# *How to talk to children about learning disabilities within the family: A siblings' perspective*

A thesis submitted in partial fulfilment of the
degree of Doctorate in Clinical Psychology

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April 2004

UMI Number: U194506

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# ACKNOWLEDGEMENTS

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## ABSTRACT

Parents have asked clinicians whether they should tell their non-disabled children about their siblings learning disability, and if so how should they do it. Current clinical practice advocates the importance of open and honest communication with children across a range of sensitive topics yet there is little research to substantiate the benefits of this practice. There is even less research discussing how parents should approach these conversations with their children. This study aimed to provide an account of how parents could best to inform non-disabled children about their siblings' learning disability. In particular information about the specific factors involved in sharing this information was needed. The aim was to provide a model that could act as a frame of reference for both parents and professionals when considering disclosing to a child. Data was obtained from interviews with six adult participants all of whom had a sibling with a learning disability, and all of whom were parents themselves. The data was analysed using the Grounded Theory methodology, and a model of the factors involved in the disclosure process was developed. Analysis showed that unlike professional to parent disclosure, parent to child disclosure was not a discreet, easily identifiable event. Instead it was more pervasive, long-term process that was entwined into the daily activities of family life. Whilst the parent facilitated the disclosure process the child was found to be an active participant who gained information through a range of different mediums. The findings of this study allow any fears about upsetting or overwhelming the child to be dispelled. Indeed, parents can be reassured that by directly addressing the issue of disability, including both the positive and negative aspects, the child can achieve an acceptance of the situation.

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# 1.    INTRODUCTION

This literature review outlines research relating to the process of disclosure, as it occurs between parents and non-disabled children in families with a learning disabled child. The term disclosure is typically used in the literature to refer to the way in which parents are told of their child's disability by a professional. However, in the context of this study, the definition of disclosure is extended to refer to the process by which a parent informs non-disabled children within the family about their brother or sister's disability.

There is scarcity of studies pertaining specifically to the disclosure of a brother or sister's learning disability to the non-disabled siblings therefore, theoretical and research evidence relevant to the questions posed in this study will be drawn from a number of additional sources. The chapter begins by providing a context for the research question by discussing the effects of living with a person who has a learning disability in the family. This is followed by a description of the literature examining the factors involved in making the disclosure of a child's learning disability a satisfactory process for parents will also be outlined. The next section accesses the developmental literature in order to ascertain whether it is possible for children to understand concepts of disability. Following this the literature describing the disclosure of sensitive information to children across a range of topic areas is presented. Finally, the aims of the present study are outlined.

## 1.1    The Effect on the Family of Living with a Child with a Disability

### 1.11    The Effect on Non-disabled Siblings

> *"I feel in my own life, half damaged, half enriched by having a*
> *sister with retardation"*
> (Dougan, 1983, cited in NICHY, 1994)

Sibling relationships can be among the most important relationships in the lives of children with disabilities (Heller, Gallagher & Fredrick, 1999). They are important because the non-disabled child's reaction to the disabled sibling can affect the overall adjustment, and development of self-esteem in both children (NICHCY, 1994).

Towards the end of the life-span, relations between siblings take on particular importance for many people as sources of support (Dunn, 2000), but this maybe especially true in relationships where one sibling has a learning disability. Research concerning the mental health of siblings of disabled children has provided inconsistent results (Hannah & Midlarsky, 1999; Roeyers & Mycke, 1995). Some studies found no differences in overall adjustment between siblings of disabled and non-disabled children (e.g. Hannah & Midlarsky, 1999; Dyson, 1989; Carr, 1988; Gath & Gumley, 1987). Other research reported a negative effect upon siblings' psychological health (e.g. Coleby, 1995; Bresalu, Witzman & Messenger, 1981). These include; higher levels of anxiety and depression, and lower levels of self-worth, social acceptance and conduct (McHale & Gamble, 1987), being perceived as more aggressive (Lobato, Barbour, Hall & Miller, 1987), and a negative relationship between age and internalisation for girls and externalisation for boys (Hannah & Midlarsky, 1999). Empirical cross-sectional investigations across different age ranges of siblings generally place pre-school age children within higher risk categories, in terms of their behavioural adjustment towards living in a family with a person who has a disability (Lobato, 1993). This highlights the need for early interventions with this group of non-disabled siblings.

