Parents' experiences of finding out their child has SEN : an interpretative phenomenological analysis

by

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2015

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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This thesis is the result of my own independent work/investigation, except where otherwise stated.
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Summary

There has been much research into support required by parents when finding out that their child has a medical need resulting in severe disability (Baird, McConachie, & Scrutton, 2000; Billson & Tyrrell, 2003; Fallowfield, 1993; Graungaard & Skov, 2007; Hasnat & Graves, 2000). There has been less research regarding the support required by parents in school when finding out that their child has a less severe difficulty (such as moderate global developmental delay or moderate learning difficulty). Parents may experience a grief reaction upon diagnosis of their child's condition which is similar to a bereavement (Bowes, Lowes, Warner, & Gregory, 2009; Bruce & Schultz, 2001; Lowes & Lyne, 2000). It is important to know whether parents can have a similar reaction when they discover that their child may have learning difficulties. A review of available literature has failed to identify adequate resources and guidelines specific to working with non-finite (on-going) loss (Collings, 2008). This research aims to investigate how parents experience the process of finding out that their child has learning difficulties. It considers ways in which parents experience school support.

This study employed Interpretative Phenomenological Analysis and Appreciative Inquiry through semi-structured interviews with four parents of children with learning difficulties who were aged 5-7 years old.

Analysis indicated three superordinate themes of: loss, social comparison and sense of belonging. Limitations and implications for future research are considered.

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1.0 Introduction

1.1 Background

This thesis arose from my experiences of working as an educational psychologist supporting children with Special Educational Needs (SEN) and their parents. School staff often reported to me that parents did not recognise the severity of their child's difficulties and appeared to be in 'denial'. Staff described a sense of frustration and sometimes requested that I help parents to develop their understanding of their child's needs.

I was interested in whether the issue that staff described as 'denial' represented part of a learning process for parents regarding their child's needs and coming to terms with the possibility of SEN being experienced. I wanted to explore how this might impact upon the relationship between school staff and parents. Interviewing parents enabled me to identify what supported them in learning about their child's needs and whether there were areas of support that they felt could be improved. Themes of loss appeared relevant to the concept of denial and interviews enabled me to explore parents' perspectives and identify to what extent loss was included within their accounts of these experiences. I also wanted to explore whether there was a need for educational psychologists to help school staff develop their understanding of the needs of parents and generate recognition of learning about difficulties being a process that therefore takes time.

I felt that the broad themes within this research would be relevant to most aspects of my work (e.g. feeding back assessment findings to staff and parents, exploring staff/parent concerns within consultations, delivering training to parents and supporting teachers in communication with parents).

1.2 Special Educational Needs (SEN)

DfE (2015) defines SEN as a "learning difficulty or disability which calls for special educational provision to be made for him or her" (p. 15). A child or young person is considered to have a learning difficulty or disability if they have significantly greater difficulty in learning than the majority of others of the same age, or has a disability which obstructs them from making use of

facilities of a kind generally provided for others of the same age in mainstream settings. There is a range of terminology used within this field. The terms "learning difficulty" or "learning disability" tend to be used within the UK (whereas the term "intellectual disability" tends to be used in the USA).   DfE (2011) states that one in every five pupils has a special educational need; about 1.7 million.

1.3   Parental support

There has been much research into support required by parents when finding out that their child has a medical need resulting in severe disability. Literature has highlighted the role of the professional including communication style, optimism, acknowledgement of the whole child rather than just deficits and recognition of where a parent is at within a process (Baird, McConachie, & Scrutton, 2000; Billson & Tyrrell, 2003; Fallowfield, 1993; Graungaard & Skov, 2007; Hasnat & Graves, 2000; North Western Regional Advisory Group on Learning Disability Services, 1992; SCOPE, 2003; Torbay Care Trust, 2010). There has been less research regarding the support required by parents in school when finding out that their child has a less severe difficulty (such as moderate global developmental delay or moderate learning difficulty). These difficulties are likely to often be identified later than severe difficulties, and often not until the child is in school. These difficulties are thought to affect around two percent of the population.

1.4   Loss

Parents may experience a grief reaction upon diagnosis of their child's condition which is similar to a bereavement (Bowes, Lowes, Warner, & Gregory, 2009; Bruce & Schultz, 2001; Lowes & Lyne, 2000). It is important to know whether parents can have a similar reaction when they discover that their child may have learning difficulties. A review of available literature has failed to identify adequate resources and guidelines specific to working with non-finite (on-going) loss (Collings, 2008). This research aims to investigate how parents experience the process of finding out that their child has learning difficulties. It considers ways in which parents experience school support.

1.5 Positivity

Research with families of children who have intellectual disabilities has typically focussed on stress and burden (Hastings, Allen, McDermott, & Still, 2002). However, some research suggests that parents may recognise positive consequences of their child having SEN. This is not always acknowledged by professionals or within research literature (Dobson, Middleton, & Beardsworth, 2001; Hastings & Taunt, 2002). Those studies that have identified positive perceptions have generally not explicitly been designed to do so, but formed part of the stress literature. This study uses methodology that aims to enable parents to be able to explore positive consequences of their child having SEN and investigate what parents find helpful within school support.

1.6 Relevance of research to schools and educational psychologists

As outlined in the Code of Practice (DfE, 2015), schools have a duty to identify and make adequate provision for children who have special educational needs. Prior to school assessments parents may not necessarily be aware of their child experiencing difficulties. Therefore school staff may be the first professionals who raise concern about a child's learning development. Research has suggested that parents may experience denial (Davis, 1987). This may occur when professionals talk about their child's difficulties. Schools therefore need to recognise psychological factors that may be impacting upon the readiness of parents to explore difficulties. These factors need to be taken into account when communicating with parents, in order to ensure that school support is matched to the needs of parents.

Schools often involve educational psychologists in identifying pupil needs and problem solving difficulties that individual pupils are facing. This often forms the majority of work educational psychologists report that they undertake (Cameron, 2006; Farrell et al., 2006).

Holland (1996) highlights the following roles of an educational psychologist which are relevant to supporting parents who have found out that their child has a learning difficulty.

- Helping parents to identify and express feelings.
- Assisting parents in understanding models of loss that may apply to their situation.
- Use of basic counselling skills (including respect, listening and understanding).
- Raising awareness of the possible emotional needs of parents amongst other professionals who are involved with the family.

Understanding the experiences of parents in finding out their child has a learning difficulty (including the support they find helpful) will inform SEN identification processes and information sharing. Identifying a psychological perspective of the processes parents face may help schools and educational psychologists to better match information sharing with the needs of parents.

1.7   Research questions

The following main research question identified from background reading of the subject was:
- How do parents experience the process of finding out their child has moderate learning difficulties?

Supplementary questions include:
- How do parents experience school support?
- What do parents find helpful from professionals?
- To what extent do parents' experiences involve loss?

The aim of the research was to investigate (from the perspective of parents) the systems available in school to support them when finding out that their child has learning difficulties. Also to highlight what support parents found helpful and to investigate ways in which parents felt support could be developed.

1.8   Organisation of the thesis

This study used Interpretative Phenomenological Analysis (IPA) (Smith, Flowers & Larkin, 2009) to explore the experiences of parents in finding out that their child has learning difficulties. In line with IPA following initial extensive background reading of the subject area, key ideas were

"bracketed off" to allow themes to emerge directly from the data without bias from pre-conceived ideas. As part of this process the literature review was the last section of this thesis to be written. It is structured around the three superordinate themes that emerged from the data (social comparison and stigma, sense of belonging and loss). The review is structured in the following way:

- Introduction to key concept / theory with empirical research to critique the concept / theory
- Application of theory / research to SEN and learning difficulties

Methodology and ethical considerations are considered before then introducing the data analysis.

The analysis is structured around the three superordinate themes that emerged from the data. Discussion is interspersed between analysis of superordinate themes. This writing structure is outlined by Smith et al. (2009).

Following the analysis and discussion section a concluding section considers key findings, implications for education, limitations of the study and future research.

The initial and final sections of the thesis are written in first person in order to locate the work within a personal context and reflect upon the impact of this context upon the research. This is in line with many studies that utilise IPA (Smith et al., 2009).

2.0   Literature review

2.1   Background

In reviewing literature related to the experiences of parents finding out their child has learning difficulties the following search terms were used within EBSCO, ERIC and PsycINFO: disability/reading disability/learning disability or learning difficulty/SEN, parents, diagnosis, identification, loss, grief, bereavement. Literature searches included accessing relevant material from reference lists that were found.

A wide range of literature was found relating to medical diagnoses. Many of these entailed severe learning difficulties. The majority of the needs were identified within the first two years of life (except areas such as diabetes, autism and acquired brain injury). Only a few studies were found which considered mild-moderate learning difficulties and loss. The most recent of these studies (Bruce & Schultz, 1996) is outlined under the theme of loss (at the end of this section). This study also included severe-profound learning difficulties and epilepsy and did not differentiate between these within analysis.

There appeared to be a significant gap within research regarding experiences of parents of children with moderate learning difficulties. Those that were identified were quantitative in nature. Information regarding the nature of identification processes for parents was therefore limited. This study sought to investigate whether the processes identified relating to severe learning difficulties were relevant to parents of children with moderate learning difficulties.

2.2   Social comparison theory

In reviewing literature related to social comparison the search terms disability/reading disability/learning disability or learning difficulty/SEN and social comparison were used with PsycINFO. In addition search terms social comparison and parents were used.

Social comparison is a key psychological process that affects people's judgements, experiences and behaviour. When people are aware of

information about the ability of others, the achievement of others (successes and failures) and the opinions of others, they relate this information to themselves (Dunning & Hayes, 1996). Similarly, when they want to make judgements about their own abilities, achievements and opinions they make comparisons with others.

Although it was developed more than sixty years ago Social Comparison Theory (Festinger, 1954) continues to be studied within empirical investigation (Johnson & Knobloch-Westerwick, 2014; Lee, 2014; Steers, Wickham, & Acitelli, 2014; Wilson & Ross 2000). Social Comparison Theory suggests that people are motivated to gain accurate self-evaluations. The theory proposes that these are achieved through comparisons. These evaluative comparisons serve to reduce uncertainty and to help individuals define themselves. The theory outlines nine main hypotheses.

1. People are motivated to evaluate their opinions and abilities.
2. Objective non-social measures are preferred but that when such information is not available individuals will compare themselves against other people. This involves subjective judgements of the opinions / abilities of others and subjective judgements of one's comparisons against those.
3. The tendency to make a comparison with a specific person decreases as the difference between his or her own opinion / ability and one's own increases.
4. In the case of abilities there is a unidirectional drive upward. This is largely absent in the case of opinions. This means that individuals are motivated to gain higher and higher scores within ability measures. Opinions can not be scaled along a continuum in the same way. The value of opinions comes instead from the subjective feeling that they are correct and valid. There is pressure to achieve uniformity within groups. When a discrepancy exists between opinion / ability there are tendencies to either:
   a. change one's own position in order to move to closer alignment with the group, or
   b. change others in the group to bring them into closer alignment with oneself, or
   c. stop comparing oneself with those that are very different.
   Action in bringing about change within opinion is largely socially

orientated. This process of social influence ceases if / when there is uniformity of opinion.

5. Changing one's ability is difficult or even impossible due to non-social restraints. However, non-social restraints are largely absent when changing opinion. This means that even if a person is highly motivated to improve their intelligence there are great difficulties in bringing about change. When attempting to bring about change in ability the pressure to achieve uniformity within the group manifests itself less through social processes but more through environmental action. Where the ability in question is intelligence, Festinger suggests the person may study harder. He highlights that movement toward uniformity may occur but will take much longer than in the case of opinions.

6. Hostility and derogation accompany the cessation of comparison, so that continued comparison with those persons implies unpleasant consequences (e.g. rejection from the group). Festinger suggested that this process occurs in the case of opinion but does not generally occur in the case of ability. In the case of ability, although comparisons cease with higher performing individuals it is usually accompanied with an acknowledgement of their superiority.

7. An increase in the importance or relevance of an ability / opinion will increase the pressure toward uniformity. The stronger the attraction to the group the stronger will be the pressure toward uniformity.

8. If people who are very divergent from one's own opinion / ability are perceived as different from oneself on attributes consistent with the divergence there is a stronger tendency to narrow the comparability. For example, this means that when performance on a test is compared people are likely to keep competing against the superior performer if they believe they are of similar intelligence. They are likely to cease comparison if they believe the superior performer has higher intelligence.

9. When there is a range of opinion or ability in a group, the relative strength of the three components of pressure (outlined in 4a, 4b, 4c above) will be different for those who are close to the mode of the group than for those who are distant from the mode. Those closer to the mode of the group will be more likely to change the position of others than narrow comparisons or change their own positions. For example, if an individual feels that most of the group disagree with

them they are less likely to change the position of others and more likely to narrow comparisons or change their own position.

Some research questions the preference for non-social measures and suggests that people continue to compare with others even when non-social measures are available (Klein, 1997). This may be partly due to comparison with others generally being a quicker and more efficient cognitive process (Mussweiler & Epstude, 2009).

Research highlights that non-social restraints on ability may be less significant than Festinger (1954) suggested. Intelligence can be perceived as fixed or malleable (Dweck, 2012). Therefore, changing social restraints (opinions and beliefs) may have an impact upon ability and performance (Lockwood & Kunda, 1997).

Further research has highlighted two types of social comparisons. Evaluations can be self-enhancing (downward comparisons with people less well off, in order to feel better about oneself) or affiliative (upward comparisons with people better off in order to learn from them and emulate their success). Upward comparison with a person who is doing better can result in hope (Taylor & Lobel, 1989). Comparing their own situation with other families who are managing can help to give confidence to parents that coping is achievable (Davies & Hall, 2005). Conversely downward comparison with parents who are not doing as well can enhance self-esteem because parents may feel they are doing well compared to others (Wills, 1981). Many parents may find that meeting other parents whose child's difficulties are more complex than their own, helps to put their struggles into perspective (Winch & Christoph, 1988). Both downward comparison and upward comparisons can be used to cognitively adapt when experiencing loss or threat (Gibbons & Gerrard, 1991; Taylor & Lobel, 1989; Wood, 1989). However, the effect of comparisons can vary depending upon interpretation. For example whilst upward comparisons can instil hope (Taylor & Lobel, 1989) seeing others who are doing better could also lead to feelings of hopelessness as parents begin to question why they are not managing so well in comparison (Dibb & Yardley, 2006).

This research highlights that sometimes people do not seek accurate feedback about themselves through comparison with similar others, as

suggested by Festinger (1954). Instead, they seek information from dissimilar others that helps them to feel better about themselves or in order to help them to improve a situation.

Research suggests there may be a greater role for downward comparisons within the early stages of adaptation to challenging situations (Affleck, Tennen, Pfeiffer, Fifield & Rowe, 1987; Wood, Taylor & Lichtman, 1985). Affleck et al. (1987) found that even if parents were not able to make downward comparisons they seemed to feel relieved at learning that their feelings and reactions to the situation they were in were not unusual (thereby suggesting use of social comparison of emotional experiences).

2.2.1   Social comparison and SEN

Hodges and Dibb (2010) studied the use of social comparison within self-help groups for parents of children with a progressive disability. Eight parents (seven mothers and one father) were interviewed about their experiences of being a member. Thematic analysis was used to identify themes. Two superordinate themes were identified: social comparison and support. Within the theme of social comparison parents identified positive upward comparison (recognising that others were still able to achieve despite their diagnosis, which provided hope). Parents also identified positive downward comparisons (being grateful that their child did not experience some of the difficulties others were experiencing). Parents identified mistakes that others had made and sought to avoid these. Some negative upward comparisons were used (feeling unable to achieve what others were managing to achieve). Negative downward comparisons included feeling as if they were looking into the future and a poor prognosis. The authors found that four strategies were used in order to manage comparison information.

1. Seeking comparisons on the same dimension (e.g. reflecting that even though others were better off they were still finding it hard).
2. Seeking comparisons on another dimension (e.g. focusing on assets or talents within a different domain).
3. Selecting new targets to compare with (e.g. children who did not have disability but were finding behaviour difficult).
4. Avoiding social comparisons (e.g. minimising contact with other

parents in order to maintain feelings of normality).

Research suggests that the use of social comparison is developmental and increases with age. Cain and Dweck (1989) suggest that understanding of intelligence does not develop until children reach school age and it matures as they experience an increasing amount of learning situations. Hames (1998) suggests that pre-school children tend to use concrete judgements rather than abstract judgements. When they develop their understanding of intelligence as a psychological concept they are likely to begin to make use of social comparison.

Hames (1998) undertook a longitudinal study of the development of young children's understanding of their older sibling's disability through 6 monthly semi structured interviews with parents. Hames identified 4 stages of development.

1. Wanting to be like the older brother or sister (copying their behaviour or disability).
2. Wanting their disabled sibling to be like themselves (e.g. walk or play).
3. Copying parents in their response to the sibling (e.g. feeding or fetching nappies). This stage developed around 2-3 years of age.
4. Disabled sibling copying their younger sibling (e.g. copying vocabulary).

Hames suggested that prior to making social comparisons to identify how good one is, the siblings were using comparisons to identify social norms. They transitioned from wanting to be like their siblings to wanting to be like their parents.

However, whilst understanding of the concept of intelligence may be limited, non-disabled children as young as 3 – 4 years of age have shown awareness of delayed development. They have been found to adjust their speech when talking to 4 year olds with mild learning disabilities but not when talking to 3 year olds who were at the same developmental level as the delayed group (Guralnick & Paul-Brown, 1989). This indicates that young children are sensitive to non-physical delayed development and can identify differences between delayed development and chronological development.

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Lewis (1995) studied the perceptions of disabilities within two groups of children (aged 7 and 11 years). Peers had weekly 'categorised contact' with children who had severe learning disabilities over the course of a year. The 7 year olds were found to understand and recognise disabilities more easily if there were accompanying physical indicators. They did not differentiate between categories of disability. The 7 year olds tended to view learning disabilities as an illness that children would recover from. The 11 year olds were able to distinguish between categories of disability. They also showed awareness of the long-term nature of learning disabilities.

Keil, McClintock, and Platow (1990) exposed children to situations where they were required to evaluate their performance and the performance of a peer. Children who said that the one who had completed more of the task had done a 'good job' and the one who had done fewer had done a 'not so good job' were identified as using social comparison. Children who said they had both done a 'good job' were identified as using a non-social comparison (as their judgement did not distinguish between themselves and the relative performance of their peer). The study found that use of social comparison significantly increased with age. 42% of children aged 7-8 years indicated use of social comparison, compared to 56% of children aged 9-10 years. However, even within the eighth grade (13-14 years) a quarter of children did not indicate use of social comparison. The study found that children who performed lower than peers and used social comparison to evaluate their performance rated their ability as lower (as would be expected from Social Comparison Theory). Children who performed lower than peers but did not use social comparison did not differ in their ratings to peers who demonstrated high levels of performance. Therefore use of social comparison was found to be associated with lower estimations of ability. Since no manipulation of measures was employed results can only be interpreted as correlational (rather than causal). No effect was found within ability evaluations between high performance and social comparison or non social comparison use. In addition, it is not possible to rule out that the children who did not report using social comparison, were still using social comparison.

Huws and Jones (2015) undertook interpretative phenomenological analysis of the views of teenagers and young adults about their perceptions of having autism. Three underlying themes were found and all of these

formed the superordinate theme 'Making Comparisons'. 1) changes over time, 2) degrees of autism, 3) degrees of ability. Huws and Jones (2015) found that young people tended to make temporal comparisons (Albert, 1977) in order to identify their progress in developing social interaction skills. They were positive about their difficulties being developmental because it meant they were able to change. Young people were found to engage in downward comparisons with people who had more severe difficulties in order to self-enhance their situation. They sometimes made upward comparisons when thinking about careers they would have liked to have pursued (e.g. engineering) but did not have the ability to.

Temporal comparisons are not thought to be used as frequently as social comparisons, although they do appear to be more common during childhood, perhaps because this is a time of great change (Wilson & Ross, 2000). This may be particularly true with developmental delays because change is expected over time.

In summary literature indicates:

- use of social comparison is evident with parents of children who have disabilities; and
- use of social comparison is developmental but children as young as two are able to show some basic awareness of social comparison.

2.3   Sense of belonging

In reviewing literature related to sense of belonging the search terms disability/reading disability/learning disability or learning difficulty/SEN and social comparison were used with PsycINFO. In addition search terms belonging, acceptance, rejection, stigma and parents were used.

Hagerty, Lynch-Sauer, Patusky, Bouwsema, and Collier (1992) defined a sense of belonging as "a person's subjective experience of being valued by or important to others and experiencing a fit between one's self and others around him/her" (p. 173).

The need to belong is a well-established psychological concept. It was identified within the first three sources of motivation for human behaviour by Maslow (1943). He indicated that belonging was more important than

esteem and self-actualisation. Rogers (1951) identified that people require genuineness, acceptance, positive regard, and empathy from others. Attachment theory (Bowlby, 1969) highlighted the need to establish and maintain relationships for healthy development.

Baumeister and Leary (1995) evolved this well-established concept into what they called the 'belonging hypotheses'. Two main features were proposed.

1. People require frequent interactions with the other person (which are mainly free from conflict or negative affect).
2. People need to perceive that there is an interpersonal bond between them that is stable and durable. The person needs to believe that they are cared for and loved.

The following components of belonging were proposed.

- The need to belong is innate and universal amongst humans.
- The need is not focused on one particular individual (and therefore differs from attachment theory). The loss of relationship, can to some extent, be replaced by significant others.
- Cognitive activity should reflect the need to establish and maintain relationships.
- The absence of this fundamental need is likely to lead to a range of psychological ill effects (including stress and loneliness) and an increase in goal orientated activity focused on developing relationships.
- The need motivates people to develop a minimum number and quality of social contacts but once that need is satisfied the motivation diminishes (i.e. further social relationships are less satisfying and less distress is experienced on ending them). Relationships are able to substitute for others, to some extent.

In a review of literature Osterman (2000) found that studies consistently indicated that greater motivation, engagement and dedication to school are found in students who experience high levels of a sense of belonging. Sense of belonging may also be related to stigma. Goffman (1963) proposed a theory of social stigma. He defined stigma as "an attribute that is deeply discrediting" (p.3). He suggested that it reduces the bearer "from a whole and usual person to a tainted, discounted one". Bos, Pryor,

Reeder, and Stutterheim (2013) state that most definitions of stigma are comprised of two elements: identification of difference and devaluation. Goffman (1963) states that stigmatised people are often shunned, rejected and insulted by others. Bos et al. (2013) suggest that stigma can be overt (such as avoidance and exclusion) or subtle (such as lack of eye contact).

Phelan, Link, and Dovido (2008) suggest that there are a number of functions of stigmatisation. Exploitation in order to maintain power and the inequality of groups is one function. Another is social norm enforcement. People are more likely to conform to group norms if they fear consequent stigmatisation. Research indicates that stigmatisation can have a negative impact on psychological well-being (Dagnan & Waring, 2004).

2.3.1   Sense of belonging and SEN

Inclusion of children with disabilities is recognised to benefit both disabled and non-disabled children. It provides an opportunity for disabled children to access positive role modelling (Buysse & Bailey, 1993) and develop friendships with typically developing peers (Buysse, Goldman, & Skinner, 2002). It enables other children to develop their awareness of the needs of others (Diamond & Huang, 2005; Peck, Carlson, & Helmstetter, 1992). However, whilst there is extensive research regarding sense of belonging within children without disabilities, Odom (2006) states that few studies have investigated sense of belonging for young children with disabilities.

Odom et al. (2006) used a mixed methods approach to investigate sense of belonging in eighty preschool children with disabilities. The children exhibited a range of disabilities and developmental levels. Two children from each of the sixteen mainstream settings had severe developmental delay or disorder. All children met their states' criteria for receiving special education. The authors used quantitative measures (time sampling observations of social interactions, peer ratings and teacher questionnaires regarding friendships) to identify children who were socially accepted or rejected by their peer group. Qualitative observations were also undertaken in order to identify patterns of behaviour. The study found that 28% of children met the social acceptance criteria and 28% of children met the rejection criteria. Results showed that social acceptance was associated with awareness-interest, communication-play and friendship-

social skills. Social rejection was associated with social withdrawal and conflict-aggression. The findings indicated that children with learning difficulties may be more vulnerable to social rejection while other disabilities may be less affected. The critical factor appeared to be whether disability had an impact on social withdrawal and conflict-aggression. Limitations of the study included small sample size impacting upon generalisability. In addition inter-observer agreement was low on some measures.

Vaughn, Elbaum, and Schumm (1996) examined social functioning of children within the junior age range. Measures of peer acceptance, self-concept, loneliness and social alienation of children were assessed at the beginning and end of the academic year. Children were identified as having learning disabilities, being low achieving or average/high achieving. Results indicated that children with learning disabilities were less well liked and more frequently rejected than average/high achieving peers. However, results indicated that students with learning disabilities were not more lonely than peers. They also increased numbers of reciprocal friendships over the course of the year. However they still tended to have fewer friendships than average/high achieving peers.

Thus there is some research that indicates that children with learning difficulties may be more vulnerable to peers in terms of sense of belonging. People with learning difficulties are recognised as often experiencing stigma (Craig, Craig, Withers, Hatton, & Limb, 2002; Finlay & Lyons, 2000; Paterson, McKenzie, & Lindsay, 2012). Goffman (1963) highlights that labels used to describe learning difficulties are frequently used as terms of insult. Finlay and Lyons (2000) highlight that people with learning difficulties are often segregated (e.g. within special schools, special youth clubs, segregated day and residential services) and this can increase their vulnerability to stigma. Dagnan and Waring (2004) identified that perceptions of stigma and negative self-evaluations were significantly related for people with learning difficulties. They suggested internalisation of the stigma being faced may have led to lower self-evaluations. Research suggests people with learning difficulties are aware of stigma associated with learning difficulties and attempt to therefore distance themselves from the label (Craig et al., 2002; Dagnan & Waring, 2004).

Finlay and Lyons (2000) interviewed 33 people with learning difficulties in

order to explore how members of a stigmatized social category may develop a positive sense of self through social comparisons and categorisations. The researchers found that downward comparisons were made with people who had greater learning difficulties or with people who did not have learning difficulties but behaved badly. Upward comparisons were rarely made. When participants compared themselves with others who had learning difficulties they focused on attributes such as ability and good/bad behaviour. When they compared themselves to the wider population they focused only on good/bad behaviour. Thereby they appeared to emphasise their similarities with others who did not have learning difficulties. The researchers concluded that it was not having a label of learning difficulty that affects sense of self but instead the way in which people perceive themselves in comparison with others that affects sense of self (Social Comparison Theory).

Paterson et al. (2012) studied the perception of stigma in 43 adults with a learning disability. They considered the relationship between stigma and psychological well-being and whether the process of social comparison impacted on this relationship. Self report measures of stigma, self-esteem and social comparison were completed by participants. Greater perception of stigma was associated with lower self-esteem. However, only the negative self-esteem factor was found to be related to stigma. The authors suggested that participants are more likely to be affected by stigma if they have low self-esteem (and vice versa). Perception of stigma was significantly related to negative social comparisons which were related in turn to low self-esteem. The level to which people felt they belonged to the same group as others in the community was not related to their self-esteem. Participants who reported feeling they belonged to the category of people with learning difficulties but were more able compared to them reported higher levels of self-esteem. This suggested that in order for people with learning difficulties to feel good about themselves they need to identify themselves as part of a group of people with learning difficulties but also within the more able continuum of the group. A limitation of this study is that it is not clear whether participants chose a particular person to compare against from within a group or whether their comparisons were with the general group of people. This may mean that participants were still making downward comparisons when it was assumed they were making lateral comparisons, for example.

