extremely damaging for a child.

Julie.10.43

I think you, you never really shake off your previous crimes. I don't think they ever go because they're always written in a list on a piece of paper so whether that was ten years ago when you were nine that's still, you are still 'Vlader the duck slayer' in somebody's mind the labelling is still …just when you think it has gone….they are statements that young people will make about themselves, 'you're just a stupid autistic boy…'

Opportunities

The need for children and families to have normal opportunities or access to opportunities was considered by the professionals in their interviews. Along with access to community services the basic theme recognised the professional's view that children with behavioural needs had different levels of access to everyday activities than their peers.

Debra described how in a special school she was aware of children whose opportunities were limited due to their behavioural needs. She suggested that this negatively affected the child's opportunities and self esteem.

Debra.6.25

Well parents get angry, the young person gets angry because they haven't had their social needs met. They feel that they can't access general activities that are going on in the community and sometimes although that's tried it's not right because the support's not there, so then that leads to failure and low esteem and then low esteem and escalating behaviour again.

Wendy also discussed children she had supported within a special school environment. She described how they had been unable to access leisure facilities and opportunities due to their behavioural needs.

Wendy.2.41

Well some of the families, their children aren't able to access something like the after-school clubs that we have both in school and within the Authority. Yes their behaviour is quite a barrier for them and some of the parents are finding it very difficult.

5.6.3   Summary of global theme: Behavioural barriers

The theme behavioural barriers contained two organisational themes ; educational inclusion, opportunities and access. The network considered how behaviour impacted on the child and family's ability to access education, community and leisure activities. Professionals discussed how the child's behavioural needs created barriers and led to experiences that resulted in exclusion and stigma for the children and their families. Some professionals discussed how their role and services responded to some of these issues and attempted to support families by creating opportunities and providing support. Professionals were often aware of the deficiencies within services but were often not able to positively effect change for the children due to their role or scope of responsibility. For those professionals who were employed within specialist residential and educational environments they described their role and services in light of the paucity of appropriate provision within mainstream services. Professionals were clear that children with behavioural needs required specialist support, but acknowledged that this was often not available within specialist or mainstream services. However, from a pragmatic stance professionals acknowledged that children with a learning disability and behavioural needs required a high level of specialist support which was more likely to be available from within specialist provision. Although not always ideal, this level of service was preferable to the alternative of no provision or support for the child and family.

5.7 Global theme: Needing to know, knowing needs

Figure 8
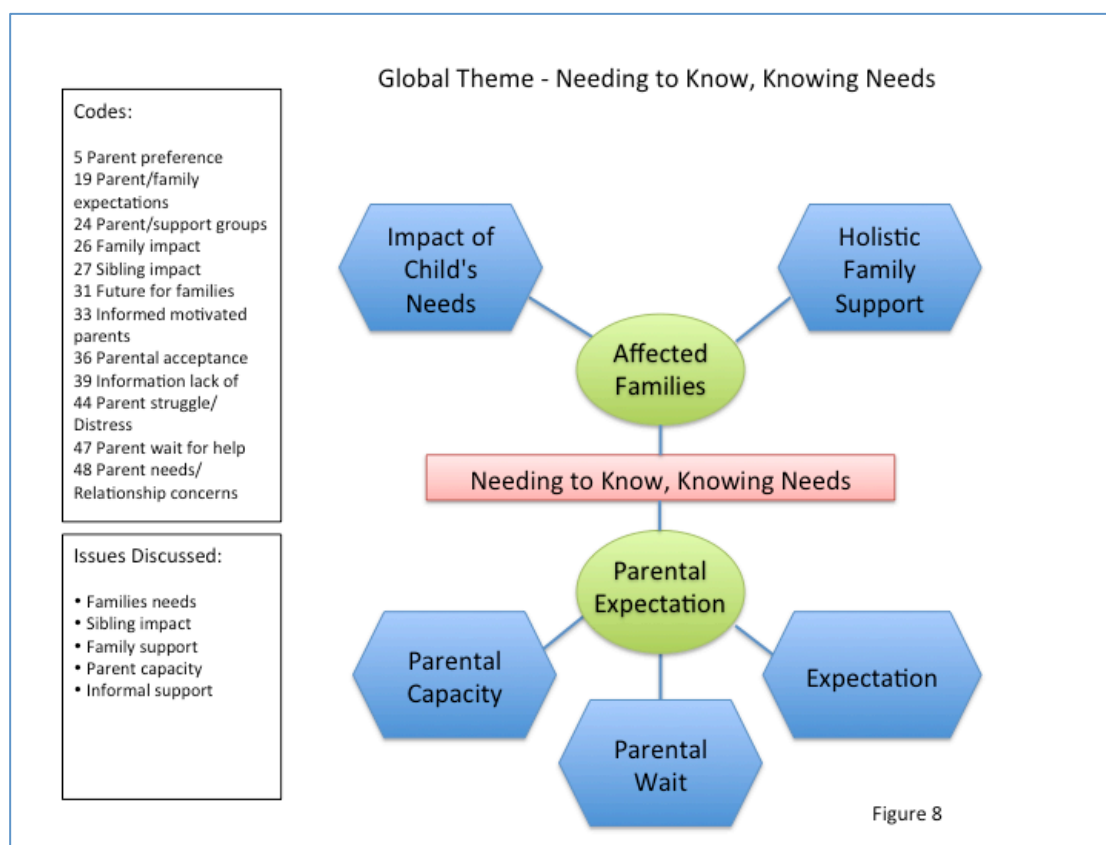
The global network of 'needing to know, knowing needs' illustrates how professionals perceived the journey of parents in supporting their children. The title of the network reflects how professionals described the journey of families from expectant parents reliant on professionals and services for advice and information, through to experienced and articulate advocates for their child. Discussion within the network centred on the professionals' view of the family's quest for help and the need for information, through to acceptance of their child's needs. The network acknowledged the professional's view that families had adopted the role of advocate for their child in order to ensure that their child had access to appropriate services and support. The global theme was derived from two organisational themes; affected families, parental expectation. The organisational themes were derived from five basic themes; holistic family support, impact of child's needs, parental wait, expectation, parent capacity.

5.7.1 Organisational theme: Affected families

The development of the 'affected families' theme was supported by the two basic themes; holistic family support, impact of child's needs. Professionals described how services

attempted to support the family as a whole through services such as sibling groups. There was recognition that the child's needs impacted on the whole family.

Holistic family support

Bob reflected that some of the families who had used the respite service he was employed in had experienced a lack of support during the early stages of their child's behavioural needs. Bob suggested that families required support in the early years of their child's life to enable a proactive approach to their behavioural needs, and highlighted the predictive nature of behavioural needs for some children with a learning disability. He suggested that access to early behavioural support and intervention could prevent children and families from reaching crisis point.

> *Bob.16.31*
>
> *I think getting parents involved is a big thing because it's very hard to get specialist input because obviously children at the extreme end can get referred to Child and Adolescent Mental Health Teams for some support but by the time you've got that far there's generally a huge waiting list – it's usually too late so the parents are at their wits end by then. I think you need to be proactive and put in lots of these things because a lot of the children you know at some stage are going to have behavioural needs or issues, especially if you've got an autism diagnosis and quite a lot of syndromes do have some challenging behaviour elements in them.*

Alison discussed the need for services to be more streamlined and connected. She identified the difficulties families experienced when dealing with a range of professionals. The difficulty was exacerbated in her opinion by poor communication and inter-agency working that she had experienced as a professional. She described how one family had waited expectantly for information from a service, which had prevented them from moving forward in addressing the support needs of their child.

> *Alison.3.31*
>
> *I think, you know, the multi-agency meetings and the multi-agency assessments, you know obviously they're going on but I think need to be developed a bit more, be a bit more coherent, and a bit more within a timescale which is suitable. I know one parent who's been assessed and it's six months down the line and has still not heard anything. And they're still in limbo-land and are still wanting to take advice from different professionals but are not sure whether that is the right way to go.*

Impact of child's needs

Karen described how some of the families that she had supported had been let down by services. She reported how some agencies had eventually excluded the child due to their behavioural needs and left the family to cope unsupported.

> *Karen.4.31*
>
> *They then may be excluded from the school environment. That means they're at home all day with mum and dad. That behaviour often then prevents them getting out. Extended family may not be able to cope with those behaviour issues and the child may then be excluded from any other services such as leisure services or respite services because people don't understand those behaviours and can't respond to them in an appropriate manner, so I think it can start off very small and might not lead to anywhere, or it can start off small and quickly escalate to a degree where everybody is feeling they can't cope with that child.*

Alison identified gaps in services related to counselling for families. She reported that this form of support for families had begun to develop, particularly for the siblings of children with behavioural needs.

> *Alison.8.27*
>
> *I think there needs to be more services addressed in relation to counselling, the emotional wellbeing of families, I think they're now getting more for siblings, there's now more and more siblings and young carers' groups and so I think their needs are being more addressed but you know the impact on siblings with behavioural difficulties that could be improved…*

Lisa described how her service attempted to consider the needs of the whole family when supporting children with a learning disability and behavioural needs. She identified access as a difficult area for this particular group of children.

> *Lisa.1.27*
>
> *We don't only look at the child; we look at obviously the family and siblings as well and obviously any access to services that they may need. Some of the difficulties really that we find in this role is how they access those services and the level of support…*

5.7.2   Organisational theme: Parental expectation

The global network of 'parental expectation' reflects the journey that families faced from waiting for support for services and finding out about their child's needs to a point when

they felt that they could advocate for their child. The organisational theme "parental expectation" contained three basic themes; parental wait, expectation, parental capacity.

Parental wait

Debra described how some parents in the school that she was employed in were unable to get support to manage their child's behaviour. She suggested that children can be caught in the gaps between services that are not available to particular age groups in their area.

> *Debra.1.47*
>
> *The help's not out there. They don't know where or what professionals they can access as in you know school staff, CAMHS, as in monitoring the behaviour and recording the behaviour so they can try and get a picture of it and things like that, but there is also big gaps in the CAMHS service as well especially sixteen to eighteen, that's only just been identified and previously that service hasn't been there and they've just been passed from pillar to post.*

Wendy described how one parent whose child attended a special school had been waiting for information from a specialist service in order to plan for her son's needs. The story depicted the issues that families faced in dealing with services. She described the parent's experience at the wait for information. Wendy also discussed how parents may be unable to recognise the need to move on in planning for their child's needs rather than wait for professionals who may not always fulfil their promises.

> *Wendy.6.47*
>
> *....Mum was really upset, things came to crisis point, very aggressive at home, and they were waiting for reports from one area he'd been in. He's got autism, so he'd been to somewhere in London and they were still waiting for a report from that which was months before. And it was just a build up of everything and they found out that this social worker she was waiting for wasn't even part of that team any more, but she was still waiting for this, but also they'd been given numbers to ring but she didn't do that, because she was waiting for the report, she was waiting for them to contact her…*

Expectation

What families expected from services compared with what could be achieved was also discussed. Participants described how part of their role was often to clarify what was available and achievable within their service for the children.

Julie, an independent speech and language therapist, reflected that parental expectations and understanding of their child's needs would change over time. However she expressed concern related to support for families in the realisation that their child had different developmental and long term needs from those of their peers. She reflected that parents may struggle to look forward due to their earlier experiences with services.

Julie.8.26

.... the experience of having ... autism changes as people grow up. What's a huge issue in a toddler is often beginning to tail off by sixteen, some of the sensory stuff - but there's other, you know the same with Down's syndrome will change over time and what parents never know is that life does not get better later ...maybe you can't do that when you're battling with a diagnosis and that battle with the early years do you really need to know...

Lisa described how some families felt misled or let down by services or professionals. She felt that part of a professional's role was to be open, honest and clear with families to promote realistic expectations.

Lisa.9.47

....at some point their experience might be 'I've not got what I need' - but sometimes I do think it's difficult, whatever part of the service you work in, you do an assessment and part of that is you need to say to that family I need to see you a minimum of every six weeks and if you can't keep to that you need to be speaking to them and saying, 'I'm sorry this is why I can't keep to this' and being honest with them and I think then the families understand and you get that working relationship with them.

Alison described a positive experience when she discussed how a child's education was managed. She discussed how professionals and the family worked together. Essentially the family felt listened to and were able to accept professional support.

Alison.8.19

...something that worked really well was when a parent wanted to still include their child in a mainstream school and was really supporting doing that. It was a very positive experience for the parent because ultimately this child went part-time in mainstream and part time in a special school, but the parents felt encouraged with that and they felt their needs were being listened to and they knew the child, but then they took on board the professionals' opinions and said that some of the needs would have been better met, and I think it's that really, thinking about the parent's perspective and not just being the professional....

Parental capacity

How families dealt with situations associated with their children and getting their needs met was discussed at length by professionals. It was clear that professionals believed that support received by families could be affected by parental ability to access services for their child. The basic theme of parental capacity encapsulated the discussion associated with families who struggled to access support for their child, but also represented those parents who had gained the confidence and capacity to advocate effectively to access appropriate provision.

Debra explained that some parents of children within a special school had been able to access support through their tenacity. Debra described parents who used this approach in her interview, and went on to suggest that although this approach was often necessary it also disadvantaged children whose parents were unable to adopt this approach.