Shulman (1988) identified three main areas in which the non-disabled sibling's upbringing is disrupted due to living with a person with a disability; family organisation, the role of the sibling, and parent-child interaction. These will be discussed in turn. Firstly, Shulman stated that family organisation needs to change to meet the needs of the disabled child. Adjustment to this situation depends on the family's ability to re-organise in a way that will meet the needs of all family members, not to do so may lead to conflict within the family. Secondly, the role of the sibling has been found to be different in families with a disabled child, in particular their relationships were found to be more instrumental (Miller, 1974 cited in Harry, Day & Quist, 1998) and asymmetrical (Stoneman, Brody, Davis & Crapps, 1989 cited in Heller et al.. 1999). Non-disabled siblings took a more dominant leadership role, even when younger than their disabled sibling, they also assumed greater care-taking roles (Heller, Gallagher & Fredrick, 1999). These differences are not necessarily negative as children were found to display significantly more nurturing and affectionate behaviours towards their disabled sibling, when compared with

interactions between siblings without disabilities (Heller, Gallagher & Fredrick, 1999). Finally, Shulman found that parent-child interaction can be affected by differential levels of attention given to siblings as a result of the demands of caring for a disabled child. This has been associated with difficult behaviours and conflictual relationships in the un-favoured sibling (Brody & Stoneman, 1996 cited in Dunn, 2000). However, achieving equality of treatment between siblings may not in itself be vital as siblings acknowledged their parents' attempts to treat them all equally even if they were not always successful in doing so (Pit, Ineke & Loots, 2000). This highlights the value of open communication between parents and their children.

There is also evidence for positive effects of having a sibling with a disability. These include an increased tolerance of difference (Matthesis, 1998; Powell & Ogle, 1985), higher levels of empathy and altruism (Bagenholm & Gilberg, 1991; Lobato, 1983), increased pro-social behaviours, and fewer agonistic behaviour patterns when matched with peers (Heller, Gallagher & Fredrick, 1999). Harry, Day and Quist (1998) found strong patterns of positive involvement and responsibility in siblings of a learning disabled children.

Powell and Ogle (1985) report several strategies to maximise the interactions between the disabled and non-disabled siblings. These strategies were suggested by siblings of disabled people, and include limiting care-giving responsibilities, involving siblings in family events and decisions, and teaching siblings how to interact with their disabled sibling. Hames (1998) states that this can be done by example, as children will emulate their parents' behaviour towards their non-disabled sibling.

## 1.12    The Effect on Parents

Further insight into the effects of living with a disabled person can be gained from examining the research concerning parents of disabled children. The news that a child has a developmental disability is one of the most frightening and confusing pieces of information that parents will ever receive (Carpenter, 1998). Indeed, most parents report their initial response to be overwhelming shock (Matthesis, 1998; Quine & Pahl, 1987). It is not surprising then that many parents may be too overwhelmed to immediately recognise and respond to the needs of the affected child's siblings

(Lobato, 1993). Interestingly, some parents who received a diagnosis later in the child's life reported finding it a relief as they had suspected something was wrong, and therefore, had faced a long period of anxiety and uncertainty which was now over (Bagenholm & Gilberg, 1991; Quine & Pahl, 1987). It is agreed that parents of children with disabilities experience considerable loss, not only of their "idealised child" (Dykens & Hoddapp, 2001, p.59) but also of their careers, their financial security, social life, health, and benefits of retirement (Goldberg et al., 1995). Indeed, the ongoing demands of raising a child with a disability is often seen as a source of prolonged stress (Shulman, 1988). Early research into the effects of living with a disabled child generally adopted a pathological view of families. The assumption was that families with disabled children were in danger of becoming disabled families (Dykens & Hoddapp, 2001). For example, parents have been found to suffer from increased rates of mood disorder, low self-esteem and a low sense of competence in comparison to parents of non-disabled children (Shulman, 1988). Research claiming to describe parent's reactions took a largely maternal focus (Dykens & Hoddapp, 2001). Indeed, mothers were found to have increased care-taking responsibility, and had often amended their life goals (Carpenter, 1998). These findings are especially concerning as Sloper (1999) reported that high levels of parental distress, and a lack of parental support may affect the well being of both disabled and non-disabled children in the family.