Paterson et al. (2012) suggested that participants with learning difficulties associated themselves with learning difficulties and used downward comparisons to feel good about themselves. However, in the previous study Finlay and Lyons (2000) found that participants with learning difficulties tried to disassociate themselves from their peers. The contradictory findings between these studies could be explained by 'courtesy stigma' where people seek social support from the stigmatised group but try to distance themselves from the support when attempting to integrate with other groups (Forrester-Jones & Barnes, 2008).

Studies have shown that people with a learning difficulty often make downward comparisons with their peers (Finlay & Lyons, 2000) and lateral comparisons with the general population (Craig et al., 2002). However, Paterson et al. (2012) found that people with learning difficulties did not make significantly different comparisons between others with learning difficulties and the wider population. The authors suggest this could be due to insensitivity within measures or that participants generally felt good about themselves regardless of the comparison group. Although Paterson et al. (2012) found that self-esteem was associated with both social comparison and stigma they did not find that social comparison acted as a mediating variable between self-esteem and stigma. This could indicate that social comparison and stigma impact on different components of self-esteem. Alternatively lack of sensitivity of the measure used could mean that moderating effects were not detected. The study found that psychological well-being could be maintained even when experiencing stigma.

Cooney, Jahoda, Gumley, and Knott (2006) undertook a study regarding perceived stigma, social comparison and future aspirations of pupils in secondary school who had learning difficulties. Approximately half of the pupils attended mainstream school, with the remainder attending special school. The majority of both groups of pupils reported experiencing stigmatised treatment in the area they lived in. The mainstream group experienced significant additional stigma at school. Both groups compared themselves positively with peers of lower and higher abilities, similar to the findings of Paterson et al. (2012). The mainstream pupils had more ambitious future goals but both groups felt they would reach their goals.

Similar to previous studies it is not possible to ascertain whether the pupils were choosing particular non-disabled peers with whom to compare themselves (rather than the group as a whole) in order to protect themselves from the effects of upward comparisons. There were socio-demographic differences between the groups which may also have influenced results. The authors reported contradictory discourses within support offered to schools: a) a need to find innovative ways to meet the educational needs of pupils, b) to reduce perceived differences and highlight that everyone is a learner. Due to the authors noting that discrimination was evident in school for these pupils and pupils were aware of their difficulties it was suggested therefore that perhaps greater emphasis should be given to recognising and celebrating difference within schools.

To summarise, the suggestion made by Dagnan and Waring (2004) that internalisation of stigma leads to lower self-evaluations does not appear to equate with all the findings of the above studies. The impact of stigma may be affected by social comparison, careful selection of dimensions on which to compare (Finlay & Lyons, 2000), previous levels of self-esteem (Paterson et al., 2012), and positive ameliorating experiences within a range of alternative social groups (Cooney et al., 2006).

2.4　Loss

In reviewing literature the following search terms were used within EBSCO, ERIC and PsycINFO: disability/reading disability/learning disability or learning difficulty/SEN, parents, diagnosis, identification, loss, grief, bereavement. Literature searches included accessing relevant material from reference lists that were found.

Traditionally loss is associated with death. However, loss covers a much wider range of experiences. It can include children changing school, children leaving home, interpersonal break ups, and leaving jobs. Martin and Doka (2000) state that there are three different types of losses. Loss can be physical (e.g. loss of a home), relational (e.g. a colleague moving away), or symbolic (e.g. losing a dream, hope or faith). Death, for example, involves all of these losses. Rando (1993) states that loss occurs continually throughout life and that almost every change involves some

loss.

Experiences of loss vary in intensity. Social support also tends to vary for different losses. Relational and symbolic losses tend to be acknowledged less than physical loss. Doka (1989) states that when loss is not acknowledged or supported grief can become "disenfranchised". This means that grief is not openly acknowledged or shared. Identifying loss as only involving death can limit the acknowledgement we give to other forms of loss and the learning we develop from those experiences.

Research has shown that parents can experience a grief reaction which is similar to bereavement, when they find out their child has a disability (Bowes et al., 2009; Collings, 2008; Davis, 1987; Lowes & Lyne, 2000). However, loss associated with disability generally does not have an end point. Olshansky (1962) introduced the concept of chronic sorrow to explain the continuing sadness parents may feel when they face diagnosis of a continuing condition. Bruce and Schultz (2001) describe this loss as non-finte and on-going.   The focus of loss changes as children grow older, compared with the developmental abilities of other children. Parents continually receive new reminders that their child is different.

The following losses have been associated with the diagnosis of a disability.

- Expected future and "what should have been" (Bruce & Schultz, 2001).
- Altered parental roles (Clark, Stedmon, & Margison, 2008).
- Changed family relationships (Collings, 2008).
- Concern about the child's future well-being and independence (Collings, 2008).

Doka (1989) suggests that non-finite (on-going) loss is often not publicly acknowledged or validated as a loss. This results in minimisation of the loss and grief becoming disenfranchised.

Theories of loss can be considered within two categories: stage theories [for example: Kubler-Ross (1969), Bowlby (1980), Worden (2009)] or process theories [for example Stroebe and Schut (1999), Martin and Doka (2000)]. An example of each of these will be considered in turn.

Traditionally, grief theorists have proposed that grief progresses through a series of predictable stages. Kubler-Ross (1969) developed one of the most well known models of grief. The model contained five stages that describe ways in which people manage grief.

1. The first stage is one of denial and isolation. Denial acts as a buffer after unexpected news which enables the person to collect themselves and with time face the situation. Kubler-Ross suggested that people are able to consider their future death for a while, but then put it aside in order to pursue life. Later in this stage people use isolation more than denial. Talking about mortality and immortality as if it were happening to someone else is characteristic of isolation.

2. The second stage is one of anger. Feelings of anger, rage, envy and resentment characterise this stage. During this stage people often ask "why has this happened to me?"

3. The third stage involves bargaining and attempting to postpone the inevitable.

4. During the fourth stage anger and rage is replaced with a sense of loss. Kubler-Ross described two kinds of depression: reactive depression and preparatory depression. Reactive depression is a response to the losses that sit alongside terminal illness (e.g. financial pressure, loss of work, the impact of hospitalisation on the family). Preparatory depression results from considering the impending losses.

5. Acceptance is reached within the final stage.

Kubler-Ross suggested that the one thing that persisted though all the stages is hope that something unforeseen and unexpected may happen. Kubler-Ross proposed that the reactions of those around the person could influence the behaviour of that person, meaning that they may display different elements of the stages depending upon who they were with.

Although the work of Kubler-Ross is generally applied to people who have experienced a death the model was not derived from work with bereaved people but from work with terminally ill patients. This may affect the validity for the population to which it is generally applied.

Research suggests that many practitioners use this model in a time-limited

way (Collings, 2008). Stage theories have generally been criticised for being time-bound. Acceptance is often thought to be reached within a year or so (Hardt, 1978). Therefore on-going loss could be considered abnormal, complicating the grief process further (Martin & Doka, 2000). Stage theories have been criticised for being linear.   Kubler-Ross and other stage theorists have proposed that the stages last for different periods of time. They may not all be progressed through. Stages may exist at times side by side. However, neither this concept nor the process by which it occurs is emphasised within stage models. Stage theories have also been criticised for being affective focused. Martin and Doka (2000) identify two grieving styles along a continuum: intuitive (affective in focus) and instrumental (focused upon thinking and doing). They propose that both styles may support the grieving process.

Bonanno et al. (2002) undertook a study of 205 participants several years prior to the death of their spouse and at 6 and 18 months post loss. Five core bereavement patterns were identified (common grief, chronic grief, chronic depression, depression prior to loss followed by improvement during bereavement and resilience). Common grief characterised by elevated depression that slowly decreased over time (as predicted by stage models) was relatively infrequent (11% of the sample). The most frequent bereavement pattern was a stable low depression or resilient pattern (46% of the sample). The study therefore throws into question the validity of traditional staged models.

Stroebe and Schut (1999) proposed an alternative model of grief. The model is not sequential but flexible. Grieving involves oscillating between two types of coping processes (loss orientation and restoration orientation). Loss orientation refers to concentrating on and dealing with elements of the loss experienced. It typically involves thinking about memories and circumstances around the death. It also involves longing for the person and imagining how they may react to different situations. Stroebe and Schut suggest that a range of emotional responses are involved in this process (from happiness that the person is no longer suffering and enjoyment of pleasurable memories to sadness and longing for them to be present). Restoration orientation focuses upon factors that need to be dealt with in life without the person. These could include learning to manage finances, cooking, or taking action to counter loneliness. The theory

acknowledges that a range of emotional reactions could be involved in this process (e.g. relief and pride at developing new skills to feelings of being overwhelmed and fear of failure). Restoration orientated work can include denial / avoidance of grief and loss orientated work can include denial / avoidance of restoration changes. The model suggests that loss coping does not occupy all of a person's time but that a person oscillates between loss orientation and restoration orientation activities that sit within a wider context of on-going life experiences. The model addresses not just the primary loss but also secondary losses (through restoration activities). The model offers flexibility that can account for different patterns of grieving.

The absence of distress within loss experiences has tended to be viewed as a form of denial by stage theorists (Middleton, Burnett, Raphael, & Martinek, 1996) or as a lack of attachment to the person who has died (Horowitz, 1990). However, process models of loss suggest that people may instead be utilising restoration orientated activities.

Bisconti, Bergeman, and Boker (2006) studied widow's self-ratings of emotional wellbeing on a daily basis over a 98 day period. Ratings tended to oscillate between high and low scores. Scores began to level out towards the end of the 98 day period. The study did not find any clustering of flat lines at different points in time, which may otherwise have indicated reaching a new stage in bereavement. The pattern of oscillation held true even for resilient widows.

Bennett, Gibbons, and Mackenzie-Smith (2010) undertook two qualitative studies with widows. This first study involved interviewing participants about life before bereavement, adjustment following loss and retrospective assessment of a typical day post loss (including support and how they felt). Their second study involved interviews focused on restoration orientated activities. The analysis showed that people who had adjusted well to loss experienced both restoration orientation and loss orientation elements. While those who had adjusted less well experienced denial/avoidance of restoration changes and distraction / avoidance of grief. However, the analysis was based on retrospective data and retrospective recall is therefore a concern. Carr (2010) suggests that retrospective data collection can often lead to overly positive reports. This may be linked to self-enhancement.

Neither of these studies have investigated the applicability of the dual process model to non-finite loss. The following two studies presented consider non-finite loss.

Collings (2008) undertook semi-structured interviews with five parents of young people who had Acquired Brain Injury (ABI) at nineteen or twenty years of age. Interviews took place between two and a half years to twenty six years following the injury. Research questions considered the incidence of grief (what the grief is like and how long it lasts), the impact of the loss of normal development, implications of the non-finite nature of their loss and the applicability of traditional stage models of grief to their experience. Data from the interviews were thematically coded. All participants reported experiencing symptoms of grief initially during the post-injury stage (including sadness, shock and disbelief, anger, guilt, depression, anxiety, impaired ability to carry out normal day to day functions, avoidance/denial). Four of the five participants reported that the intensity of grief gradually reduced but remained re-current. One participant reported that her grief was on-going for the twenty six year duration of her son's condition. Four of the participants reported that the acute phase of grief lasted between twelve to eighteen months. The participants who reported recurrent grief found that this was more short-lived than the initial phase (lasting only minutes or hours). Participants reported a conscious effort to not remain immersed in their grief.

Some literature predicts that loss of idealised future complicates non-finite grief (Bruce & Schultz, 2001). However, parents of young people with ABI chose not to dwell on what might have been. However, the authors state that the level of concern parents may have experienced in managing the young person's needs may have inhibited any tendency to idealise imagined futures. Most participants were able to identify positive outcomes of their experience which is in line with assertions of Attig (2004) that hope can co-exist with grief. Collings (2008) found that there was a link between non-finite loss and the nature of grief for participants. However, for the four participants who reported recurrent grief this did not appear to be their prevailing state. They made efforts not to focus on it. The author identified that there is a risk that over-reliance on linear models may lead to an interpretation of this strategy as being one of denial rather than coping.

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Coping strategies for participants in the study included making decisions not to focus on their loss, sharing their experiences with others, focusing on other aspects of their life such as work and social events. The author therefore found support for the idea of oscillation within the Dual Process Model of Grief. It was concluded that process orientated models (which are not linear or time bound) appear more applicable to on-going nature of non-finite loss.

Retrospective recall is a concern within this study as analysis was based on retrospective data. This could lead to overly positive reports (Carr, 2010). There was a wide difference in time frame between injury and interview (2 and half years to twenty six years). This may have also impacted upon findings.

In order to investigate whether grieving is an on-going feature of parenting children with disability Bruce and Schultz (1996) undertook a longitudinal study with forty nine parents of children who turned three, six, nine, twelve, fifteen or eighteen years of age in 1989. The children had one or more disabilities which were either congenital or sustained within the first two years of life, and with a prognosis of no cure. 69% of children were considered to have mild/moderate learning difficulties. 31% of children had severe/profound learning difficulties. 29% of the children also had epilepsy. Data was collected through structured interview using a number of self-report measures. Data was collected on an annual basis for three years. Measures included:

- Experiencing the impact of events (including intrusion of thoughts and feelings and avoidance of thoughts, feelings and situations). The items were considered in relation to the last seven days.
- Experience of stress (participants were required to consider their current level of upset when thinking about the time when they first realised their child's disability).
- Persistence of wishing for what might have been (parents completed a five point Likert scale ranging from never to always against how much they wished their child was like other children on different attributes).
- A schedule of recent events scale was included in order to evaluate presence of events that may confound measurement of grief specific to the child's disability.

The schedule of recent events did not indicate any significant changes for participants over time. Results of the study indicated on-going grief for parents. There were no significant differences found over the three points of contact.

Limitations to generalisability apply given the nature of the sample. The extent to which the sample is unrepresentative of the target population is unknown due to the self-selected nature of the sample. Selection bias may impact upon the results. The presence of epilepsy within a third of the sample may also have affected results, since epilepsy is a condition that can change over time and significantly impact upon learning (Aldenkamp, Overweg-Plandsoen, & Arends, 1999). The study also included a range of learning needs from mild to severe/profound. The authors do not indicate any analysis of difference in experience related to level of child need. Whilst the study indicates the presence of on-going grief for parents little information is provided about the nature of these difficulties for parents (e.g. the nature of support systems they accessed).

2.5   Positivity

Wehmeyer (2013) states that disability has typically been associated with "differentness".

Hastings and Taunt (2002) suggest that both theory and research with the disability field has generally neglected the positive aspects of families' perceptions. Helff and Glidden (1998) analysed research trends on adjustment in families of children with disabilities from the 1970s-1990's. Their analyses indicated that negativity in published research decreased over time, but that there was no increase in positivity over the same period. The authors suggest that although there has been a small shift away from writing about negative factors, researchers still pose negatively biased questions and hypotheses within their investigations. In the majority of articles reviewed the authors did not indicate any positive factors associated with having a child with a disability.

Yet some research suggests that positive experience and perceptions are encountered by the majority of families of children with disabilities (Greer,

Grey, & McClean, 2006; Lehman & Roberto, 1996; Scorgie & Sobsey, 2000). Greer, Grey and McClean (2006) found that the majority of parents rated agreement or strong agreement with statements that their child was: a source of happiness or fulfilment; a source of strength and family closeness; and a source of personal growth and maturity. Some families reported feeling a need to become stronger due to feeling they would need to solve a lot of problems by themselves (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008).

Mullins (1987) undertook a content analysis of 60 books written by parents of children with disabilities. Whilst significant emotional stress was identified, the majority of authors felt that their lives had increased meaning and enrichment as a result of their experience with their children.

Hastings and Taunt (2002) reviewed a number of studies and found some consistent themes reported by parents.

- Pleasure / satisfaction in providing care for the child.
- Child is a source of joy / happiness.
- Sense of accomplishment in having done one's best for the child.
- Sharing love with the child.
- Child provides a challenge or opportunity to learn and develop.
- Strengthened family and / or marriage.
- New or increased sense of purpose in life.
- Development of new skills, abilities or new career opportunities.
- Become a better person (more compassionate, less selfish, more tolerant).
- Increased personal strength or confidence.
- Expanded social and community networks.
- Increased spirituality.
- Changed one's perspective on life (e.g. clarified what is important in life, more aware of the future).
- Making the most of each day, living at a slower pace.

3.0   Methodology

The methodology selected for this study is discussed in relation to ontology and epistemology. Ontology refers to the beliefs and assumptions that people have about the world/reality/truth (Frost, 2011). Ontology influences epistemology. Epistemology concerns the theory of knowledge. It involves methodology and how we go about discovering knowledge (Howitt & Cramer, 2007).

3.1   Appreciative Inquiry

Some research suggests parents may recognise positive consequences of their child having SEN but this is not always acknowledged by professionals or within research literature (Dobson et al., 2001; Hastings & Taunt, 2002). Research on families of children with intellectual disabilities has typically focussed on stress and burden (Hastings et al., 2002). Those studies that have identified positive perceptions have generally not explicitly been designed to do so, but formed part of the stress literature. This study utilises Appreciative Inquiry (AI) methodology which is designed to avoid negative bias noted above. Appreciative Inquiry was developed by researchers at Case Western University as a tool for promoting change within organisations.

Cooperrider and Whitney (2005) define Appreciative Inquiry as:
> ...the cooperative, coevolutionary search for the best in people, their organisations, and the world around them. It involves systematic discovery of what gives life to an organisation or a community when it is most effective and most capable in economic, ecological and human terms (p. 8).

3.1.1   Ontology

AI proposes that reality is socially constructed and that the language and questions we use can lead to new discoveries. It is also built upon the notion that what we focus our attention upon becomes our reality. Knowledge is believed to be collaborative and co-constructed (Cooperrider & Whitney, 2005). AI is built upon the premise that organisations grow in

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the direction of what is studied. AI therefore highlights the need to search for what is true, good and better within organisational systems (McKergow, 2005). The AI process aims to help organisations create positive images of the future based on the successful moments of the past and present. AI postulates that organisations will be drawn towards these positive images and therefore create hope and renewed commitment to change (Postmar, 1998). The approach aims to learn from the best of what is to stir up the imagination of what might be better yet (Michael, 2005).

3.1.2 Epistemology

AI is distinguished from traditional problem solving approaches which focus on identifying problems before then working on solutions. Cooperrider and Whitney (2005) suggest that the basic assumption of problem solving is that an organisation is a problem to be solved, whereas the basic assumption of AI is that an organisation is a mystery to be embraced. Instead of starting with a problem the AI framework explicitly seeks out strengths and what is working well. AI suggests that practice can be developed by doing more of what works, rather than less of what does not work (Reed, Jones, & Irvine, 2005). Indeed, by examining positive factors it is possible to then develop them further (Reed et al., 2005). The AI process can highlight positive outcomes that have previously been overlooked.

Cooperrider and Whitney (2005) outline five principles of AI.

1. *The constructionist principle* suggests that knowledge and destiny are intertwined. That is, the process of making sense of situations and planning accordingly is constant. In this way organisations are human constructions. This principle suggests that our beliefs shape our thoughts and actions (and that these develop from relationships). Through interaction people co-construct their organisations. Knowledge is believed to be communal and collaborative. Through collaborative inquiry new knowledge (ideas and possibilities) can be generated.

2. *The simultaneity principle* states that inquiry and change are not separate processes but occur simultaneously. The questions that are asked lead to discoveries and from these future ideas are constructed. The questions that are initially asked can significantly

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impact upon future action. This principle shifts the focus from finding answers to reflecting upon the impact of the question upon relationships and whether it is helping to generate conversations about positive possibilities.

3. *The poetic principle* proposes that organisations are constantly co-authored. Pasts, presents and futures are sources of inspiration and learning. Human experiences (e.g. inclusion/exclusion, enthusiasm/low morale, well-being/stress) can be studied within any organisation. The means and ends of an inquiry are linked through the questions that are generated. Consideration is given to the way in which words are used to inspire future outcomes.

4. *The anticipatory principle* suggests that positive ideas about the future lead to positive action and outcomes. Change is brought about through collaborative discussion about the future. Discussion shapes expectation, action and thereby outcomes, rather like a self-fulfilling prophecy.

5. *The positive principle* states that the most effective way to promote change is to increase positivity (expectation, enthusiasm, relationship, commitment). The more positive the questions asked the more long-lasting the change produced.

The AI process involves four stages of Discovery, Dreaming, Designing and Destiny. The first phase involves appreciating or 'discovering' the best of the memories in an organisation and its people. The next stage involves building on these memories by envisioning and 'dreaming' about what the organisation could become. The third stage involves 'designing' and planning the future that has been envisioned before finally agreeing to each person's role in achieving that 'destiny'.

This research did not concern developing change with participants, therefore only the initial stage (discovery) was used. Michael (2005) was first to develop use of AI as a standalone interview tool. She developed use of AI with a research aim rather than organisational change aim (using a mini version of the discovery phase only). That is, she used AI to explore perceptions in depth rather than using the later stages to intervene or achieve change within an organisation. This study utilised a similar approach in order to elicit the perceptions of parents.

Research suggests that while professionals often focus on negative effects of parenting a disabled child, parents attribute their stress to the difficulties of managing their relationships with professionals (Hodge & Runswick-Cole, 2008).   Tensions are likely in a relationship where one party seeks optimum resources/support and the other party works within a political context in which 'efficient use of resources' must be considered and the needs of one has to be balanced against the needs of others (Hodge & Runswick-Cole, 2008). As noted previously, although the methodology chosen in this study avoids negative bias it still allows participants to choose to explore problems and negative experiences in working with professionals. Researchers argue that if we can start research with the problem we could equally start with the prospects (and these can be more motivating and energising). Hammond (1986) states that AI does not dismiss problems but offers an alternative way of them. Michael (2005) suggests that AI can often lead to a better understanding of both the negative and positive within an experience than would a problem solving approach which begins at the level of the negative. This is echoed by examples of use of AI in prison, Chicago gang organisations, and non-governmental organisations (Easley, Sorenson, & Yaeger, 2001; Liebling, Price, & Elliott, 1999; Michael, 2005).

AI was used within this study for the following reasons:
- to avoid negative bias and enable exploration of positive factors;
- to enable use of open and positively phrased questions which do not prevent participants from disclosing negative experiences but reduce the risk of participants feeling obliged to do so; and
- to allow the researcher to use discussion flexibly and alter wording, cease a line of questioning or provide breaks if a participant appears to become distressed by discussing their child's needs.

3.2   Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was used to gather and analyse data. This is a qualitative research approach that aims to examine in detail interviewees lived experiences and the way in which they reflect upon and make sense of those experiences (Smith, 2004).

3.2.1 Ontology

IPA is rooted within the experiential dimension with its detailed examination of individual experience and the interpretation an individual makes of this. However, IPA also acknowledges social constructivism in that language, social action, culture and history are recognised to influence and construct our individual meaning making (Frost, 2011).

3.2.2 Epistemology

IPA has three theoretical underpinnings: phenomenology, hermeneutics, and idiography (Smith et al., 2009).

1. Phenomenology refers to the study of conscious subjective experience. IPA is a method for hearing the interviewees' experiences and allowing them to elaborate upon these. The approach encourages interviewees to discuss any relevant information that supports details conveying their experience (Smith et al., 2009).

2. Hermeneutics is concerned with the interpretation and analysis of how a phenomenon appears. The researcher is involved in facilitating and making sense of the phenomenon along with the interviewee. IPA therefore involves a double hermeneutic process where the researcher makes sense of the interviewee, who makes sense of their own experience (Smith, 2004; Smith et al., 2009).

3. That is, IPA involves a participant making sense of their experience and a researcher interpreting the participant's account in order to understand their experience. The researcher is able to provide an additional perspective on the experience being examined. This perspective will include analysis of the reported experience, consideration of connections which emerge through having an overview of a larger data set and through links to psychological theory (Smith et al., 2009). Therefore, IPA is interpretative and not just descriptive. Smith and Osborn (2003) state that the approach involves asking questions such as: what is the person trying to achieve here?, is something leaking out here that wasn't intended?,

do I have a sense of something going on here that maybe the participants themselves are less aware of?

4. Idiography is concerned with the study of individual instance in depth and detail as opposed to developing laws based on the general. IPA aims to analyse in detail the experiences of particular people and the sense those people make of their experience, within a particular context. As the approach is idiographic, claims about the wider population can not be made. However, IPA can be used to demonstrate existence of phenomena rather than incidence. Hefferon and Gil-Rodriguez (2011) state that within IPA there is more of a focus on the possible transferability of findings from group to group rather than generalisation. IPA can also be used to point to flaws in existing theoretical claims and may then lead to ways to revise theory (Smith et al., 2009). Whilst nomothetic psychology involves representative samples and generalising findings to the wider population which only enables group level claims, IPA enables researchers to say something substantive and specific about the individuals taking part in the study (Smith, 2004). Smith et al. (2009) suggest that deeper analysis in this way can take us closer to the universal, in that we are better positioned to consider concepts that are shared across humanity. The specifics are unique, but they are connected to what is shared and communal.

Smith (2004) states that IPA has three characteristics: idiographic (described above), inductive and interrogative. IPA is inductive in that it enables researchers to approach topics flexibly, which allows themes to emerge during analysis. There is no attempt to test specific hypotheses on the basis of literature. Instead broader research questions are generated and extensive data is gathered. Avoiding testing hypotheses can be argued to reduce researcher bias. For example interview questions are designed to be open, broad and general in order to allow the interviewee to define the limits of the topic, rather than the researcher. This avoids the researcher forcing their understanding of the phenomenon upon the interviewee's account (Smith et al., 2009). Interpretation is subjective and therefore different researchers may draw different conclusions from the same data. This means the approach could still be vulnerable to researcher bias to some extent. To address this, the approach encourages

the researcher to 'bracket off' preconceived ideas by noting these separately from the analysis. The third characteristic identified by Smith (2004) is that of interrogating existing research. The results of data analysis within IPA do not stand alone but are discussed with regards to psychological literature. Therefore IPA draws heavily upon psychological theory.

In summary, the following factors were considered whilst undertaking IPA:

- the perspectives of interviewees may not be stated explicitly within the data but may emerge through analysis;
- the need for the researcher to distinguish between what the interviewee said and interpretation;
- the interpretation of data being reliant upon the researcher – the research is therefore vulnerable to bias or the researcher missing relevant themes;
- investigation was reliant upon gathering rich data and interviewees being willing to share their ideas and the interview approach will therefore be critical; and
- findings can not be generalised to the wider population.

IPA was used within this study because:

- it allowed deep and detailed analysis of the experiences of parents, which is consistent with the epistemological basis of the research question;
- the approach is concerned with cognition, perceptions and perspectives;
- the study is focused upon developing understanding of experiences rather than testing particular hypotheses (the methodology allowed parents to talk freely and set the parameters for the topic);
- it allowed the researcher to approach the topic flexibly, allowing themes to emerge during analysis; and
- the approach draws heavily upon psychological theory.

3.4 Data collection

Data was gained through semi-structured interviews with parents. The approach was chosen because it built upon existing literature of the experiences of parents in finding out their child has a need (Clark et al.,

2008; Collings, 2008; Graungaard & Skov, 2007; Woodcock & Tregaskis, 2008).

The interviews were constructed using an AI approach. This involved using the initial phase of AI (discovery) to elicit the perspectives of parents. It also entailed constructing questions which were open, appreciative in nature and focused upon what works well.

In line with IPA methodology a purposive sample was used (rather than probability/random sample). Purposive sampling involved the researcher selecting the sample on the basis of their ability to grant access to a particular perspective on the phenomena under study (Frost, 2011).

Combining Appreciative Inquiry and IPA within methodology is not a widely used approach. Searching both these terms on PsycINFO and PsycARTICLES databases yielded one result from Ewing (2011). The study utilised Appreciative Inquiry by

- following a four stage process (outlined in previous section)
- constructing questions which were appreciative in nature.