> *Debra.3.33*
>
> *I think the people who tend to get the help are the people who shout loudest, or make the most fuss, or are constantly on the phone, or who will go to a higher level.*

Jenny described how parents accessed support for their children within her service. She was employed within a specialist independent school. The school provided independent assessments that were usually unavailable within statutory provision. The assessment was normally funded directly by families or on occasion an education department that had agreed to parental requests. She clearly acknowledged that her service supported only those children whose family had the capacity and resources to successfully access the provision.

> *Jenny.9.33*
>
> *But the parents are more informed, this is what the child needs and they fight but of course we get the parents that have the ability to fight who are keen to seek things out. There's a whole host of families there who 1) haven't got the financial; 2) haven't got the knowledge or the inclination to be able to do something about it so ours is a very selective service unfortunately I would like it to be very different but it can't be.*

5.7.3 Summary of global theme: Needing to know, knowing needs

The network of 'needing to know, knowing needs' described the family journey from waiting for support and advice to actively accessing support for their children. Codes ascribed to the data described the struggle, distress and impact that the child's behavioural

needs had on parents and siblings within the family. Professionals were clear that supporting this type of child had a profound impact on the child and family's ability to access appropriate services and support. The network acknowledged the journey of parents from a needing-to-know and expectant position to one of acceptance and control of the situation. It was clearly acknowledged by professionals that not all families were able to make this journey. For those families who were unable to progress along this path professionals discussed how their needs were unlikely to be met and that their child would be less likely to receive the specialist support that they required. Professionals, although clear that this was the situation, were also clear that part of their role was to support all families. The boundaries associated with their role were considered to be blurred when supporting children with behavioural needs and their families. Professionals reported that they often had to extend their traditional role in order to effectively meet the needs of the families and children in this group. Although the professionals suggested that they were willing to fulfill this role they also acknowledged that often the needs of the children were outside the usual capacity of the services in which they were employed. All the professionals were employed within specialist settings for children with a learning disability. The need for support to be enhanced above and beyond that provided in those settings were clearly expressed within the interviews. Children and their families were considered to have complex needs which required the support of highly skilled practitioners within a flexible and child centred framework of provision.

5.8   Summary of professional findings

The professional interviews provided data that reflected their perspectives of the lived experience of children with a learning disability and behavioural needs. Four global themes were deduced from the findings;

- The behaviour of services
- The complexity of need
- Behavioural barriers
- Needing to know, knowing needs

The 'behaviour of services' global theme considered how professionals viewed the support that was available to children and their families. The network considered the support that

was available to children and concluded that due a child's behavioural needs their choices of services was limited. Professionals considered that what was available to children was not always child and family centred. The view was expressed that often children were fitted into existing forms of provision that then struggled to meet their behavioural needs, and in some cases led to their exclusion from that service. The value base of provision was also considered within this network with professionals suggesting that staff and services were not always motivated or skilled to support this group of children.

The need to provide support that was useful and targeted towards the child and families' needs was advocated by professionals. The effective support of children with behavioural needs was considered to be a specialist skill that was not always available across mainstream or specialist provision. This was attributed to the paucity of appropriate training and a lack of access for staff due to resource issues. Many of the professionals in the research had completed accredited training in behaviour support and considered this to be essential to support this group of children; as a group they represented a highly motivated and skilled group of practitioners. It was however highlighted in this network that professionals felt that their role was extended when supporting children with behavioural needs. They often worked across professional disciplines and felt that this required commitment and confidence in order to support children and families effectively.

The global thematic network of 'the complexity of need' reinforced and extended the perspectives discussed within the 'behaviour of services' network. Professionals considered the children's needs to be more complex than those associated with their learning-disabled peers. It was highlighted that transition and frequent movement between services aggravated the situation for children who were often both formally and informally excluded due to their behaviour. The child's progress was hindered by the response of services to their behaviour.

The needs of the family were also discussed within this theme. The child's impact on family life was discussed at length with professionals clear that parents and siblings struggled to cope with their child's needs. Often professionals highlighted the isolation that families experienced due to their child's needs. This theme considered how services needed to be able to address the holistic needs of the whole family in order to support the child effectively. Safety of the child and family were also considered due to their vulnerability and lack of support.

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'Behavioural barriers' was the third network identified in the professional findings. The participants considered how the child's behaviour reduced their opportunities and access. This network identified the impact of stigma for children. Professionals discussed multiple examples of exclusive practice both within services and the community which directly affected the child's access to everyday experiences. The concept of reputation was considered in the findings with professionals clear that children were known within services because of their behavioural needs. This limited their opportunities for integration and inclusion. Once again this was noted across mainstream and specialist provision with the child's access to their community affected by their requirement for support that was often not available. Examples included access to specialist play schemes. This situation placed children and families at an increased risk of emergency and crisis situations due to their lack of support, particularly at times such as school holidays.

The final network developed was the 'needing to know, knowing needs' theme. Once again the needs of the family were considered within this theme, related to their ability to support their child often in the absence of appropriate service provision. Areas such as the future for families and the impact on the child's siblings were highlighted. The name of the network was derived from professional discussion of the journey of families. They described how children were kept waiting for support and provision in their early years by services that were bureaucratic and unresponsive. This situation was perpetuated by the simple naivety of parents who trusted professionals and provision to fulfil their supportive roles. However the participants also discussed their experience of parents who had realised that it was they who needed to advocate for their child in order to ensure that they could receive appropriate provision and support. Professionals acknowledged the inequity of the situation, and highlighted that not all parents would be able to take on the role, which could leave many children vulnerable within services.

Interpretation of the family and professional networks will be considered in Chapter 6. This will complete the final stage of Attride-Stirling's (2001) model of thematic analysis, interpretation and consolidate the overall findings of the research. Key issues have been identified by participants in both phases of the study. Their perspectives of the lived experience of children with a learning disability and behavioural needs will ultimately form the conclusions of the research and the thesis.

6   Chapter 6: Discussion

6.1   Introduction

This study has presented the findings of semi-structured interviews with parents and professionals who support children with a learning disability and behavioural needs. The aim of the research was to consider family and professional perspectives on the lived experience of this group of children. Children were not included in the study. The research is therefore based on interpretation of their experience. As asserted by Heidegger (1962) it is impossible to live and have experiences without interpretation. Participants have provided their perspectives, which supports the hermeneutic process of moving between knowledge and experience (McConell-Henry et al 2009).

The process of interpretation is central to this study, it is multi-layered (Benner 1994, and Bryman 2008) and inexhaustible. The reader will interpret the findings and consider their own perspectives in relation to the conclusions and recommendations from the study.

The research was conducted in two phases. Ten interviews with family members (parents) were conducted in phase one, and ten interviews with a range of professionals were completed in phase two of the study. Each participant offered a unique insight into their perspectives on the 'lived experience' of children with a learning disability and behavioural needs. Generalisation across the two phases was not an aim of the study and is generally not appropriate in the pursuit of true lived experience within qualitative research design (Mayring 2007). Further to try and condense the findings in an attempt to generalise or fuse the data would not have been appropriate. Convergence however of perspectives are reported in this study and must be considered as significant. Both phases of the research and the subsequent findings are inextricably linked. The parallel viewpoint of participants emerged during the process of iterative analysis. They were at times interchangeable and supportive of each other's perspective. Importantly for this research, consistent and convergent findings could not be disregarded as they occurred naturally in a quest for individual participant perspectives on the lived experience. Uniqueness and commonality are noted features associated with participant experience (Todres 2005), and confirmation of perspectives on experience should as proposed by Vickers (2002) be considered as significant.

To briefly review the methods chosen for the research, prior knowledge and experience as a clinician, and the perspectives of families and professionals formed the basis of the hermeneutic circle (Annells 1996, McConnell-Henry 2009). Interpretation of the findings has been multi-layered, with each stage of the research process involving levels of interpretation (Benner 1994, Bryman 2008). The interpretative process commenced with perspectives on the children's experience described by participants. My interpretation followed during the initial stages of analysis, and the further coding and contextualisation of the findings. The final stage of interpretation has commenced, and resides with the reader.

A model of thematic analysis was chosen to visually illustrate the process of interpretation for the reader (Attride-Stirling 2001). This was selected to support the transparency of the analytical decision making process. The temptation to extend the exploration of findings using Attride-Stirling's (2001) model of analysis has been avoided. Potentially continuation of thematic networks into the findings chapter would have involved a move from global or 'super-ordinate themes', to the construction of overarching or macro themes. This form of representation would have illustrated the convergence of findings within the thematic networks for the two phases of the study. This may have been useful as part of the hermeneutic analytical process. However the consideration of phenomena through different perspectives has been central to the research (Moustakas 1994), and although Attride-Stirling's model was useful for analysis and provided a systematic and illustrative representation of themes, the model may have confined the discussion of findings into a systematic and prescriptive formulation. The opportunity to discuss the findings as they emerged from the data was chosen and has involved the construction of a timeline of events. Although the timeline cannot be viewed as representative of all children discussed in the study, it encapsulates the significant events and times identified by participants that shape a child's experiences associated with their behavioural needs. As illustrated in Figure 10, the experience of inclusion and exclusion are central to the child's experience and are a constant theme in the perspectives discussed by the participants.

Readers of the research will be able to form their own conclusions related to the integrity of the findings discussed. As highlighted the reader's final interpretation will contribute to the hermeneutic circle. However a finite understanding of the studies' findings may never be achieved, as the process of interpretation can never be exhausted (Ormiston and Schrift

1990). Indeed the process of interpretation will continue through dissemination and presentation and facilitate a deeper understanding of the information presented.

In answer to the question of 'what are family and professional perspectives on the lived experience of children with a learning disability and behavioural needs?' I claim that the children discussed in the research experience a level of marginalisation that is pervasive and significantly more than that experienced by other children.

Children with behavioural needs experience discrimination perpetuated and reinforced by current forms of service provision and their local communities. Within learning disability provision this group of children do not fit. Within mainstream services children experience disproportionate levels of discrimination and stigma due to their behavioural needs. The inappropriate implementation of integration and inclusion strategies has rendered this group of children, and furthermore their families, at an increased risk of displacement and exclusion. The children at the core of this research experience an inability to fit in. The findings of the research will be discussed within this chapter with reference to contemporary literature and current evidence.

This chapter will therefore contextualise the experiences of children through the perspectives of those who support them. Children with a learning disability are children first (DCSF 2007), and their experiences should be considered in the context of the outcomes for all children (DE 2003). However I propose that the children who are the focus of this research need to be considered separately from their non-disabled peers, and also their learning disabled peers. This study demonstrates that their experiences are unique. Children with a learning disability and behavioural needs have complex and pervasive needs. As a discrete and minority group of children they experience services, support and presence in their communities in very different ways than other children.

This chapter will therefore consider the messages devolved from a total of eight identified global themes from both phases of the research; the child and family, finding our way, the behaviour of services, behaviour touches everything, behavioural barriers, belonging, complexity, square services round needs, needing to know knowing needs. Discussion will consider the implications of these findings in the pursuit of understanding the lived

experience of children with behavioural needs, from the perspectives of those who support them, families and professionals.

6.2 Research themes

The following diagram (Fig 9) illustrates the eight global themes that convey the overall findings. It also represents how the themes are linked and associated to each other. As well as themes evolving from both phases of the research the diagram reflects how they converge. All themes identified are related to each other and the experience of the child and the family. The study was focused on the lived experience of the child. The needs of the family could not be (and maybe should not have originally been) separated from those of the child. One cannot exist without the other. A child's experiences ultimately have an impact on their family. Similarly the decisions taken by parents have an impact on the types of experiences that the child will encounter. This could be seen as the most normal of parent child relationships and therefore have been incorporated in the discussion and subsequent recommendations. Without the voices of parents the findings would be one dimensional and neglect the most intimate understanding and perspective on the child's holistic experience. Parents provided their perspectives to support the study of their child's lived experience. Their interpretation of experience is at the very core of the research.

Global theme: The child and family

Figure 9

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All research can provide an insight into areas that are not necessarily the subject or focus of the research question (Curry et al 2009). For this piece of research the journey of families through their child's experiences has been a key finding. The impact of families on the lived experience of their children formed a large part of the interviews conducted. How parents described their perspectives on managing the lived experience of their child has been extremely enlightening. Without parental involvement in the study there would be limited findings to discuss. The effect that families have on their child's experiences in all aspects of their lives is to some extent assumed, as with all children. However for the parents in the study and in reference to current literature the skills and decisions of the family unit monumentally affect the experience of children with a learning disability and behavioural needs (Mencap 2006, McGill et al 2006). Indeed it is my assertion that supporting and nurturing a child with a learning disability and behavioural needs is a very different experience from that of other parents. Parents did not ask, or were prepared to embark on this journey of difference with their children, and so their narratives of supporting children have been a fundamental part of their perspective on their child's experience. The poem "Welcome to Holland" by Emily Perl Kingsley (1987) encapsulates one parent's perspective on this experience. She uses the example of planning a holiday to Italy, but describes the experience of arriving in Holland;

> *... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go.*
>
> *That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very, very significant loss.*

The parents in the research were keen and willing to take part in the interviews. They had something they wanted to say and share about their child's experiences. Multiple themes in the findings were related to the parent's journey with their child. This should be considered as a fundamental part of the child's journey also. If a parent described how difficult it was to attend appointments due to their child's needs, this implies that the child may also have experienced difficulty in this situation.