Much of the research into the effects of living with a disabled person has focused on examining levels of pathology in family members. More recently another, smaller body of literature is emerging which goes beyond pathology to examine the meaning given to the experience of living with a person who has a disability. Todd and Shearn (1997) used the concept of "fragmentation" to describe how parents' beliefs and aspirations concerning their expectations for the future, their own and their child's, are violated at the time of diagnosis. Thus it is not surprising that parents' reactions at this time have been compared with those of a bereavement (Quine & Pahl, 1987; Cunningham & Davis, 1985). Olshansky (1962) identified numerous occasions throughout the parent's life when these intense grieving feelings were re-evoked. Therefore, unlike a time-bound model of bereavement, what the parents of children with a disability experienced was a more of a recurrent type of loss. Goldberg et al. (1995) devised the term of "Chronic Sorrow" and linked the re-occurrence of grief to

significant times within the altered life cycle pattern of families with a disabled member. They reported that grief may be re-experienced as the implications of the disability become increasingly apparent, both for the life of the affected person, and for the lives of other family members.

The parental response to having a disabled child can change over time, Rienders (2000) refers to this as a "Transformation". He describes this as the experience of accepting the loss of one's old identity and expectations in the face of a future that is somewhat uncertain. This experience allows a new self to be developed, one which can give parents the strength to respond effectively to the situation of having a disabled child (Reinders, 2000). Scorgie (1997, cited in Reinders, 2000) outlined three elements involved in making the transformation to becoming a more successful parent of a disabled child. They are; the ability to live with uncertainty, a positive reframing of one's fragmented beliefs and attitudes, and accepting the disability. Acceptance in this sense is not a resignment to the loss of the "idealised" child, but an embracement of the value of living with a disability. This does not obliterate the moments of grief but frees people to express their emotions rather than be captivated by them. Reinders (2000) found that whilst parents may embrace the disability, they also experience some ambivalence. Despite all the difficulties they experience they love and value their disabled child, but they express doubt as to whether they would actively have chosen this life, had they been given the choice.

The opportunity for parents to speak about the sometimes hard reality of living with, and caring for, a disabled child is often denied in today's culture where effective coping strategies are highly valued (Sloper, 1999). Saetersdal (1997) argues that if you deny the suffering of a person with a disability, and their carers, you do not acknowledge an important dimension in their life, or in the life of their family. This acknowledgement of difference has parallels with Systemic Practice which advocates that issues of difference be thoroughly explored in order to establish a safe and secure base from which to conduct therapy.

The research discussed in this section was conducted in relation to the parents' experience of adjusting to life with a disabled child. However, these ideas could also fit with the non-disabled sibling's experience. For example, the non-disabled sibling's

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expectations may also be fragmented, perhaps by future-oriented concerns relating to their role in caring for their disabled sibling (NICHCY, 1994). Non-disabled siblings may also experience feelings of loss, or chronic sorrow, at significant stages in their own, or the families life cycle. Similarly, positive effects have been found to be gained from having living with a person who has a disability. It is possible that a non-disabled sibling could experience something similar to Reinders (2000) process of Transformation thereby allowing them to accept and adapt to the situation more positively.

## 1.13    Families in the Wider Social Context

A family does not exist in isolation. Family members operate within the wider social context, and as such will meet with indiscreet and negative reactions towards disability from some of the people around them (Todd & Shearn, 1997; Anderson 1988). Therefore, it is important to note that the definition of Learning Disabilities attended to in this study goes beyond the traditional medical definition, which is summarised as sub-average intellectual functioning (IQ<70) existing concurrently with impaired adaptive functioning (AAMR, 1992 & DSMIV, 1994), to incorporate the social model of disability (UPIAS, 1976, cited in Fawcett, 2000). This model looks beyond individual impairment to recognise social disadvantage or restriction. According to this model disability is not seen solely as an individual's problem but also as a social and environmental issue. For example, within the medical model stresses on the family are seen as occurring as a direct result of the child's impairment. The social model of disability employs a broader view focusing on the social and environmental factors that affect families of disabled children, such as social attitudes towards impairment and inadequacies of support (Sloper, 1999). A criticism of both models is that they view disabled people as a homogenous, unified group (Fawcett, 2000). Yet disabled people form an extremely heterogeneous group, incorporating people of both genders and from all religions, ethnic backgrounds, and socio-economic levels (Smith & Mitchell, 2001). Research (e.g. Danforth & Navarro, 1998; Snow, 1998; Luckasson & Reeve, 2001) has shown that one of few shared characteristics is that all disabled people face prejudice and discrimination.