The use of IPA entailed

- 'bracketing' or putting to one side prior knowledge and allowing information to emerge from data (therefore not constructing hypotheses)
- 7 step process of data analysis (outlined in section below)

This study used the same approach as Ewing (2011), except that only the first AI stage of 'Discovery' was utilised, as described by Michael (2005).

3.5   Data analysis

Smith (2004) states that data analysis starts with detailed examination of one case. When the case has been analysed the researcher then moves on to analyse the second case. Only when individual analysis of every case has been completed does cross case analysis of convergence and divergence of themes commence.

Analysis followed the 7 step process of analysis outlined by Smith et al. (2009).

1. *Reading and re-reading* (while listening to audio recording)

   The aim of this step is to slow down reduction and synopsis. During this step some initial and most striking observations about the transcript are recorded in a note book, in order to help the researcher bracket them off and put them to one side, to allow the focus to remain with the data for a while.

2. *Initial noting* (including descriptive, linguistic and conceptual comments)

   This step within analysis is the most detailed and time consuming. The researcher is required to remain open minded and note any points of interest within the text. This involves a free textual analysis. The authors state that there are no requirements to divide the text into units and assign a comment to each unit. Noting includes the following elements.

   - Descriptive comments about the content of the text.
   - Linguistic comments about the way in which the interviewee conveys meaning [including pronoun use, pauses, laughter, repetition, tone, degree of fluency (articulate or hesitant), metaphors by the interviewee].
   - Conceptual comments which engage with the text at an interrogative and interpretative level. This involves a shift of focus from explicit statements from the interviewee towards the interviewee's overall understanding of the concepts discussed. The focus is generally not about finding answers but about opening up a range of potential meanings. This part of the analysis is critical in moving beyond the superficial and descriptive towards deep and sophisticated understanding.
   - Deconstruction whereby parts of the text are read backwards to focus upon particular words and meanings. This avoids superficial reading.

   Throughout this step the researcher analyses similarities/differences and contradictions within the text. As part of this process the researcher asks questions about what words, phrases and sentences mean for them and aims to check what they mean for the

interviewee.

3. *Developing emergent themes*

   During this step the researcher aims to reduce the volume of data (transcript and notes) whilst maintaining complexity. This involves focusing upon the initial notes rather than the transcript. Comments are analysed to identify emergent themes (through both units of text and recall of what was learned through initial noting). Each theme reflects both description and interpretation. Each theme includes psychological understanding of what is happening for the interviewee (using language that reflects psychological concepts/theory).

4. *Searching for connections across emergent themes*

   Up until this step analysis is chronological (detailing information in the order in which they emerged within the interview). During this step the researcher links the themes together semantically. Clusters of themes are placed together. Super-ordinate themes are developed which subsume several emerging themes. During this process oppositional relationships are also considered by focusing upon difference instead of similarity. A graphic representation of emergent themes is developed.

5. *Moving to the next case*

   Only when the first case has been analysed using the process outlined above, will the researcher move on to the next case. Ideas that have emerged from the first case will be bracketed off to allow the researcher to analyse the second case in its own right. This is in line with idiographic philosophy. Following the process outlined above systematically should allow new emergent themes to develop with each case.

6. *Looking for patterns across cases*

   Once analysis of all cases has been completed graphic representations of each case are compared. Connections, prioritisation and impact of themes in one case upon another are considered. This can lead to a re-labelling of themes. Superordinate themes in one case may highlight concepts that other

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cases share. IPA can identify both differences and similarities between individuals. A graphic representation or table is developed to represent analysis undertaken for the group. This illustrates the way in which themes are clustered within superordinate themes.

Hefferon and Gil-Rodriguez (2011) state that a smaller number of themes tends to represent a more thorough analysis. They provide good examples of IPA methodology where three main themes were developed.

7. *Writing the analysis*

A large proportion of the results section contains transcript extracts. Detailed interpretations form the remainder.

Smith (2004) states that the write up should highlight two elements to the reader. These are a) the emergent themes that interviewees share, but illustrated in particular ways and b) the individual's own account. In this way the write up should show something about the important generic themes in the analysis but also show the world of particular participants who have shared their stories.

3.6   Selection criteria

IPA utilises small homogenous samples so that within the sample convergence and divergence can be examined in detail (Smith et al., 2009). Hefferon and Gil-Rodriguez (2011) state that it is important sample sizes are kept small in order that enough depth is reached within data and analysis. Smith (2004) states that it is only possible to carry out the detailed and nuanced analysis required by IPA on a small sample. The sample size obtained for this study was four. Smith et al. (2009) suggest that sample sizes of between three to six should provide sufficient cases to form meaningful elements of similarity and difference between participants but not so many to risk being overwhelmed by the amount of data accumulated. Smith (2004) states that researchers are increasingly advocating a single case study approach with IPA in order to provide highly complex analysis of data and in depth understanding of phenomenon.

Within IPA the aim is to find a reasonably homogenous sample, so that

similarities and differences can be studied in some detail within the sample (Hefferon & Gil-Rodriguez, 2011; Smith et al., 2009). The following selection criteria were therefore used.

- The parents had children who had learning difficulties and were receiving support at 'School Action Plus' level or 'Pupil with a Statement' level of the Code of Practice in school.

- The children were in National Curriculum Years 1-3 and attaining within National Curriculum P levels. Only around 2% of children are achieving these levels in these year groups nationally. Therefore the level of need was likely to be large enough for parents to discuss the impact of difficulties. Also, children in Years 1-3 were young enough for the SEN identification process to be fairly recent for the parents.

- Primary schools were situated within the area covered by one locality team of an Educational Psychology Service within a large local authority in the south of England.

3.7   Selection process

The sample was not approached by the researcher but by school staff, who acted as gatekeepers, in order to ensure only those parents who felt ready to discuss their reactions to their child's needs participated in the study (Woodcock & Tregaskis, 2008).

Contact was made via schools in a neighbouring local authority to that in which the researcher was based. This reflected the message given to parents that input with the researcher would not have any bearing on support or assessments undertaken with the child. This may have helped parents to feel free to comment on support without anxiety regarding possible consequences for support.

One area team within the Educational Psychology Service approached the schools they covered. Schools were provided with an information pack and opportunity to discuss the project with the researcher. Those schools that agreed to participate in the project approached parents who fulfilled the selection criteria above. Parents were provided with information packs that were written by the researcher. The researcher did not initiate contact, in order to minimise the possibility that parents felt obliged to participate

(Hughes, 2012).

Schools were approached on a one by one basis. Parents from three schools took part in the project.

3.8   Ethical considerations

Ethical approval for this study was granted by the Ethics Committee at Cardiff University. The following issues were highlighted for consideration for the committee.

3.8.1 Value of the research

- This research explores areas that are working well and areas for development from the perspective of parents. There has been little previous research regarding support for parents who find out their child has learning difficulties which are not severe. A review of available literature has failed to identify adequate resources and guidelines specific to working with nonfinite (ongoing) loss. Through data analysis, this research will consider the extent to which parents' experiences can be explained by theories of loss.
- This research utilises a positive methodological approach through Appreciative Inquiry, which has not been widely used within the field, in order to enable parents to more easily identify supportive factors within early identification of learning difficulties.

3.8.2 Informed consent

Due to the researcher working within the field that the sample was drawn from action needed to be taken that would avoid parents feeling under pressure to participate (based on relationship already developed or feeling that participation will result in further support for their child).

- The sample was sought from a different local authority to that within which the researcher worked.
- Consent was sought from the Educational Psychology Service and the head teacher of schools becoming involved.

- The researcher did not approach potential participants directly with requests to participate (Hughes, 2012).   Instead initial contact was made through teaching staff within schools that the researcher was not involved with.
- Information sheets provided to potential participants made it clear that the research project was separate to service involvement or school support and that participation or non-participation in the project would therefore not impact upon the nature of service involvement or school support.
- Information sheets outlined:
  - research aims, methodology and process (in order to aid informed consent);
  - the nature of the main questions used within the interviews;
  - confidentiality, anonymity and examples of when confidentiality may be breached (e.g. if there was concern regarding risk to self or others);
  - right to withdraw from the study without giving a reason;
  - when recordings have been transcribed, data will be made anonymous;
  - prior to the data being made anonymous, participants would be offered the option of amending, adding to or withdrawing any of the content;
  - what would happen with audio recordings
  - what would happen with the results (anonymised summary fed back to the school)

Consent was explicitly sought at two stages in the process (prior to inclusion in the research and at the close of the interview). Consent was sought through use of a consent form at each of these stages.

3.8.3 Confidentiality

There was a risk that the openness of the interview and rapport developed with the researcher may lead participants to make disclosures that they later regret. The following information was given to participants.

- Opportunity to review the tape was given at the end of the interview so that any sections that the participant wanted to remove could be deleted.

- Confidentiality was protected through use of pseudonyms and the removal of identifying data such as names of any other people, schools and local authorities.

- Three schools were used in the study in order to protect anonymity of parents.

- Information sheets outlined situations where confidentiality may need to be breached (e.g. concerns about safety). These were discussed with participants. If the concerns were to relate to child safety the researcher will pass these on to Social Care.

- Participants were made aware that audio recordings would be given to a transcription service (UK Transcription) for typing. The service is regularly used by universities, HMRC, NHS and Gov.Uk. Audio files were uploaded to a 128 bit SSL secure server and file transfers encrypted. All files are permanently destroyed by the service after 10 days. Transcripts are securely stored online for 60 days. Only authorised key staff had access to the server. The website is subject to a quarterly security audit by an external security firm. All staff and typists are subject to a legally binding non-disclosure agreement. Delivery of the transcript to the researcher was arranged by secure download.

- The original audio copy was to be destroyed by the researcher when the study was completed. Full anonymised transcripts will be incorporated into appendices within the write up.

3.8.4 Consequences

Studies have identified positive impact of qualitative interviews in similar scenarios (including increased awareness of positives within situations). Studies have also identified negative impact upon participants (including feeling distressed by discussing the needs of the child and feeling a sense of loss). In one study one mother described the process as an 'ordeal' because it brought back unhappy memories although another mother described the experience as 'uplifting' (Runswick-Cole, 2011). Parents may not independently identify potential factors that could later cause them concern (including emotional impact of discussing child's needs).

- Information sheets outlining these possible consequences were provided to potential participants prior to them agreeing to become part of the research.

- Use of Appreciative Inquiry meant that questions were open in nature and positively phrased (biased towards finding strengths and positive experiences). Although this did not prevent participants from disclosing negative experiences it did reduce the risk of participants feeling obliged to do so.

- The methodology was chosen to allow the researcher to use discussion flexibly and alter wording, cease a line of questioning or provide breaks if a participant appeared to be feeling uncomfortable. In these situations the participant was to be reminded of their ability to cease the interview and withdraw from the study at any time. Signs of distress are not always visible. Therefore the researcher reminded the participant of their ability to break, cease interview or withdraw from the research at any time.

- Use of single rather than repeated interviews limited the risk of development of quasi-therapeutic relations and participants disclosing information they may later regret.

- Parents were made aware that they could request to meet with the researcher or an educational psychologist within the service following the interview, if they would like to discuss anything that arose from the interview. This would not be at any financial cost to the parent or school.

4.0   Methods

The study took place within the geographical area covered by one area team of an Educational Psychology Service. The service was part of a large local authority on the south coast of England. In line with IPA methodology Purposive sampling was used. The Educational Psychology service approached schools with information packs about the study, written by the researcher. Schools that gave their consent to participate in the study approached parents who fulfilled selection criteria.

The selection criteria were:
- The parents had children who had learning difficulties and were receiving SEN support at school.
- The children were in National Curriculum Years 1-3 and attaining within National Curriculum P levels. Only around 2% of children are achieving these levels in these year groups nationally. Therefore the level of need was likely to be large enough for parents to discuss the impact of difficulties.
- Children in Years 1-3 were young enough for the SEN identification process to be fairly recent for the parents.
- Primary schools were situated within the area covered by one locality team of an Educational Psychology Service within a large local authority in the south of England.

Schools provided parents with information sheets about the project. The details of parents who consented to taking part in the study were sent from parents or schools to the researcher. The researcher then made contact with parents in order to set up semi-structured interviews at times and venues convenient to them.

4.1   Participants

Five participants met the selection criteria above and took part in the project. Participants were parents of children who went to three different schools.

One of the participants piloted the interview. The following information was obtained through the pilot interview.

- Interview questions were flexible and allowed the participant to set the parameters of the topic.
- Supplementary prompts were helpful and used on a few occasions.
- Unfortunately recording equipment failed and no data was therefore obtained. The pilot interview did not form part of the analysis. Additional recording equipment was obtained in order to back up the four future interviews.

Data was obtained through four interviews. In one case both the father and mother asked to take part in the study. Two participants were therefore parents of the same child. In enabling both parents to take part in the study the following issues were considered.

- Themes are more likely to overlap because experiences are similar. However, IPA aims to identify homogenous samples which often involve 'snowballing' or 'purposive' sampling. Representative sampling and generalisation of findings are therefore not employed.
- The situation provided an opportunity for two perspectives of the same situation to be explored. This fitted well with IPA methodology since it focuses not only on similarity of themes but differences between individual participants. This was particularly relevant for the theme of denial, in this case.

The table below contains details of the participants. Pseudonyms are used throughout the study to ensure confidentiality. In order to protect anonymity within the small number of participants and schools involved no other classifying data is included. All of the children were in Year groups one to two at school.

Table 1

Participants

Name of parent	Name of child
Amanda (mother)	Ben
Sally (mother)	Sam
Meg (mother)	Max
Mike (father)	

4.2   Analysis

The 7 step process of analysis outlined by Smith et al. (2009) was utilised. In analysing themes for a group, extended extracts from single participants followed by short extracts from others and/or summary tables were used in order to demonstrate the presence of the theme across cases.

The following transcript notation was used:

…	significant pause;
[ ]	material omitted; and
[her husband]	explanatory material added by researcher.

Smith et al. (2009) state that the definition of recurrence of a theme is important. They state that a theme could be considered recurrent if it exists in a third, half or most stringently in all interviews. In this study superordinate themes were present for all of the participants. Subordinate themes were considered recurrent if they were present in at least half the interviews. The table of results at the end of each section of analysis displays examples of recurrence.

4.3   Chronology

1. Information pack sent to local authority
2. Gatekeeper letters sent from local authority to schools.
3. Schools approached parents who met selection criteria and provided information packs.
4. Schools and/or parents returned consent to researcher.
5. Researcher contacted parents and arranged interviews on a case by case basis.
6. Data analysis on a case by case basis.
7. Researcher undertook analysis of patterns across cases.

4.4   Interview questions

Hefferon and Gil-Rodriguez (2011) state that interview schedules should be short with open ended questions in order to allow participants to set the parameters of the topic without being led by the researcher. Smith et al. (2009) suggest that for adult, articulate participants, a schedule with

between 6 - 10 open questions, along with possible prompts will tend to occupy between 45-90 minutes of conversation, depending on the topic.

At the start of the interview the following information was given to participants.

- Discussion usually takes between an hour to an hour and a half.
- Although I have some ideas of questions I would like to ask, I do not have a pre-set agenda and I am interested in what you have to say about the topic, in as much detail as you would like to give.
- I am interested in you and your experiences. Therefore there are no right or wrong answers.
- During our discussion I will say very little, because I am interested in hearing and learning as much as I can about you and your experience.
- Some of my questions may seem self-evident but that is because I am trying to hear how you understand your experience.
- It will be helpful to take your time in thinking and talking to allow you to reflect on your experiences and give as full answers as possible.

4.4.1 Main questions

How did it become apparent to you that your child has SEN?

Possible prompts:
- Can you describe what happened and how you felt when you found out that your child had SEN? / How did you come to know that your child has SEN?
- If you could go back in time, what would you tell yourself as you were finding out your child had SEN?

Thinking about when you first found out your child had SEN to now, how would you describe the relationship between you and your child's school(s) over time?

Possible prompts:
- Are there ways in which having a child with SEN has affected your relationship with school?

- What have you appreciated most about the way in which the school has worked with you?
- Are you aware of things that the school has not done/avoided which has helped develop your relationship?
- In what ways could your relationship with your child's school(s) be developed further?

What has helped you to manage as a parent of a child with SEN?

Possible prompts:
- Personal
  - What do you do to help you cope currently (and in the past)?
  - What personal traits do you draw upon?
  - Are there any thoughts that help you?
- Others
  - How do school (staff) support you? How are your needs met?
  - Were you aware of things that the school did not do, that really helped you?
  - What do you feel about the support being offered to you?
  - What have you appreciated most?
  - What would be the best help right now? / How do you feel support for you could be developed further?

Can you describe your feelings about raising a child with SEN?

Possible prompts:
- Thinking back to when you first found out your child had SEN to now - do you experience things differently now?

Has having a child with learning difficulties changed you in any way (values, expectations, priorities)?

Possible prompts:
- Are there any positive consequences of your child's difficulties?
- How has your awareness of positive consequences changed over time?

What thoughts and dreams do you have about your child's future?

Possible prompts:

- How do you feel about those?
- How have your thoughts and dreams changed over time?
- How have you managed that?

How do you think other people see your child?

Possible prompts:

- What affect do their views have on you?

Finally...
If you heard about another parent who had just found out their child had SEN what would be the best piece of advice you could give them?

4.4.2   Appreciative Inquiry and interview questions

This study utilised Appreciative Inquiry in order to avoid the negative bias that has been identified in research with families of children with learning difficulties (Hastings et al., 2002). The approach involves appreciating or 'discovering' the best of situations. As noted previously, although Appreciative Inquiry avoids negative bias it still allows participants to choose to explore problems and negative experiences in working with professionals. AI can offer an alternative way of viewing problems (Hammond, 1986) and lead to a better understanding of both the negative and positive within an experience than would a problem solving approach which begins at the level of the negative (Michael, 2005). Questions were designed to therefore be open and positive or neutral. In constructing questions the interview structure provided by Michael (2005) was analysed. Michael (2005) was the first to develop use of AI as a stand alone interview tool. She incorporated a range of positive and neutral questions. Positive questions within this study explicitly sought what was working well (e.g. "What have you appreciated most about the way in which the school has worked with you?", "Are there positive consequences of your child's difficulties?", "What thoughts and dreams do you have about your child's future?"). Neutral questions provided a stimulus for discussion (e.g. "How did you come to know that your child has SEN?", "Has having a child with

learning difficulties changed you in any way?"). The interview was
constructed to avoid any negatively biased questions. The interview
questions were piloted and it was evident that it was possible to respond to
both positive and neutral questions with both positive and negative
descriptions of experiences. This meant that the structure did not preclude
negative experiences from being discussed but avoided negative bias.

5.0   Analysis and discussion

Analysis of each transcript was conducted following the 7 step model described by Smith et al., (2009) and outlined in section 3.5.

1. The transcript was read and re-read twice (while listening to the audio recording). This allowed the researcher to internalise and hear the voice of the interviewee during subsequent re-reading. Transcripts were generated within two days of the interview having taken place. This was in order that the content was relatively recent to the researcher and that additional notes could therefore be added where appropriate (e.g. tone, emotion, pauses/hesitation, laughter, crying).   Some amendments to the typing were also made at this stage (e.g. where the transcriber had misheard a word). The initial and most striking observations about the transcript were recorded in a note book in order to enable these to be bracketed off.

2. During the third reading of the transcripts descriptive comments (about key words/phrases) and linguistic comments (about pronoun use, metaphors, repetition) were made in the right hand margin of the text. During the fourth reading of the text conceptual comments were added to the notes in the right hand margin. These focused upon the range of potential meanings that could be drawn from the interviewee's description. Phrases that appeared particularly striking were underlined within the text and commentary regarding why these appeared important was made within the right hand margin.   Many of these underlined sections became quotes that were used in the write up of the analysis. On occasion parts of the text were read backwards (this was in order to focus on particular words and meanings and avoid superficial reading).

3. During the fourth reading of the text the notes in the right hand margin were focused upon rather than the transcript itself. Comments were analysed to identify emergent themes using language that reflected psychological concepts/theory. These were noted in the left hand margin. This process was repeated a second time in order to avoid missing concepts that may become evident during a second reading.

4. All the emergent themes were typed up into a chronological list. Themes were then moved around to create clusters. Superordinate themes were developed which subsumed several emerging themes. The process of subsumption involved an emergent theme becoming a superordinate theme as it brought together a number of emergent themes. Abstraction was also used in generating superordinate themes. This involved placing similar themes together and developing a new name to encompass them. For example similar themes "loss of expected schooling" and "loss of perfect story/fairytale" were encompassed by "loss of ideal/expected future".

5. The researcher then moved on to the next case and repeated steps 1-4.

6. Printed copies of themes from each case (obtained in step 4) were then compared. Superordinate themes in some cases highlighted concepts that other cases shared. Table 2 was created to represent the way in which themes were clustered for the group. Appendix 1 was generated in order to pull together evidence for themes from each participant. Superordinate themes were present in all cases. Emergent themes were considered recurrent if they were present in half of the interviews.

7. The analysis was then written up with tables of themes, descriptions of emergent themes and descriptions of similarities/differences between individual accounts. These were illustrated with some of the quotes that had been highlighted during the analysis.

The following analysis is structured by superordinate theme. Each superordinate theme is broken into subordinate themes. Analysis of each subordinate theme is presented, followed by discussion related to literature, before then moving on to analysis of the next key theme. Smith et al. (2009) propose this structure enables researchers to weave analysis and discussion together.

Three superordinate themes were identified.

- Social comparison of performance.
- Sense of belonging.
- Loss.

Each of these superordinate themes incorporated a number of other key themes. Table 2 outlines the themes that were illuminated.

Table 2

Themes that were illuminated through analysis

Superordinate theme	Sub-ordinate themes	Component themes
Social Comparison of performance	*Comparing Progress*	*Comparison with peers/siblings or developmental norms*
		Professionals modelling use of social comparison
		Frequency of social interaction restricting social comparison
		Comparisons instigated by others uncomfortable (leading to loss and jealousy)
	Comparison of parenting	*Comparison of parenting approaches with sought advice*
		Judgement of others
	Children's awareness of comparisons	*Child's comparison with peers*
		Peer comparison with child
Belonging	*Child's sense of belonging*	*Inclusion vs. exclusion and stigma amongst peers*
		Parental protection from social exclusion
		Ability to participate in social interaction
		Equality of recognition from staff
	Parents' sense of belonging	*Inclusion vs. exclusion and stigma amongst parents*
		Loneliness
		Recognition from staff
		Identity
Loss	*Loss*	*Guilt and searching for meaning*
		Loss of ideal/expected future
		Loss of 'normalcy' (impacting on belonging and comparison)
	Denial	*Self doubt*
		Avoidance – due to fear of loss (stigma and belonging)
	Positivity	*Identifying strengths*
		Reducing importance of difficulties
		Correcting negative thoughts

Appendix 1 contains a table of complete results for the study.

5.1   Social comparison of performance

One superordinate theme present in all interviews was social comparison. This theme appeared to have a number of functions. For example, participants used comparison with peers to evaluate whether their child was experiencing developmental delays. Participants compared their own parenting experiences with that of others in order to evaluate whether their approach was adequate. Parents were aware that children were also using comparisons (possibly modelled by others) and were concerned with the impact of this. Subordinate themes within the superordinate theme are illustrated in Table 3.

Table 3

Themes within Social Comparison of Performance

Social comparison of performance
<u>Comparing progress</u>
Comparison with peers / siblings or developmental norms
Professionals modelling use of social comparison
Frequency of social interaction restricting social comparison
Comparisons instigated by others uncomfortable (leading to loss and jealousy)
<u>Comparison of parenting</u>
Comparison of parenting approaches with sought advice
Judgement of others
<u>Children's awareness of comparisons</u>
Child's comparison with peers
Peer comparison with child

5.1.1 Comparing progress

5.1.1.1 Comparison with peers/siblings or developmental norms

Two mothers described being aware of their child experiencing difficulties at a young age, well before starting school. They described comparing their child's progress against developmental milestones.

> Erm, it was qui- well, it was quite early on that I th- I thought he was a bit behind his peers. This was, you know, we're talking, erm…I mean, at six months he was doing everything bit delayed, and he didn't walk till he was 17 months, which perhaps isn't that late. He kind of reached all the milestones, but kind of just.
> Amanda (lines 8-14)

> Erm, Sam, from a very early age, erm, was quite late in doing a lot of things, like crawling, walking, erm, talking, erm and my Mum had a stroke before he was one. So I was the carer of my Mum for quite a long time. So Sam used to come with me, my Dad used to take him up to the farm. Erm, so he wasn't around other children, erm, a lot. So some of me thought his speech was behind because I had spent so much time over there.
> Sally (lines 17-28)

Parents did not describe where they found information relating to developmental norms. It is not clear whether they sought this information due to concerns or whether this information triggered their concern. Comparisons with developmental norms in these cases did highlight the delays for their children. However, both of these parents expressed a sense of doubt regarding the significance of difficulties for their children. Amanda indicates Ben "kind of" reached milestones "kind of just", indicating an uncertainty in her evaluation of his performance. Sally expressed doubt about the significance of Sam's difficulty, implying he may catch up when he spends more time with other children.

Although Mike did not explicitly refer to developmental norms he did indicate a sense of evaluating unusual strengths within his child (which indicates a sense of norms and therefore comparison). At times comments made by Mike and Sally indicated a possible difficulty understanding typical development and developmental norms. This could lead to over-estimating strengths and considering them to be atypical.

> … he's like a sponge. He absorbs everything that's told to
> him. He just can't write it down.
> Mike (lines 196-198)

> So he has got like Lego games and he's an absolute whizz
> on it.
> Sally (lines 215-216)

> And he, he's - it's - I dunno what it is. I don't - I can't explain
> it, but information is just inside his head, and it just baffles
> around, and he comes out with these amazing facts, and
> you think, "Where the hell did that come from?"
> Mike (lines 202-206)

This potential difficulty understanding developmental profiles could also be linked to Amanda and Sally's uncertainty regarding their evaluation of skills.

In addition, difficulty understanding development and learning processes could lead to considering normal learning processes part of an underlying learning difficulty. For example the need to develop accuracy prior to fluency (Haring, Lovitt, Eaton, & Hansen, 1978) and need to consolidate learning being misunderstood as evidence of an underlying learning difficulty. Experiencing difficulty evaluating progress against norms could create a sense of confusion about a child's development.

> And you could spend say ten minutes and he could improve,
> but if he did it again say an hour later, you would be back to
> square one again. Which obviously is frustrating because,
> you, you know, he should be retaining some of what he is
> supposed to be doing, and the same with letters.
> Sally (lines 151-156)

> So nothing is a set rule with Sam. Sometimes you don't
> think he's going to understand something and he does.
> Sally (lines 402-404)

> Yeah. I don't know, it just doesn't make sense what he can
> and can't do.
> Sally (lines 1628-1629)

Sally described being concerned about a possible difficulty and then being reassured by peer comparison (as if she was uncertain of typical development).

> Erm, but when he's with his friends and they are all excited
> and erm, they're all doing exactly the same things. I don't
> know why I'm worried that he is doing certain things.
> Sally (lines 1551-1554)

All of the mothers interviewed described comparing their child's progress against the achievement of peers and/or siblings.

> In Year R…in my head… I sort of knew deep down… he was definitely falling behind because it…because I thought then like where they all were. Like where he was he was getting further and further behind.
> Meg (lines 26-29)

> But I suppose I just, from spending time with other mums and stuff- I just sensed that there was things that he was per- perhaps a bit behind on.
> Amanda (lines 18–26)

> And, you know, Millie picked up on things quickly, Sam didn't. But then I think that helped show me how bad Sam was at certain things, and that he wasn't so, probably why I picked up on things from the beginning.
> Sally (lines 1921-1925)

> Erm, but then they are growing up at a different speed, his friends, erm, and you know the conversations that you have with them when you take them to Beavers and everything, it's completely different to the way Sam speaks.
> Sally (lines 584-588)

Comparisons therefore helped parents to evaluate whether or not their child may have developmental delays.