Essentially the findings reflect that parents and professionals in the study have similar perspectives on the lived experience of children with a learning disability and behavioural needs. Although expressed in different terminology and with different perspectives the findings concur. The experience of children with a learning disability and behavioural needs

is different from their peers. Importantly it is different from their learning disabled peers. A child's experience of services and community participation are dominated by their behavioural needs. It would appear that a child's behaviour affects all their experiences, everything they can do and achieve.

6.3   Findings diagram

In order to structure the final discussion a diagrammatic representation of a child's journey will be used. Significant times in the life of a child with a learning disability and behavioural needs have been identified. These events and experiences are not represented chronologically for the children in the study, but represent times identified by participants as key issues related to a child's experience. The diagram represents the child's experiences of; diagnosis and realisation of difference, service support, educational provision, transition and finally the future

Figure 10

Within the key areas identified in Fig 10, two central tenets are at the center of the child's journey and experience; exclusion and inclusion. Both of these tenets are directly related to a child's behavioural needs. The concepts are present throughout the research, both discussed explicitly but also implicitly described by participants associated with the child's experience. The literature is clear that people with a learning disability experience exclusion (DH 2001). How this impacts on the experiences of children with behavioural needs will be discussed within this chapter.

6.4   Exclusion

People with a learning disability are one of the most excluded groups within society (DH 2001, WHO 2007). Exclusion (described as a prerequisite for social exclusion (Burchardt et al 1999) ran through the interviews as a central tenet and was present in all the themes. An individual may be physically present in a community but this may not guarantee that they are able to take part in its activities.

For the children in the research their experience of exclusion was exacerbated by their behavioural needs. How they had been accepted within their community and local services shaped the child's journey and ultimately affected choices made about them and on their behalf. Decisions related to types of provision and activities (although limited for this group of children), were usually made by parents, with reference to the child and families' early experiences of services and community participation.

For children with a learning disability and behavioural needs opportunities for integration and inclusion were directly affected by the type of provision they received. Parents discussed their rationale for the choices that they made related to their child's inclusion and integration. This was particularly prevalent in discussions associated with education, where some parents had embraced the philosophy of inclusive education and others were heavily critical of the implications for their child and their experiences.

Access to social activities for children was also considered by participants. Families discussed how they felt isolated in relation to community networks, family activities and social involvement. They believed that their child's needs dictated everything that they were able to do as a family. The level of support required by children negated their ability to

participate in leisure activities and formed another barrier to integration. This meant that some families had opted for the provision of leisure activities through specialist services. This type of provision was often associated with, and provided by, the child's special educational provision. From a purely practical view professionals acknowledged that specialist provision was often the only way that children would be able to attend leisure pursuits and activities as well as develop social networks outside the family home. Examples included attending swimming sessions at local special schools. This type of activity required a number of support staff and was often not an option for families that had other children. Although acknowledged as not ideal for children to remain separated from their peers it was considered that specialist support was preferable to the child not being able to access activities. The situation was considered by both groups of participants to be a compromise rather than a desirable situation. It was generally considered that, for the children in the research, access to mainstream activities was difficult. Children had tried to access community facilities and local activities but their experiences had reinforced their level of exclusion from their local community and their dependence on specialist provision.

Significantly exclusion for this group of children is not only related to mainstream environments. Exclusion was also experienced by children within what Hall (2004) described as, relatively safe spaces, such as those associated with specialist provision. Professionals and parents described how children with behavioural needs were often 'screened' by specialist services and excluded from specialist provision. Risk to other children or the inability of staff to support behavioural needs were often given as a rationale for their exclusion. An example of exclusive practice within specialist provision included play schemes for children with a learning disability, that would not accept children with behavioural needs. The paucity of appropriate childcare for children with a learning disability has been recently highlighted by SCOPE and KIDS who reported that two thirds of families surveyed (1,192) found it difficult to find appropriate summer childcare during 2011. One in ten parents reported that their child had been refused a childcare place, and 60% of parents had difficulty accessing childcare that could meet their child's additional needs (SCOPE, KIDS 2011). This situation suggests that children with a learning disability and their families struggle with appropriate childcare support to meet their needs. The children in the research have additional needs that can exclude them from specialist provision. Children with behavioural needs are therefore more likely to be excluded from

provision than their peers and further more likely to experience exclusion from specialist provision.

Decreased opportunities for integration have been considered to affect the accessible world for people with a learning disability (Dyck 1995). Participants in the research agreed that exclusion was a pre-disposition for this group of children, predominantly based on their behavioural needs. Providers' attempts to integrate children with behavioural needs must consider this pre-disposition (Mandipour et al 1998). However recent evidence supports the view of participants in the research that children are let down, and artificially maintained within inappropriate and under resourced environments, which further reinforces their vulnerability and exclusion (Connolly et al 2012).

Safety was often the reason stated for the exclusion of children from provision and their communities. This was considered by participants to be related to a lack of appropriate skilled support for the child, and also the level of risk that their behavioural needs posed to other children. The presence of aggression and behavioural difficulties has been correlated with an increased risk of exclusion of children from their peer groups (Deater-Deckard 2001, La Fontana and Cillessen 2002). The situation can only be exacerbated if children are placed in inappropriate environments that can leave children with behavioural needs vulnerable due to the lack of skilled support (DH 2007). Successful inclusion must be related to successful and supported integration for this group of children.

Further exclusion from communities, services and local networks increases the demand placed on families, and isolates children. People with learning disabilities have been described as existing outside their community. A situation that displaces and seeks to over protect individuals from their communities can create total exclusion (Hall 2004), a potential 'asylum without walls' referred to by Wolch (1981, pg225). For the families in this study loneliness and their child's isolation were real issues that they struggled to overcome.

The behavioural needs of the children in the research created a situation in which they were unable to conform to the expected norms of local groups and peers as also reported by Emerson et al (1994). Indeed children with behavioural needs appear to fall outside all of their potential social groups, both within services and communities, and across mainstream and specialist provision. Community integration, or a presence in the local community can

be achieved for this group of children, but can exist in the absence of true social integration (Gilbert et al 2005).

In response to the children and families' experience of exclusion, several parents discussed how they instigated and created bespoke types of provision to support their own and other children and families' needs. Parents were aware of local children who also experienced a paucity of appropriate provision and exclusion from their communities. As a direct result of social exclusion and a lack of access to social networks and services, parents facilitated the creation of 'safe spaces', considered by Hall (2004) and Pierson (2002), which could provide the necessary social and geographical networks to support their children.

The ultimate exclusion experienced by children with a learning disability and behavioural needs must be the placement of children in out-of-area residential educational provision. Significantly the numbers of children placed in this form of provision has risen (DH 1993, McGill 2008), with commentators comparing it to historic forms of congregate residential support (Pritchard 2003, Goodman 2006). Without doubt children who have been placed in this form of service are excluded from their local communities (Goodman et al 2006). Two professionals and one parent in the research discussed this type of service. As a form of provision, residential support for children was considered to be a last resort, and symptomatic of local service failure. Reference in the research was made to children who had returned home from residential placements to their original familial area.

As well as considering circumstances that had led up to the admission of children to such services, participants recognised that the situation that had precipitated the need for such a service had not been resolved for the child on their return home. Indeed professionals in the research had been involved in supporting families to consider this situation before accepting their child home. Although a difficult position for a professional, those who reported this stated that this may prevent a relapse of family support, and further admissions for the child in the future.

Families were understandably anxious about their child's return, reinforced by their concerns related to family and local service ability to meet the child's needs. Residential placement has been noted to be the direct result of, and in response to, crisis situations experienced by children and their families. These extreme circumstances have been associated with a lack of

local provision to effectively meet the child's needs (Goodman et al 2006, McGill 2008). It must be considered that during such difficult periods the ability of families to advocate effectively for their child's needs would have been reduced, which places children and their families at risk of accepting emergency provision that is merely available rather than chosen. Reflection on these circumstances created anxiety for parents who had little confidence that service responses to their child would have improved in order to facilitate an effective return home for the child. Parents and professionals described vividly the impact of the child's behavioural needs on the whole family during these difficult periods. Participants considered residential support as a form of emergency provision that was a direct result of unmet needs, rather than a fault of the family or child (McGill 2008), and therefore the ultimate form of exclusion for both the child and their family.

Exclusion in the context of this research is related to children with a learning disability and behavioural needs ultimately experiencing an inability to fit in. This affects their presence in the local community. They experience exclusion that is exacerbated by their behavioural needs. As a minority group within a minority group, children with a learning disability and behavioural needs experience a disproportionate level of discrimination, labelling and stigma. Services designed to support people with a learning disability do not appear to be able to support children with behavioural needs. Children experience both formal and informal exclusion from services that do not have the ability, resources, skills or value-base to effectively support them. Ultimately children with a learning disability experience displacement. They cannot be supported in mainstream environments in large part due to inappropriate implementation of integration strategies. They are also unable to access specialist provision due to their behavioural needs. This situation raises the profile of a child within services, they are difficult to place and therefore become stigmatised as complex, a label rather than a diagnosis, as discussed many years ago by Goffman (1963). As children first and foremost they require the same support as child. However their needs appear to dictate a needs led approach concentrated on their label of complexity rather than a child centred one. The child becomes stigmatised, which reinforces their difference and perpetuates a view that they are different from their peers.

6.5   Inclusion

The two concepts of inclusion and exclusion are inextricably linked for this group of children. It would appear that the children in the study can experience both conditions

simultaneously and therefore these are directly linked to one another. Miller and Katz (2002, p9) proposed that the process of inclusion should create '… a sense of belonging…. supportive energy and commitment from others….'

Experiences and opportunity for inclusion for the children in the research were directly related to the decisions made by parents for their child. It is possible that this explicit form of decision making affects other groups of individuals, but in view of the combination of learning disabilities and behavioural needs experienced by the children in this study, it is unlikely that it would take such a pervasive form.

Choices related to inclusion and integration were considered by participants to directly affect how children moved forward within both service provision and their local community. The form of educational provision chosen for a child within this group of children is central to the discussion of inclusion, as the choice of a special school placement for a child directly affected whether, how and with whom they were able to access future opportunities and experiences.

Choice of school provision must therefore be acknowledged as a potential conduit for integration and inclusion. Generally children who attended mainstream school were considered to be more likely to experience inclusion within their community. Families who gave examples of how their children were recognised by peers and neighbours, considered this a positive and fundamental reason for the choice of mainstream education.

For some of the children in the research integration and inclusion had proven too difficult for the child and family. This opinion was usually based on previous experience, in some cases following a mainstream placement for education and a later move to specialist provision. The child's safety, in relation to their own behavioural needs, support and the reaction of others were discussed as barriers to mainstream activities for children. Further the child's level of vulnerability was also considered to be heightened in mainstream environments with participants raising issues of bullying and inappropriate treatment by their peers. It was perceived that a child's behavioural needs made them extremely visible in mainstream environments and therefore potential targets for discrimination and abuse. Behavioural needs places this group of children as more likely to be excluded by their peers as highlighted by Deater-Deckard (2001) and La Fontana and Cillessen (2002).

Related to community participation parents had made conscious decisions associated with what they believed was best for their child socially. It was considered by all participants that children with behavioural needs required skilled support to maximise opportunities, however this had proved to be difficult to access. Parents also suggested that support in mainstream environments often inappropriately raised the profile of the child amongst their peers, and was therefore often viewed as negative and counter-productive, views expressed importantly by the children themselves and relayed by their families.

Special school provision was discussed by participants as a way of facilitating supported access to community and leisure activities. It was however acknowledged that it also managed to exclude children from 'normal' community based opportunities with participants supporting Gilbert et al's (2005) assertion that presence in a community did not always equate to participation and social integration. Some of the children discussed were considered to be precluded from social activities and opportunities due to their behavioural needs. Examples included children with autism who may be unable to manage sensory situations or crowded environments. Participants reported that support for a child's behavioural needs was not available and prevented the meaningful inclusion of children with their non-disabled peers.

Conversely, to consider mainstream schooling as a catalyst for inclusion participants felt that this choice of provision was a way of ensuring that children could interact with their peers, and may therefore be included. It was identified in both phases of the study however that the support required to enable them to be part of mainstream activities also identified them to their peers, and thus served to exclude them. This was considered to be counter-productive in the pursuit of true integration in mainstream provision. Several of the children discussed were described by participants as unhappy with the support they received for this very reason.

The behavioural needs of children have been shown to affect interactions with peers (Byrne and Hennessy 2009). Children are less likely to interact with peers who display behavioural needs (Graham and Hoehn 1995), and more likely to exclude them from their social groups (Fontana and Cillessen 2002). For children who suffer exclusion from their peer groups there is an associated increase in the incidence of psychological difficulties in their later years

(Byrne and Hennessey 2009). For those children in this research who attended mainstream provisions, professionals and parents acknowledged that inclusion was associated with risk for the child. This situation was largely considered to be virtually unavoidable, and one considered to be of major concern. Families and professionals were involved with or knew of children that had been integrated within mainstream provision. Decisions associated with educational inclusion had been clearly considered by parents. In most cases parents were emphatic about the possibility of effective integration for their child. Professionals had supported children that were involved in specialist and mainstream provision. The issues identified were consistent across both phases. It was the needs of the child that prevailed and for some of the children discussed their behavioural needs created a huge disadvantage for them in the pursuit of inclusion.