Research in the field of chronic ill health, has shown that individuals can resist the full force of social stigma through the support given to them by significant others, including family members (Charmaz, 1987 cited in Todd & Shearn, 1997). Powell and Ogle (1985) advocate providing siblings with the opportunity to meet other children who also have disabled siblings. Indeed, parents report that friendships with other families who have a disabled child are vitally important because of the "depth of understanding...they have been there too" (Carpenter, 1998, p.3) and can therefore share many of the experiences of living with a disabled person in the family. Despite the stigma experienced by all members of the disabled person's family (Todd & Shearn, 1997), studies also cite social benefits which stem from the experience of living with a person who has a disability. For example, it can politicise family members, making them more conscious and committed to issues of social justice, and help them to gain greater sensitivity to other forms of oppression and disadvantage around them (Rolland, 1997). Saetersdal (1997) reported that parents felt that they, and their non-disabled children had gained a new view of "weakness" which gave them insight into what is of value in life, they viewed these changes to be positive.

## 1.2    The Examination of Protective Factors

Faced with a wealth of different outcomes concerning the implications of living with a disabled child, for both parents and non-disabled siblings, researchers have abandoned the concept of homogeneity of families (Roeyers & Mcycke, 1995). Instead the focus has moved to examine the role of mediating, or protective factors (e.g. Senapati & Hayes, 1988; Gath, 1974) which are hypothesised to affect the non-disabled sibling's adjustment. Such factors have included socio-economic status, family size, birth order, gender, gender-match, and type and severity of the affected child's disability. However, once again findings were inconclusive (Loboto et al., 1987).

The concept of resilience has emerged as a potentially protective factor for children who have experienced a range of difficult life events. Gilligan (2002) defines resilience as the ability to transcend adversity. Non-disabled siblings of a person with a learning disability fall into this group. They will inevitably have to face changes in their family system and may experience a range of other problems, such as care

issues, prejudice, or differential parenting. Their well being is influenced by how resilient they can be when dealing with these difficulties.

In his work on resilience Gilligan (2002) cites three sources of vulnerability. These are; the child's own personal characteristics (e.g. age, I.Q., temperament), factors within the family context (e.g. poverty, social isolation, the amount of warmth and cohesion), and finally factors in the wider social world (e.g. a poor relationship with school or run down support services). One could therefore imply that these vulnerabilities, once reversed constitute potentially protective factors which may aid the child in the face of adversity. As expected an accumulation of adversity can lead to serious problems (Rutter, 1990, cited in Gilligan, 2002). However, the reverse is also true cumulative protective factors can lead to disproportionately positive effects, even when the child is still exposed to significant distress (Runyan, 1998, cited in Gilligan, 2002).

Furman (1993) believes that in order to fully understand sibling relationships one must examine the qualitative and dynamic features of relationships within the context of the family. Research findings highlight the interactions between family processes and sibling adjustment (Dyson, Edgar, & Crnic, 1989). For example, siblings growing up in the same family, who one would expect to have shared similar experiences have been found to differ notably in personality, adjustment and psychopathology (Dunn & Plomin, 1990, cited in Dunn, 2000). Lobato (1993) states that the individual sibling's cognitive and temperamental characteristics will influence the way they interpret family behaviour and any changes that occur within that system. This highlights that not only are researchers unable to generalise between families, they also cannot generalise within them. Stamp (1991) hypothesises that the key to understanding the extremes of family well being and family psychopathology lie within an understanding of real-life family conversations and family interactions.

The role of protective factors have been further developed to endeavour to gain insight into how individual siblings, within the same family can report different experiences (Dykens & Hoddapp, 2001). It is hoped that this will help to identify those at risk of suffering adverse effects as a result of living with a person who has a

disability, in addition to highlighting ways to promote the non-disabled child's well being. Some possible explanations are presented below:

*Stressors and protective factors* - Research in this area has had a primarily negative focus (Senapati & Hayes, 1988), which reflects the assumption that a handicapped child in the family is a significant, ongoing stressor (Crnic, Friedrich & Greenberg, 1983). Even if this were true, the presence of a stressor alone is not necessarily enough to lead to negative outcome for family members. There is an interactional relationship between the stressor and other factors which may protect against the stress of living with a disabled child, factors such as dispositional attributes, family cohesion and warmth, and the availability of external support systems (Luther & Zigler, 1991).

*Individual Appraisal* – The work of Lazarus and his colleagues (Lazarus 1966; Lazarus & Folkman, 1984 cited in Glasberg, 2000) provides an explanation that may shed light on the inconsistency of adjustment outcomes for non-disabled siblings. They described a process of "primary cognitive appraisal" which determines whether or not an individual will view an event as stressful. The individual is seen as an active agent who is able to influence the impact of stressors through cognitive, behavioural and emotional strategies. A key feature of this model is that individuals may differ in their appraisals of similar events and circumstances. These appraisals are affected by the resources available to each individual, resources which include material factors such as the availability of information, psychological resources, and social factors. Therefore, researchers have suggested that providing children, and parents, with access to information can buffer the negative effects of a potentially stressful event (Pain, 1999; Harris, 1994, cited in Glasberg, 2000).