5.1.1.2 Professionals modelling use of social comparison

Three parents identified that professionals helped them to recognise the level of need that their child had through also using comparison.

> And then we had an appointment with Mrs Smith [deputy]. And she went through where he was in his stage. To where the others were at key stage…and how far back he had fallen.
> Meg (lines 10-13)

> Well he just started falling behind the rest of the class. It…it became noticeable um at the parent's evenings and everything. And uh… my wife thought there was a problem in Year R and I just thought it was the fact that everybody learns at different speeds. And then it, it was really brought apparent to us this year, year 1…By like the teachers basically.
> Mike (lines 11-25)

> Erm, well they had done different tests on him and he
> scored very, very low, erm, 0.1% on a lot of them. And the
> things that he was stronger on, he still was very below. Erm,
> which I knew to some degree but not quite how bad.
> Sally (lines 619-623)

Both Meg and Sally identified that it was teacher discussion that helped fathers to recognise the level of difficulty their child was experiencing. Comments indicate that teachers used comparison with peers to help parents recognise delays.

> I think all the meetings that I have been to about Sam, it's
> been myself on my own, because Mark works very long
> hours. And even though I've discussed it with him, but
> hearing it from somebody else seems to sink in a lot more.
> Sally (lines 544-548)

One function of comparison appeared the evaluation of 'normal' and the opposite construct 'abnormal'.

> And, it's the fact that we are trying our hardest to make him
> feel e.g. normal…
> Sally (lines 518-519)

> They've treated him just like a normal child.
> Amanda (line 1769)

> 'cause he's not going to learn perhaps in the same way as
> perhaps a [whispers] 'normal child'
> Amanda (lines 384-385)

> Erm, but I just felt he needed to learn what was normal.
> Because he essentially is, in my eyes, he's just a bit behind.
> You know. 'Cause he gets to it, he gets to every, you know,
> he just gets there a little bit later than people.
> Amanda (lines 1049-1056)

Comments indicated a need to help children feel normal but an implied sense that things were not normal. Amanda indicates a sense of discomfort in using the word 'normal' by the way she whispers this. She highlights development as following the typical pattern (despite being delayed) as if this perhaps offered some compensation. Data analysis indicated that evaluation of 'normal / abnormal' may be linked to recognition of a need to belong. This is explored within the following superordinate theme of 'sense of belonging'.

5.1.1.3 Frequency of social interaction restricting social comparison

Social comparisons are largely dependent upon opportunity for social contact (through which comparisons can then be made). Parents had different opportunities to compare development (particularly due to work commitments). Amanda identified that she had more opportunities to compare the development of children.

> And I would spend more time with other children - because Chris was at work, he didn't do the coffee mornings and that, you know - so he wouldn't necessarily see how different Ben could be at times.
> Amanda (lines 114-117)

> Erm, but I, but I think realised that I could see it more because I saw the comparison with other children that they [grandparents] didn't see so for them it was easier to deny.
> Amanda (lines 1968-1971)

> It's taken my dad a long time to realise that, it's just again, not seeing the comparison between other children which is what I saw and I was much closer to that. Whereas, the grandparents aren't, okay, I've got two nephews but they weren't at a similar age at the same time, they were a bit older and it's easy to forget what they were like.
> Amanda (lines 1917-1923)

Meg described being aware of differences through parents in the playground.

> I sort of knew through other parents in the playground where their child were but I was thinking "oh, he'll be fine, he'll be fine" but … he just doesn't quite… grasp it, bless him.
> Meg (lines 18-21)

Both Meg and Sally describe their husbands not agreeing that there was a significant difficulty for their child until they met with school staff.

> I think I just knew and I kept talking to Mike about it. He said "no he'll catch up, he'll catch up". And it wasn't until we had parent's evening in Year One that he actually realised that Max was falling way behind.
> Meg (lines 6-9)

> I think Meg knew. But I thought he'd just catch up. But his spellings or tricky words wasn't… he wasn't catching up with the other kids that were doing the tricky words. But I didn't

> realise the severity of it … until Year One.
> Mike (lines 51-55)

> Well he just started falling behind the rest of the class. It…it
> became noticeable um at the parent's evenings and
> everything.
> Mike (lines 11-13)

> … but I think all the meetings that I have been to about
> Sam, it's been myself on my own, because Mark works very
> long hours. And even though I've discussed it with him, but
> hearing it from somebody else seems to sink in a lot more.
> Sally (lines 544-548)

While Amanda and Sally state that their husband's work commitments reduced comparison with others or discussion with school staff, Meg and Mike do not indicate whether Mike had less contact with school and fewer opportunities for comparison. However, Meg does indicate that she was able to make comparisons in the playground (implying that she was taking/collecting Max from school).

Data analysis indicated that where social opportunity for comparison was available this was used (sometimes in conjunction with developmental norms). When opportunity for social comparison was not clearly available this was facilitated through formal meetings with staff.

5.1.1.4 Comparisons instigated by others uncomfortable (leading to loss and jealousy)

Although all the mothers were choosing to utilise peer comparisons they also identified that they did not always find comparisons helpful (particularly when instigated by others).

> You know, Year R, they'd come home with paintings and
> stuff like that - Year one, you know, was quite hard. As much
> as they all knew, it was never a secret, I never kind of hid it,
> it was quite hard to listen to them kind of saying how
> wonderful their, what their child had done and Ben hadn't.
> Amanda (lines 1255-1261)

> You go to crèches, "Oh my child is doing this." So there is
> pressure on you from day one to be a certain way. And, you
> know, if you don't feel great or whatever, post natal stress, it
> makes you feel like a failure from day one.
> Sally (lines 1914-1918)

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A lot of people do boast, on social media sites, about how well their children are doing, and that sort of thing especially like his year. And that makes you think, "Oh," you know, "he's not doing as good as them," sort of thing. But I just feel [sighs] just try to ignore it, really. Just try to ignore it. But I think all my close friends just think of him as Max. They don't ever say anything about, "Oh, why isn't he doing this?" No-one ever questions me. I talk to them about it, just to talk to someone about it. But nobody ever questions me, "How's he doing with his reading? Can he do his tricky words yet? Can he write?" You know, "What can he write?" Nobody ever questions me, but I will speak to them about it. But they just think him - of him as Max, and you know, and they're quite encouraging, really. [Pause]. And also, another positive is that he always… even in actual assembly … they have assembly each week, and you get awarded for special things you've done in class, or special pieces of work. He gets act- nominated so often, and get put up so often. Even though he's not up there, he still gets actually awarded for all his efforts.
Meg (lines 430-465)

None of the participants highlighted that others made direct comparisons with their child. However, others talking about their own children's attainment caused participants to spontaneously reflect on comparison between the children. Comments from Sally and Meg indicate that they may feel other parents were deliberately making comparisons between the children. Meg suggests this through her use of the word "boast" and Sally through her reference to external pressure. Meg highlights appreciation of others not making comparisons or asking questions but instead accepting and encouraging her child as he is. Comparisons that highlight difficulties could be uncomfortable because they invoke feelings of loss. Comments from all the mothers indicate a sense of loss through comparison (recognition of their child not being able to do something). Sally goes further to indicate that she felt she was failing due to her child's delay. As if his performance was linked to her ability as a parent. Amanda indicates that with loss she also felt a sense of envy or jealousy.

…I don't get jealous. I suppose I did, you know, of what all these other kids did. I don't get jealous because I just…Now I'm in a position to celebrate what he does [cries while continues talking].
Amanda (lines 1320-1325)

Amanda appeared sad whilst talking about celebration, which indicated a possible sense of on-going loss whilst celebrating. Loss and celebration appeared to co-exist for Amanda. This is echoed in her later comments.

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And you know, just hearing how happy they are about the
fact that their kid's done this, that and the other. That's quite
difficult to think he won't, he won't ever do that, or he's not
doing that.
Amanda (lines 1276-1280)

I sometimes look at other parents who've got two kids that
are really bright and are always do this and I sort of think,
"Do you appreciate, do you appreciate what you have
because I don't think you do until you have something
slightly different."
Amanda (lines 1366-1370)

Amanda's last comment indicates a possible on-going sense of envy in that
she is wanting others to appreciate what they have. This is also echoed
below.

But I'm looking forward to having a child that goes through
school without the issues. You know what I mean? To be
able to be in that position to go, "Isn't that brilliant? Yeah
look, she's done the same," you know?
Amanda (lines 1334-1338)

In Meg's comment above (lines 430-465) she highlights that she tries to
ignore boasting on social media sites. She follows this by talking about her
child's achievements and the recognition he receives for those. Mike and
Amanda also appeared to use a strategy of focusing upon personal
achievements rather than using comparisons with others, at times.

It also helped that he was getting help and he was starting
to write and he was reading stories and stuff like that. So I
could see that there was light at the end of the tunnel. It
didn't feel quite so. You know, if other kids came out, I could
see that their writing was that size [indicates small], you
know, and Ben's was like that size you know [indicates big],
but I was able to celebrate all of his achievements because
he was achieving then, you know.
Amanda (lines 1303-1311)

[…] he's got his own- set of goals that he's got to achieve,
and he did. He achieved them. Erm, by the end of the term,
he's gotta… This is like one, two, three, four, five, and then,
after that, there's like key stage one and everything. He's got
to where Mrs Smith wanted him to be. So he's, he's done
that. So his progress, you're, you're just dead proud that
he's done the progress he's doing in his time, you know?
Mike (lines 57-68)

However, Amanda highlights that she wants to be able to participate in

comparisons and find similarities and that she looks forward to doing this with her next child (lines 1334-1338).

She highlights the on-going appeal of social comparison. Despite currently ceasing upward comparison with other mainstream peers she looks for opportunities to make comparisons with peers who have greater needs. She describes one way in which she can continue to use comparison to self enhance her situation.

> …when he got diagnosed with global development delay, I joined a Facebook group or something and "My child's got global development delay," and actually, I mean, in a way, selfishly I quite like looking at it because there are people on there with a whole lot more problems than I've got, um, but a lot of them say the same thing, you know, "You wouldn't be without them." And I know that's a cliché but I wouldn't, because I wouldn't.
> Amanda (lines 2149-2157)

Amanda's comment indicates that she finds it reassuring to know that she is not the only family experiencing developmental delay and that there are others worse off. Her use of the word 'selfish' seems to imply that she is aware that she is engaging in social comparison in order to help herself feel better and that she may also be aware that she is only achieving this through others experiencing greater difficulties.

Table 4

Summary of themes within comparison of progress for parents

Social comparison of performance - Comparing progress				
Transcript extracts				
(Numbers in brackets refer to lines in transcripts)				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Comparison with peers / siblings or developmental norms	*"kind of reached all milestones" (8-14)* *"he was perhaps a bit behind" (18-26)* *"growing up at a different speed" (584-588)*	*"[he] was quite late" (lines 7-28)* *"he's an absolute whizz" (215-216)* *"doesn't make sense" (1628-1629)* *"Millie [sister] picked up" (1921-1925)*	*"further and further behind" (26-29)* *"how far back he had fallen" (10-13)*	*"he's like a sponge. He absorbs everything" (196-198)*
Professionals modelling use of social comparison		*"he scored very very low, erm 0.1%" (619-623)*	*"she went through where he was" (10-13)*	*"falling behind the rest of the class" (11-25)*
Frequency of social interaction restricting social comparison	*"I saw the comparison with other children" (114-117, 1968-1971, 1917-1923)*	*"hearing it from somebody else seems to sink in" (544-548)*	*"I sort of knew through other parents in the playground" (18-21)*	*"I didn't realise the severity" (11-13, 51-55)*
Comparisons instigated by others uncomfortable (leading to loss and jealousy)	*"what their child had done and Ben hadn't" (1255-1261)* *"I don't get jealous. I suppose I did." (1320-1325)*	*"Oh my child is doing this." (1914-1918)*	*"people do boast, on social media" (430-438)*	

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5.1.1.5   Discussion regarding comparison of progress

All participants used comparisons of progress to some degree (Mike to a lesser extent) to evaluate their child's progress. Mike's lack of comparison may have been due to him not initially having concerns about his child's difficulties. Conversely, limited awareness may also have been caused by lack of comparison.

In line with research (Klein, 1997; Mussweiler & Epstude, 2009) parents appeared to continue to choose to make use of social comparison alongside developmental norms, where available. Mussweiler and Epstude (2009) suggest that this can be due to social comparison being more efficient and easier than complex decision making against criteria. Despite this, parents appeared uncertain of their evaluations. Limited understanding of learning processes (Haring et al., 1978) also impacted upon ability to assess whether a difficulty was part of a typical learning process or indication of a special educational need. Peer comparison sometimes resolved this difficulty (e.g. Sally, lines 1551-1554).

School staff were identified as using social comparison and this helped Ben and Max's fathers to recognise difficulties. It is not clear from the interviews how much staff may also have used data alongside comparison with peers. Although Amanda and Sally had difficulty recalling specific information about assessments undertaken, Sally did recall a test result (likely a percentile score). The fact that Sally was able to recall the test result (but not the details of the tests) suggests that the comparative data was significant to her. It appeared to help her recognise the severity of Sam's difficulties, although she did not appear as clear about what this meant. Research indicates that parents often do not understand assessment data and consideration needs to be given to the way in which data is explained (Eissenberg & Rudner, 1988; Flanagan & Caltabiano, 2004; Mansell, James, & The Assessment Reform Group, 2009).

Despite parents being keen to use social comparison to identify whether there were differences/difficulties for their child they were keen for their child not to feel any different than their peers and for staff to acknowledge them in the same way they did for other children. Data analysis indicated that this may be linked to parents recognising their child's need to belong.

This theme will therefore be explored further in the following section regarding belonging.

Social comparisons are dependent upon social contact (Festinger, 1954). Mothers appeared to recognise that their identification of difficulties resulted from opportunity to engage in social comparison (e.g. observing children playing during coffee mornings and at 'Beavers clubs', playground discussion with parents, social media sites and discussion with parents at crèche). Availability for social comparison appeared to be impacting upon the ability of some family members to make use of this approach in identifying difficulties (e.g. grandparents and fathers). The role of school staff seemed particularly helpful for Mike in this instance in providing comparative data.

All of the mothers in the study talked about others celebrating their own children's progress. Although mothers were not explicitly encouraged to do so they all made comparisons of an upward nature in response. This is in line with evidence from Dunning and Hayes (1996) who found that simply being aware of information about others leads people to relate the information to themselves. Upward comparisons in this context led to mothers indicating a sense of loss/envy when their child did not match the comparison. This echoes findings from previous research (Gibbons & Gerrard, 1991; Taylor & Lobel, 1989; Wood, 1989).

Amanda, Meg and Mike reported either ignoring comparisons or beginning to focus upon their child's achievements and use self-comparisons instead. Ceasing comparisons with others that are very different is in line with hypothesis four within Social Comparison Theory (Festinger, 1954). The comparison of self through time identified within parents of this study is omitted within Social Comparison Theory (as this strategy does not involve comparison with others) but it is perhaps one way parents were able to continue comparisons without negative effects. This concept has been identified within Temporal Comparison Theory (Albert, 1977). The theory proposed an extension to Social Comparison Theory (Festinger, 1954) to allow temporal or historical comparisons to be made for the same individual between two different points in time. Albert (1977) proposed that temporal comparisons were more likely to occur when the quality of the present is negative and individuals are seeking to analyse what may have caused

deterioration. However, for the parents in this study temporal comparison was being made in order to celebrate progress and a more positive present. This is supported by more recent research which has found that when people are wanting to enhance themselves temporal – past comparisons tend to be used (Wilson & Ross, 2000). These comparisons tend to be preferred when they indicate progress over time. Although, social comparisons may again be favoured when people are focused upon accurate self-evaluation. This could explain Amanda's desire to be able to use social comparison with her daughter and typically developing peers.

Amanda highlights the on-going appeal of social comparison for her. Although she ceases upward comparisons with typically developing peers peers she identifies that she can use downward comparisons in order to experience self-enhancing comparisons. Research has found that people tend to make self-enhancing comparisons of a downward nature when they are feeling low (Johnson & Knobloch-Westerwick, 2014; Vogel, Rose, Roberts, & Eckles, 2014). Comparing their situation to a worse situation can help people to feel better off (Gibbons & Gerrard, 1991; Taylor & Lobel, 1989; Wood, 1989). Studies have indicated that social media is often used with social comparisons (Johnson & Knobloch-Westerwick, 2014; Lee, 2014; Steers, Wickham, & Acitelli, 2014) in the way that Amanda describes. Amanda's sense of discomfort in using downward social comparisons in this way is echoed by research investigating the experiences of parents in social support groups (Hodges & Dibb, 2010).

Although there is evidence that downward comparisons improve well-being (Wills, 1981) it is not possible to identify whether it served this function in the instances described within this study. However, it seems possible to identify possible benefits of comparisons being used in this way such as how looking at how developmental delays are less severe than other people's on Facebook might help a parent to reflect on their child's comparative strengths. Downward social comparison may also help parents to reflect on the limited impact that developmental delay has had upon their life, in comparison to children who require 24 hour care that Amanda describes (Huws & Jones, 2015).

5.1.2   Comparing parenting approaches

Data analysis indicated that parents used social comparison in order to evaluate parenting approaches. Two methods were used:

1. Comparing parenting approaches with sought advice
2. Judgement of others

5.1.2.1   Comparison of parenting approaches with sought advice

Data analysis of all interviews highlighted a role for social comparison in order to seek advice about ways in which to develop their support for their child. Parents tended to compare their approach to advised approaches in order to evaluate whether they were making the best provision for their child. Advice tended to be sought in three ways:

1. published information;
2. feedback from other parents; and
3. professional support.

Both Sally and Amanda sought written advice about their child's needs. Although Sally reflected the difficulty of using comparison when even published advice differs.

> You know, when she said what the issues were, when I read about it I was like, "Absolutely that." That's it, it's a, it's a motor planning…
> Amanda (lines 615-617)

> Erm, the thing is, a first time parent, okay, like I said, there's no rule book. From, some people have never had anything to do with children at all. And all that they go through to begin with, "Am I doing this right?" And read loads of books and everything says something different. Erm, and then yeah and then they start learning. Some of them pick up things quickly, some don't. "Am I doing this wrong?" You go to crèches, "Oh my child is doing this." So there is pressure on you from day one to be a certain way. And, you know, if you don't feel great or whatever, post natal stress, it makes you feel like a failure from day one. And then erm, you know, you never know if you're doing things right, all you can do is your best.
> Sally (1906-1920)

Sally implies that she may have done lots of reading to find out how to

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support her son but that advice differed. Evaluation proves difficult when standards differ. Sally's suggestion for first time parents implies that other parents may rely on previous experiences of parenting to try and work out how to approach a child's needs. However, previous experience may be of little help if current experiences are very different. Sally has an older daughter and still describes difficulties evaluating her approach. Sally's need to evaluate indicates a possible concern that her approach is not working. Comparison is acknowledged to increase pressure for Sally.

Sally felt that she would like to seek greater support from other parents and that teacher support had cost her this in some ways.

Sally:	But then talking to other mums with their, about their children's problems, they are all totally different, different needs of how erm…That helped me slightly though, to know that Sam wasn't the only one, and to know that erm, you know they are having trouble but in different aspects. Erm, because I think sometimes it can feel quite lonely, thinking that you're – you know Sam's the only one with problems, erm, but it's just getting to know how to help him.
Interviewer:	How did you talk to other parents? Is that just sort of through being in the playground together and just chatting?
Sally:	Yeah.
Interviewer:	Yeah, so it's just informal?
Sally:	Or when I'd gone in early in the mornings, erm, one mum had been in early in the morning and I'd just overheard her saying, making a comment. Erm, so I approached her and erm, so and it's just gone on from there really, sort of. I don't see her that often because obviously going in early you don't always see parents from the same class. So, in one respect I haven't got to know people that well, because of that. Erm, but I think it is important maybe to, you know, other children in the school with problems, maybe that they can help you in some way and give you some different feedback of what helped or erm…
Interviewer:	What …other parents giving you that feedback, about what helped in their situation?
Sally:	I think, I think because every child's different, but you can take something out of what that

child has been like and what has helped them or what is not helping them, to put in your situation. So I think it, you know, but you can't put on the newsletter whatever children with special help meet at a certain time for a chat. It's not like that, but by talking to one person, then they know somebody erm…

(Lines 1078-1133)

Sally reflects that peer support helped her to know that she was not on her own in facing difficulties. This means that her field of comparisons then had the potential to change (to others who are also experiencing difficulties). It may also have restored some sense of 'normality' that Sally made reference to seeking, in earlier comments. Sally highlights that seeking support from the teacher in the mornings had cost her parent support to some extent because there was less opportunity to mix with other parents at that time. This suggests that teacher support was perhaps more important to Sally but that she wanted both forms of support. Her comments indicate that she has been proactive in seeking out parental support. It is not clear why she felt informal networking was more appropriate than an organised group approach. Data analysis indicated that this could be related to embarrassment or stigma or alternatively that group support may be less beneficial because of the range of needs represented. Sally felt that parental support is hindered by the level of similarity / difference between children's needs but recognised that some support can be applied to different situations.

All parents sought professional advice either from teachers or external agencies. Amanda sought professional support from a private occupational therapist. Meg, Mike and Amanda sought professional support from private speech and language therapists. They all identified a need for further support that was not available from the National Health Service (Amanda lines 269-271; Mike lines 622-632).

And he had speech therapy with the, the National Health people. They were absolutely a- rubbish. You know, you get a block set of like three or four. Then they don't see you for three months. And then you get another three. You know, it's abs… that's why we've got private now… to, you know, to try and keep it going, you know.
Mike (lines 622-632)

So she [occupational therapist] said, "Oh, I'll get the school

OT to, you know, come and talk to you or whatever." But she gave us - well I took, she sort of talked about the whole kind of, "Yes, we can get him to sit on mats, and we can get him to wear jackets, and all this sort of stuff." And I was like, "Oh that sounds really good, and it makes sense, and I can see-" It did help to understand this whole, you know, he's a sensory seeker- So he loves playing with my hair. He likes being tickled. He needs to be rubbed and tickled, particularly in the morning, just to kind of, you know, get those messages going.Er, so that really helped to understand what some of his behaviours were.
Amanda (lines 142-163)

Amanda highlights that professional support helped her to understand Ben's needs and the function of his behaviour. Her comments indicate that she was able to make sense of his behaviour in the light of assessment information. There is a sense of her comparing this information to her parenting and changing her approach accordingly (e.g. providing more sensory experiences).

5.1.2.2   Judgement of others

Parenting was evaluated to some extent through the judgements of others. Feedback from others was either encouraging or discouraging. Feedback from staff tended to be encouraging. Feedback from other parents was mixed (perhaps due to difficulty identifying children's needs).

Parents described encouraging feedback as including:
1. recognition of children's progress;
2. identifying parenting strengths
3. identifying children's strengths (as evidence of positive parenting)

Mike and Meg identify that they were proud of the pride of others in their son.

And also Mrs Smith really encouraged him, and she was really proud. So that made us feel happy that school were proud of him.
Meg (lines 96-98)

But I'm really proud for achieving what he's trying. 'cause he's got his own t- like, with Mrs Smith, he's got his own- set of goals that he's got to achieve, and he did. He achieved them. Erm, by the end of the term, he's gotta… This is like one, two, three, four, five, and then, after that, there's like

key stage one and everything. He's got to where Mrs Smith
wanted him to be.
Mike (lines 55-62)

Mike identified that the teacher had set realistic targets which enabled them to identify and track progress. Mike describes a sense of pride and achievement in meeting targets. Pride indicates a sense of investment in his son.

Meg talked about a certificate Max received from staff.

And the teachers even done one, at the end of last year, for
his special effort in his trying so hard at all his work. And that
was from the head teacher and the teachers that gave him
that. That's only two in the whole of his year that got that.
Meg (lines 477-481)

Meg used comparison to indicate how many other children received a staff certificate. Frequency appeared to add to the significance of the occasion. It is not clear how many times Max may have experienced being in the "top two".

Pride may increase positive evaluations of parenting in the way Sally describes below.

Because a lot of parents feel that, you know, their children is
as good as the parenting […]
Sally (lines 633)

Sally's comment suggests that people can attribute children's performance to the actions of parents. This is likely to increase a sense of responsibility for children's behaviour. This may explain why Sally feels a sense of guilt when things are not going right.

Amanda describes how another person recognising her parenting strengths impacted upon her.

But the first time or the second time I took him and I know
he's [cranial osteopath] only saying the right thing to me but
it stayed with me. He said [crying while continuing to talk],
"Children come to the right person because you can deal
with him." You know? He said, "He's come to you for a
reason because you're the right person." […] And so I kind
of took a lot of strength from that because he said, "You're

> dealing with it really well and you're doing all the right things for him and that's why he's with you because you're here to help him and look after him."So I kind of, I do see that, because I know there are a lot of my friends who couldn't and don't have the patience. Whether they'd develop it, I don't know but for whatever reason, they're not, he came to me, he didn't come to somebody else. Yeah, I kind of, I do think that.
> Amanda (lines 1623-1651)

Amanda indicates the significance of the osteopath's comment in stating "it stayed with me". Her tears seemed to indicate a sense of relief as she relayed the comment. She later indicates she wants to find meaning and know why her child has needs. Amanda identifies that she has found strength from the osteopath's comment. There is a possibility that through the osteopath's comment she has found purpose within her situation. Her role is identified as one of nurturing (helping and "looking after" Ben). There is a sense that the comment has enabled her to look at her strengths (patience) and feel reassured with her parenting skills. Again, there is an element of comparison with other people in identifying that she is the right person for the job and that there are a lot of friends who would not have the required skill (patience) to manage Ben's needs. Amanda's description suggests an element of destiny. She describes there being a reason that Ben came to her - that she was identified as the right person for him.

Sally describes the positive feedback of friends.

> Erm, other friends have said, "You know, you can't be good at everything, he's good at other things." Erm, so some of them have been very careful, sort of careful at what they have said to me, erm, and you know have tried to turn it around, you know, "He can do this, he can do that" which is really nice.
> Sally (lines 1170-1176)

Sally seems to appreciate friends recognising her child's strengths and focusing upon those rather than on difficulties.

Parents identified they sometimes received discouraging feedback. This feedback often related to Sally's earlier comment about difficulties being a reflection of parenting (lines 633-634). The difficulty appeared to arise when parents did not understand the nature of the child's needs and over-estimated their ability.

But I am incredibly patient and I have to be, you know, with him, to an extent. And interestingly, my sister is quite different in that respect. She's not very patient and whether she's developed that because of her family situation, I don't know. But we, we have situations where we might go out all day together with the kids. Now, James, if he's tired, or urghh, he will get quiet. If Ben's getting tired, hungry, whatever, he will get loud. They are kind of…just different [laughs] in how they respond to the same kind of emotion. So for my sister, it's really hard to see Ben getting loud and blah, blah, blah. And she's quite firm as a, you know. […] She's always…You know, her friends think she's quite "Blimey, she's quite hard." Quite firm with her, kind of, techniques for parenting. She finds it quite, she has found it quite difficult. Why am I not, you know, stamping down on this behaviour?