The experience of one parent of two children with learning disabilities and behavioural needs, exemplified the dilemmas discussed by many parents. Lynn felt very strongly that her sons should be included in mainstream services and their community. She considered that their presence in their local community would keep them safe. Their inclusion in mainstream schooling (although described by her as difficult to manage and a constant struggle), meant that they were known in the local area, by their peers and neighbours. Lynn acknowledged that her boys were considered as different from other children in the community, by their peers and adults, however it was their difference that she felt made them stand out and potentially be known. Safety for people with a learning disability can be related to the quality of their relationships (O'Brien and O'Brien 2002). Lynn's view captures the risks, disadvantages and potential advantages considered in the research associated with inclusion. She had decided that difference enabled her boys to be distinguished and recognised in their community, which in her view outweighed issues associated with risk and safety. Models of specialist provision for children with learning disabilities have been criticised in their attempts to manage such issues through a focus on safeguarding and risk management, with such approaches negating an ethos of inclusion and meaningful life experiences for individuals (for example O'Brien and O'Brien 2002).

Children with behavioural needs can be excluded through inappropriate attempts to include them. Some authors suggest that all children could be included in mainstream provision regardless of their needs (Jupp 2002, Pitonyak 2007). It is the responsible pursuit of inclusion that appears to be the issue, as for this group of children the risk of exclusion is

disproportionately higher than that of their disabled peers. Inclusion at the price of dependence for individuals has been fostered by the irresponsible pursuit of integration and inclusive practice as noted by Gilbert et al (2005). Professionals and indeed families recognised the juxtaposition posed by the inclusion agenda. Whether inclusion can be truly experienced by people with a learning disability was raised by Hall (2004). Indeed the criteria may be unachievable. For children with behavioural needs the conditions, and stigma associated with their behaviour may create a situation in which integration may not be worth pursuing for the modest gains it could produce.

Whilst acknowledging the role that specialist provision could play in the support of leisure and social activities for children, participants considered this as part of the limited options available to them. Often the child's behavioural needs meant that they had to rely on specialist support. This was in the absence of proactive planning within other forms of provision to meet the needs of children. However specialist provision was also not able to support the child, which left families and children without any form of childcare provision (KIDS, MENCAP 2011). Most participants believed that children were more likely to receive appropriate support within specialist leisure and community activities. Mainstream provision was considered to increase the chances of a child being unsupported and therefore potentially more vulnerable. Practical issues associated with transport and staff support were acknowledged to be extremely important for this group of children, and could only be accessed through specialist provision. To this end the educational setting of children with behavioural needs were considered by the participants to affect a child's opportunities to take part in leisure and social activities.

For this group of children the social constructs of communities and services may serve to reinforce an exclusive society. For those involved in the study, inclusion was perceived as a philosophy rather than a reality for the children. Behavioural needs were perceived to be the aspect of the child's disability that created this situation. Society and services therefore may be able to support inclusion if that process does not disrupt the status quo. Needs which require support and can lead to social exclusion are therefore far more difficult to tolerate in a society geared up to social norms and expectations, and within services that perpetuate dependence.

The concepts of inclusion and exclusion affect all aspects of the lived experience of children with a learning disability and behavioural needs. Key points in the child's journey have emerged through consideration of lived experience, and will be used to structure the remainder of this discussion (see Figure 10).

6.6   Perspectives on the lived experience of children with a learning disability and behavioural needs

One of the most defining moments for the parents in the research was their child's diagnosis and the realisation of their child's difference. This period of time, although protracted for many of the children in the research, was felt to be a pivotal point for all families. It shaped the child and family's journey, specifically the way in which they were able to interact and receive support from services.

6.6.1   Diagnosis/realisation

At the very beginning of a child's life, birth and later realisation of difference are defining for all families. Parents in the research reflected upon the difficulties they experienced during this period of time, which appears consistent with the literature in the area (Scope 2006). For the children and families in the research their experiences centred on difficulties associated with protracted assessment and lengthy deliberation of diagnoses. For several of the children in the research, diagnosis was not confirmed until they had reached primary school, despite families seeking support for their children before this time. Diagnosis has been highlighted in the literature and was considered by parents and professionals to be key to the access of appropriate services and support (Limbrick 2007).

The impact of the birth of a child with a learning disability has been widely considered in the literature, with consensus that a child's disability has a multiplicity of implications for family adjustment. Parents struggle to consider the needs of their child that has a diagnosis but also the effect of this on the whole family both socially and environmentally (for example Falik 1995, Trute and Hiebert-Murphy 2002).

Methods and models of diagnosis, breaking the news and follow up support have been considered widely in the literature (Quine and Rutter 1994, Heiman 2002, Scope 2006). Although best practice suggests that families should be given information associated with their child's diagnosis as soon as possible from a knowledgeable practitioner (Skotco et al

2009), for the families in the research this had not been their experience. In the child's early years the children with behavioural needs had been described by services as naughty, lazy, disruptive and uncooperative both to parents and professionals. Often the child's behavioural needs were symptoms of a diagnosis that followed later in the child's development (for example autism). Evidence suggests that an obstetrician and paediatrician are considered to be the most relevant professionals to inform parents of their child's diagnosis (Pueschel and Murphy 1977), however delays in diagnosis negated this possibility for most children in this study, with parents receiving the news from a multitude of different professionals. Practice was reported to be contrary to that indicated in the literature, which implies that the most important pre-requisites for the role should be the individual's knowledge and skill (Pueschel and Murphy 1977, Skotco 2005). This ad-hoc and often inappropriate way of informing families of their child's needs was considered by professionals to exacerbate a situation in which families could become caught between stages of grief (Kubler-Ross 1969), experiencing difficulty in moving forward and acknowledging their child's needs.

Families experienced difficulty in making sense of 'snippets' of information that they received from services, with the child's diagnosis considered to emerge as the child developed. Behavioural needs in particular became more prevalent as the child grew older (Murphy et al 2005). Only two parents in the research experienced a form of diagnosis at the birth of their child. This was related to the physical symptoms of cerebral palsy apparent at birth. Whilst referred diagnosis is an unavoidable possibility for some children, how this is managed, with reference to the associations made in the literature between language, developmental delay and behavioural needs, must be considered (Murphy et al 2005). Models exist such as the 'Team Around the Child" approach (Limbrick 2007), that place the child and family clearly at the centre of assessment and the diagnostic process. The impact of inappropriate management has ramifications for the child, the family and subsequent services.

Parents were able to recount vividly how the news of their child's condition was disclosed, and by whom. Informed and sensitive discussions related to the implications of a diagnosis, and follow up appointments, as recommended in the literature, were replaced by an absence of support, ad hoc conversations and limited information (Cunningham et al 1984, Quine and Rutter 1994, Ablon 2000). Orlander et al (2002) further highlighted the difficulty that professionals experienced in the disclosure of diagnostic information to families. A

combination of these issues may have contributed to the parent's feelings of isolation and confusion that they reported at this important time in their child's life. Parents felt unclear about where to go for help or what that help could be.

Professionals were aware that families were often left waiting for prolonged periods of time for news or information associated with their child's needs or diagnosis. Supporting children and families during these periods was challenging for professionals as they acknowledged that they often provided services during the early stages of a child's life without a clear picture of the child's needs. Further they acknowledged the pressure on parents to make fundamental decisions about their child's future support. A lack of diagnosis, the need to make decisions and the experience of the child struggling to fit into services made children and their families feel extremely vulnerable. Parents are ultimately disempowered in the decision making process. The resilience of families in such situations has been related to the management of diagnosis in a child's early years as considered by Cunningham et al (1984) Lavin (2001) Heiman (2002) and Scope (2006). Parents rely heavily on professional support and guidance during the child's early years, whilst services also struggle to effectively support the needs of children and their families in this situation.

Although formal diagnosis was often protracted for children, the parents described how they had begun to realise that their child's needs were different. Grief associated with the diagnosis of a child's disability has been extensively reported in the literature (Kubler-Ross 1969, Lavin 2001). Healey (1997) reported six stages; shock, denial, anger, resignation, acceptance, moving on. Although parents were often waiting for a formal diagnosis, their narratives articulated these stages, as their initial shock and denial moved onto the stage of anger at the inability of services to identify or meet their child's needs. Simultaneously parental concerns were confirmed as their child experienced an inability to fit into services, and continued to display increasingly atypical behaviours. The effective adjustment to a diagnosis that can support families to move forward and manage their child's needs effectively (Fuller 2007), was once again compounded. Parents described feelings of guilt at the disruption that their child created during everyday activities such as shopping or days out (Farrell and Polat 2003). Powerful language and words were used by parents to articulate their journey through their child's early years with professionals acknowledging the paucity of skill and services able to support parents through this process. Parents were therefore

isolated in relation to support and information with periods of grief and acceptance unrecognised, suppressed and protracted.

As discussed by Limbrick (2007) the children's early years were dominated by appointments and the medical model of assessment. Formal diagnosis can enable children to access specialist support, however for this group of children a delay in diagnosis extended their interface with, and exclusion from, mainstream provision. Although this could be perceived to support the notion of inclusion, it did not support families and children in the study. Mainstream services struggle to meet the needs of children with behavioural needs (DH 2007). Parental feelings of isolation and increased exclusive experiences for the child resulted from this situation. Ultimately the child's needs were often misinterpreted and, most importantly, unmet. Children and families in the research were unable to take advantage of early intervention programmes considered key in the support of families to manage and effectively intervene for their children (Webster-Stratton1990). Such programmes have been associated with reductions in parental stress and improved outcomes for a child's behaviour (Stormshak et al 2002, Webster-Stratton 1990).The inappropriate management of behavioural needs can contribute to the inadvertent reinforcement of behaviours (Noone et al 2006), which will consequently affect future interventions. A crucial period of time for support and intervention was neglected for the children in this study. Appropriate support was not offered to families, whilst children were experiencing their inability to fit into mainstream systems.

Associations away from formal diagnoses have been associated with the presence of a learning disability and the higher incidence of behavioural needs (Baker et al 2003). The early signs of behavioural needs have been shown to be predictive of continuing behavioural issues as the child develops (Murphy et al 2005). Further literature suggests that if a child struggles to meet developmental milestones and displays communicative delay behavioural needs may be indicated, with recommendations for the provision of early intervention services (Murphy et al 2005). For the parents in the study opportunities to consider their child's behavioural needs in their early years were not available, despite the National Service Framework for Children Young People and Maternity Services (2004) advocating that early intervention to support a child's behaviour would enable families to proactively support their child. Most parents described their child's early years as chaotic and dominated by the medical model. Whilst this process was ongoing, parents experienced feelings of

disempowerment associated with their child's behaviour; they felt unable to control or predict their child's behaviours. Some parents actively sought specialist support during their child's early years. Although described as difficult to access, when they were available parents and professionals considered them to be beneficial to the child and family.

Once a diagnosis was confirmed parents felt that they were more able to understand their child's difficulties. Further it allowed parents to feel that the behaviour was not a result of their parenting skills or care, and for some it eased feelings of guilt, as discussed by Farrell and Polat (2003). Parents described how they were considered to be to blame for their child's behaviour by services, with professionals stating the same experience in relation to the knowledge and skill of people involved in services (DH 2007). A diagnosis however did not equate to parents becoming more able to manage the behavioural needs of their child, but allowed parents to begin to consider their child as different from their peers. It was the recognition of difference, supported by a diagnosis, that allowed parents to begin to understand their child's needs more effectively.

Whilst managing their child's complex and undefined needs parents were coping with a plethora of service provision, assessment, diagnosis and managing their own feelings. Parents in the research described their early struggles to meet the child's complex behavioural needs as well as support the family and manage their own health. Mencap (2006) and Murphy et al (2006) highlighted the physical and mental impact of prolonged caring for parents of children with a learning disability. Stress has clearly been correlated with the caring role (Glasberg et al 2006, Hassiotis and Chaytor 2011), and further exacerbated by the early signs of behavioural needs (Murphy et al 2006, Glasberg et al 2006). Several families discussed their long-term health issues, some of which they attributed to the physical impact or injury caused by management of their child's behaviour. The vulnerability of children and their families in such situations places their needs as significant, related to their role as carers and in relation to their peers. Several of the parents expressed their fear of returning to situations in their child's history when the impact of their behaviour was so severe for them and the family that they had reached crisis point. It is at these points in time when a child is most likely to be placed by services in residential provision (Abbott et al 1991, Goodman et al 2006, McGill 2008).