*Coherent Stories* - The concept of "Coherent stories" is a frequently used technique in attachment and narrative based therapies (e.g Main & Goldwyn, 1984), it involves facilitating the individual to develop an understanding of their experiences. The meaning the individual attaches to their personal experience is said to shape their perception of that event, as well as their longer term adjustment to it. Children are found to be more resilient if they are able to develop and reflect upon a coherent story about what has happened, and what is happening to them (Gilligan, 2002). For

example, Mary Main (1984) found that children who had been abused where less likely to be abused again if they had developed a coherent story around the abusive incident.

Main (1984) saw the development of a coherent story as a vehicle through which the person can make sense of their experiences. She recognised that adults can overcome difficult life events if they are able to account for them in a coherent way. Therefore, it is not the experience itself that is critical to the person's adjustment but how it is processed and understood (Talyor, 2002). This mechanism would account for individual differences between siblings in the same family, and for the inconclusive findings reported when researchers investigated static mediating factors.

Initially, it is thought that children learn to narrate life experiences from their caregiver who provides the structure and content for the story, material the young child is unable to supply. As the child's skill increases they take more personal responsibility for the story and the caregivers input is needed less to scaffold the child's story (Wahler & Castlebury, 2002). This early co-authorship between parent and child is crucial in facilitating the development of the child's understanding. It will provide the foundations of understanding which with then be built upon by the individual. Vygotsky (1962) views storytelling as representing a shift from an inter-psychological process of co-construction to one that is intra-pychological.

These coherent stories, or narratives, are more than recounted experiences. They provide people with information which guides them in interpreting and responding to new experiences (Applebee 1978, cited in Wahler & Castlebury, 2002), acting as a chart of their understanding (Ricoeur, 1983; Brook 1984, cited in Wahler & Castlebury, 2002). Whilst the facts of the situation are important it is equally necessary to explore the child's feelings in relation to those facts as a crucial part of the narrative.

The task of therapeutic work is to help young people establish their own coherent story. It may be a similar task for the disclosure process. This account shows the need for the process of discussing difficult situations to begin early in the child experience in order to be able to co-author an adaptive script, that could potentially lead to increased understanding and well being.

When exploring these protective factors it is important to acknowledge that the responses and feelings of the non-disabled child towards the sibling with a disability are not static. Rather they tend to change over time as the sibling adapts to living with a disabled sibling, and copes with the day-to-day realties (NICHCY, 1994). Indeed, Lobato (1993) states that recognising the unique experiences and concerns of non-disabled siblings is an important first step towards enhancing their adaptation and development. This could be seen to mirror the transformation process reported in parents. This highlights the need for disclosure to be a flexible process that can adapt to the needs of a dynamic and changing family system.

## 1.3    Disclosing to Parents

Much of the research investigating the disclosure of a learning disability focuses on how professionals, such as doctors and nurses, inform parents about their child's disability. Whilst not directly applicable these findings may provide some insight into how parents could manage the process of disclosure with their non-disabled children. Sharing the diagnosis of their child's learning disability with parents is the first step in the continuing management of the disabled child. Evidence has found that how parents are informed affects both the way in which they adjust to the situation, and their early treatment of the child (Quine & Pahl, 1987). This suggests that the way the disclosure is managed may have long-term implications for the whole family. The practice of disclosure, from professional to parent, has been shown to vary according to the doctors' assessment of parents' ability to understand the information. This decision has been found to be based on factors such as socio-economic status, the parent's perceived emotional stability, and the severity of their child's condition (Turner & Sloper, 1992; McDonalds et al., 1982). Paediatricians highlighted several other restrictions on their disclosure practice. For example, they reported not always being able to prepare for the disclosure interview because they may have to spontaneously respond to direct questions from the parents, or follow-up information already given by other professionals. They also cited inadequate follow-up services and a lack of training in how to manage disclosure as being problematic (Turner & Sloper, 1992).