We had one day out […] where tensions were kind of rising. And I was getting, I get cross because she, I don't have an issue with her disciplining Ben at all. She's never done it inappropriately and it's always absolutely fine but then she won't discipline James and I'm like, "Well, I'm sure James understands so why do you focus on Ben and not on James?" Anyway, I think, and then, something was said and things kind of came out verbally which had, you know, perhaps been going on in her head. Mum kind of gets, not caught in the middle because we're not fighting about it but mum will talk to my sister about it and she'll talk to me about it and mum said, "I think the two of you need to go out for a drink and just talk about it." And we did and it was interesting because she, I was able to explain why I don't necessarily, I pick my battles, you know, with Ben. If he's up here, I don't go in like that because we'll end up up there. Sometimes it's best just to let him…it takes him twenty minutes sometimes, just let it out of his system, give him some food or whatever and then he'll be a different kid whereas if I fight it, we just battle with each other and we end up up here. Equally she said, "I don't always discipline James because actually his level of understanding is so much lower". We're like, "I'm sure he would understand if you, you know…" But actually Hannah said, "No, his level of understanding of behaviour is actually at like age three" or something, which was backed up by someone at his school. So you know, that's been quite interesting even like within the family. What are people's perception and what and how, you know, how people sort of perceive the way you do things. But I think that can be said for any, I think even parents of children who, you know, don't have additional problems deal with it in different ways don't they. And you might agree, you might not, so you know.
Amanda (lines 1503-1561)

Amanda's discussion indicates that different parents have different qualities, just as children do. She reflects that different approaches are needed for different children but that it is hard to tailor approaches to new

situations that have not been practised. When Amanda quotes the views of friends there is a sense that she may be seeking to provide comparative evidence that supports her view. She highlights that friends, family and even she make comparisons and judgements about other people's parenting. Judgements are likely to be based on comparisons with previous experience. However, in this example the judgements made prove misguided due to lack of information about the child's needs. Communication about their differing perspectives helped them to understand their different viewpoints, reduce judgement and resolve the difficulty. Communication helped the sisters to understand their children's needs differently.

Sally and Amanda highlight that misguided judgement can be even more evident when children's needs are not quickly evident to others. They described the concept of a hidden disability.

> […] if somebody looks normal, you expect them to be
> normal. And, you know, it's a disability in some respects that
> you can't see, so how would you expect people to
> understand?
> Sally (lines 526-530)

> 'Cos our old neighbours next door had a lad with autism and
> he looked perfectly normal and she said, "It's the hardest
> thing because he looks normal." Whereas with James, he's
> got learning difficulties and he looks like he's got learning
> difficulties so nobody judges, nobody. People kind of almost
> expect it of him.
> Amanda (lines 1603-1609)

Amanda describes having learnt from experiencing judgement.

> I know I look at other children who are behaving badly. And I
> guess, where I am better is when we go out, if there's a child
> misbehaving, my mum will probably go, "Urghh…why are
> they letting him do that?" And I say, "He might have an issue
> like Ben you know." And she'll be like, "Yeah, he might,
> mightn't he?" You know, I'm on the other side of that and I'm
> like, "Don't judge people because we have no idea what
> they are having to deal with because people would look at
> me, you know, and think…"
> Amanda (lines 1592-1602)

She describes a sense of judgement sometimes appearing an automatic response and needing to actively employ strategies to prevent this.

Table 5

Summary of themes within comparison of parenting

Social comparison of performance - Comparison of parenting *(Numbers in brackets refer to lines in transcripts)*				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Comparison of parenting approaches with sought advice	*"so that really helped to understand what some of his behaviours were." (142-163)*	*"[…]maybe that they can help you in some way and give you some different feedback of what helped" (116-117)*		*"'[…] What can we do at home?' And she come up with all these wonderful ideas that we wouldn't have even dreamed of." (160-166)*
Judgement of others	*"You're dealing with it really well and you're doing all the right things for him and that's why he's with you" (1642-1644)*	*"Because a lot of parents feel that […] their children is as good as the parenting" (633-634)* *"Get a grip of him" (1198)*	*"That's only two in the whole of his year that got that [certificate]" (480-481)*	*"He's got to where Mrs Smith wanted him to be" (61-62)*

5.1.2.3   Discussion regarding comparison of parenting

Parents sought advice from others in order to develop parenting and support for their child's needs. The focus of the support seeking seemed to be upward, in that parents were seeking advice and information from others who were either doing well or had more knowledge about how to manage (Hodges & Dibb, 2010; Taylor & Lobel, 1989). Sally suggested that parents may also use temporal comparisons (Albert, 1977) with previous own parenting experiences in order to evaluate actions and obtain ideas of other actions that could be taken. However, temporal comparisons may be of limited support when previous experiences differ from current experience. Use of comparison tends to reflect an underlying concern about performance (resulting in the need for comparative information). The use of comparison therefore seems to reflect a level of uncertainty in the most appropriate way to support their children. As noted previously, downward

comparisons made by other parents with Sally caused pressure for her, presumably because she engaged in upward comparison in response. However, Sally continued to seek comparative support from parents. She explained that this helped her to recognise that others are in a similar situation. This need has been identified by Hodges and Dibb (2010) who found that parents were supported by knowing that they were not the only ones facing a difficult situation. Parents in this study did not discuss finding it helpful to check out emotional responses / coping strategies of other parents in the way that has been highlighted elsewhere in research (Affleck et al., 1987; Wood, Taylor & Lichtman, 1985). It is possible that this was because the emotional strain was not as great compared to the situations researched by Affleck et al. (1987) and Wood, Taylor and Lichtman (1985). Alternatively parents may not have wanted to focus upon emotional strain within the interview (in line with their general positive focus) and therefore chose to omit this aspect. Research has highlighted the difficulty of illuminating social comparison mechanisms and that strategies that are used are not always described by participants (Keil et al., 1990; Paterson et al., 2012).

For Sally, information seeking from staff cost her ability to seek information from parents, to some extent. This was due to time constraints regarding availability of others. Sally appeared to prioritise support from the teacher (possibly because she was more confident that she would be able to apply their information). Sally described some difficulty using comparison with parents when the situations they may be facing were different.

Sally identified that she would find it helpful to obtain more support from other parents and was proactive in seeking out opportunities to gain this. Use of social comparison has been found to be encouraged through support groups (Hodges & Dibb, 2010). Support groups may provide increased opportunity for information sharing and modelling of positive comparisons. However, they may also cause some difficulties (such as negative comparisons). Sally indicated that informal networking was more appropriate than a formal support group. Data analysis indicated this could be related to embarrassment or stigma. Finlay and Lyons (2000) highlight that segregation can increase vulnerability to stigma and perhaps support groups would be viewed by some as highlighting difference between parents. The range of need that may be represented within a support

group (and therefore the applicability of support to individual situations) may also hinder effectiveness. Other parents did not identify as great a need for information seeking from other parents. Although, Amanda may have sought opportunities to engage in comparison through social media due to lack of availability of downward comparisons elsewhere.

All parents highlighted a need for greater professional support from external agencies (Speech and Language Therapy Service and Occupational Therapy Service). They were looking for greater frequency of therapy sessions. Amanda, in particular used information from professionals in order to develop her understanding of her child's needs and alter her approach accordingly. While Mike and Meg were keen for practical ideas of ways to support their child, Amanda focussed upon developing understanding of his needs, motivation and the communicative function of his behaviour. She described this understanding enabling her to develop her own strategies. This indicates that for Amanda, understanding of her child's behaviour was more important than provision of strategies.

Parents described encouraging feedback as including recognition of strengths and progress. These elements are found within positive approaches to change, such as Solution Focused Brief Therapy, Appreciative Inquiry, and positive psychology (McKergow, 2005).

Throughout their interviews Meg and Mike frequently express pride in their son. They also described feeling proud of the pride of others in their son. Pride is thought to be based upon superiority (Webster, Duvall, Gaines, & Smith, 2003). It is experienced when people do better than others and are recognised for this. Webster et al. (2003) suggest that success or failure is mainly identified through social comparison. Success usually means that one has performed as well as or better than most people while failure usually means one has performed worse than most people. Meg and Mike's pride may stem from social comparison of the frequency of positive recognition that their son received related to others. Meg noted that only two people in his year group had received the feedback Max was given. Amanda also discussed the provision of awards. Through provision of public feedback (e.g. praise and awards) school appeared to be enabling parents to focus on alternative dimensions (e.g. effort rather than attainment) in order to be able to engage in positive comparisons. Webster

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et al. (2003) found that public feedback did not significantly increase pride. However, when praise or social comparison praise was combined with public feedback, pride was enhanced. Through the school assemblies that parents described staff were fulfilling the above criteria (praise for effort through awards, public feedback through assembly and social comparison through frequency of award).

Through individualised targets school staff enabled parents to focus on temporal comparison rather than upward comparison. Parents were able to focus on progress over time for their child, rather than against other children. Ensuring targets were specific enabled Mike to have confidence that his child had got to where his teacher had predicted.

Pride may increase positive evaluations of parenting. Since pride is thought to be related to social comparison and feelings of superiority (Webster et al., 2003) when parents are feeling proud of their child they may relate this feeling to their parenting and interpret that they are doing a good job. Sally comments that when her child is happy it is evidence that she is doing something right. However, this could also lead to an opposite action when things are not going well. Attributing children's performance to the actions of parents means that parents may feel guilty when their child experiences failure. This may explain the guilt that Sally and Amanda describe when thinking about the cause of their child's difficulties.

Encouraging feedback from friends or professionals highlighted strengths and exceptions. The technique of finding strengths is recognised as an empowering approach within positive psychology, Appreciative Inquiry and Solution Focused Brief Therapy (McKergow, 2005). This technique also enables parents to change the focus of comparison and select another domain on which to compare (i.e. choose a strength where the child will compare more favourably). This may compensate for negative comparisons (Hodges & Dibb, 2010).

Amanda highlighted that sharing spiritual ideas of destiny and being chosen helped her to make sense of her situation to some extent and find meaning and purpose. Spiritual and religious beliefs have been identified as resources and influences within parental coping (Beresford, 1994). Amanda also finds a sense of coping in downward comparison with other

parents who she feels do not have the necessary skills to manage her son's needs.

However, parents identified that they sometimes received discouraging feedback from others. Often this was related to misunderstanding of children's needs. Judgements were based on previous experiences but this did not always apply to children with SEN. Without key information about a situation a comparison can become groundless. This difficulty becomes even more evident in the case of 'hidden' or 'invisible' disability. These are umbrella terms for disabilities without a physical manifestation which impact on day to day living (Mullins & Preyde, 2013). This does not appear to be a well researched area within psychology. A literature search on PsycINFO using terms of 'hidden disability' or 'invisible disability' revealed only sixteen and twenty one articles respectively. None of these involved school children or social comparison. However, two participants in this study highlighted this as being a significant area of difficulty for them. The difficulty was related to unrealistic expectations of their children due to people not taking account of their SEN. Lack of information meant that other parents then did not understand the parenting approaches that were being taken. This can lead to downward comparisons with the participants.

Despite experiencing downward comparisons related to hidden disability Amanda highlights that it can be a difficult process to prevent and her family still make judgements of the parenting of others without considering the possibility of the existence of a hidden disability. This may be related to cognitive processing of information such as the continuum model (Fiske, 2012). Within this model people default to category based processes to form impressions of others. This involves often responding very rapidly without considering all possible interpretations of a situation.

5.1.3 Children's awareness of comparisons

5.1.3.1 Child's comparison with peers

Amanda and Sally described their child beginning to compare their own performance with peers. Amanda described Ben avoiding learning because he found it difficult (lines 316-322).

Because he has noticed that different people, his best friend

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is a very good reader and Sam had said, erm, "You can read that?" And John said, "Yes." So Sam was quite surprised. And we'd gone camping with some friends as well and her son is three weeks older than Sam and the spellings that he had to learn when we were away were quite difficult, and Sam, you could see, he switched off. He went really quiet and thoughtful erm, because he knew that he couldn't – which is good that he realises.
Sally (lines 305-315)

Erm, I know at school, because he was in Class A, but there was Reception children as well, they took him out of his small group of Class A and they put him in another group with the Reception children. And he actually improved and became a bit more confident, erm, because with his peers obviously they were at a completely different level. And yet some of them in Reception who were on the lower level, erm, he did find the confidence in the fact that he could understand things a bit better, and he felt a bit more confident to, you know, put his hand up.
Sally (lines 187-198)

Sally implies that Sam is aware of both peer comparisons and the level of work being set and that these factors impact upon his confidence. Although Sally feels it is good that Sam is developing self-awareness and makes comparisons she also recognises the danger that he will withdraw from the comparison and therefore learning opportunities. These comments link to issues around special school placement that will be explored in the following superordinate theme of 'sense of belonging'.

Mike also highlighted the importance of work being individualised and differentiated so that Max knew his personal targets and was able to track his achievements against those (lines 105-111).

5.1.3.2 Peer comparison with child

Although Mike and Meg do not describe their child using comparisons, all of the parents describe peers becoming aware of comparisons and their concern with the reactions of peers.

Mike: I don't think anybody's ever really picked up, or picked holes in the fact that he can't do anything, really. There was one time. One child said something to him. They said, "Are you from another country? 'Cause you speak funny." But no-one - that's the only time anyone's ever said anything to him. That was

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just a kid. And like I said to Meg, kids don't
understand when they're hurting you. They
don't…you know, it's … I'm sure there was no
malice involved. It was just a… [long pause]

Interviewer: curiosity?

Mike: Yeah, just a little comment, you know. And it
was just thrown up there, and then it was all
forgotten about. 'Cause he's never, ever come
home and told us anything else has ever been
said, apart from that. That was the only time he
come home and said it.

(Lines 515-539)

Mike acknowledges a sense of hurt in another child making comparison
however he rationalises this by considering that the child was not aware of
the impact of their comment or the hurt that was caused. Mike may feel
that the comment was significant for his son (in that his son talked about it
and that he would be likely to do so again if it re-occurred). Mike highlights
that it has only occurred once. However, Meg seems to have greater
concern about other children being unkind to Max when he transfers to
junior school (lines 68-70). Meg and Sally's concern around peer reaction
seems to stem from their recognition of vulnerability. This will be explored
in the later superordinate theme of 'sense of belonging'.

Whilst Amanda is aware of children's comparisons she appears to have
more confidence in their reactions.

[…] socially, he's a little bit behind in his interaction, erm, but
because he's been with the same class, and he's pretty
much going to be with the same class at Juniors, they know
him, they get him, there's no problems.
Amanda (lines 1037-1041)

Amanda's confidence appeared to be related to the class 'knowing' Ben.
There was an implied sense of 'knowing' and 'getting him' being associated
with understanding and acceptance. Acceptance links to sense of
belonging.

Comparisons are designed to highlight similarities and differences. All
parents used this strategy and Sally expressed appreciation for her child

beginning to use it. Yet all of the parents described not wanting their children to be singled out as different. This links with the following theme of belonging.

Table 6 summarises themes within 'children's awareness of comparisons' and links to example quotes within transcripts.

Table 6

Summary of themes within children's awareness of comparison

<table>
<tr><td colspan="5"><u>Social comparison of performance</u> - Children's awareness of comparisons

(Numbers in brackets refer to lines in transcripts)</td></tr>
<tr><td>Theme</td><td>Amanda</td><td>Sally</td><td>Meg</td><td>Mike</td></tr>
<tr><td>***Child's comparison with peers***</td><td>*"I can't do this" (921-922)*</td><td>*"He went really quiet and thoughtful erm, because he knew that he couldn't […]" (305-315)*</td><td></td><td></td></tr>
<tr><td>***Peer comparison with child***</td><td>*"[…]they know him, they get him, there's no problems." (1037-1041)*</td><td>*"Yeah some of them do take advantage of him, or if they have done something, blame him." (1363-1365)*</td><td>*"I'm worried about junior school, that he's gonna get further and further behind and get picked on." (68-70)*</td><td>*"Are you from another country? 'Cause you speak funny." (518-520)*</td></tr>
</table>

5.1.3.3   Discussion regarding children's awareness of comparison

Research suggests that children make increasing use of comparison as they develop (Guralnick & Paul-Brown, 1989; Hames, 1998; Keil et al., 1990; Lewis, 1995). Amanda and Sally identified that their children were beginning to compare their own performance with peers. This suggests that even though the children had developmental delays they were able to

begin to make use of comparison to evaluate performance. Sally's appreciation of Sam using social comparison (despite some negative consequences) may reflect her awareness of the developmental nature of comparison. His use of this strategy indicates growing self-awareness. Both children's withdrawal response to social comparison can be explained by discomfort resulting from upward comparison and withdrawal in order to cease comparison (Festinger, 1954).

Parents highlighted the importance of individual targets and differentiated work in order to allow them (and presumably children) to track progress. This strategy relates to use of temporal comparison whereby they are able to focus on progress across time rather than progress against other pupils (Albert, 1977; Wilson & Ross, 2000). Temporal comparison could offer a protective strategy by allowing parents to cease uncomfortable upward comparisons and focus on progress. In addition, differentiation may allow children to measure progress by successful completion of task (activity outcome) rather than social or temporal comparison. This may be an easier concept for children to access (Keil et al., 1990).

All of the parents highlighted that other children seemed to have become aware of differences for their child although their understanding of difference was perhaps not well developed, as predicted by research (Lewis, 1995). Mike implied that he felt hurt by the comparison made by another child, although he rationalised that the comparison was not intended to hurt. Mike's response could be explained through comparison highlighting difference or sense of belonging being impacted through comparison (Paterson et al., 2012).

Parents differed in their level of concern regarding current experiences of peer comparison. Amanda expressed greater confidence in peer behaviours. This appeared to be related to the class 'knowing' Ben. There was an implied sense of 'knowing' and 'getting' being associated with acceptance and therefore sense of belonging.

5.2   Belonging

Data analysis revealed a recurrent theme of belonging throughout interviews. Hagerty et al. (1992) defined a sense of belonging as "a

person's subjective experience of being valued by or important to others and experiencing a fit between one's self and others around him/her" (p. 173). Themes regarding belonging are outlined in Table 7.

Table 7

Themes related to belonging

Belonging
<u>Child's sense of belonging</u>
Inclusion vs. exclusion and stigma amongst peers
Parental protection from social exclusion
Ability to participate in social interaction
Equality of recognition from staff
<u>Parents' sense of belonging</u>
Inclusion vs. exclusion and stigma amongst parents
Loneliness
Recognition from staff
Identity

5.2.1   Child's sense of belonging

5.2.1.1   Inclusion vs. exclusion and stigma amongst peers

Mike, Meg and Sally expressed fear about their children being left out socially. Fears appeared to be based to some extent upon the experiences parents had had at school.

> I suppose when I was at school, special needs meant you were the dunce, and you, you, you know, you were just left behind when I was at school. You know, erm, I remember, we all went in to do our exams, and all the specials needs kids went and sat in another room and done like a lower paper. And it was obvious that they were never gonna get any grades or anything. Whereas now, they really push, and they, they do things for them.
> Mike (lines 306-318)

Mike's use of a derogatory label indicates a sense of stigma / isolation linked with special educational needs. He seems to imply that special educational needs impact upon social identity through use of labelling. His contrast with schools currently pushing and doing things indicates that Mike

perceives school support is greater than in the past. Mike later described his fears being alleviated by staff explaining support for special educational needs and by seeing his son making good progress (lines 327-333). His comments indicate a growing confidence in higher expectations and support.

Sally:	I'm dyslexic, my Dad is, erm, and well I presume it runs in families, I don't really know. Erm, so I know how I struggled and I think that's why I feel even worse, because I don't want the same treatment. When I was at school it was awful. I was just thrown into a classroom and expected to get on with the work, the teacher was never in the room erm, people laughed when you read out loud. And I think that's why some of my insecurities, is probably why I feel more protective over Sam.
Interviewer:	You don't want him to go through the same thing?
Sally:	Yeah.
Interviewer:	Yeah, you know what it feels like.
Sally:	[…] I became very good at covering up bad spelling and things, by writing slanted and really small, so it googles your eyes when you read it, so they don't pick up on spelling mistakes. Erm, but it's just, I just don't want Sam, I think if the schools are more understanding of what a child has to go through with a learning difficulty, in it's not just the teacher, it's the children as well. But then like I said, you know, my friend's little girl, she's only, what she's seven, only a year older, but to be told, you know, that he's not quite the ticket sort of thing. Erm, you know I don't want children to be told, you know, just that "Sam needs a bit of extra help sometimes" would be nice. Erm…
Interviewer:	Can you tell me a little bit, I can imagine what your feelings were, but just to, to kind of hear those things. Can you tell me a little bit about how that felt and what sort of things you were thinking in that moment when you heard what the little girl had said?
Sally:	I just turned around and said, "That's not quite, very nice is it?" Erm, but I felt hurt at the fact that erm, you know how words are changed by parents and, you know, my friend is very blunt anyway, so erm. But I don't want

people to feel, to think badly of Sam

(lines 464-513)

Sally identifies with Sam's needs because she experienced learning difficulties at school. She is able to recall the emotions she experienced and imagine Sam going through the same. She identifies that this makes her worry worse for Sam. Like Mike, Sally also identifies lack of support for special educational needs. The word "thrown" seems to indicate a lack of care. There is a sense of her experiences leading to lasting insecurities. She learnt to hide her difficulties, which suggests a feeling of shame. A need for staff and parents to empathise with children's difficulties appears to be identified. This may be more difficult for people who have not experienced the difficulty. Sally describes feeling protective of Sam (and more so because of the difficulties she has experienced). Emotions from past experiences appear to be motivating action for both Sally and Mike.

Although Mike and Meg expressed confidence with peer relationships in the current school (Mike: lines 214-218, Meg: lines 205-211) Meg described anxiety about social exclusion upon transfer to the next school.

> […] 'cause I'm worried about junior school, that he's gonna
> get further and further behind and get picked on.
> Meg (lines 68-70)

Amanda did not express strong concerns about peer relationships but she did recognise the importance of Ben having access to peer interactions and that he did not have many friends.

> He doesn't, he's got some friends at school but he doesn't
> have loads that we'd necessarily invite back and things like
> that.
> Amanda (lines 1468-1470)

> I kind of think the more children that Ben interacts with, the
> better.
> Amanda (lines 1401-1402)

Although parents highlighted that they wanted their children to be treated the same as others where possible, they also recognised that their children had different needs and required different provision at times.

> And also, he's got his own - like I said, his own plan of, erm,

goals…to where they want him to be, and where they think he should be for - just for Max. It's not what everybody's doing. It's what Max should be doing.
Mike (104-111)

Mike communicates a sense of valuing the individually tailored approach that school provided.   Parents highlighted concern about the potential intervention delivery impacting upon social inclusion within the class.

Meg:	He's doing writing with the teacher. He's doing his phonics with the teacher. He gets taken out of the class work to do his own… to try to build him up. But we said, "We don't want him taken out too much" 'cause we don't want him to feel taken out of the class what the class topics are doing. But they have done so much. But they don't wanna give him too much, they said, because otherwise his brain will just go… But they're doing - they're saying like when he goes back in September, he'll have nothing, not until after the first term. And then he will get his own private little plans that he does. Because-
Interviewer:	Is that so they can kind of assess where he's at in that first term?
Meg:	Yeah, and so that he doesn't - when he's back in September, it's all new. A new class, new teacher. So it's getting used to it, yeah, so that he's not s- straight away taken out… which is a good thing. (lines 169-195)

Parents wanted their children to have most intervention within class so that children did not feel withdrawn and excluded from the class.

5.2.1.2   Parental protection from social exclusion

Sally and Meg expressed a desire to protect their children from social exclusion.

> I just feel like standing sometimes and just watching
> everything he's doing all the time, just so he doesn't slip up
> and get told off, or, because I don't want him to be told off all
> the time.
> Sally (lines 1488-1492)

> I'm worried about the older children because he is so timid
> and shy, and because of his speech. I don't want him to be
> picked on. I've got a real issue, 'cause he's so timid, he
> really is, that the old - because he's gonna be one of the
> younger ones that he's gonna be picked on because of his
> speech as well. And I don't know how he'd cope with that, to
> be honest. I don't think he would cope. I think - because he's
> very clingy now about going into school, even now. So I
> think if anything happened in junior school, it'd make it really
> hard. But we're just gonna have to really keep an eye on
> things, and… I'm sure if his friends - they'll support him.
> Meg (lines 547-566)

Sally and Meg imply awareness of special educational needs resulting in vulnerability for their children. Meg highlights concern about emotional well-being and her son's ability to cope. Both parents describe a sense of being needed by their children. Their comments lead to a feeling of possible underlying anxiety about not being able to fully protect their children whilst they are at school. Meg identifies a compensatory factor in friends and their ability to support her son.

5.2.1.3   Ability to participate in social interaction

All the mothers expressed concern about their child's difficulties impacting upon their ability to participate in social interaction.

> He'll watch before he then joins in, he, he likes to look
> around at what's going on. And I just feel at the moment that
> he needs that. He needs to see what other people are
> doing, to try to aspire to do that. And I just - and, and again,
> socially, he's a little bit behind in his interaction, erm, but
> because he's been with the same class, and he's pretty
> much going to be with the same class at Juniors, they know
> him, they get him, there's no problems. Erm, but I worry that
> he won't learn what is normal social interaction. And again, I
> could be being completely misguided, and you could say,
> "Oh, there's lots of special needs schools out there that
> would be brilliant." Erm, but I just felt he needed to learn
> what was normal. Because he essentially is, in my eyes,
> he's just a bit behind.
> Amanda (lines 1033-1051)

Amanda recognises that Ben learns from others modelling interactions to

him. She implies a sense of wanting him to fit in, to be accepted and interact 'normally'. Social interaction is linked to fitting in. There is a sense of doubt regarding normality with her use of "essentially" and justification of "in my eyes". Perhaps this fuels her need for Ben to experience modelling of social interaction. Amanda does not discuss bullying, although she does make reference to Ben's class knowing and understanding him. This suggests awareness of the possibility of a different situation occurring in a different setting where Ben is not known or understood.

5.2.1.4   Equality of recognition from staff

Parents highlighted the importance of equality of staff recognition and encouragement.

> Mrs Smith really encouraged him, and she was really proud.
> So that made us feel happy that school were proud of him.
> And that school aren't thinking, "Oh, let's not bother with
> Max" and they're still really encouraging.
> Meg (lines 96-100)

Parents appreciated staff communicating that their child was valued. This was evidenced through spending time in encouragement. As noted previously, public recognition through certificates / awards in assembly was particularly valued (Amanda, 1763; Meg, 459-481).

Although parents were generally positive about the way in which their children had been recognised by staff, Amanda had some concerns about the inclusiveness of the head teacher (although she appeared to be keen to explain that she liked the head teacher).

> And they have a budget, and they have, you know, and the,
> "Oh God, child with special needs, nobody wants one of
> those." But everyone else - and then she's [head teacher]
> lovely […]
>
> They haven't, as much as I think the head teacher - not in a
> bad way - would have wanted to ship him out, 'cause it
> doesn't look good on their SATs results or whatever.
>
> You know, apart from perhaps, you know, the Head and stuff
> and I'm not even sure that's her, I think that's just the system
> that you know, that tries to challenge that.
> Amanda (lines 403-406, 942-945, 1777-1780)

For Amanda, the head teacher's suggestion about change of placement represented Ben being different and unwanted. Despite this powerful assertion there is a sense that Amanda has not taken this personally and wonders if the head teacher's view is a reflection of the system rather than a personal view. Amanda's view of the system is not clear. She may be questioning inclusion throughout the educational system. It is unclear what Amanda is perceiving as the system (e.g. local authority, statutory assessment team, Code of Practice). It is possible that the idea of a system depersonalises negative feelings.

Sally felt that the head teacher had limited knowledge about special educational needs.