It is in light of the discussion of the child's early years that parents had to make key decisions related to their child and their inclusion in services. Choices of educational provision for a child, such as special educational schools or local mainstream schools were often affected by the child and family's early experiences of services and the ongoing uncertainty associated with their child's support needs. Parents described how they made such decisions based on their child's early experiences of inclusion and exclusion amongst their wider community, such as nurseries and social networks. The children in the research were all considered to have experienced exclusion and the impact of this in their early years. Parents described articulately how their child was often not included in school and nursery activities due to their behaviour. Families reported how they experienced feelings of guilt about the way that their children behaved and the disruption that their behaviour caused to services and professionals (Farell and Polat 2003). Following diagnosis some parents expressed their regret at the way they had perceived and attempted to manage their child's behaviour. Compounded feelings of guilt and grief may exacerbate a journey already fraught with problems for families. It is unsurprising that once families were able to accept and understand their child's needs they began to see themselves as true advocates for their children, assert themselves on behalf of their child and seek appropriate provision of services to meet their needs. Awareness that the child was considered unpopular within services was discussed by many of the participants. For this group of children the process of labelling and stigma began in their early life and set the tone for many of their future experiences.

6.6.2 Service support

For the children in the research their contact and reliance on services would be lifelong. This long term relationship had begun in difficult circumstances for the child and the family. The complexity of the child's needs had begun to emerge during the child's early development. The children discussed in the research truly reflect current definitions of complexity associated with the receipt of multiple services and intervention (Rankin and Reagan 2004, Limbrick 2007, Scottish Government 2007). The professionals in the research were all employed within specialist services for children with a learning disability. As a group of individuals they were able to give a valuable and often candid insight into current issues within a range of services. Professionals and parents voiced parallel concerns about the ability of services to meet the complex needs of this discrete group of children.

Current service provision and support for people with a learning disability are based on contemporary philosophies and evidence. The Valuing People White Paper (DH 2001) began a move towards a model of person-centred support and provision. How the white paper was translated and applied for people with a learning disability has been the focus of the more recent Valuing People Now (DH 2009) agenda. The paper focused on four key areas: rights, inclusion, independent living and control. The paper clearly articulates a focus of provision on the empowerment of individuals.

How services facilitated empowerment for children was interlinked with descriptions of how services responded to their behavioural needs. During the child's early years, particularly related to diagnosis and assessment, the medical model was clearly dominant (Limbrick 2007). For parents, early interactions with services were crucial in their attempt to understand their child's needs. Families began their interactions with services as people who required support and advice related to their child. Some of this support was provided within mainstream environments, as for all children. Their original interactions began with health visitors and usual General Practitioner appointments. However as the needs of their child became less typical children were referred across services and to multiple professional groups. Interaction with multiple agencies, interventions and practitioners were considered by families and professionals to create the situation described by Lacey (2001) as 'benevolent chaos'. Families struggled to get their children to the multitude of appointments they were required to attend, reinforcing the challenge of caring for their child (Limbrick 2007). Participants agreed that services tried to do their best to support families. However fragmented provision and a lack of inter-agency communication meant that services were neither child nor family-friendly. How children were received and supported to access services was often a problem for parents. Appointments for repeated assessments were often conducted in environments that were unable to cater for the child's needs, particularly their behaviour. Parents felt that a large proportion of appointments were repetitive and pointless, but felt under pressure to attend (Limbrick 2007). Early experiences of clinic appointments often stayed with parents who felt unable to access or fit into normal mainstream provision due to the reactions of other families and professionals. Participants agreed that services were not able to meet the very specific needs of the children. This was not always associated with a lack of motivation within services but was considered to be contingent on the skills, resources and confidence of staff within services. The value base of individuals within services often affected the child and families experience. When individuals within services

endeavoured to accommodate the individual needs of children this often positively affected their experience.

Not all outcomes are related to resources but rather the application of user-friendly models of service delivery, and further the value base of the individuals employed. Parents were able to identify a single professional within their experience that had been most useful to their child and family. The professional they described was considered to be both skilled and knowledgeable. They were able to consider the child holistically and had a good practical knowledge of the management of behavioural needs. In contrast to Mansell's (DH 2007) assertion that people with behavioural needs required specialist support above and beyond that found within mainstream services and learning disability provision, often the professional discussed by families was not from a specialist background. Health visitors and mainstream teachers were given as examples. Although a professional's behavioural knowledge was key, it was once again the positive value base of an individual towards the child that was most important to the parents. This must be considered in light of the child and families' experiences associated with exclusion and their inability to fit in. Having identified that children and families were involved with multiple professionals and services, the identification of a lone individual may be indicative of the lack of quality provision that parents and professionals believed that the child experienced. Service response for children with behavioural needs has been suggested to require specialist services and skills as well as broad multi-agency approaches to support services and managers in the development of family centred services (Lowe et al 2007). The literature suggests that comprehensive 'trans disciplinary' teams (Chen 1999) built around the needs of the child and family are required to support children with complex needs (Chen 1999, Lacey 2001, Limbrick 2007). The value base of staff and provision however must be addressed to avoid the application of exclusive practices within such teams (Connolly et al 2012).

It was the value base of services as well as the need for skilled and trained staff that dominated the discussion of services by participants. Families expressed their concern that services often saw their role as caring for, rather than promoting their child's independence. Those employed to support individuals with a learning disability should have the skills and motivation to empower them. However, professionals supported the parent's assertions, that a philosophy of person centred support was not always present within services. Ineffective and inappropriate services can inadvertently erode relationships for individuals. Professional

roles and provision can negate natural opportunities and meaningful interactions for people with a learning disability (O'Brien and O'Brien 2002).

Most of the children discussed in the study were supported in specialised environments away from their peers and mainstream learning opportunities. Such forms of provision may not always be required or desired by individuals and can further isolate them from their peers (Pitonyak 2007). The debate associated with mainstream and specialist provision for children with learning disabilities cannot be considered within this discussion. It does however apply in the context of this research, as children with behavioural needs struggle to fit into services across all types of provision. Jupp (2002) suggested that within mainstream environments children with learning disabilities can experience more opportunities to establish genuine friendships and access levels of support that are are based on 'normal' opportunities and interactions. Indeed Pitonyak (2007) suggests that the 'specialisation' of individuals within service provision can reinforce an individual's difference. The application of true inclusion for this group of children is therefore a significant challenge. Behaviour not only stigmatises individuals but clearly identifies them within services and ultimately society. For the minority of children included within mainstream provision in the current research their needs required significant levels of additional support. It was this support that identified them as different. Appropriate and discrete additional support was difficult to achieve for children with behavioural needs. A philosophy of inclusion appeared to be difficult to apply for this group of children. Inclusive practice that can isolate children from their peers and emphasise difference may be considered as exclusion.

The skill of individuals within child environments, both mainstream and specialist areas, is fundamental to the support of children with behavioural needs. A lack of behavioural knowledge has been clearly linked with the quality and validity of support offered to people with behavioural needs (Swap 1991, Felce et al 1993, Hatton et al 1995, Bromley and Emerson 1995, Hastings and Morgan 1998, Meyers and Evans 2006, Campbell 2007). The Mansell report (DH 2007) highlighted the 'specialist' nature of supporting individuals with behavioural needs and suggested that this level of professional skill was above and beyond that found in traditional environments. Despite such evidence Campbell (2007) concluded that individuals with complex behavioural needs continued to be supported by people with limited or no training. A lack of training has been shown to affect the motivation of staff to support people with behavioural needs (Watts et al 1997, Meyer and Evans 2006, Noone et al 2006), and indeed may reinforce difficulties exacerbated by the value base of individuals

within services. If staff are unable to understand or manage a child's behaviour this can lead to inadequate and inappropriate support and thus exclusion. Participants in the research expressed their frustration at the lack of skill and knowledge within services to support children. Effective intervention for this group of children must involve a multi-element approach, implemented by individuals with the requisite knowledge, skill set and competence (DH 2007).

The children discussed in the research require support from skilled and motivated individuals. However roles within services for people with behavioural needs have been associated with higher levels of stress and anxiety than other support roles (Hastings and Remington 1994, Bromley and Emerson 1995, Meyers and Evans 2006, DH 2007). The literature reflects a level of disempowerment and influence experienced by staff within services for this group of children (Quine and Pahl 1985, Quine and Pahl 1989, Felce et al 1993, Qureshi 1995). Mitchell (2000) proffered the concept of 'parallel stigma' to describe the shared experience that people, paid to support people with learning disabilities, experienced exclusion alongside people with learning disabilities themselves. Even the professionals in this study suggested that their roles with children with learning disabilities and behavioural needs often left them outside the mainstream of their profession. They empathised with families who reported that services were difficult to communicate with and access, as they too experienced this as part of their working lives. The evidence therefore suggests that children with behavioural needs have every chance of being supported by staff who are not trained or prepared adequately for their role. They report increased levels of anxiety and stress as highlighted by Campbell (2007) which is exacerbated by the stigma they experience from within their professional groups. This situation places staff and children at risk that ultimately contribute to their levels of vulnerability.

The paucity of training to facilitate the understanding of an individual's behavioural needs has been highlighted in the literature (Hastings and Remington 1994b, Bromley and Emerson 1995, Meyers and Evans 2006, DH 2007). Limited training budgets and the multiple reconfiguration of services has led to people with behavioural needs being supported in environments that are characterised by a high staff turnover (Allen et al 1990). Behavioural training for service staff is vital, as evidence suggests that how
 staff view a child's behaviour can have a major impact on the support that they receive (Swap 1991, Bromley and Emerson 1995, Hastings and Morgan 1998, Meyers and Evans

2006). However studies have also concluded that the provision of specialist training cannot always be correlated with improved working practices (Cullen 1988,1992, Foxx 1996, McBrien and Candy, 1998).

As discussed above the participants believed that it was the value base of staff that significantly affected the level and quality of support offered. Parents commented on the dissonance of a situation when staff were employed to support their child's behavioural needs but did not necessarily believe that the child could, or indeed should be, included in their community. Participants in the research felt that often staff concentrated on the containment and management of the child's behaviour rather than the communicative intent of the behaviour (Emerson 1995). Inappropriately supported behaviour can exacerbate a situation for a child and further inadvertently reinforce their behaviours, whilst also exacerbating a situation of unmet need (Noone et al 2006).

Staff support for children with behavioural needs has therefore been identified in the literature and within this study to be affected by numerous variables including a lack of training, support and resources. The impact for children with behavioural needs can be profound. Professionals can detach themselves from individuals and their needs, which can ultimately serve to exacerbate their level of exclusion, erode relationships and disempower people with a learning disability (O'Brien and O'Brien 2002, Pitonyak 2007). This situation is considered to be particularly prevalent within segregated systems such as special classrooms and units, sheltered workshops and group homes. If however, a lack of skill and commitment within services, both specialist and mainstream, can be identified this situation seems almost inevitable. The exclusion of children within specialist environments together with staff that feel unable to effectively engage with children will prevent the promotion of ordinary everyday life experiences (Pitonyak 2007). As highlighted by Peckham (2007) and Parley (2011) children with a learning disability and behavioural needs are therefore an exceptionally vulnerable, disempowered and socially excluded group of individuals.

Whilst considering the skills, needs and stigmatisation of staff within services for people with a learning disability, the professional participants identified their own personal perspective of supporting children with behavioural needs. They described the challenges they faced within service settings. Professionals identified that their role with families with children with behavioural needs was different from that with other families. This was

described as an extended role (Lowe et al 1996). All professionals were keen and motivated in discussion about their roles but identified that they were often working across boundaries and outside their traditional role in order to meet the needs of the children and their families. The difficulty described by professionals lay in their extended role being at odds with the ethos of their employing service. This manifested itself, for example, in the amount of time required to effectively support the children and family compared to the needs of other service users. Professionals committed to supporting children effectively were frustrated by current service agendas and the need to plan work within the narrowly defined parameters of their role. Professionals described a position were they individually negotiated and managed their workload to facilitate effective support for children and families. This practice was often an informal and 'off the record' way of working for the professionals.

Alongside the extended role of the practitioner, participants across both phases of the research identified an unspoken level of collusion between professionals and families. Professionals spoke of how they advised families to negotiate with services in order to get their child's needs met. Although not a traditional route for professionals, the families they supported experienced a disproportionate reduction in access to provision due to not only a paucity of provision, but also the skill and ability of services to meet the child's needs. Professionals in the research felt they should be able to signpost families to appropriate provision. Parents were aware that often professionals functioned outside their usual roles in meeting their child's needs. They valued such professionals as skilled, useful and relevant in the support of their child. Parents had been supported to complain about their child's experiences, and further to approach organisations to gain support. Examples included professionals who had referred and supported parents to access respite following difficult periods in the child's behaviour and during times of family crisis. Children discussed in the research had often been excluded from or unable to access respite due to their behaviour and their perceived risk to other children. This type of facilitation was recognised by both groups of participants as necessary. Professionals felt strongly that what was usually required would have been ordinarily available to children with a learning disability.

As families remained isolated within their community and networks the usual levels of support and informal information were not available to them. Informed and motivated professionals tried to make a difference to how a child's needs were considered and supported in services. Professionals made no apologies for their extended role in supporting children but did express regret that services were unable, and indeed often unwilling, to

support children in the most child and family centred way. This type of 'discrimination' often within specialist provision for children with a learning disability, was considered by professionals in this study to place responsibility for the care of the child, particularly during difficult times such as school holidays, with the family. As highlighted by Mencap (2006, 2010) the inability of services to meet the needs of this type of family and child not only serves to isolate them from their community, but can also exacerbate the child and families levels of vulnerability and heighten the risk of children being placed in appropriate emergency provision (McGill 2008).