The disclosure situation is loaded with unexpected stresses for parents (Matthesis, 1998). Information given to parents at this stage is often not fully understood or remembered (Firth, 1982), so it is important to avoid overloading them with information at an early stage (Quine & Pahl, 1987). Firth (1982) states that follow-up sessions are vitally important, indicating that disclosure is a process rather than the single discussion often implied in research studies. Unfortunately, Cunningham et al. (1984) found that this type of follow-up service was not yet standard practice. Indeed, parental dissatisfaction with the disclosure interview is relatively high (e.g. Pearson, Simms, Ainsworth & Hill, 1999; Cunningham et al., 1984). Criticisms included parents not being told of their child's difficulties when they were together. The doctors' use of an inappropriate manner, a lack of sympathy, an overemphasis on the negative aspects of the child's condition, not being unable to understand the information given, and being told too late (Cunningham et al., 1984; Haranda & Pye, 1981). Some parents reported that they had suspected something was wrong with their child but had only received information after their persistent questioning, indeed in many cases parents are the first people to have concerns about their child (Office of Population Census & Surveys, 1989; Murdoch, 1983). Finally, parents reported not being give direct or honest answers to questions (Cunningham et al., 1984). This is particularly difficult as parents reported wanting to be told the truth, indeed they described feeling bitter when information was withheld, or when they were wrongly reassured (Quine & Pahl, 1987). Interestingly, when the parents were given what they perceived to be a justifiable reason for a delay in disclosure, or not being told together they made no criticisms of the service provided (Cunningham et al., 1984), thus highlighting the value of open communication between professionals and parents.

In a seminal paper Cunningham et al. (1984) asked whether dissatisfaction with disclosure was inevitable due to the nature of the task. They developed a "model service" for the disclosure of diagnosis to parents of children born with Down's Syndrome. This model incorporated many factors found to increase satisfaction with disclosure in the literature (e.g. Cunningham, 1979; Lucas & Lucas, 1980; Springer & Steele, 1980). When implemented Cunningham's model disclosure service increased the rate of satisfaction to 100%, compared with only 20% for the control group (Cunningham et al., 1984) which they claim negates the assumption that dissatisfaction with disclosure is inevitable. However, this study was conducted with a

small sample (N=7), drawn from a Downs Syndrome population. This is a disability which can be diagnosed early (usually at birth), and one which has an identifiable cause. Both of these factors have been found to increase the rate of parental satisfaction in routine disclosures (Quine & Pahl, 1987). Cunningham et al. (1984) highlighted factors which they felt should be incorporated into the disclosure process. These included giving parents a positive, yet realistic focus in terms of the child's prognosis as well as an insight into the services and support available to them. He advocated allowing parents further access to the same person who told them the initial diagnosis, and finally parents identified meeting other families with similar children to be a beneficial experience. Medvene (1992) found that meeting other parents of a disabled child reduced feelings of isolation, and parents felt they learnt from the experiences, and ways of coping of others in a similar situation.

Despite the potential for improvements in disclosure practices (Pearson et al., 1999; Cunningham, 1984), a significant amount of parents still felt that they did not receive accurate and realistic information about their child's disability at the time of disclosure (Pearson et al., 1999). Perhaps this is an unrealistic expectation in that context, but it is of concern as information was found to assist parents in the process of adjusting emotionally to their child's disability, it enhanced their management of the child, and was vital in facilitating and understanding of the practical implications of the disability (Pain, 1999).

## 1.4    Children's Concept and Understanding of Illness and Disability

*"Toddlers are, by nature, egocentric in their perspective, magical in their thinking, and reliant on appearances in their understanding of cause and effect. Their unique cognitive and emotional characteristics render them especially vulnerable to misunderstanding their brothers' and sisters' disease or disability"*
(Lobato, 1993).

This section reviews the research examining a child's ability to understand concepts related to disability, this is done in order to evaluate whether it is feasible for parents to talk to children about their siblings' disability. Traditionally, research into a child's

understanding of illness and disability has taken a Piagetian stage approach, such as the Bibace and Walsh (1981) model which outlines the development of a child's understanding of health related concepts. This approach assumes that the child's beliefs progress systematically through different stages reflecting the child's developmental shift from pre-operational to formal-operational functioning (Eiser, 1990). However, there is a growing body of evidence which shows that children as young as two years old have the ability to achieve a more sophisticated understanding of their illness experience (e.g. Eiser, 1990; Kendrick et al., 1986). Research has found that having regular exposure to a disabled child have been found to significantly enhance a child's understanding of illness or disability (Liversley & Bromey, 1973). However, others argue that exposure alone does not lead to an increase in accurate information about the situation. This comes from participation in family discussion and through the provision of developmentally appropriate information (Townes & Wold, 1977, cited in Lobato, 1993). This led Eiser (1990) to conclude that changes in children's beliefs about illness and disability are as much a function of their experiences, as developmental change. These findings are difficult to explain when taking a Piagetian perspective, as these children should be unable develop this level of understanding due to their cognitive immaturity.