> Erm, but I think, like with Mr. Black, erm, we had a few meetings with him, but I think, because it's a different matter with children with, you know, need extra learning, erm, I don't think he knew a lot about it.
> Sally (lines 802-806)

Sally identified that children with special educational needs may require different support and that staff may not always be aware of the details of this. It is not clear what gave Sally this impression but she describes Mr Black as appearing to feel awkward in discussing Sam's special educational needs. Sally appears to attribute this to lack of knowledge but it could also be attributed to concern regarding the impact of information for parents.

All parents seemed aware that other parents may have had less positive experiences with staff elsewhere.

> Yeah, we're not, we're not too happy at the moment. With what we've heard about the junior school, is that it isn't very good for the special needs. Yeah, we've heard some pretty horrific story.
> Mike (lines 545-551)

> Well, Max has that he's got some very good teachers and a brilliant headmistress and deputy head. You know, that's a positive. Not all schools are gonna get that, are they? We've just been very lucky with the way the staff have encouraged Max.
> Meg (lines 657-666)

> Because she's [therapist] seen children go through there as she's seen children go through other schools and had said, "No, they will do the best they can for him." That was her experience seeing other children. So I think I had the perception that perhaps that wasn't the same everywhere. Amanda (lines 1810-1815)

Table 8 summarises themes and links to transcripts within 'children's sense of belonging'.

Table 8

Summary of themes within 'children's sense of belonging'

<table>
<tr><td colspan="5"><u>Sense of belonging</u> - Child's sense of belonging

(Numbers in brackets refer to lines in transcripts)</td></tr>
<tr><th>Theme</th><th>Amanda</th><th>Sally</th><th>Meg</th><th>Mike</th></tr>
<tr>
<td>***Inclusion vs. exclusion and stigma amongst peers***</td>
<td>*"[…]he's got some friends at school but he doesn't have loads that we'd necessarily invite back […]" (1468-1470)*</td>
<td>*"[…]so that he doesn't feel left out, the older he gets, and humiliated[…]" (564-568)*</td>
<td>*"I'm worried about junior school, that he's gonna get further and further behind and get picked on." (68-70)*</td>
<td>*"I suppose when I was at school, special needs meant you were the dunce […]" (306-308)*</td>
</tr>
<tr>
<td>***Parental protection from social exclusion***</td>
<td></td>
<td>*"I feel more protective over Sam." (469-474)*
"[…] I think I try and wrap him up a bit too much […] (1424-1425)</td>
<td>*"I don't think he would cope […] so we're just gonna have to really keep an eye on things" (561-566)*</td>
<td></td>
</tr>
<tr>
<td>***Ability to participate in social interaction***</td>
<td>*"I worry that he won't learn what is normal social interaction" (1045-1046)*</td>
<td>*"But because he had said sorry he thinks everything is okay." (248-251)*</td>
<td>*"[…] he is so timid and shy" (547-549)*</td>
<td></td>
</tr>
<tr>
<td>***Equality of recognition from staff***</td>
<td>*"[…] they absolutely love him to bits, and they've been amazing." (479-480)*</td>
<td>*"I think the teachers together try to help every single pupil […]" (792-793)*</td>
<td>*"[…] school aren't thinking, 'Oh, let's not bother with Max' and they're still really encouraging." (96-100)*</td>
<td>*"[…] he's got his own […] plan of, erm, goals […]" (104-109)*</td>
</tr>
</table>

5.2.1.5   Discussion regarding child's sense of belonging

Mike, Meg and Sally expressed fear about their children being left out socially. Research has indicated that children with learning difficulties are at risk of social rejection (Odom et al., 2006; Vaughn et al., 1996). Temporal comparisons (Albert, 1977) with their own experiences of schooling were used to evidence concerns. For Sally and Mike empathy resulting from their own experiences appeared to motivate them to avoid the same experiences for their children. Their own schema's of school and SEN (based on previous experience) appeared to lead to their concerns (Bruce & Schultz, 2001). Both parents identified historical lack of school support.

Mike identified past experiences of stigma and derogatory labels (Goffman, 1963) being linked to his concerns. Sense of belonging appeared to be restored for Mike through staff highlighting inclusion of children with SEN through planning, support and high expectations.   High expectations may have enabled Mike to feel he would be able to make temporal comparisons of his son's progress in the future. Sense of difference may have been ameliorated through these inclusive practices (Cooney et al., 2006; Paterson et al., 2012) allowing Mike to change his schema relating to school and SEN.

Sally is able to recall emotions she experienced related to her learning difficulties (e.g. sense of shame associated with being laughed at) and imagines Sam going through the same. This appears to increase anxiety. Sally also identifies insecurities that have lasted from childhood experiences. This links to research that indicates that there is association between self-evaluations and stigmatising experiences (Dagnan & Waring, 2004; Paterson et al., 2012).

Parents appeared to identify friendships as an ameliorating factor and there is some evidence for this within research literature (Vaughn et al., 1996). However, the ability to establish friendships with other peers following transition was a concern to some extent for Meg. This links with research around impact of transition upon friendships and sense of belonging (Knesting, Hokanson, & Waldron, 2008; McMahon, Parnes, Keys, & Viola, 2008; Sancho & Cline, 2012).

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For Amanda peer relationships were important for her son's ability to learn socially acceptable interaction patterns. This links to Social Learning Theory (Bandura, 1963). For Amanda it was therefore important to increase the range of peer interaction for her son.

Parents appeared to associate intervention delivery with sense of belonging. They wanted their children to be treated the same as others where possible, despite recognising that their children had different needs and required different provision at times. Parents were keen to avoid intervention impacting upon social inclusion in class. Vaughn et al. (1996) found some evidence of increased sense of belonging within pupils who were included within classroom intervention, rather than withdrawn.

Mike and Meg discussed individual planning and target setting and being able to focus on progress with this. Folkman and Moskowitz (2000) suggested that setting achievable goals leads to feelings of mastery and control in families. It is possible that individual planning and progress tracking at school (combined with intervention activity at home) may help parents to feel a sense of mastery and control. Scorgie, Wilgosh, and Sobsey (2004) highlighted that the development of a sense of personal control was one of the main mechanisms that enabled parents to cope when raising a child with disabilities.

Establishing that their child had special educational needs appeared to lead to Sally and Meg identifying a desire to protect their children from social exclusion. They seemed aware of vulnerability. This has also been identified within research literature (Odom et al., 2006; Vaughn et al., 1996). Previous research has identified that mothers tend to assume the role of nurturer and protector within families where there are special needs (Essex, Seltzer, & Krauss, 1999).

All of the mothers in the study expressed concern about their child's difficulties impacting upon their ability to participate in social interaction. Research has considered the impact of different developmental needs and indicates that learning difficulties which impact upon social interaction/withdrawal are associated with increased risk of social rejection (Diamond, 2002; Odom et al., 2006). This could link to further impact of

limited social modelling (Bandura, 1963) therefore causing a viscous circle. Amanda seemed particularly keen to provide opportunities of social modelling through peers.

Equality of recognition appeared to help parents feel that their child was valued. As noted previously, one of the mechanisms to achieve this was through public recognition and awards within assembly.   Graungaard and Skov (2007) found that one of the challenges parents faced within a diagnostic process was professionals focusing upon deficit. They reported wanting professionals to recognise their whole child and their individual strengths. Within this study public recognition may have been one way teaching staff achieved this. Although parents were generally positive about the way in which their children had been recognised by staff, two parents had some concerns about head teachers. These related to inclusion and knowledge of SEN.   Systemic barriers such as budget constraints and publication of test results appeared to impact upon perception of inclusion. In reviewing the experiences of parents of children with disabilities Hodge and Runswick-Cole (2008) concluded that tension within the parent-professional relationship is unavoidable. However, in this study Amanda was the only parent to raise this issue.

Table 8 summarises themes and links to transcripts within 'children's sense of belonging'.

5.2.2   Parents' sense of belonging

As well as recognising children's sense of belonging, the sense of belonging of parents was also felt important.

5.2.2.1   Inclusion vs. exclusion and stigma amongst parents

As outlined earlier in the previous superordinate theme of 'social comparison of performance', parents felt a sense of exclusion when other parents celebrated achievements and compared children's progress. Parents often described feeling judged by others and this could lead to feeling excluded and not belonging.

> They didn't try and kind of say, "Yes we're need to meet
> every week and you're going to walk out of school and all
> the mums are there and they are going to wonder why you
> are there." It was very much a, "We will meet and if there are
> any problems, we'll get the relevant people to come along."
> But any other time, they were very open but it was very
> much up to us if we wanted to. And even in like, in reception
> when his behaviour was more difficult, she'd just give me a
> wink or a [signals thumbs down] you know, whereas
> sometimes she would come out and go straight to a parent
> and everyone would go, "Woah, wonder what they've done."
> She'd just kind of do a thumbs up or a thumbs down for the
> day and if it was a thumbs down then I might just go and
> have a chat with her. But no one else would have kind of
> picked up on that, whereas, I've been aware with some
> other children that mum's talking to the teacher again, you
> know what I mean?
> Amanda (lines 1842-1861)

Amanda outlines that fear of judgement impacted on the nature with which she felt comfortable to meet staff (i.e. meeting without other parents being aware). She appreciated discreet communication at other times. There is a sense of Amanda attempting to protect herself and/or Ben from judgement.

> And other parents that I've got close to, obviously they know
> there's an issue so they don't judge. They don't, you know,
> they don't not ask us to go out and stuff like that.
> Amanda (lines 1465-1468)

Amanda identifies that friends have included her and Ben in social activities outside of school. She implies that friends don't judge because they are aware of Ben's needs. This raises questions about what their response might be if they were not aware of Ben's needs and is reminiscent of earlier comments about disabilities that are hidden.

All of the mothers described friends and family who did not judge, being supportive.

> But I've found that the friends that are stronger characters
> have been the ones that accept that he's not with it, you
> know, just do your best sort of thing. Then it's my sort of
> softer friends that have said, "Oh but he can do that, and
> what about trying this?" And sort of given me more advice,
> rather than sort of, putting their hand up and saying, "Yeah
> that's how it is, deal with it."
> Sally (lines 1181-1188)

Sally contrasts strong friends with softer friends. Softer seems to mean focusing upon strengths/positives, providing advice and problem solving. This indicates hopefulness about change. For Sally 'stronger' friends seem to be 'blunt' (line 512), more pessimistic about change seem to see intelligence as fixed. There is a sense of Sally feeling that some friends have categorised Sam.

Meg identifies supportive friends as not initiating questions about her child's progress but listening when Meg talks about this.

> They [close friends] don't ever say anything about, "Oh, why isn't he doing this?" No-one ever questions me. I talk to them about it, just to talk to someone about it. But nobody ever questions me, "How's he doing with his reading? Can he do his tricky words yet? Can he write?" You know, "What can he write?"
> Meg (lines 443-452)

Sally described staff lack of judgement as supportive.

> Interviewer: What sort of things have you found particularly helpful? You've made reference to something that the school have sent through, and what are the other things that you think, "This is what I really value, this is what I think schools need to be doing more of."
>
> Sally: Well, it's just more, I think basically just the fact that they didn't make me feel that I'd done anything wrong. They didn't erm, expect anything from me, well apart from the support.

Sally describes struggling with feelings of guilt and responsibility for her child's difficulties (lines 679, 1874, 1913, 1918). Sally found it helpful that staff did not reinforce her self-blame.

5.2.2.2   Loneliness

Sally and Amanda described a need to identify with other parents of children with special educational needs.

> Erm, because I think sometimes it can feel quite lonely, thinking that you're – you know Sam's the only one with problems…

Sally (lines 1087-1089)

As outlined previously, Sally described a need for greater informal support for parents of children with needs in school (lines 1076-1136). In a similar way, Amanda identified with parents of children with special educational needs on a Facebook group (lines 2148-2156).

All of the mothers interviewed described a sense of being alone in their anxiety because they were initially the only person identifying their child's difficulties. When others began to recognise difficulties the feelings of loneliness and paranoia dissipated.

> I knew as a parent, in Year R- that he was struggling. So I'm glad now it's finally been about, and that we're working as a team to help him. Whereas in Year R, I felt I was quite alone and that they weren't helping me, sort of thing.
> Meg (lines 306-314)

> You're like, [sounding disappointed] "Oh, it wasn't just going on in my head, it is a reality." But equally, ooh it's a bit of a release that I'm not having those battles in my head anymore. I've got someone else who is going to make a decision for me.
> Amanda (lines 2002-2006)

5.2.2.3 Recognition from staff

Sally and Meg indicate a sense of being valued by the time that school staff gave them for communication.

> I've got more of an actual rapport with the school. I feel like the school act…probably recognise me more as a parent, and I could feel I can talk to the school more. And they know Max. All the teachers seem to know Max. He's not just a number. He's not left out, and I feel that's positive. Whereas some parents have nothing to do with the teachers, school. They just pick their children up, take them to school, don't speak to the teachers. Whereas I feel positive, because I know that I can always speak to the teachers…and they recognise me and Max, and he's not just like a figure. He's Max. As Mrs Smith said, "He's Max, and he- you know, he'll get there in his own time". So I feel like it has, in a way, been positive that I'm not just dropping him off and picking him up.
> I've got the relationship…together with the school. And for Mike, on sports day, they were calling him to help out. 'Cause they knew Mike because he's come and helped …you know, spoke to them about Max. It's be- become

> more closer to the school. Which is positive.
> Meg (lines 367-407)

Meg described her child's needs as leading to her developing a closer relationship with the school. Her comments indicate a sense of identity and status as a parent. There is a sense of her being recognised (where other parents might not be). Her comments suggest that the communication has allowed her to hear more positive messages which have reassured her. She seems to value her husband being needed by the school. Her comments indicate that the relationship they have with school staff is not just focused around their child's needs. This suggests reciprocity within the relationship. Meg seemed to value them being needed by the school.

Meg's later comments indicate that although the relationship has provided her with a sense of value and opportunity to hear positive messages she has also engaged in it in order to raise awareness of her son.

> I just think, because, you know, we have that relationship
> with the school, they are more positive towards Max. All the
> teachers are more aware of Max. And I just think that they
> include him more. Yeah, so I think that relationship with the
> - you know, helps as well. [Pause]. Yeah, I just feel, you
> know, they've been really - helped us as parents. They've
> not just helped Max; they've helped us.
> Meg (641-648)

Loss of rapport is one the things Meg fears about junior transfer (lines 521-526).

The relationship Amanda described with school staff appeared to be more focused around her child's needs. She did not describe a sense of family or being needed by school.

5.2.2.4   Identity

Parents did not mention identity explicitly but their discussion indicated a sense of identity.

Two elements of identity were considered.
1. Child advocate.
2. Expectation of son reflecting parent's identity.

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Amanda and Meg described a sense of being needed and providing for others. They identified themselves as advocating for their child and needing to seek the best support for them.

Amanda's comments (outlined previously) indicate that in her search for meaning (as to why her child has special educational needs) she has found purpose in seeking support for him (lines *1644-1657).*

> I think there are a lot of other parents…Again, I'll be
> politically incorrect and say they are probably uneducated,
> you know? They don't expect their child to achieve so that if
> they're not, it's no big deal. And I'm not saying that I'm
> pushy but I always dreamt that they would achieve. I'm not
> saying that you have to go to university and all that, but
> that's what my life expectation was and I want them to do
> the best they can.
> And, I understand that you know, that where Ben gets to
> might not be, you know, what is in a perfect world. But there
> is no perfect world, is there? But I still want to strive to give
> him every opportunity to be the best he can. Whereas I
> guess there are other parents who wouldn't even recognise
> that there was a problem because that's not the world that
> they're in or you know, they haven't recognised it or they
> just, you know.
> Amanda (lines 1657-1675)

Amanda uses comparison to evaluate parenting support. She suggests a correlation between level of education and expectation. Amanda seems to identify herself with constructs of 'educated' (line 2107) but 'not pushy'. This appears to involve being able to recognise difficulties and establish high expectations that allows her child to reach his potential.

Parents described an expectation that their children would mirror their expectations or identities in some way. This could cause tension when constructs were opposed to each other e.g. 'educated' vs. 'learning difficulties'. It is not clear whether Amanda finds it difficult to accept that she may not be able to consider her child as belonging within this group.

Amanda identifies that she had life expectations that she transfers to her children to some extent. She has become more aware that her expectation is now tempered by their needs. However, she does identify that Ben has 'potential'.

> I remember Miss Black in reception, she said to me, she
> said, "There are children in this class who are non-
> achievers. Ben is not one of them." You know, she said,
> "You can tell. I know the ones that are just not
> gonna…There's nothing wrong with them. They are just not
> going to achieve." But she said, "Ben isn't one of those,
> he's..." and I think that's why she really pushed to get him
> the help he needed in year one because she could see that
> the potential was there and that you know, and that we could
> do something about it and stuff.
> Amanda (lines 1684-1694)

Similarly, Mike describes not wanting his child to have special educational needs. This may be linked to his sense of identity as a father of a child with special educational needs.

> And maybe, in a way, I didn't wanna think that he had… I
> dunno, maybe, in a way, I didn't wanna think, "Oh, my boy's
> got special needs."
> Mike (lines 297-299)

Meg appears to consider negative comparisons but then seems to accept her son's identity on his own terms.

> So I did feel a bit… wi- with other parents, but I'm thinking,
> "No, he's still Max. He's still my son." He still tries. And that's
> how - that's Max.
> Meg (lines 79-85)

Meg earlier talked about pride when her son received certificates. In the comment above there is a personal sense of awards for her. In a similar way, Sally indicates that children's achievements are sometimes considered to reflect something of their parents (and parents therefore finding a sense of identity within their child).

> …a lot of parents feel that, you know, their children is as
> good as the parenting…
> Sally (lines 633-634)

> So there is pressure on you from day one to be a certain
> way. And, you know, if you don't feel great or whatever, post
> natal stress, it makes you feel like a failure from day one.
> Sally (lines 1914-1918)

Both Sally and Amanda identify themselves as not wanting to be pushy parents.

And the parents are so pushy, some of them. And I think
that's awful.
Sally (lines 1884-1885)

My feeling sort of going forward is yes, he's behind, he's,
that gap will never get smaller, we just don't want it to get
any bigger.
Amanda (lines 912-914)

[Parents]…have put so much pressure on their kids to do
well, they probably haven't realised they're putting that
pressure on and the kids have fallen over in a anxiety,
mental health kind of way and I'm thinking, "My God, I bet
those people never thought that would happen."
Amanda (lines 2109-2114)

Sally and Amanda may have been using social comparison to identify an
alternative dimension that they could identify they were comparing better
than others on.

Table 9

Summary of themes within 'parents' sense of belonging'

Sense of belonging - Parents' sense of belonging				
(Numbers in brackets refer to lines in transcripts)				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Inclusion vs. exclusion and stigma amongst parents	"[…]and they are going to wonder why you are there." (1842-1861) "Who is going to want me with a difficult child…?" (2042-2043)	"I've heard, you know, other people say, "Oh he's a bit simple." And erm, and you can't put into words how you feel."(1295-1300)	"They [close friends] don't ever say anything about, "Oh, why isn't he doing this?" No-one ever questions me." (443-452)	
Loneliness	"[…]I could see it […] for them it was easier to deny." (1969-1971)	"[…] It can feel quite lonely […]" (1087-1089)	"I felt I was quite alone and that they weren't helping" (306-314)	
Recognition from staff		"I just had five minutes, every single morning […] But they took it out of their time to do it, […] which I don't think you would get in many places." (895-900)	"[…] that is definitely the key in the door. The actual relationship with your school will help your child." (610-612)	"[…]feels like a little family […]" (369-371)
Identity	"I'm in a position to really help him" (1644-1657) "[…] I guess we're educated people […]" (2107-2108)	"[…] [other] the parents aren't interested." (955)		I didn't wanna think, "Oh, my boy's got special needs." (297 -299)

5.2.2.5   Discussion regarding parents' sense of belonging

Analysis indicated that sense of belonging was important for parents as well as children.

As discussed within the superordinate theme of comparison, exclusion from social comparison appeared to lead to feelings of difference for parents. This seemed to impact upon their sense of belonging with other parents, because they were not able to engage in comparison and differences were highlighted between them.

Research of the experiences parents raising a child with disabilities has found that their social networks tend to be smaller. Parents generally receive decreased levels of support (McConkey et al., 2008). Factors such as other parents avoiding the family due to finding it too difficult to deal with the emotional impact (Clark et al., 2008) or the family having less time and energy available to engage in socialising (McConkey et al., 2008) have been identified. The parents in this study did not raise concern regarding the size of their social network. Amanda, in particular, highlights that her friends include her and her son in social activities. The factors identified above may be less prevalent in cases where needs are less severe. Literature has typically found that the emotional impact of non-finite loss is generally under estimated by others (Doka, 1989; Martin & Doka, 2000). This may be even more evident in cases where needs are less severe (such as moderate learning difficulties). However, parents in this study did identify different response styles amongst friends. Sally described these as softer or stronger friends. Softer friends appeared to empathise with Sally's needs and provide encouragement about possible change whilst stronger friends appeared more pessimistic about change and encouraging Sally to move on. Collings (2008) found that the on-going nature of loss of parents was not strongly validated amongst social support networks. Meg identified supportive friends as not asking questions about delays. This may be related to research that found that parents wanted others to not focus on disability but to focus on the individuality of the child (Graungaard & Skov, 2007; Todd & Jones, 2003).

Literature regarding the needs of parents of children with disabilities indicates that parents often have feelings of inadequacy about their

competency to deal with their child's needs (McConkey et al., 2008). This may lead to them being particularly vulnerable to judgement. Amanda particularly valued the discretion of the teacher as she felt this reduced judgement of others. Professionals not reinforcing self-blame was particularly important for Sally.

Loneliness also appeared to impact on sense of belonging for parents. Loneliness was attributed to feeling they were the only parents experiencing problems. This echoes findings from other research where parents felt a sense of relief when they found they were not the only ones experiencing difficulties (Hodges & Dibb, 2010). Both Sally and Amanda felt a need to identify with parents who were experiencing difficulties. All the mothers interviewed also described being alone in their anxiety because they were initially the only person identifying their child's difficulties. For Meg, school not recognising difficulties compounded her sense of feeling alone. Hodge and Runswick-Cole (2008) suggest that

when parents feel professional knowledge carries disproportionate weight in the parent-professional relationship a consequence may be that parents feel they can not only be parents but also need to become a para-professional in education, advocating for their child's needs. This may increase anxiety.

Recognition from staff was highlighted as important for parents. This was displayed in two main ways:

- being available on a regular basis for communication; and
- reciprocity (sense of family).

Sally and Meg highlighted the importance of regular communication in order to discuss any concerns. Sally did this for five minutes on a daily basis. Meg highlighted that the relationship provided her with a sense of value and opportunity to hear positive messages. Mike indicated that communication with staff helped him to feel more positive. Discussion with professionals who listen, validate and normalise experiences has been associated with increases in parents' understanding of their child's difficulties and improved their ability to cope (Clark et al., 2008).

Meg described a sense of reciprocity and being needed by the school.

Meg may have valued this aspect to the relationship because it provided status and identity as a parent. She described feeling 'known'. She suggested that through being known she was able to raise awareness of her son and increase his inclusion. This position seems to draw upon elements of social exchange theory (Homans, 1958) which proposed that individuals invest in relationships in order to receive gains. Every relationship is considered to have costs and rewards. Meg appeared to be investing in the relationship, in part to gain rewards for her son. Some disability research has indicated that parents are very aware of the consequences of being perceived as difficult and asking too many questions or sharing different perspectives (Azzopardi, 2010). They may fear the actions they take could lead to withdrawal of services (Murray, 2000).

Parents did not mention identity explicitly but two parents indicated a sense of identity within their discussion. Two elements of identity were considered.

1. Child advocate.
2. Expectation of son reflecting parents' identity.

Parental role of child advocate has been identified within disability research (Azzopardi, 2010; Essex et al., 1999). Scorgie et al. (2004) identified one of the mechanisms that enabled parents to cope was forming new identities (e.g. competence in parenting a child with a disability). One strategy that Amanda and Sally appeared to use, which may support sense of identity, was comparing with parents on an alternative more favourable domain. For example they both described themselves as 'not pushy' with their children. This appeared to be due to recognising that their child would not achieve at the same level as other children in some domains.

5.3   Loss

Data analysis revealed a recurrent theme of loss and denial throughout interviews. Themes are outlined in Table 10.

Table 10

Themes related to loss

<u>**Loss**</u>
Guilt and searching for meaning
Loss of ideal / expected future
Loss of 'normalcy' (impacting on belonging and comparison)

<u>**Denial**</u>
Self-doubt
Avoidance – due to fear of loss (stigma and belonging)

<u>**Positivity**</u>
Identifying strengths
Reducing importance of difficulties
Correcting negative thoughts (reframing)

5.3.1   Guilt and searching for meaning

Amanda and Sally both described wanting to know if anything they had done has caused their child's difficulties.

> Erm, but I can't change the past, I can't change what I've done with him, erm, and to be honest I think if I'd done things a lot differently I don't think he would be any different now. And that's what I think I truly have to accept. I think it's very – it's alright saying things, erm, but I think anything for with your children you always feel it's your fault and you could have done better and you can do this and that. With hindsight, there isn't a rule book on how to do things and, how to look after your own children, and it's trial and error most of the time. Erm, and it's like them growing up, they are learning so much information all the time, and if it's going in a bit slower then there's not a lot you can do about it.
> Sally (lines 1240-1253)

Sally reflects that she has not yet 'truly accepted' that she did not cause her son's difficulties. She reduces self-blame through imagining different pasts with present consequences. At different points during the interview there is a sense of her not being certain of her view and perhaps trying to persuade

herself that her son's needs are not her fault. She seems to acknowledge that guilt is a normal part of parenting. This is reminiscent of earlier comments regarding there being no 'rule book' for parenting and needing to rely on trial and error. Her desire for a 'rule book' suggests insecurity in her own approach and a need for feedback regarding performance (particularly in light of her concerns that she may be contributing to difficulties).

Although this theme was less prominent in Amanda's interview she similarly questions whether anything she has done has contributed to her son's needs.

> 'cause you do wonder why. Erm, you know, I think, did I do anything when I was pregnant, all that sort of stuff. I don't think I did particularly. The birth was all right, I don't know whether that has contributed. But knowing that it's - there's traits like that within the family somehow helps. Somehow makes you think, "Oh, well that's probably where it's come from, it wasn't me".
> Amanda (lines 1226-1240)

Amanda's questions do not seem to have been resolved. She remains unsure about her possible contribution to Ben's needs. The thought that there may be genetic factors underlying needs seems to assuage her guilt because she can attribute this factor to something outside of her control. As outlined previously, Amanda seemed to find comfort and a sense of purpose in the idea that Ben 'came to her' because she is the right person to support him (lines 1631-1637). Again, this may be due to her being able to attribute responsibility to something outside of her control.

5.3.2   Loss of ideal / expected future

Amanda describes a sense of surprise about life not happening in the way she had envisaged.

> Well, I think you, you, you just think it all just happens, don't you? It's that natural progression, you have a kid, they er, they go to university, they get married. You know, all that sort of stuff. And, and going through the divorce as well, has kind of - I mean we're still on really good terms, but it - my life up to that point was a rose-tinted window [starts crying while continuing to talk]. You know, it was all there, it was perfect. You know, not saying everything in life was perfect, but- I mean, I had a lovely childhood, Chris and I met when we were really young, we had a really happy marriage.