This situation can leave children with a learning disability and behavioural needs in very vulnerable situations. Individual professionals should not and cannot be relied upon to effect change for children and families within services. Current provision is unlikely to be effectively challenged from within by staff that may feel disempowered and un-skilled in their work with individuals. Services are therefore providing support to children and families that does not meet their needs. The evidence from this study is clear that the reality of lived experience for the children and families is of services that are ineffective and often counter-productive to inclusive practice. The ideology expressed in standard 8 of the National Service Framework for Children, Young People and Maternity Services, states that children with complex needs should receive good quality family orientated care to support social inclusion and promote their everyday experiences (DH, DSE 2004). For this group of children this has proved difficult to implement and has yet to be achieved.

6.6.3 Education

Education, as for all children, was central to the lives of the children in the research. Significantly for a child with a learning disability education is linked to their inclusion or exclusion within communities. Parents were aware that choice of educational provision for the child, had and continued to have, an impact on their daily lives and their experience of inclusion in their community. Some of the parents felt that their child required specialist support and that this could only be accessed within a specialist environment such as special educational needs provision. The Mental Health Foundation (2002) however suggested that special schooling can impact on a child's confidence, resilience and emotional awareness. A few of the children in the research had attended mainstream school but had later moved to specialist provision. Difficulties in placement were often ascribed to the child's behavioural needs and the inability of provisions to support these for the child. Children with behavioural

needs are considered to be most at risk of exclusion from and by their peer group (Deater-Deckard 2001, La Fontana and Cillessen 2002), and further at associated risk of psychological difficulties (Byrne and Hennessy 2009).

The complexity of inclusion for children with learning disabilities and behavioural needs within education has been reported extensively in the literature. The findings of the current research concur with Elkins et al's (2003) study which reported parental belief that their inclusion in a mainstream school would provide children with access to increased levels of social interaction, independence, understanding whilst promoting tolerance from their peers. Positive behavioural role models were also considered by parents across both studies to be a strength of mainstream schooling.

However the policy context for children with special educational needs has been considered to foster a 'disabling' approach (Holt 2003), with recent evidence reporting that children with special educational needs are eight times more likely to be excluded (Connolly et al 2012). Indeed children with disabilities are more likely to be excluded from schools across both mainstream and specialist provision (Gray 2006). The odds therefore already appear to be weighted against children in the research across all educational systems.

Parents in this study discussed the frequency of both formal and informal forms of exclusion that their children experienced. Significantly the Children Commissioner's 2012 report (Connolly et al 2012) suggested that the exclusion practices applied to children with special educational needs had been 'unlawful'. Participants discussed a level of resignation that exclusion was part of the child's experience, and that there was little that could be done to improve this situation within current service design and policy.

Parents in this research discussed how children had been actively encouraged to stay away from school due to their behaviour and an inability of schools to effectively manage this. Frequent and informal exclusion were perpetuated by both parents and the school, usually in a desire to avoid the official exclusion of the child. This situation was clearly highlighted in the Children's Commissioner Report (Connolly et al 2012). The report highlighted and supported the position of the parents in this research who felt unable to challenge their child's exclusion, due to a lack of awareness of their rights and also their trust that schools would act in the best interests of their child. The inquiry acknowledged parents as

disenfranchised in this situation. Disempowered families accepted the actions of schools as they feared that ultimately their child's placement and education would be affected (Paffrey 1995, Connolly et al 2012, Gray 2006).

For the children in this study parents and professionals believed that the presence of behavioural needs was the single most defining factor that prevented them from experiencing education similar to that of their disabled and non-disabled peers. Families believed and were supported by professionals in their view, that their child's place in school was tentative. Parents had been informed both formally and informally that their child could be asked to leave the school if it was felt that the provider could not meet the child's needs. For the children in the study their choice of school was already significantly limited due to their needs, and in some circumstances their behavioural reputation. Children with behavioural needs are not a popular group of children, with negative attitudes towards inclusion expressed by teachers in the literature (Avramidis and Norwich 2002). All children in the research had experienced difficulties in their educational experiences. Parents were very aware that alternative educational provision for their child, if excluded, would be very difficult to access. Parents and professionals considered the placement of children across all forms of educational provision to be at risk primarily due to the inability of services to effectively support their behavioural needs. Maintaining a child's educational placement was considered by many parents to be part of a constant struggle. Relationships with schools were often tentative and difficult, completely at odds with the current agenda of inclusion.

Ultimately this type of situation places children, their families and the professionals that support them in vulnerable positions. The children have little support from those around them in advocating for their needs due to the powerful dynamics involved. Consequently children are placed in compromised situations that are not comparable to their disabled or non-disabled peers. Professionals and families further appear to be placed in compromising situations for personal, ethical and moral reasons. Both groups of participants expressed their motivation and desire to support children, but realised that their influence and ability to effect real change was limited whilst educational systems were inflexible and entrenched in practice. Consequently the children in the study, whatever their educational environment, experienced levels of stigma and exclusion that affected their ability to be included, and achieve their educational potential.

6.6.4 Transitions

Periods of transition for a child with a learning disability and behavioural needs were identified by participants as difficult, with some reference to the effect that the labelling of a child with behavioural needs had on the child's ability to move forward and be included. Movement between and across services was considered to be more complex for this group of children, and provoked high levels of anxiety for parents. The children in the research were often known within services and as such had often acquired a 'reputation' associated with their behavioural needs. This type of labelling was considered by participants to affect provision for the child at both a systems and personal level.

Movement between provisions, particularly from child to adult services, can be problematic for children with complex needs (Hudson 2006), with best practice guidance specifically targeting this group of children (DCSF, DH 2008). In the current research, participants discussed the experience of transition and forthcoming points of transition to be stressful for both the child and family. The type of provision attended (for example mainstream education or special school provision) did not appear to affect the difficulty of transition. It was indeed a change of provision that created difficulties.

Parents described how they had accepted provision (often services that were not required or useful) to illustrate their willingness to support their child, and to ensure access to more relevant areas of service provision. This experience supported a concept of bargaining and negotiation with and between services. This form of brokering has been noted in the literature (Davies and Morgan 2010) and was explicitly discussed by the research participants. Examples included the need to have a designated social worker for a child in order to access respite provision. The parents in the Davies and Morgan study belonged, as in the current research, to parent support and action groups. Membership of parent led organisations appear to be significant in empowering parents to advocate effectively for their child. Although not representative of all parents the ability of parents who are supported and able to access information from their peers appears to significantly enhance the child's opportunities.

Participants agreed that parents often had to take on the role of service co-ordination in order to manage their child's interaction with services. Children were involved in multiple interventions that were uncoordinated and significantly affected the child's experiences.

Limbrick (2007) suggested that children and their families can become lost in webs of service provision. The parents in the study discussed how they had adapted to meet the demands placed upon the family unit by services. Thus rather than services being delivered in the context of an empowered family as advocated by McConkey et al (2007), children's needs were facilitated at great cost to families, through the effective co-ordination of services by parents rather than professionals.

The move between child and adult services was a transition that all participants considered to be particularly difficult for families. Transition points within services can vary widely across provisions. Children can remain in specialist educational provision until they are 19 whilst having their support needs delivered by adult provision. Parents were particularly concerned about their child's move to adult services, whilst other parents felt it could only be positive, based on their experience of children's services. As a vulnerable group of children transitional arrangements have been addressed through the production of government policy and guidance (DCSF, DH 2008). The application of this for the children in the study was however largely related to parental ability to negotiate and advocate for their child. Professionals highlighted the difficulties faced for children who were not supported by knowledgeable and empowered parents, but for whom the process of transition would be service driven rather than child focused.

All participants believed that opportunities available for children with behavioural needs were limited and affected by the child's ability to fit into services. Emerson (1995) proposed that behavioural needs could affect an individual's access to their community and ability to take part in activities. For this group of children it was clearly their behaviour that exacerbated their situation, with limited support and specialist provision as children moved between child and adult provision their needs would become more pronounced and more difficult to support (McGill 2008).

6.6.5   The future

The early stages of the child's life and the search for help described by families created a reflective style for the interviews. Parents were generally happier with their child's provision at the time of the interview than they had been in previous years. This did not however represent their confidence in the ability of services to be able to continue to meet the needs of their child, particularly associated with transition between services such as educational

providers and the move from child to adult provision. Professionals were clear that provision for this group of children was tentative and related to the family's ability to be confident, consistent, tenacious and dogmatic with services in order to secure and maintain appropriate support. Two professionals in this research (behaviour analysts), were employed independently by families. These participants were aware that this was not an option for all families, and was not considered to be a sustainable option. It did however indicate a lack of specialist provision available to children with behavioural needs in those areas. In the immediate future it is probable that a position of inappropriate provision may be exacerbated by recent political reforms, which indicate that the future provision of services to families and children will be subject to the application of more stringent eligibility criteria due to cuts in resources (The Learning Disability Coalition 2011). As specialist behavioural provision is already difficult for children to access, this situation may only serve to increase the marginalisation of this group of children.

In their interviews professionals recognised a journey that parents had undergone with their children. Born of necessity they described how parents developed into individuals who were assertive and articulate in their dealings with services and professionals (Murphy 2006). Parents also recognised this transformation and reflected on their early experiences of waiting for service provision and professionals to provide what their child and family required. This often involved families waiting for long periods of time for information, and created unnecessary delays in meeting the child and families' needs. Unlike other families, children in the research had been subjected to periods of protracted diagnostic assessments whilst experiencing a lack of early intervention and proactive support to enhance the child's progress and skill, highlighted by Limbrick (2007). Professionals were clearly aware of the impact that delays, poor quality service provision and a lack of holistic support had on families, particularly in the child's early years. It was as a result of this early experience of services and professionals, that parents came to realise that they were the true experts on their child's needs. Participants suggested that parents experienced a journey, reflected in the global theme of 'needing to know, knowing needs', one in which they had concluded that they needed to ensure that their child received appropriate support. This was clearly considered by participants to be in the absence of professionals and services that could represent their child and families' best interests.

The negotiation of service provision for a child was effectively achieved by parents who were able to broker and bargain with services and professionals. Unsurprisingly this enhanced role has been reported to elevate the levels of stress experienced by families (Murphy et al 2006). Professionals in the study suggested that parents had resorted to this role often reluctantly and in response to their personal situations. Participants identified across both phases of the research that limited support and provision had resulted in protracted waiting in the child's early years which exacerbated the families' circumstances. For the children in the research who had experienced early exclusion within their communities and services, the wait for support and appropriate information could perpetuate a situation in which they could become 'invisible in their communities', ultimately vulnerable and more isolated (Mencap 2006 p15).

The traditional role of the parent therefore for families with a child with a learning disability and behavioural needs appears to be different. Following a period of uncertainty and difficult experiences for their child, the parents in the research extended their role to that of advocate and broker. Parents considered services to be reactive in their approach to support for their child. It is the reactive nature of provision that has created the situation in which behavioural needs has become the main predictor for admission of children to residential provision as reported by McGill (2008). The positive impact of proactive parents on the outcomes for a child were identified by professionals. However this was in contrast to the support of vulnerable children whose parents were unable to adopt this role. As considered in the literature and advocated by individuals in both phases of this study the most important and effective aspect of informed provision for children and their families lay in the ability of services to listen to parents (Limbrick 2007, Slevin et al 2011).

Respite for children in the research appeared as a consistent issue across both phases of the research. This area has been extensively considered in the literature. For this group of children however their behavioural needs place them at a significantly increased risk of exclusion from their communities and local services (McGill 2008). The behavioural needs of a child can become more difficult to manage, often related to their physical stature but also in relation to their move into adulthood and associated transitions. Emerson (1995) proposed that behaviour described as challenging can not only mean that the '…physical safety of the person or others is likely to be placed in serious jeopardy…' but that the behaviour can also '… seriously limit the use of, or result in the person being denied access

to, ordinary community facilities' (Emerson 1995, p4). The definition acknowledges the possible consequences of a child's behavioural needs in the widest possible sense.

For families in the study the provision of appropriate respite was fundamental to their child and family. Supporting a child with behavioural needs is a major challenge for families (Glasberg et al 2006, Hassiotis and Chaytor 2011). As discussed in the Mencap 'Breaking Point' campaign (2007) and reinforced in the 'Still waiting for a break" campaign (Mencap 2010) some of the most vulnerable families received little or no respite care for their child. Each family in the study expressed their individual preference for how support could be delivered to meet their individual needs. This ranged from overnight respite provision to support in the home or access to community facilities. Families had often experienced 'inappropriate' respite, which was considered to be that which was available rather than what was suitable for the child. Some parents were clear that the facilities provided for their children were unsuitable and therefore not accessible. Mencap (2010) highlighted that emergency respite care had been experienced by most families of a child with a learning disability, usually as a direct result of inappropriate and limited local provision. Current provision therefore appears unable to support children with a learning disability without behavioural needs. The use of emergency support and reactive provision can only increase a child's level of exclusion and significantly increase their levels of vulnerability (McGill 2008, Winterbourne View 2011).