The work of Vygotsky (1962, 1978) bridges the gap between these new findings and Piagetian style stage models. His theory of development emphasises the role of social interaction in learning and cognitive development, he suggests that learning first appears on the social plane before becoming part of the individuals store of abilities. In common with stage models, Vygotsky recognised that at a given point in time there is a limit to what the child can understand. However, he hypothesised that further development can be facilitated through the "zone of proximal development". This is defined as "*the distance between the actual developmental level as determined by independent problem-solving and level of potential development as determined through problem-solving under adult guidance or in collaboration with more capable peers*" (Senapati & Hayes, 1988, p.107). When applied to a child's concept of illness and disability, the Vygotskian graduated, prompting model suggests that young children have the potential to understand more than they initially seem able to, if their learning is facilitated in a supportive environment.

It has been posited that the concept of learning disabilities may be more elusive for pre-school children to understand (Hames, 1998). Research suggests that young children's understanding of illness and disability is relatively concrete, relying on observable, physical signs (Hames, 1998; Potter & Roberts, 1984). However, by the age of five children are beginning to broadly classify others in terms of disabled and non-disabled (Lewis, 1995). It is thought that before the age of 11 years old children are unable to distinguish between different types of disability, often confusing learning disabilities with sensory disabilities or illnesses from which the child would eventually recover (Hames, 1998). It is these broad categories that begin to form so early in the child's life that will constitute the basis of their social comparisons and development of social categories. The child will attach value judgements to these categories based on their experience, and the attitudes of others (Lewis, 1995). Therefore, by addressing the issues of disability early in the child's life parents may be able to influence the nature of the values assigned to the meaning of disability.

## 1.5    Disclosing to Non-disabled Siblings.

There is currently little information available for parents informing them about how to tell their non-disabled children about a sibling's disability (McConachie, 1991). Many parents report facing a dilemma as to how to approach these discussions with their children, when to tell, how to explain it, and fears about their child's reaction (AT Society news). Research (e.g. Perrin & Gerrity, 1981; Potter & Roberts, 1984) has shown that parents would welcome guidance on how to explain these issues. Parents reported finding it particularly difficult to talk to pre-school siblings as they felt that they may not fully understand the implications of the information given. A consequence of this is that young children generally receive less information than older children (Lobato, 1993). This review has shown the importance of information for parental adjustment, the same may be true for non-disabled siblings.

In one of the only studies on this topic, Hames (1994) interviewed parents of children with Down's Syndrome about the disclosure of their brother or sister's disability to older siblings. She found that the sibling's age was one mediating factor parents used to decide when, and how they would disclose the diagnosis of a learning disability to their non-disabled children. Sibling aged over four years old at the birth of disabled

child were told within the first three months (Cunningham, Glenn & Fitzpatrick, 2000; Hames, 1994). In this "immediate" type of disclosure parents were found to take the initiative in the situation (Hames, 1994). However, for children who were classified as "told later", including the majority of pre-school siblings, parents waited for questions from the child to signal an appropriate time to disclose. Parents reported that siblings had started to ask questions, and make comments, between the ages of four and eight years old. Initially, the non-disabled sibling's questions related to the disabled child's physical appearance or practical issues, such as when their disabled sibling would walk or talk. Later, questions had more of a social trigger, such as the non-disabled child making comparisons between their disabled sibling and others, or asking why the disabled child has to go to a different school, or why professionals visited the house (Cunningham, Glenn & Fitzpatrick, 2000). Questions were often based on the child's own observations and experiences (Cunningham, Glenn & Fitzpatrick, 2000) which suggests that a child notices difference whether or not a parent chooses to talk about it with them. Hames (1994) reported that the youngest age at which a sibling questioned his parents was 2.5 years, again suggesting that a delay in disclosure due to age may not be necessary.

In line with parents' continuing need for information (Pain, 1999), disclosure for children was also found to be an on-going process, one which develops over time as the child gains an increasingly sophisticated understanding of disability (Stallard et al., 1997; Hames, 1994). Parents were sensitive to this and provided increasingly detailed explanations (Cunningham, Glenn & Fitzpatrick, 2000). Based on the findings from her study Hames (1994) offers several recommendations about disclosing information regarding about disability to healthy siblings:

- Children should be told immediately, or as soon as they start asking questions
- Questions should be answered honestly and openly (also cited by Powell & Ogle, 1985)
- Parents should respond when children identify differences between disabled and non-disabled people, even if the child may not fully understand.
- Pre-school children may misinterpret disability as an acute illness, therefore they may need to be re-told that their sibling will not recover.