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> Everything was that quintessential kind of, what's the next page in the book, you know? And I think, I think it just - I kind of think of it now as, that was a, knowing, finding out about Ben was like having a crack in that window. You know what I mean, that's how it felt. Just, it wasn't quite perfect, it was still all right, but it wasn't quite perfect.
> *Amanda (lines 1179-1206)*

> I think by the time he got to Year two, and I think because of what had happened in my personal life, that window was completely shattered. It didn't exist anymore. There was no rose-tinted window. Life. This is life now. Life's a bit shit, you know what I mean? So in a lot of ways, it's helped me to deal with Ben a lot better because I still… Prior to that, I still had this perfect life with a kid that was a little bit more difficult and I was still trying to match those, still trying to have the perfect life with a kid that was a little bit more difficult. Whereas now, life was, what a lot of people are saying now, (laughs) "God it's just rubbish," you know? Life was rubbish. So there was no pre-conceived ideas. I wasn't trying to live up to a, kind of a, rose-tinted window anymore. That window was completely smashed in. This is life. Life's gonna be different from now on. You know what I mean? So in actual fact, I think that helped me to deal with Ben. Just to accept him for what he was…
> *Amanda (lines 1282-130)*

The description of a rose-tinted window appears similar to the concept of rose tinted glasses. Amanda may be referring to the existence of positive bias within her view of the world. She introduces an image of looking through a rose tinted window at life. This is echoed in her description of a 'perfect life' which she then corrects as 'not everything in life was perfect'. Amanda describes an assumption that the next chapters of her life would be perfect, because everything in her life had been fairly good up until that point. There is a sense that the following events were more of a shock to her because she had a different assumption of the future.

Amanda describes initially trying to manage the expectation of 'perfection' within the reality of something different. She implies that it was harder to fit a child with special educational needs into her notion of a 'perfect life' than it was to give up the notion of a 'perfect life'. There is a sense of her initially clinging to previous understandings and attempting to fit her life into those, before then deciding to change her understanding of life. Although Amanda now thinks life is 'a bit shit' she describes finding this easier (because she is no longer holding two perspectives that she finds contradictory).   She describes letting go of pre-conceived ideas. It is not clear how Amanda expects life to be different. She may be referring to looking at life through a

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different perspective (rather than through a rose-tinted window). This may include the possibility and acceptance of negative experiences.

One of the significant factors considered for the future was school placement. Meg and Mike discussed their child going to mainstream junior school. They did not mention whether change of placement to a special school had been considered. School staff did initiate discussion with Sally and Amanda about possible transfer to special school.

Sally was not surprised when school staff raised the option of special school. This suggests the possibility that she may already have been aware of this option. Sally implies that lack of surprise was due to her experience of difficulties at school leading to her thinking about things in a different way. She reflects that others who have not experienced difficulties in school may not have the same level of awareness.

> I don't think it was a surprise to be honest, for me. Erm,
> when my husband, he never had trouble at school, he's
> intelligent, my daughter's intelligent, but because I had the
> trouble, it makes you think of things in a different way.
> Sally (lines 644-648)

Amanda did not expect special school to be an option. Therefore the discussion school staff initiated was the first time she had considered the possibility of a different placement.

> …it's still there, in my head for the future - that he may not
> go to a normal secondary school. But I probably hadn't
> thought that. So it was h-hard perhaps to hear at the time,
> but actually probably did help me to put it into perspective,
> and realise actually he might not go.
> Amanda (lines 1163-1174)

Amanda's description of the conversation 'being hard to hear' is reminiscent of her description of earlier discussions that were had confirming her son's difficulties. 'Hard to hear' indicates a possible sense of loss and disappointment.

Sally described a perception that school placement impacts upon identity.

> So erm, a special school seems such a, it's not a cliché is it?
> It's such a, you know, you've been tarnished, is it?

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Sally (lines 657-659)

Erm, and then when they said about a special school, erm, I had very mixed emotions. Erm, to the fact that, you know, all you want is the best for your child and if it did mean going to a special school, and it would help, then you know, he would have all the support. But it makes you feel a bit of a failure.
Sally (lines 624-629)

Sally's comment seems to link to the earlier concept she described about parents feeling responsible for children's performance. In this way she may feel she has lost some of her sense of identity in successfully parenting. Sally felt that school placement may also impact upon inclusion and sense of belonging in the future for her son.

So at the moment I'm in two sort of conflicts of what is actually going to happen. Erm, because in one respect going to a school where there's children that do have difficulties, won't make him feel different. Erm, but he is very settled in the school, with his friends, erm, so obviously that's on the back burner at the moment to see how he does get on.
Sally (lines 600-606)

Amanda questioned how much staff were willing to include Ben. As outlined previously she referred to systemic issues such as budget constraints and SATs results (lines 403-406, 942-945). Both parents described a sense of uncertainty regarding placement outcome and their level of involvement in the decision making process.

And I think the school are going to come through for him, erm, but we were told if he doesn't come up to a certain level then he may have to go to a special school. And I've been told by somebody else from another school who teaches, that normally they would want them to stay in mainstream school.
Sally (lines 594-599)

[…]or was she just preparing us for the possibility that other people might start to put the pressure on, might start to make - not force our hand, 'cause at the end of the day it's our decision - but you know […]
Amanda (lines 1097-1101)

Er, I think that, I, I got the impression perhaps that the SENCO was under pressure from the Head, if I'm honest. That was… Because at the end of the day, if the Head was like really saying, "Well actually he really shouldn't be here," would she have the final say? I don't know.
Amanda (lines 1089-1094)

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Both parents seemed uncertain about their level of control around school placement decisions. However, they described needing to wait and monitor progress before making a decision about placement.

> …we will cross the bridge when it comes sort of thing.
> Sally (lines 607-608)

> Because I think, you know, even early on they start thinking about, you know, shipping them off to somewhere else.
> Amanda (lines 380-382)

Amanda suggests that alternative placements are thought about too early. Her comment indicates a sense of depersonalisation within decision making (which could impact upon sense of belonging).

All of the parents describe there now being a limitation on future aspirations for their children.

> Yeah, you know [sighs], no I don't anticipate him going to university but actually that doesn't really matter. It would have done, probably before but it, erm, whatever he can achieve. We've talked at school about just wanting to bring him up to be independent. That's really what it's about. Him being able to live on his own. Have a life of his own. Work. It doesn't matter what he does, you know what I mean? But being an independent person I think, is what we're striving for.
> Amanda (lines 2074-2083)

> But you do worry about like his future, like you know, is he gonna make something of himself? I'm sure he would, but you do worry deep down.
> Mike (lines 229-231)

All of the parents talked about not minding what career children followed but wanting to focus on happiness for them.

5.3.3 Loss of 'normalcy' (impacting on belonging and comparison)

Amanda and Sally reflected that they no longer had normal experiences of parenting. As previously identified, this impacts upon their ability to engage in comparisons that are used by other parents. This may also affect their sense of belonging.

> Erm, but it's just I don't want – you can see that he's started to recognise that he's different, which I think it's good that he has, but not to some degree, because you know getting frustrated, what do you, how can you deal with it? You can't really. Erm… I would just like to wave a magic wand and for everything to be what people call normal. Erm, but obviously we've had Millie and Millie picked up on things right from birth as such, you know, and then to have another child that is slow for everything and then doesn't understand and erm, you know you feel how can you have two such different children?
> Sally (lines 684-698)

Sally is pleased that her son is becoming aware of differences as this indicates developmental progress. However, she is concerned about the impact of difference upon his emotional well-being. Her description of a 'magic wand' may indicate that she knows the situation is difficult to change through intervention. Magic is usually referred to things that are otherwise impossible to achieve. It is unclear what Sally would consider normal (but this may relate to previous discussions regarding social comparison). Her comparison with her daughter may demonstrate what she has lost with her son. Whilst Sally seems confused that she has two such different children, having a child without special educational needs appears a comfort to Amanda.

> But I guess, knowing I've got a child that will do it without problems makes it easier. I sometimes wonder if I only had Ben, (hesitates) would I feel like I'm never going to experience that normal that I always, I know the window's gone, but that pre-conceived idea we all have about how your child is going to develop and grow and blah, blah, blah. Would, if I thought I was never going to have that, how easy would it be? You know? Whereas I know I'm going to have…I mean, who knows what's gonna happen in the future but you know, for Beth's school, I don't envisage there being too many problems and has that made it easier to deal with Ben? Knowing that I will have one that does it normally and I've got one that won't, you know what I mean?

Amanda (lines 1343-1358)

Amanda's comparison with her daughter may be indicative of pride. She later discusses wanting to be able to engage in social comparison through her daughter (lines *1334-1338)*. Amanda also describes losing 'normal' pre-conceived ideas about development. (This also links to the earlier subordinate theme of loss of expected future). Within this quote Amanda seems to catch herself describing pre-conceived ideas again, and she corrects this. This suggests she is still consolidating her understanding of altered expectations, that were described in the theme above. Amanda describes the sense of loss of 'normalcy' being reduced by knowing that she will experience some of what she has lost, through her daughter.

Table 11

Summary of themes within loss experiences

	Loss - Loss experiences			
	Participants' extracts			
	(Numbers in brackets refer to lines in transcripts)			
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Guilt and searching for meaning	*"[…] so initially it was really hard, 'cause you're still battling with, you know, why, and you know, will Ben ever do that."* *(1274-1276)* *…it wasn't me." (1240)*	*"I've gone through how I could have done things differently […] So I still feel guilty about it, but my Mum is my Mum and needed help."* *(668-680)* *"…you always feel it's your fault" (1245)*		
Loss of ideal/ expected future	*"my life up to that point was a rose-tinted window" (1184-1185) "finding out about Ben was like having a crack in that window" (1203-1204)*	*"[…]you've been tarnished, is it?" (657-659)* *"[…] it makes you feel a bit of a failure." (624-629)*	*"And he's not gonna be any super intelligent professor" (85-88)*	*As for what the future holds for him, I haven't got the slightest clue, really. [Sighs]. But you never know, he might pick up one day. You never know. (446-448)*
Loss of 'normalcy' (impacting on belonging and comparis-on)	*I sometimes wonder if I only had Ben, would I feel like I'm never going to experience that normal…(1343-1352)*	*I would just like to wave a magic wand and for everything to be what people call normal. (688-690)*		

5.3.4   Discussion regarding loss experiences

Guilt is considered one of the common emotions associated with loss (Bruce & Schultz, 1996). Attribution theory (Weiner, 1985) proposes that people search for meaning within threatening or uncomfortable situations in order to try and understand, predict and control their experiences. Amanda and Sally's search for meaning and sense of guilt may be related to negative attributions where they believe that they get what they deserve and deserve what they get (Stewart, 1989). Both Amanda and Sally explore internal attributions (such as not providing enough experiences of social interaction or difficulties in pregnancy) but reduce self-blame through external attributions (father's genetics, sense of destiny or within child factors). The interviews suggest that this sense of guilt has been on-going for years (given the time of incidents quoted being birth or early development). Therefore, despite attributions appearing to reduce self-blame, guilt and consequent need for attributions appears to be on-going. The sense of guilt may be related to attempting to find meaning from the situation.

In describing her sense of the loss of an ideal / expected future Amanda goes beyond specific losses and talks about her understanding of life having changed. Bruce and Schultz (2001) suggest that through adapting to non-finite loss people change their schemas of the world. They state: "In the process of adapting, individuals are caught between two worlds but cling desperately to the first world, the one that they are accustomed to navigating" (p. 150). Amanda's description adds some support to the concept of changing schemas through loss. Research has also indicated that key mechanisms parents use in order to adapt include attempts to find meaning and personal control within their situation (Scorgie et al., 2004). Use of attribution and change of schemas appears to be one way that Amanda can develop this. None of the other participants described this sense of changing schemas. It can not be ruled out that they experienced this process but chose not to discuss this element. Meg and Mike were very focused on describing the importance of remaining positive. This may have led to them framing the interview around only those examples (Carr, 2010). Sally on the other hand, identified with some of the needs of her

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son because she had some similar experiences at school. This may have led to her having pre-existing schemas that enabled assimilation of her current experience of her son's difficulties. She describes already thinking of things in a different way because of her experiences of school (lines 644-648). Sally links this to her lack of surprise when special school placement for the future was considered.

Sally describes a sense of future placement impacting upon identity and being 'tarnished' by the placement. It is not clear whether she is referring to her or her son being tarnished, but she later confirms that she seems to view the placement as evidence of having failed her son. This seems to link with previous research indicating that guilt is a common emotion experienced within loss (Bruce & Schultz, 2001). Amanda's description of the conversation 'being hard to hear' is reminiscent of her description of earlier discussions that were had confirming her son's difficulties. 'Hard to hear' could indicate sense of loss and disappointment. This is also an example of loss adjustments needing to be made throughout development as the nature of difficulties are realised as the child grows (Collings, 2008). For both Sally and Amanda, school placement therefore appeared to be another area of loss of expected future. Loss of expected future has been highlighted as a common experience within non-finite loss (Clark et al., 2008).

Placement also appeared to be viewed as impacting upon identity. Sally's use of the word "tarnished" is similar to the definition of stigma involving being "tainted" provided by (Goffman, 1963). She also described a sense of failing. In this way she may feel she has lost some of her sense of identity in successfully parenting. Some disability research indicates that parents can feel a sense of inadequacy about their competency to deal with their child's needs (McConkey et al., 2008). Guilt that is commonly found within loss may link to a sense of failure (Bruce & Schultz, 2001).

Amanda and Sally reflected that they no longer had normal experiences of parenting. Analysis indicated this could include loss of ability to engage in social comparison with other parents and siblings to a certain extent. This links to the process Bruce and Schultz (2001) describe of re-adjusting schemas to accommodate new learning about assumptions of the world.

Amanda highlights use of compensatory strategies such as being able to experience through her daughter some of what she has lost with her son.

Her comparison with her daughter may demonstrate what she has lost with her son. Whilst Sally seems confused that she has two such different children, having a child without special educational needs appears a comfort to Amanda.

Losing normal pre-conceived ideas about development has been identified within loss literature. Clark et al. (2008) found that parents developed new expectations about their child which helped them to cope. For example when told their child's skills were about two years behind they started to compare development with younger children and lower expectations. This appears to link to earlier discussion regarding comparison on different domains or use of temporal comparison as a way of managing difference.

5.4   Denial

5.4.1   Self-doubt

All of the mothers in the study identified their children's needs more readily than the fathers. As outlined previously, opportunity to compare children's needs appeared to contribute to this. Although mothers had greater access to social comparison Amanda and Meg expressed a sense of doubt in their suspicions.

> Because you, you're like, "Oh, someone else is realising it,
> maybe there is a problem." But in the back of my mind I kind
> of knew there was, but for someone else to notice it and
> comment on it is, is not that easy, necessarily, to take.
> Amanda (lines 92-99)

Amanda and Meg described a sense of hoping that they were wrong about their child's difficulties and appeared to think about the situation on two levels. There is a sense of some thoughts existing in the back of the mind and not being focused on.

Amanda and Meg also describe this process feeling like paranoia.

> And Mike didn't really believe me. He just thought it was me

being a paranoid mother… and, and I was like, "No" [stops talking].
Meg (lines 359-361)

"[…] I don't want to be a paranoid mum but if I get something in place now, surely that's better than realising it when he's ten?"
Amanda (lines 1996-1999)

When confirmation came Amanda described it as a 'double edged sword' (line 2007) because it was a relief to finally resolve her doubt but a disappointment to find her child had difficulties. This indicates that the process of holding two opposing thoughts simultaneously was uncomfortable and letting go of one brought relief, despite it meaning that her son's difficulties had been confirmed.

5.4.2   Avoidance – due to fear of loss (stigma and belonging)

Mike and Amanda's husband are described as not wanting to face the possibility that their child had problems. Mike's denial appeared motivated in part to fear of stigma, lowered expectations and lack of support.

Mike:	And maybe, in a way, I didn't wanna think that he had… I dunno, maybe, in a way, I didn't wanna think, "Oh, my boy's got special needs." 'Cause until we actually come about and we realised that there are - it, it's not, you know, it's nothing to be worried about, and that they are gonna do something about it… I suppose when I was at school, special needs meant you were the dunce, and you, you, you know, you were just left behind when I was at school. You know, erm, I remember, we all went in to do our exams, and all the specials needs kids went and sat in another room and done like a lower paper. And it was obvious that they were never gonna get any grades or anything. Whereas now, they really push, and they, they do things for them.
Interviewer:	Mmm. So there might have been an element of you thinking, "I don't want that for Max"?
Mike:	Yeah, yeah. So I sort of maybe tried to ignore it. Maybe subconsciously, just thought, "No, I'll just shut my eyes to that, and…" But then it … like I say, it's nothing… now we've had it all explained to us, and, you know, what the processes are, and what they can do. And, and we've seen the proof in the pudding of how

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well they've done…

(lines 296-333)

Mike describes choosing not to think about his son having difficulties. He describes using comparison to evaluate what the consequences of difficulties might be. Comparison with his own experience of school indicates potential risk of stigma, lowered expectations and lack of support. These fears also link to sense of belonging and feeling different.

Mike's description indicates the possibility of SEN impacting on his son's identity. His use of "my boy" indicates that he may also be reflecting upon his own identity and the impact of being a father of a child with SEN.

Amanda suggested that Chris did not know how to deal with the problem so he avoided it (lines 1925-1929). Amanda described her family as being in denial (lines 1422-1424). Amanda and Sally both state that nobody wants to think there is a problem (Amanda 1898-1899, Sally 812-813). For both Sally and Meg's husbands meeting school staff helped them to identify that there were difficulties.

Mike describes understanding of SEN systems giving him confidence to face his son's difficulties. Understanding helped to discount his fears. Meeting school staff appeared to be a pivotal turning point for Mike and Sally's husband. There appeared to be several key functions within the meetings.
- Use of social comparison to evidence delays.
- Addressing fears through:
    - outlining lack of stigma within school systems;
    - communicating realistically high expectations; and
    - outlining SEN support processes.
Sally identified in addition that hearing news from another professional directly (rather than second hand) may have contributed to her husband's ability to accept the situation (line 548).

Mike demonstrates a significant change of mind when he states that SEN is "nothing". Later discussion indicates that SEN is still having an impact on Mike. For example he considers changed expectations for the future and not being sure whether his son will make "something of himself" (lines 229-

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230). When Mike describes SEN as nothing he may therefore be reassuring himself by playing down concerns.

Despite Mike recognising his son's difficulties at several points throughout the interview he appeared to be searching for an alternative explanation to learning difficulties.

> I think once he's - I, I think that his speech holds him back.
> And wi- like I said earlier on, we're having private speech
> therapy for him. And I think once his speech really gets…
> 'Cause that's really improved over the last year as well. I
> think once he gets the confidence - 'cause I think it's the
> confidence.
> Mike (lines 448-454)

He communicated a sense of hope about the impact of intervention. He seemed to be anticipating that greater improvement may be evident when other difficulties are resolved.

It is not clear whether Mike felt speech difficulties and confidence may have less of a long term impact than a learning difficulty (and are therefore more of a desirable need). Alternatively, he may have been reflecting upon the complexity of the interaction between factors and the difficulty separating out the impact of each.

Table 12

Summary of themes within denial

<table>
<tr><td colspan="5" align="center"><u>**Loss**</u> **-** Denial

Participants' extracts

(Numbers in brackets refer to lines in transcripts)</td></tr>
<tr><td>**Theme**</td><td>**Amanda**</td><td>**Sally**</td><td>**Meg**</td><td>**Mike**</td></tr>
<tr>
<td>*Self-doubt*</td>
<td>*"[…]'maybe there is a problem.' But in the back of my mind I kind of knew there was"* (92-99)</td>
<td></td>
<td>*I sort of knew […] but I was thinking "oh, he'll be fine, he'll be fine" but … he just doesn't quite… grasp it, bless him.* (18-21)</td>
<td></td>
</tr>
<tr>
<td>*Avoidance – due to fear of loss (stigma and belonging)*</td>
<td>*"[husband] […] stuck his face in the sand […]"* (1925-1929)</td>
<td></td>
<td></td>
<td>*"So I sort of maybe tried to ignore it."* (296-333)</td>
</tr>
</table>

5.4.3   Discussion regarding denial

Although Amanda and Meg were the first to recognise the difficulties of their sons, they experienced doubt regarding their concerns. This may be linked to uncertainty regarding social comparison (described previously). They describe a sense of hope and doubt existing simultaneously. The theory of cognitive dissonance (Festinger, 1957) proposes that mental stress and discomfort is experienced when individuals hold two opposing beliefs. Amanda and Meg describe two actions taken to reduce this discomfort.

1. Limiting consideration of the undesired thought (pushing it to the back of the mind). This seemed to involve self-persuasion ("he'll be fine, he'll be fine").

2. Changing the thought pattern (rejecting the old thought and fully accepting the new thought).

Reluctance to change thought patterns initially may be due to new thought patterns taking effort to establish (Beck, 1967). It is also likely to be due to one thought being more desirable than the other. In this way it may be linked to denial. Kubler-Ross (1969) suggested that hope can be evident when denying a situation. Amanda and Meg's descriptions may also link to the Dual Process Model (Stroebe & Schut, 1999) to some extent. Their avoidance of the undesirable thought may allow them to focus on restoration orientated activities (avoidance of loss) rather than loss orientated activities.

Mike and Amanda's husband were described as not wanting to face the possibility that their child had problems. This is indicative of possible denial. Mike's denial appeared motivated in part to fear of stigma, lowered expectations and lack of support. These fears may also be related to loss of belonging (Baumeister & Leary, 1995). Mike appears to describe using temporal comparison (Albert, 1977) to evaluate what the consequences of difficulties might be. This suggests the risks felt too great to consider. This is similar to the strategy described within the five stage model where denial is used as a buffer in order to allow the person time to face the situation (Kubler-Ross, 1969).

Research indicates that people may attempt to distance themselves from the label of learning difficulty because they are aware of stigma attached to the label (Craig et al., 2002; Finlay & Lyons, 2000; Paterson et al., 2012). This may explain why Mike initially did not want to consider that his son may have learning difficulties and possibly why he continued to emphasise other explanations for his delays (e.g. confidence/speech).

Mike's description indicates the possibility of SEN impacting on his son's identity. His use of "my boy" indicates that he may also be reflecting upon his own identity and the impact of being a father of a child with SEN. Scorgie et al. (2004) suggest that one of the key mechanisms that enable parents to adapt to loss is the need to form new identity (e.g. competence in parenting a child with SEN).

Mike's fear of lowered expectations may be related to concern about

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expectation becoming self-fulfilling by leading to less support and limited progress (Merton, 1948). Meeting staff enabled fears to be addressed. Hearing news directly / first hand may also have helped to allay the fears of fathers. Mike talked at length about action plans. He was keen to contribute to interventions at home. These may have helped him to feel a sense of control over the situation. Actively managing change and enabling a sense of control over events has been found to support families with loss (Bruce & Schultz, 2001; Judge, 1998). This could also link to the restoration orientated aspect of the Dual Process Model (Stroebe & Schut, 1999). It may also link to instrumental grieving (focusing upon thinking and doing) that was proposed by Martin and Doka (2000).

Throughout Mike's interview, although it was evident that he had become accepting of his son having delays he continued to appear to search for alternative explanations to learning difficulties. It is possible that Mike experienced continuing denial in some areas. The model proposed by Stroebe and Schut (1999) enables explanation of this process through oscillation. Mike's search for alternative explanations may be motivated in part to the often long term nature of learning difficulties and therefore fear of unexpected futures (discussed in previous section).

Mike describes a significant change of mind when he says SEN is "nothing". As discussed through the analysis, this did not appear to match some of his other comments. He may have been attempting to reduce concerns through self-persuasion. The tendency to present a situation in a positive light has been highlighted by Carr (2010).

5.5 Positivity

All the parents identified that remaining positive was important to them. They appeared to use three approaches to positivity:

- identifying strengths;
- reducing importance of difficulties; and
- correcting negative thoughts (reframing).

All of the parents identified strengths and highlighted those. Sally identified that she felt encouraged by friends using a similar approach.

> Erm, other friends have said, "You know, you can't be good
> at everything, he's good at other things." Erm, so some of
> them have been very careful, sort of careful at what they
> have said to me, erm, and you know have tried to turn it
> around, you know, "He can do this, he can do that" which is
> really nice.
> Sally (lines 1170-1176)

Mike and Sally appeared to use a strategy of reducing the importance of difficulties.

> Everybody …it …the way I look at it is everybody writes.
> When they get to 18, 19, everybody can write. How good it
> is, or how bad it is, everybody can write to a level. You know,
> so he's gonna read or write at some point. And he'll be able
> to - if, if all he wants to do is drive a lorry, he'll be able to
> read and write enough to drive a lorry, you know.
> Mike (595-601)

Use of this strategy may enable Mike and Sally to feel they are reducing the size of the problem and putting their child's difficulties into a longer term perspective. It seemed to enable them to focus upon their child's aspirations still being achievable. Sally was able to draw upon her own experience of finding her 'niche' and achieving despite difficulties.

All of the parents used strategies of correcting or countering negative thoughts with more positive thoughts. Parents sometimes magnified negative thoughts and then self-corrected.

> "[…]he won't ever do that, or he's not doing that."
> Amanda (1279-1280)

Throughout Mike and Meg's interviews there was a sense of finding it difficult to voice negative issues. In Mike's case negative factors were generally not elaborated upon but quickly followed by a positive statement. There was limited acknowledgement of negative emotion which may have led to understatements and denial of anxiety. In Meg's case there were many half finished sentences (leaving a sense of something being unsaid) which was then concluded with a positive sentence (e.g. lines 62, 114, 438).

> We try to like not let it show that we're affected by it. Deep
> down, I think to myself, "Oh, how, how is he gonna be?"
> Meg (lines 247-249)

It is not clear whether Meg and Mike are hiding their difficulties from their son or whether they are also to some extent hiding their difficulties from themselves, through lack of acknowledgement. "Deep down" is again indicative of two levels of thought (which was discussed previously).

> Just always be positive. Always try to be positive. And not be negative.
> Meg (lines 684-686)

There is a sense of Meg not allowing herself to express negativity.

A range of social comparisons were used by parents and others (as discussed in the first superordinate theme of social comparison). In order to avoid negative effects of comparisons and maintain positivity parents appeared to use a range of strategies.

1)   Comparison on another dimension. All of the parents identified their child had strengths in other areas.

> "Ben's very sporty. […] his hand-eye coordination is particularly good, probably above his peers."
> Amanda (lines 577-578)

> "[…] He's good at other things"
> Sally (lines 1170-1176)

> […] they said his effort's amazing.
> Meg (lines 419)

> "[…]he comes out with these amazing facts […]"
> Mike (lines 204)

2)   Selecting new targets to compare with. Both Sally (lines 1884-1888) and Amanda (lines 2107-2122) compare themselves and their child to other families who have placed pressure on their children and suffered negative consequences.

3)   Only one parent described avoiding social comparisons (Meg, line 438). Amanda (lines 921-922) and Sally (lines 305-315) described their children withdrawing from comparison.

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Table 13

Summary of themes within parents' positivity

<table>
<tr><td colspan="5"><u>Loss</u> - Positivity

Participants' extracts

(Numbers in brackets refer to lines in transcripts)</td></tr>
<tr><th>Theme</th><th>Amanda</th><th>Sally</th><th>Meg</th><th>Mike</th></tr>
<tr>
<td>***Identifying strengths***</td>
<td>*"Ben's very sporty. […] his hand-eye coordination is particularly good, probably above his peers." (577-578)*</td>
<td>*"[…] He's good at other things" (1170-1176)*</td>
<td>*"[…] his effort's amazing."(419)*</td>
<td>*"[…]he comes out with these amazing facts […]" (204)*</td>
</tr>
<tr>
<td>***Reducing importance of difficulties***</td>
<td>*"[…] no I don't anticipate him going to university but actually that doesn't really matter […]" (2074-2076)*</td>
<td>*"[…] everyone is different in their own different field. […] personally I wouldn't want to sit in an office, because I love being outside […]" (482-486)*</td>
<td></td>
<td>*"[…] he'll be able to read and write enough to drive a lorry[…]" (595-601)*</td>
</tr>
<tr>
<td>***Correcting negative thoughts***</td>
<td>*"[…]he won't ever do that, or he's not doing that." (1279-1280)*</td>
<td>*"[…] it's completely different to the way Sam speaks. Erm, but Sam will come out with surprising words sometimes." (587-589)*</td>
<td>*"[…] even though he's…it's still not holding him back" (62-63)*</td>
<td>*"[…] he don't wanna be a banker, or – I dunno. You never know. You never know." (412-413)*</td>
</tr>
</table>

5.5.1   Discussion regarding positivity

Research indicates that parents need to retain hope about their child's situation (Collings, 2008; Graungaard & Skov, 2007; Singer et al., 1999). The parents in this study emphasised positive approaches, which may have helped them to maintain hope. All of the parents identified their child's strengths. Sally, in particular seemed to draw upon the idea of multiple intelligence (Gardner, 2006) in order to find strengths. Strength seeking is a growing area within psychology (McKergow, 2005) and includes areas such as Solution Focused approaches, Positive Psychology and Appreciative Inquiry. Use of temporal comparison (Albert, 1977) also appeared to help Sally gain perspective.