A lack of appropriate respite provision for children with a learning disability and the complexity of their behavioural needs has been proven to be a prerequisite for admission to residential provision for children with a learning disability (McGill's 2008). For families in the research the complexity of meeting their child's needs was not a new situation, however a lack of support and the prolonged impact or frequency of their child's behaviour had led to emergency situations. All families had experienced crisis situations, and although some parents expressed relief that services had eventually stepped in to support their child, the parents were clear that the situation could have been avoided if appropriate family and child centred services had been deployed earlier. Mansell's report on services for people with behavioural needs identified that '…although their needs for a short break may be very high, local authorities may discriminate against them because traditional local respite services find it hard to provide the support required (Mansell 2007 p15). Placement away from families

and their community cannot facilitate the appropriate planning or capacity building required to ensure that children can return home (McGill 2008).

The vulnerability of people with a learning disability in society has been extensively considered within the literature and the national media (Peckham 2007). Unfortunately recent media coverage has been associated with extreme and very difficult incidents (DH and Home Office 2000, Mencap 2010, Winterbourne View 2011, Parley 2011). Interviews for the study took place before the more recent press exposure related to Winterbourne View. It must be noted that incidents of abuse associated with people with learning disabilities appear to be a regular feature within the press, which must serve to reinforce parental concerns for their child's future. Children with behavioural needs are more likely to be placed in residential services (Emerson et al 1996, Goodman 2006, McGill 2008), often out of their local area due to a lack of appropriate local provision (Jenkins and Johnson 1991, Parahoo and Barr 1996, Mansell 2007). The vulnerability of the children at the centre of the study and their families is therefore extremely clear. Although not directly addressed by parents in the interviews the fears discussed for their children often focused on their child's future and their ability as families to protect them.

In response to the Winterbourne View exposé (2011), the Care Quality Commission's (CQC 2012) review of learning disability services has recently reported on 150 inspections conducted within statutory and independent provisions. The results have significantly raised the profile of the paucity of provision related to people with learning disabilities, their safety and care. For families such information must be startling. For services the implications remain that specialist services are unable to support people with the most complex needs and levels of vulnerability.

Families were concerned that their child's behavioural needs would continue into their adult years which would render them difficult to place in adult provisions, such as supported living, and further increase their vulnerability. Based on the child's experiences of exclusion in their early years and their inability to fit into services parents felt that their child's future needs would continue to be complex. Parents had fought for provision to meet their child's and families' needs and did not envisage that the situation would change. If we recognise that families are vulnerable because of a lack of appropriate support, but also identify that within specialist provision individuals with a learning disability may also be vulnerable

(CQC 2012), for the children considered in the research, future provision must be a serious concern. Skills and services to meet the needs of people with complex care requirements do not appear to be available in the required quantity or quality.

The children in the study are children first both within the Every Child Matters and the Every Disabled Child Matters reports (DES 2003, DCSF 2007). Two reports, one written specifically for disabled children could reinforce the inequalities for disabled children. I would argue that this inequity is more pronounced for the group of children at the centre of this research. The original aspirations for all children however must apply. Although the contrast in equality is particularly marked when considering the experiences of children with behavioural needs. Participants in the research felt strongly that they needed to advocate for children in order to support access and inclusion to services and resources that would ordinarily be available to their peers.

7 Chapter 7: Limitations, Conclusions, Recommendations and Areas for Future Research

7.1 Limitations

This piece of work was intended to consider family and professional perspectives of the lived experience of children with a learning disability and behavioural needs. To achieve this, interviews were conducted with parents and professionals to gain their perspectives of the child's experiences.

As in all research there are limitations to the findings and the process of research undertaken that require discussion. I do not intend to propose that the research conducted could not have been improved. Although the strength of the study lies in its transparency, identification of areas that may have improved and reinforced the process and findings must be considered. This is intended to not only support future work in the area but to focus and consolidate the current research findings.

The research was intended to consider the experience of children with a learning disability and behavioural needs through the perspectives of families and professionals. Due to difficulties associated with the sensitive nature of the subject matter and discussion of children with significant communication needs, children were not actively involved in the study. To this end the child's experiences are perspectives perceived and interpreted by raconteurs. Although this fits with the hermeneutic circle of interpretation (Heidegger 1962) the voices of children are not present in the research. Families described some of their child's experiences through their reflection and interpretation of key events. It is likely that key events for the child would also be thus for the family. However a parent's understanding is notably different from that of a child, consequently the ramifications, particularly of early experiences, may not have held the same interpretation for the child. A key recommendation from this research will be to continue to consider the lived experience of behavioural needs through discussion with children themselves. Although research with people with a learning disability can be difficult, their voice must be central to any study related to their needs and future wishes (Lewis and Porter 2004).

Professionals too provided their interpretations. Although keen and motivated to be included in the research they interpret experience through a professional perspective. They encounter children and their families often in controlled and contrived situations; as professionals with defined roles and responsibilities, where a balance of power may be unavoidable. Consequently a professional perspective on experience must be considered in that context. One of the emergent findings from the study was the parallel perspective of professionals with that of the parents. This not only reinforced the integrity of the findings but indicates the analytical and empathetic nature of the professionals included in the study.

All participants were volunteers and keen to be involved. However parents were referred or accessed via a parent support group, 'Partners in Policymaking'. A group that is keen to be considered 'partners' in future developments for children with a learning disability. To this end the parents who took part in the research may represent an empowered and politically active group of individuals that may not be representative of other parents. As a collective, individuals discussed how the 'partners' group had been instrumental in supporting them and their families. Several of the parents interviewed had been or were involved in supporting other parents in their local area, examples included specialist play schemes and school-based parent support groups. All parents were motivated and articulate; they were keen to affect national policy change, as well as local services for children with a learning disability and behavioural needs. This group of parents were instrumental in the research, both in their willingness to be involved but also in their ability to share often intensely personal experiences with me, a relative stranger. All of the parents that showed a level of initial interest in the study took part in an interview. Accessing vulnerable groups can be difficult in qualitative studies. Parents were keen to refer other parents and friends from the group to the research. This enabled a number of highly appropriate participants to be accessed. Behavioural needs can be a very difficult subject for families; the parents in the research proved to be parents of integrity, who were highly supportive of each other. Indeed, as a discrete and hard to reach group of individuals I feel very honoured that I was able to spend time with them and listen to their accounts. The application of research findings to other groups of families however must be considered in light of the study participants belonging to a discrete, supportive and defined group of individuals. Generalisation of experience across groups was not the aim of the research. The integrity of the family findings however was reinforced by the interviews with the professionals in the second phase of the research. The professionals in the study discussed families across all sectors of provision and communities,

and therefore discussed some of the most vulnerable children that they had supported. Potentially it is these children and their families that would be more difficult to access and less likely to be able to take part. Their discussion of children's experiences confirmed those relayed by parents. Convergence therefore must serve to validate the assertions made based on the research findings, and add to the body of knowledge available in this area.

The professionals included in the research were recruited from a special interest group for professionals involved in the support of children with a learning disability. The participants came from a range of professional roles and shared a commonality of interest. As with the parents, this places them as a discrete group within a group, a minority group, which echoes the experiences of the children considered. Individuals employed to work with children with a learning disability and particularly those who support children with behavioural needs are in the minority amongst the children's workforce. This is particularly pertinent with the advent of inclusive policies that have meant that children receive support from mainstream provision and personnel. All professional participants were employed in learning disability service provision. Eight of the ten professionals interviewed had undertaken specialist behavioural training (accredited externally by a university). As individuals, behavioural needs were an area of interest. Referral for participation in the research between individuals was also a feature of the professional participants. Surprisingly, professionals were extremely candid in their discussions; they covered sensitive issues such as the value-base of services with a level of honesty and skill that was refreshing. Their motivation to be involved included their desire to be able to affect change. Although this was not considered possible directly within their employing services, they were keen to be listened to by an independent person who may be able to articulate their views on their behalf. As a group of individuals the professionals in the study were not necessarily representative of all professionals in learning disability or children's services. However their views supported the parental perspectives of the child's experience, and as such must be considered to have an essential resonance with the study aim of considering perspectives of the lived experience of children with a learning disability and behavioural needs. As with all academically regulated research the parameters of the study may have confined the exploration of some of the emergent issues (Whitehead 2004). The original question related to perspectives on the lived experience, however the emergent issues focus on the central tenets of inclusion and exclusion for this group of children. These have been discussed across the findings but would benefit from a more in-depth analysis within further studies.

Although research with people with a learning disability may be challenging, particularly when considering meaningful rather than token involvement (Lewis and Porter 2004), the inclusion of children with a learning disability and behavioural needs is vital to this research area. Their experiences are fundamental and essential in the development of our understanding of the needs and experiences of this group of children.

The methodology chosen for the study relies heavily on perspectives and subsequent interpretation of experience. Although this framework supported the study it cannot generate a finite understanding of a research question (Ormiston and Schrify 1984), consequently all the findings presented are open to further interpretation. Although a limitation, I argue that the product of extended and ongoing interpretation can only lead to a strengthening of understanding and reinforce interest and enquiry in the area.

7.2   Conclusion

The key findings from the research are considered in this section. The study was conducted to consider perspectives on the lived experience of children with a learning disability and behavioural needs. The findings of the study have led to several conclusions and generated recommendations for practice and areas for further study.

The study has demonstrated the multi-factorial elements involved in exclusion experienced by this group of children.

1. Children with a learning disability and behavioural needs are excluded from services and their communities.

The negative impact of behavioural needs on a child's everyday life and experience was clearly articulated throughout the research. The participant's perspective was that a child's behaviour affected their access to everyday experiences and services. Terms such as challenging behaviour are readily applied to people, labelling them as difficult and often unpopular in services that are not able to adequately support them. As originally conceived, the term was intended to signify the challenge to services of meeting an individual's needs, and not as a descriptive label (Blunden and Allen 1987). It is common in current practice for the term challenging behaviour to be used to describe an individual. A person may be described as having autism and challenging behaviour. Whole services have been

commissioned to support people with behavioural needs, however their very function and identity for example a challenging behaviour team, reinforces negative labels that have become attached to individuals. Families and professionals felt that children were discriminated against, both formally and informally, from the level of stigma associated with their needs. This was described within mainstream provision, specialist provision and in relation to community activities such as children's groups and leisure pursuits.

2. Services are unable to support this group of children effectively.

Due to policies related to the inclusion and integration of children with a learning disability within mainstream services, the children in the study had experience of, and attended a range of provisions. All participants in the study perceived services to be ineffective in the support of children with behavioural needs. This opinion was discussed across all types of services. The literature and the findings from the study evidence a lack of skills and knowledge within services to provide support for a child's behavioural needs. Further concern must be considered in relation to the level of motivation and the value-base of staff within services, particularly when staff reported feelings of disempowerment and marginalisation within services. The situation is exacerbated by a reported lack of resources and training available to personnel to reinforce their understanding and interventions.

3. Families play a pivotal role in their child's ability to access services and be part of their community

The empowered parents that took part in the study were potentially those parents who felt able to volunteer for an interview, and discuss their child's experiences, that primarily related to their inclusion and exclusion within services. It was the child's experience that directly affected the families' decisions associated with provision and integration. Negative experience of community and service inclusion lead parents to make decisions based on perceptions of their child's vulnerability and need for protection. This ultimately usually led to a choice of segregated and specialist service provision for the child. When services were not available for their child, parents were able to describe how they had developed their own forms of support. Typically parents were not constrained by bureaucracy, policy or procedure. They recognised needs and used practical problem solving skills to support these. Their motives were philanthropic in nature, which concerned the support of children, and provision of practical solutions to the 'so called' complexity of support for children with

behavioural needs. Parental support solutions are cost effective, child and family centred and appropriate. A child's level of inclusion and integration is based on informed choice, although options are limited. Decisions are based on the level of parental confidence that the service will meet the child's needs.

4. Current inclusive practices and integration do not support this group of children

How children with a learning disability and behavioural needs are included and integrated is affected by family decisions based on the child's experience. I argue that current policy and practice associated with this group of children does not support their integration. SENDA (2005) advocates for the inclusion of all children in mainstream schools. Without appropriate resources and training schools are unable to meet the needs of children with behavioural needs. This places them at an increased risk of exclusion and further reinforces their marginalisation within society. Communities are known to be reluctant to engage with people considered to be different (Harris 2000, Holt 2003). When children are unable to fit into systems they become isolated and vulnerable. This exacerbates their situation and alienates them from their peers. O'Brien and O'Brien (2002) assert that relationships within a local community enhance people's lives and can ultimately protect them. Current policy and practice negates opportunities for this to happen for these children.

5. Children with a learning disability and behavioural needs are more vulnerable than their peers.

The study highlights predisposing factors that place children in this group as particularly vulnerable. They experience levels of stigmatisation and marginalisation that place them on the outside of their communities. These communities have historically instigated the removal of people with a learning disability (Wolfensberger 1972, Sibley 1995). Behavioural need is the reason most cited for the placement of children in emergency and residential support (McGill 2008, McGill et al 2006). This is particularly associated with a lack of appropriate local provision (DH 2007). This type of support is difficult to regulate (Beadle-Brown 2006) and therefore places children at risk of abuse and isolation. Recent exposés, such as that at Winterbourne View, have reinforced fears for families and may increase their reluctance to accept support, which will ultimately exacerbate the child and families' situation.