Parents described reducing importance of difficulties and gaining perspective through thinking long-term and visioning aspirations being reached through new expectations. This approach has been found elsewhere within research. Clark et al. (2008) identified that parents developed new expectations about their children which helped them to cope. Collings (2008) found that parents reported that in order to cope they needed to make a conscious effort not to entertain certain thought patterns. This may link to Meg's interview containing lots of half finished statements that sounded as if they were going to be negative in focus. Other parents countered negative statements with positive ones. This approach can be seen within cognitive behavioural approaches or solution focused approaches. Patterson (1993) proposes that in adjusting to a child's disability parents may focus on and emphasise positives and minimise limitations of the child and problems caused for the family. Collings (2008) found that in learning to cope some parents reported choosing not to entertain certain thought patterns.

Positive strategies appeared to be used persuasively. There seemed to be an element of doubt in what parents were saying (evidenced by contradictions and corrections). This may link to having two patterns of thought (described by parents as negative and positive). Cognitive dissonance (Festinger, 1957) may impact upon the processing of these two patterns.

Hodges and Dibb (2010) identified four strategies that parents of children

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with a progressive life limiting condition made in order to manage comparisons and maintain positivity.

1. Seeking comparisons on the same dimension (e.g. reflecting that even though others were better off they were still finding it hard).

2. Seeking comparisons on another dimension (e.g. focusing on assets or talents within a different domain).

3. Selecting new targets to compare with (e.g. children who did not have disability but were finding behaviour difficult).

4. Avoiding social comparisons (e.g. minimising contact with other parents in order to maintain feelings of normality).

This study found that parents of children with learning difficulties used similar processes. They did not evidence using the first strategy of seeking comparisons on the same dimension. However, parents did use the remaining three strategies. Temporal comparisons were used in addition. Therefore, parents of children with learning difficulties in this study appeared to be using similar strategies that have been identified with more severe difficulties.

6.0 Conclusion

6.1 Findings

A recurrent theme of loss and denial was found throughout interviews. Themes such as guilt and searching for meaning were found. Some evidence was found for the mechanism of changing schemas (Bruce & Schultz, 2001). All parents reflected on loss of possible / imagined future. This has been highlighted as a common experience within non-finite loss (Clark et al., 2008). Evidence of loss adjustments needing to be made throughout non-finite loss was found (Collings, 2008). Two parents described loss of 'normalcy'. This could include loss of ability to engage in social comparison with others. Use of temporal comparison and comparing within different domains may have been associated with loss of normal pre-conceived ideas about development. Doubt and denial (through avoidance) may have been associated with concepts such as cognitive dissonance and changing schemas. Denial appeared to be an on-going theme despite parents recognising difficulties. The process of oscillation described by Stroebe and Schut (1999) appeared relevant to this. For some parents denial appeared to be related to fears regarding stigma, lowered expectations, limited progress and identity. This study found that parents of children who had moderate learning difficulties appeared to be experiencing non-finite loss.

All of the parents identified that remaining positive was important to them. Three approaches were used: identifying strengths, reducing importance of difficulties and correcting negative thoughts (reframing). This seemed to support research findings about the need to maintain hope within non-finite loss (Collings, 2008; Graungaard & Skov, 2007; Singer et al., 1999). This study found that the comparison management strategies identified by Hodges and Dibb (2010) which were used by parents of children with severe progressive conditions were being used by some parents of children with moderate learning difficulties within this study.

Data indicated that the main process through which parents became aware of their child's needs was through social comparison with peers or developmental norms. Three parents identified that school staff helped them to recognise the level of need that their child had through also using

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social comparison. Frequency of social interaction was restricted by opportunity to compare development (particularly due to work commitments for some of the fathers in the study). When opportunity for social comparison was not clearly available this was facilitated through formal meetings with staff. Despite choosing to make use of social comparison all of the mothers in the study also identified they did not always find comparisons helpful (particularly when instigated by others) because they led to uncomfortable feelings of loss/jealousy due to differences being highlighted. Evidence of both downward and upward comparisons was found.

Parents also used comparison in order to evaluate parenting approaches (against sought advice and judgement of others). The focus of support seeking seemed to be upward. Two of the parents highlighted that their child's needs being not immediately obvious to others lead to unrealistic expectations. Comparison helped some parents to recognise that they were not the only parents with difficulties, which brought some comfort. Parents did not discuss finding it helpful to compare emotional responses / coping strategies of other parents that have been highlighted elsewhere in research (Affleck et al., 1987; Wood, Taylor, & Lichtman, 1985). It is possible that this was because emotional strain resulting from moderate learning difficulties was not as great as compared to other severe disabilities. Alternatively parents may have omitted discussion regarding emotional comparison (in line with their general positive focus).

Although research indicates that use of comparison is developmental, parents identified that at age 6-7 their children's delayed development was not preventing them from comparing their own performance with peers (Guralnick & Paul-Brown, 1989; Hames, 1998; Keil et al., 1990; Lewis, 1995). Evidence was also found of peers using comparison.

Parents demonstrated awareness of the risk of social rejection for children with learning difficulties. Their own experiences of schooling was a powerful source of information. Two mothers expressed a strong desire to protect their children from social exclusion. All of the mothers in the study expressed concern about their child's difficulties impacting upon their ability to participate in social interaction. Parents identified public recognition of strengths as supporting sense of belonging.

Parents also described concepts relating to their own sense of belonging. Judgement of others appeared to impact upon their sense of belonging. All of the mothers in the study described a sense of loneliness (either in being the only person to recognise their child's need initially or feeling that they were the only parent with difficulties). Parents identified different response styles amongst their friends with some being supportive and others dismissive of their difficulties. This seemed to link with loss literature that suggests non-finite needs are generally underestimated by others (Doka, 1989; Martin & Doka, 2000). Recognition from staff was highlighted as important for parents.

6.1.1 Implications for schools

Parents in the study highlighted a number of factors that supported their understanding of their child's needs and ability to remain positive about their situation. These factors are based upon the experience of four parents and therefore can not be generalised to the wider population. Further research is needed to test the applicability of these factors to parents more generally.

- Use of social comparison to help parents recognise the nature and level of children's needs. Social comparison should be used with caution however, as parents may not be ready to accept the possibility of their child having difficulties. Social comparison can lead to upward comparisons which are uncomfortable and could lead to feelings of loss and jealousy.
- Social comparison may increase sense of loss and guilt and may be associated with feelings of inadequacy about competency in parenting and meeting a child's needs. Encouraging temporal comparison may counteract this effect.
- Use of differentiation (with realistic and achievable targets) in order to help parents and pupils recognise progress and support their ability to make temporal comparisons. Public positive feedback in order to help parents and pupils focus upon temporal comparisons and identify strengths in different domains.
- Considering how to make available channels of communication clear to parents. Providing opportunities for parents to discuss their

child in a discreet manner in order to minimise awareness (and social comparison) of other parents.

- Providing opportunity for parents to explore concerns at length and feel listened to (even if concerns are not initially agreed with). This may counter the loneliness mothers expressed.

- Considering how to enable parents to find support from each other (particularly through informal networking opportunities).

- None of the parents describe transition support. This is something schools may consider for children who are vulnerable to limited sense of belonging. Involvement of parents in this process could be considered in order to address anxiety.

- Considering how to deliver intervention support in order to promote sense of belonging. Some parents expressed concern about children being withdrawn from class too much. This links to previous research (Vaughn et al., 1996).

- Reflecting upon messages regarding placement and systemic issues that parents may receive (such as budgets and test results) and the impact this may have on sense of belonging.

- Modelling positivity and a sense of hope. Parents in this study frequently corrected negative thoughts within interviews. They described teachers enabling positivity through evidencing progress and celebrating this through certificates and awards.

- Publicising SEN provision and processes.

6.1.2 Implications for educational psychologists

This study indicated a process of realisation of children's difficulties for parents. This is echoed by other research (Bruce & Schultz, 2001; Graungaard & Skov, 2007). SENCos and EPs are likely to need to take account of this and provide information at the rate at which it is required. One role for EPs may be to provide information to schools about the loss process in order to support their communication with parents.

Parents in this study indicated that they wanted to be active partners of decision making and intervention delivery. Parallels can be drawn with the practice of consultation (Wagner, 2000) which emphasises empowerment of consultees and co-operative decision making. Consultation may have been a particularly helpful approach for the parents in this study.

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This study indicates that assessing and addressing factors that may be contributing to reluctance to accept difficulties can lead to rapid change of mind-set for some parents. EPs are well placed to use psychological skills to assess these factors within consultations.

Identification of strengths appeared very important for the parents in this study. The technique of seeking strengths is recognised as an empowering approach within Positive Psychology, Appreciative Inquiry and Solution Focused Brief Therapy. Further consideration could be given to ways in which these approaches are used with parents when exploring SEN.

6.1.3   Limitations

The methodology employed within the study enabled detailed analysis of the description of parents. The researcher was required to interpret meaning from these. Studies using IPA are therefore vulnerable to researcher bias. This study is limited by not have discussed findings with participants. Discussion could have enabled participants to clarify, challenge or add to interpretations. The principle of the 'double hermeneutic' (Smith et al., 2009) meant some preliminary analysis occurs within data collection and this enabled the researcher to check initial analysis with participants to some extent.

This study highlighted a number of important results for the participants of finding out their child had SEN. The methodology employed in this study allowed for in depth analysis of the views of these parents. However, the methodological approach does not enable results to be generalised to the wider population.

The parents who were willing to take part in the research may have been those who were coping either particularly well or particularly badly. This means that their experiences may be significantly different than other parents.

The study was based upon retrospective data. This means participant recall bias may have influenced results to some extent. Undertaking research with parents of children in school years one to two may have limited this effect to some extent, because events being recalled occurred

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within the last 6 years (and the events which related to school occurred within the last 3 years).

6.1.3.1 Personal reflections

I was aware throughout this research that my role as an educational psychologist was likely to have influenced the conduct of the study. I learnt about Social Constructionism within my initial training as an educational psychologist and this is a concept that has continued to shape my practice since. Basing my research approach upon social constructionism meant that I remained aware of the interplay between the experience of participants, the interpretation of participants upon their experience and my interpretation of the interpretation of participants (as a double hermeneutic). I was aware that I may be more sensitive to exploration of constructs that I share and spend time thinking about, because this is my frame of reference. Therefore I may pick up on some concepts within data that someone else may not. Equally I may not pick up on concepts that someone else might. Therefore different conclusions could be drawn from the same data set. Within IPA it is accepted that different analysts will find different themes within data due to different interpretations. This is accepted because within Social Constructionism all beliefs are based upon perception, interpretation and social construction.

This research stemmed from my experiences of working with school staff who wanted parents to acknowledge children's difficulties more quickly. I became aware that the needs of parents may not be well understood in schools and I sought to develop understanding of some of the possible needs of parents through this research. I was particularly sensitive to the possibility of loss and this probably increased the likelihood of this theme emerging from the data. When hearing parents express concerns and emotions it is not possible for me to detach my emotions from the experience. I believe I should not try to do so as empathy may lead to better understanding of the experience. However, empathy is likely to steer the research in a particular direction as concepts in line with the emotions being experienced are likely to be highlighted more than others. This may also have emphasised concepts such as loss within the research.

School staff descriptions of 'denial' have been echoed within this research

as a subordinate theme. It is possible that my prior experience of this concept with staff increased my sensitivity to these elements within interviews.

The principle of the 'double hermeneutic' (Smith et al., 2009) meant some preliminary analysis occurred within data collection and this enabled me to check initial analysis with participants to some extent. In addition initial analysis was checked with a supervisor in order to assess credibility.

When I started this work the frustration school staff expressed led to feelings of frustration in me, because parents did not appear to be given the time they needed to come to terms with the situations they were facing. I was aware that I needed to 'bracket off' these experiences in order to avoid bias within analysis. I found some evidence of greater staff support being required (e.g. sensitivity around messages regarding placement, budgets and test results and the impact this could have upon sense of belonging). I was likely to have been more sensitive to these factors within interviews due to prior experience of parents raising these issues within my work. However, parents were generally very positive about the support they had received. They often reported having recognised difficulties before staff had, so staff concerns had not come as a surprise. Therefore my prior experience of limited staff understanding/support, which I attempted to bracket off, did not become a large theme within the analysis.

I was aware that my own understanding of child development impacted upon analysis to some extent. I questioned whether Mike and Sally experienced difficulty understanding typical development and whether this may lead to over-estimating strengths and considering them atypical. I also noted that difficulty understanding development and learning processes could lead to considering normal learning processes part of an underlying learning difficulty (e.g. not recognising the need to practice and develop accuracy prior to fluency). These factors were explored in section 5.1.1.1. I drew upon my understanding of child development and psychological concepts when analysing these elements. Had I not been an educational psychologist or had I not come across these concepts previously in my work, these concepts may not have emerged through the analysis.

My presence within interviews may have affected data to some extent.

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Parents sometimes asked whether their contribution had been helpful. They may have wanted to give answers that they felt I was looking for (despite me having highlighted that I was interested in their thoughts and that there were no right/wrong answers). Verbal ability may have affected the ability of parents to express perceptions. I was aware that some parents appeared more articulate than others. This may have led to greater need for interpretation on my part. I found that greater clarification of questions was requested in places. It is possible that this could have been due to the novelty of questions that they had not expected within the interview.

6.1.3.2   Appreciative Inquiry and data

The questions posed within interviews may not have been questions the parents had ever considered. Researchers have found that questions used within AI may appear novel to participants (Michael, 2005). Therefore the questions I asked could have affected the data by highlighting concepts that had not previously been considered important by parents.

Utilising open questions within AI allowed parents to explore perspectives and discuss concepts they wanted to consider (rather than being constrained by my perspective through narrowly focused questions). The concepts explored within the interviews could have been magnified through spending time thinking and talking about them (this is in line with AI which highlights that we grow in the direction of what we study and talk about). Therefore the themes that emerged could have become stronger through the interview process. Within Social Constructionism it follows that if things are the way they are perceived (as opposed to a fixed reality) it would be possible to change them into how we would rather have them be. Carr (2010) suggests that participants are motivated to show they have grown and found meaning through stressful events. This could imply that the growth that is communicated does not necessarily reflect reality and may therefore be considered to impact on data accuracy. However, Social Constructionism asserts that there is no fixed reality and that beliefs are shaped by the perceptions we construct. I was aware of the possibility that parent motivation to evidence change within interviews may have led to greater awareness of change and therefore stronger perceptions of it. This highlighted the importance of constructing positively phrased and neutral

questions within interviews (to avoid negative impact for the participants). As outlined by AI, questions can in themselves become an intervention and lead to change.

In line with AI the questions posed within the interviews were positive or neutral. This avoided negative bias that has been highlighted within disability research (Hastings & Taunt, 2002; Helf & Glidden, 1998). However, it still enabled parents to choose to explore problems and negative experiences. Negative factors that emerged included: loss, denial, stigma, impact of difficulties upon sense of belonging and the negative impact of social comparison. However, these were within the context of more positive factors such as remaining positive (e.g. identifying child's strengths), staff encouraging sense of belonging and facilitating equality, and using strategies to counter negative social comparison (e.g. comparing on alternative domains). Therefore the use of AI did not appear to have precluded exploration of problems but allowed these to sit within a wider context of the experience. In this way Michael (2005) suggests that AI can often lead to a better understanding of both the negative and positive within an experience than would a problem solving approach which begins at the level of the negative.

As outlined within the methodology section, AI and IPA draw upon Social Constructionism. Had I used a different approach data, analysis and conclusions may have looked very different. The inductive approach I took meant that themes emerged directly from the data (rather than through testing of specific hypotheses). This allowed me to consider connections between social comparison, loss and sense of belonging. These themes and the connections between them were unlikely to otherwise be identified as they were not all concepts I had previously considered and I would not therefore have sought evidence regarding these through data collection methods. The inductive approach taken therefore helped to illuminate concepts within the experiences of parents.

6.1.3.3   Analysis of themes

Table 2 was constructed to illustrate the themes that emerged from the data. The construction involved numerous decisions about how to group themes. Some of the themes overlapped. For example parents described

not being able to engage with social comparison in the same way due to their child's difficulties. This involved a sense of loss. I decided to include this theme within 'comparison with peers' rather than within 'loss' but it could have been included in either place.

I broke the superordinate theme of belonging into two subordinate themes of 'child's sense of belonging' and 'parents' sense of belonging'. These were further broken down into component themes. The position of the themes in this section could have been swapped so that the component themes became subordinate themes and vice versa.

Themes were interconnected and impacted upon each other. For example 'comparison with peers/siblings' could lead to 'loss of normalcy' and 'sense of belonging' as well as contributing to 'inclusion vs. exclusion and stigma'.

Themes of denial and positivity were difficult to differentiate from each other at times. For example, reducing the importance of difficulties might be seen to be part of denial of the severity of difficulties (rather than part of positivity). I attempted to differentiate between these by considering whether the parent was acknowledging the difficulty and attempting to locate it within a wider context of life skills rather than solely diminish the severity of the difficulty.

6.1.4   Future research

Meg and Sally appeared very concerned about other children's awareness of difference through social comparison leading to bullying. However, this potential mechanism does not appear to have received much study within psychology. Combining search terms "bully" and "social comparison" on PschINFO database indicated only two journal articles in this area and these were related to victim coping experiences rather than perpetrator influence. Research has focused on the role of family factors, such as parenting style (Smith & Myron-Wilson, 1998), peer rejection (Boulton & Smith, 1994) and loneliness (Rigby, 1996). Since the mechanism of social comparison is linked to evaluation of difference and consequent acceptance/rejection (Festinger, 1954), research into antecedents to bullying may be broadened by consideration of the role of social

comparison within bullying behaviour.

Future research could build upon these findings by considering the extent to which parents use social comparisons at specific stages in supporting their child. Research could also consider whether the nature of comparisons employed changes over time as children develop (for example considering whether greater or fewer temporal comparisons are used as the child develops).

This research solely focused upon the experiences of parents. Their views indicated that children were becoming increasingly aware of social comparison (possibly through modelling of comparison). Future research could consider the social comparisons children employ in identifying their own learning needs and the impact of this upon sense of belonging.

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Appendix 1

Table of complete results for the study

Table 1

Summary of themes within comparison of progress for parents

Social comparison of performance - Comparing progress

Transcript extracts

(Numbers in brackets refer to lines in transcripts)

Theme	Amanda	Sally	Meg	Mike
Comparison with peers / siblings or developmental norms	*"kind of reached all milestones"* *(8-14)* *"he was perhaps a bit behind"* *(18-26)* *"growing up at a different speed"* *(584-588)*	*"[he] was quite late"* *(lines 7-28)* *"he's an absolute whizz"* *(215-216)* *"doesn't make sense"* *(1628-1629)* *"Millie [sister] picked up"* *(1921-1925)*	*"further and further behind"* *(26-29)* *"how far back he had fallen"* *(10-13)*	*"he's like a sponge. He absorbs everything"* *(196-198)*
Professionals modelling use of social comparison		*"he scored very very low, erm 0.1%"* *(619-623)*	*"she went through where he was"* *(10-13)*	*"falling behind the rest of the class"* (11-25)

Frequency of social interaction restricting social comparison	"I saw the comparison with other children" (114-117, 1968-1971, 1917-1923)	"hearing it from somebody else seems to sink in" (544-548)	"I sort of knew through other parents in the playground" (18-21)	"I didn't realise the severity" (11-13, 51-55)
Comparisons instigated by others uncomfortable (leading to loss and jealousy)	"what their child had done and Ben hadn't" (1255-1261) "I don't get jealous. I suppose I did." (1320-1325)	"Oh my child is doing this." (1914-1918)	"people do boast, on social media" (430-438)	

Table 2

Summary of themes within comparison of parenting

<u>Social comparison of performance</u> - Comparison of parenting				
(Numbers in brackets refer to lines in transcripts)				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Comparison of parenting approaches through comparison with sought advice	*"so that really helped to understand what some of his behaviours were." (142-163)*	*"[…]maybe that they can help you in some way and give you some different feedback of what helped" (116-117)*		*"'[…] What can we do at home?' And she come up with all these wonderful ideas that we wouldn't have even dreamed of."* *(160-166)*
Judgement of others	*"You're dealing with it really well and you're doing all the right things for him and that's why he's with you" (1642-1644)*	*"Because a lot of parents feel that […] their children is as good as the parenting" (633-634)* *"Get a grip of him" (1198)*	*"That's only two in the whole of his year that got that [certificate]".* *(480-481)*	*"He's got to where Mrs Smith wanted him to be" (61-62)*

Table 3

Summary of themes within children's awareness of comparison

<u>Social comparison of performance</u> - Children's awareness of comparisons *(Numbers in brackets refer to lines in transcripts)*				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Child's comparison with peers	"I can't do this" (921-922)	"He went really quiet and thoughtful erm, because he knew that he couldn't […]" (305-315)		
Peer comparison with child	"[…]they know him, they get him, there's no problems." (1037-1041)	"Yeah some of them do take advantage of him, or if they have done something, blame him." (1363-1365)	"I'm worried about junior school, that he's gonna get further and further behind and get picked on." (68-70)	"Are you from another country? 'Cause you speak funny." (518-520)

Table 4

Summary of themes within 'children's sense of belonging'

	Sense of belonging - Child's sense of belonging *(Numbers in brackets refer to lines in transcripts)*			
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Inclusion vs. exclusion and stigma amongst peers	*"[…]he's got some friends at school but he doesn't have loads that we'd necessarily invite back […]"* *(1468-1470)*	*"[…]so that he doesn't feel left out, the older he gets, and humiliated[…]"* *(564-568)*	*"I'm worried about junior school, that he's gonna get further and further behind and get picked on."* *(68-70)*	*"I suppose when I was at school, special needs meant you were the dunce […]"* *(306-308)*
Parental protection from social exclusion		*"I feel more protective over Sam."* *(469-474)* *"[…] I think I try and wrap him up a bit too much […]* *(1424-1425)*	*"I don't think he would cope […] so we're just gonna have to really keep an eye on things"* *(561-566)*	
Ability to participate in social interaction	*"I worry that he won't learn what is normal social interaction"* *(1045-1046)*	*"But because he had said sorry he thinks everything is okay." (248-251)*	*"[…] he is so timid and shy"* *(547-549)*	

Equality of recognition from staff	"[…] they absolutely love him to bits, and they've been amazing." (479-480)	"I think the teachers together try to help every single pupil […]" (792-793)	"[…] school aren't thinking, 'Oh, let's not bother with Max' and they're still really encouraging." (96-100)	"[…] he's got his own […] plan of, erm, goals […]" (104-109)

Table 5

Summary of themes within 'parent's sense of belonging'

Sense of belonging - Parent's sense of belonging				
(Numbers in brackets refer to lines in transcripts)				
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Inclusion vs. exclusion and stigma amongst parents	"[…]and they are going to wonder why you are there." (1842-1861) "Who is going to want me with a difficult child…?" (2042-2043)	"I've heard, you know, other people say, "Oh he's a bit simple." And erm, and you can't put into words how you feel."(1295-1300)	"They [close friends] don't ever say anything about, "Oh, why isn't he doing this?" No-one ever questions me." (443-452)	
Loneliness	"[…]I could see it […] for them it was easier to deny." (1969-1971)	"[…] It can feel quite lonely […]" (1087-1089)	"I felt I was quite alone and that they weren't helping" (306-314)	
Recognition from staff		"I just had five minutes, every single morning […] But they took it out of their time to do it, […] which I don't think you would get in many places." (895-900)	"[…] that is definitely the key in the door. The actual relationship with your school will help your child." (610-612)	"[…]feels like a little family […]" (369-371)

Identity	"I'm in a position to really help him" (1644-1657) "[…] I guess we're educated people […]" (2107-2108)	"[…] [other] the parents aren't interested." (955)		I didn't wanna think, "Oh, my boy's got special needs." (297 -299)

Table 6

Summary of themes within loss experiences

	Loss - Loss experiences
	Participants' extracts
	(Numbers in brackets refer to lines in transcripts)

Theme	Amanda	Sally	Meg	Mike
Guilt and searching for meaning	*[…] so initially it was really hard, 'cause you're still battling with, you know, why, and you know, will Ben ever do that.* *(1274-1276)*	*I've gone through how I could have done things differently […] So I still feel guilty about it, but my Mum is my Mum and needed help.* *(668-680)*		
Loss of ideal/ expected future	*"my life up to that point was a rose-tinted window" (1184-1185)* *"finding out about Ben was like having a crack in that window" (1203-1204)*	*"[…]you've been tarnished, is it?" (657-659)* *"[…] it makes you feel a bit of a failure." (624-629)*	*"And he's not gonna be any super intelligent professor"* *(85-88)*	*As for what the future holds for him, I haven't got the slightest clue, really. [Sighs]. But you never know, he might pick up one day. You never know. (446-448)*

Loss of 'normalcy' (impacting on belonging and comparison)	*I sometimes wonder if I only had Ben, would I feel like I'm never going to experience that normal…(1343-1352)*	*I would just like to wave a magic wand and for everything to be what people call normal.* *(688-690)*		

Table 7

Summary of themes within denial

	Loss - Denial Participants' extracts *(Numbers in brackets refer to lines in transcripts)*			
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Self-doubt	*"[…]'maybe there is a problem.' But in the back of my mind I kind of knew there was"* *(92-99)*		*I sort of knew […] but I was thinking "oh, he'll be fine, he'll be fine" but … he just doesn't quite… grasp it, bless him.* *(18-21)*	
Avoidance	*"[husband] […] stuck his face in the sand […]"* *(1925-1929)*			*"So I sort of maybe tried to ignore it."* *(296-333)*

Table 8

Summary of themes within 'parent's positivity

	Loss - Positivity Participants' extracts *(Numbers in brackets refer to lines in transcripts)*			
Theme	**Amanda**	**Sally**	**Meg**	**Mike**
Identifying strengths	*"Ben's very sporty. […] his hand-eye coordination is particularly good, probably above his peers."* *(577-578)*	*"[…] He's good at other things"* *(1170-1176)*	*"[…] his effort's amazing."(419)*	*"[…]he comes out with these amazing facts […]"* *(204)*
Reducing importance of difficulties		*"[…] everyone is different in their own different field. […] personally I wouldn't want to sit in an office, because I love being outside […]"* *(482-486)*		*"[…] he'll be able to read and write enough to drive a lorry[…]"* *(595-601)*

Correcting negative thoughts	*"[…]he won't ever do that, or he's not doing that."* *(1279-1280)*	*"[…] it's completely different to the way Sam speaks. Erm, but Sam will come out with surprising words sometimes."* *(587-589)*	*"[…] even though he's…it's still not holding him back" (62-63)*	*"[…] he don't wanna be a banker, or – I dunno. You never know. You never know."* *(412-413)*