6. Children with a learning disability and behavioural needs require bespoke and child-centred provision to meet their needs

As indicated in the study and across the literature this group of children have discrete needs from their peers. They experience higher levels of exclusion, vulnerability and stigma from within services and their communities. Families become isolated in their desire to support and protect their children. In light of these factors bespoke provision is required that can holistically meet the needs of this discrete group of children. As described by Gray (2006) the number of children who will require this level of support is low. The impact of their needs however is high, both in relation to their quality of life but also related to the financial impact of reactive provision for this group of children. Child and family centred provision that provides pro-active, evidence-based support that takes account of pre-disposing factors for behavioural needs will support a system that can respond effectively to this group of children.

7.3   Recommendations

As a clinician I believe that research serves a purpose. It should be able to generate knowledge that can support interventions and evidence practice. To this end the study has strengthened and extended my knowledge in the area of supporting children with a learning disability and behavioural needs. It has also however reinforced my desire to affect practice, stimulate debate and identify areas for further research.

1. Improvement in the early identification of behavioural needs amongst young children with a learning disability. Current evidence has highlighted the association between cognitive impairment, language delay and the incidence of behavioural needs in people with a learning disability (Murphy et al 2006). As identified in this research, children who require support with their behaviour are identifiable by parents and professionals in their early years. The impact of not responding to early needs serves to increase the risk of children to exclusion, as the presence of behavioural needs is the main predictor of residential care for children with a learning disability (McGill 2008). Specialist training for early years professionals in the identification of children and families in need of specialist support would enhance access to services, support multi-agency approaches and reduce the need for emergency and crisis

intervention.

2. To facilitate identification and effective intervention for this group of children high quality, relevant behavioural training should be available across generic and specialist children's services. The current research highlighted the wait for appropriate specialist behavioural support that families endured when seeking support. Training would enhance the knowledge of staff, and improve the identification and referral of children to appropriate enhanced service provision. As recommended by Mansell (DH 2007) services to support the behavioural needs of people with a learning disability require an enhanced level of training, above and beyond that currently received within specialist provision. Further evidence suggests that there is a paucity of training received by professionals in learning disability provision (Sevin 2004). The inability of services to meet people's behavioural needs within local services has been directly correlated to the removal of people from their local communities into out of area specialist provision (DH 2007, McGill 2008). Timely and appropriate support from local services must be considered a priority within services (Limbrick 2007, DH 2007) to positively affect the outcomes and vulnerability of children with behavioural needs.

3. Recognition from commissioners and managers of services that children with a learning disability and behavioural needs have enhanced, enduring and pervasive long term needs that require consistent and appropriate support and intervention (DH 2007). Consideration of the long-term impact of behavioural needs will support the development of services that are able to respond effectively to children both in relation to expertise and child and family centred provision.

4. Recognition of an extended role for practitioners who support this group of children and their families. The study identified that professionals working with children with behavioural needs were perceived by participants as most effective when they adopted an extended role to support children and their families. Professionals highlighted the lack of understanding within their service of the complex needs of this group of children. The concept of key professionals to provide continuity and

expertise to families has been considered within the literature (Barnardos 2001) and continues to be a priority for future service development. Motivated, trained and supported practitioners can provide families with the targeted bespoke support that they require to effectively care for their child.

5. The development of multi-agency complex child co-ordinator roles (behaviour specialists), to support and co-ordinate the identification of children at risk of exclusion from services. This study and associated evidence have highlighted the problems experienced by families and professionals in the co-ordination of multiple and complex multi-agency support (Lacey 2001, Limbrick 2007). This senior role within services would enhance the role of the keyworker (recommendation 4) and support close liaison and support within services. This would facilitate a coordinated and responsive approach to children and their families. The role of a complex co-ordinator would be to reduce the risk of exclusion of children from their families, community and services due to crisis situations that have been created by unresponsive and reactive service provision (DH 2007, McGill 2008).

7.4   Areas for future research

1. The development of longitudinal inclusive qualitative studies designed to elicit the child's view of exclusion associated with their behavioural needs.

2   Longitudinal studies that can track a child's holistic journey and experiences through services, within their family and community. The findings would provide evidence to support the provision of child and family centred provision based on experience rather than service led agendas.

3   Research to consider the marginalisation of specialist services from mainstream provision. In-depth qualitative interviews could facilitate an understanding of the impact of segregated provision on the professional roles and identity of individuals within services. Findings could support understanding of the affect that marginalisation can have on professionals and its ultimate impact on the service user.

4   Following the Winterbourne View scandal (BBC 2011) and the subsequent Department of Health Final Report, 'Transforming care: A National response to Winterbourne View Hospital' (2012), research into the quality of out-of area-provision and factors that support the placement of people with a learning disability away from their families and communities must be considered a priority.

5   The 'Transforming care' (DH 2012) report places priority on local authorities to return people in residential out of area provision to their area of origin. Research which can consider how children are re-integrated into their local communities, and the ability of services to meet their needs would be timely and support the future development of targeted service provision.

6   The research findings highlighted issues associated with the value base and levels of empathy of staff employed in both mainstream and specialist settings, towards children with behavioural needs. Research that could consider these factors and their impact on the experience of exclusion by children with behavioural needs would support future priorities for training and recruitment within services

7   Following on from the research findings associated with the provision of inappropriate and unresponsive services, research that could identify alternative models of service delivery and support would enhance knowledge towards the commissioning of future provision for children with a learning disability and behavioural needs. Longitudinal studies to consider the impact of new models of delivery would develop evidence in the area and support future cost-effective, quality provision.

Appendix1

Participant Information

Joann Kiernan

Study
I am writing to invite you to be involved in a research study. I am currently enrolled to study for a PhD at Manchester Metropolitan University. As part of this study I am hoping to interview parents about the experiences their child has had due to their learning disability and behavioural needs.

I will also interview professionals involved in supporting children with learning disabilities and behavioural needs.

Everyone interviewed will be a volunteer who is happy for their information to be used in the study.

Title
Family and professional perceptions of exclusion experienced by children with learning disabilities and behavioural needs.

Invitation
The researcher would like to invite you to be part of this research study. Before you decide, I will explain why this research is being done and what taking part in this means for you. Please take time to read the following information carefully and talk to others about the study if you wish.

The purpose of the study is to consider the experiences of children and those that support them in order to find out how they have been able to access services. I would like to interview those willing to take part in the study for approximately an hour to discuss some of these issues. Interviews will take place at a time and place convenient for you. I would like to record the interviews and type them up afterwards. This will ensure I do not lose or miss information during the discussion and to help with analysis. I will send you an information sheet and consent form for you to read before the interview and I will ask you to sign the consent form on the day of the interview. I would like to reassure you that if you do agree to take part and then later decide that you do not wish to participate at any stage your wishes will be respected.

You will not be identified by the recording of the interview and afterwards the recording transcript will be made anonymous by giving a code number. No names will be used on the tape or in the typed written notes. All data and recordings will be stored in a locked filing

cabinet and only available to the researcher. My contact number and e-mail address will be given to you so that you can contact me following the interview if you have any questions.

The purpose of the study

The study is designed to consider the experiences of supporting children who have a learning disability and behavioural needs. I am a Learning Disability Nurse with 26 years experience of supporting individuals and families and I currently teach student nurses at Edge Hill University. The ways in which families have been supported over the years has changed and I am interested in the support and relevance of services that are provided for children who have behavioural needs.

Your invitation

You have been invited to take part in this study as a paid carer or professional who is involved in supporting children with a learning disability and behavioural needs.

Do I have to take part?

You can decide at any time to withdraw from the study. I will discuss the study and go through the information sheet with you to enable you to decide if you are willing to be interviewed. You will be asked to sign a consent from and are free to withdraw at anytime without giving a reason.

What will happen to me if I take part?

I will contact you via letter or phone if you have agreed to take part. You will then receive by post a consent form and information sheet for you to consider. My contact number will be given to you so you can ask any questions that you may have. We will then arrange either by letter or phone for a suitable meeting time and place for the interview to take place.

The interview will take approximately an hour, but a little time will be needed before and afterwards to go through the information sheet and consent form. I will leave a contact number following the interview so you can contact me after the interview if required. During the interview I will ask some questions and the discussion will be recorded. I will also ask you for consent to allow for the study results to be published.

Expenses

Unfortunately as this is part of an educational programme I will not be able to offer payment of expenses. I will travel to the agreed interview place to make sure it is convenient for you.

What are the benefits of taking part?

I am keen to ensure that the voices of those who care for and support this group of children are heard. I hope that the information gathered will be used to support children and their families in the future.

Complaints

If you are unhappy or have any concerns about the study please contact my academic supervisor -Duncan Mitchell at Manchester Metropolitan University.
duncan.mitchell@mmu.ac.uk

My contact details

Joann Kiernan- 01695 657094
kiernanj@edgehill.ac.uk

I am hoping this study will be able to represent the true experience of children, their families and those who support them at the current time. I would like to take this opportunity to thank you for considering being involved.

Appendix 2

Family interview guide

At what point did you become aware that your child had behavioural needs?

How did you find out?

What type of needs do they have?

Do your child's behavioural needs affect their life experiences? If so how?

Do your child's behavioural needs affect family life? If so how?

What has helped/ not helped you and your child in relation to their behavioural needs?

What could help? What would support you and your child?

Can you talk me through key events in relation to your child and their behavioural needs?

Appendix 3

Professional Interview Guide

Professionals/ paid carers

Thank you for agreeing to take part in this research. This is the second phase of the study and the interview you have agreed to take part in is designed to consider your perspectives on the lived experience of children with a learning disability and behavioural needs.

It would be useful if you could discuss your role with children and their families, and any issues you feel are important for this group of children. Their experience of inclusion and how their behaviour affects their experiences is particularly relevant to the research and your comments on these areas would be most appreciated.

Once again many thanks for agreeing to take part and please feel free to contact me in relation to the research at any time.

Many thanks

Joann Kiernan

Tel- 01695 657094

Appendix 4 Study Consent Form

CONSENT FORM-

Title of Project: Family and professional perceptions of exclusion experienced by children with learning disabilities and behavioural needs

Name of researcher: Joann Kiernan

Please initial box

1. I confirm that I have read and understand the information sheet dated…April 2010 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

3. I understand that relevant sections of data collected during the study may be used for dissemination through publication or presentation and that audio clips may be used. All data will be anonymised. I give permission for information given by me for the purpose of the research to be used in this way.

4. I agree to take part in the above study.

_____   _____   _____
Name of participant   Date   Signature

_____   _____   _____
Name of person   Date   Signature
taking consent

Appendix 5 - Family Coding Framework

Family Coding Framework

1 Realisation/diagnosis
2 Needs
3 Different
4 Never be
5 Affect
6 Helplessness
7 Try to find out what was wrong
8 Understanding behaviour
9 Battle
10 Family life affect
11 Tiredness/exhausting
12 Manage life around needs/behaviour
13 Skills/positive attitudes
14 Group/social activities
15 Making things safe
16 The wait for help
17 Information given/not
18 Informal networks/support groups
19 Service usefulness
20 Extended family events
21 Other people's reactions
22 Struggle
23 Bad parents
24 Inappropriate/useless services
25 Self belief/ confidence in own abilities
26 Reflect on journey
27 Behaviour specialists
28 Child fits in
29 Progress of child
30 Medicalisation appts
31 Lack of co-ordinated services
32 Looking for a cure
33 Got to deal with it/realisation
34 Change of expectations for carers/priorities
35 Parenting hang ups
36 Specialist school networks for kids
37 School/struggle to stay in mainstream
38Behaviour affecting school experience
39 Battle
40 SEN statement
41 Exclusion

42 Recognised in community/inclusion

43 Safety/vulnerability

44 Criminality

45 Future support wishes

46 Peer support

47 What is achievable for child

48 Need for child to reach potential

49 Get the child to fit in/conform

50 Relationship/partner issues

51 Transitions

52 Guilt

53 Letting go/independence

54 Emergency/crisis

55 Other people's agenda

56 Anger

Appendix 6 - Professional Coding Framework

Professional basic codes

1 Integration
2 School
3 Mainstream
4 Special school
5 Parent preference
6 Finance funding of services
7 Working with families
8 Understanding behaviour
9 Behaviour specialists
10 Cost of services
11 Needs of child
12 group activities
13 Behaviour plans
14 Communication/ language difficulties
15 Aggression
16 Impact on education
17 Barriers
18 Childs progress/ reach potential
19 Parent/ family expectations
20 Diagnosis
21 Early intervention
22 Access to services
23 Statementing
24 Parent/ support groups
25 Access community services
26 Family impact
27 Sibling impact
28 Multi-disciplinary working
29 Independence
30 Residential placement
31 Future for families
32 Transition
33 Informed motivated parents
34 Inclusion
35 Exclusion
36 Parental acceptance
37 PCP
38 Assessment
39 Information- lack of
40 Safety

41 Normal opportunities
42 Peers
43 Stigma of behavioural needs
44 Parent struggle/ distress
45 Holistic care
46 Medical model
47 Parent wait for help
48 Parent needs- relationships- counselling
49 Ability of services to meet family needs
50 Impact of working with families
51 Professional training
52 Complex needs
53 Role blurring

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