She also found that during disclosure parents preferred to use everyday language rather than medicalised terms. Whilst this may promote understanding it sometimes meant that many siblings did not have the words to explain why their brother or sister was different from others. Having an appropriate label, or the ability to explain their sibling's difficulties may be important as studies have shown (e.g. Hames, 1994; Begenholm & Gilberg, 1991) that non-disabled siblings are better able to cope with questions, and other people's reactions if they have a simple explanation that they can share with others outside family.

## 1.6    Disclosing to Children in Other Settings

Current clinical practice advocates that parents should talk to their children as early as possible about situations which may be deemed sensitive or difficult, such as adoption (Watkins & Fisher, 1993), and bereavement (McGovern & Barry, 2000). Research has also recognised children's need for information in medical settings (e.g. Cohen, 1999; Bearison, 1991). Further studies have shown the substantial communication needs of siblings of children with chronic illness, especially younger siblings (e.g. Kramer, 1981; Stallard et al., 1997). The benefits gained from providing children with information have been highlighted. For example, access to more information can determine how a child adjusts to a siblings' illness, and it can also lead to more adaptive illness experiences in the affected child (Glasberg, 2000). Information giving has been found to facilitate the child's understanding, is gaining this understanding a necessary step in order for the child to adapting to the situation of living with disability or illness? Rushforth (1999) argues that the more recent culture of information giving, reflects the cultural recognition of the child's right to be informed about their condition and treatment, and to be actively involved in decisions pertaining to their care.

In a study of siblings of children with cancer, those who reported more communication with parents scored lower on the general impact scale, and thus perceived their lives to be less affected by their brother or sisters illness (Havermans & Eiser, 1994). This suggests that open communication between siblings and parents is critical, and may act as a protective factor for siblings of the affected child. However, parents report that sometimes they do not share information with siblings in

an effort to protect them from anxiety (Stallard et al., 1997). This has not been substantiated in the research (Cunningham, Glenn & Fitzpatrick, 2000). Indeed, children who are not told that their brother or sister is disabled are likely to recognise the parent's distress and may become increasingly upset themselves if they do not know the cause of the distress. Therefore, not telling may actually have negative consequences (Hames, 1994). In her work Lobato (1993) concluded that children, even the very young, benefit from the provision of information about their brothers or sister's condition. She states that in the absence of an accurate, understandable explanation children may rely on their imagination in an attempt to a understand what has happened to their sibling. The explanation they create may only partially reflect the reality of the situation. Lobato also found that due to their egocentric nature young children are particularly vulnerable to misconceptions. In that they are more likely to blame themselves for problems in the family or see these as a punishment for their own misbehaviour (Perrin & Gerrity, 1981, cited in Lobato, 1993). Lobato (1993) found that in the absence of information young children are more likely to blame their parents for their brother or sister's illness, as they perceive them to have failed to protect them. Lansdown (1987) encouraged parents to communicate with their children in order to help them reduce their anxiety. He felt this was particularly important as it is sometimes hard for adults to appreciate how anxious children can be and what misapprehensions they may have. NICHCY (1994) found that having information also helps siblings to cope with any embarrassment they are likely to experience at some time due to having a learning disabled sibling. These findings encourage clinicians to support parents to communicate openly and honestly with both the ill child and healthy siblings about the illness. This is especially important as studies have consistently found that siblings would prefer their parents to be the source of any information provided (Stalled et al., 1997). What is lacking in the literature are guidelines on how to approach these conversations, these would be particularly welcome as parents report feeling uncomfortable when considering discussing these issues (McGovern & Barry, 2000).

Many of the findings in the studies of siblings of children with chronic illnesses can be generalised to siblings of disabled children as they have been found to experience many similar difficulties and have the same need for information (Havermans & Eiser, 1994). However, the author postulates that the field of chronic illness and many

other disclosure conversations, for example about bereavement or parental separation, could be said to lack a dimension experienced by siblings of a learning disabled person. That is, they do not live with the potential for social stigma, something which has been found to be associated with learning disabilities (Gibbons, 1985, cited in Todd & Shearn, 1997). There is an emerging body of literature that may provide some useful insights into the area of disclosing information to children in areas that incorporate elements of stigma and prejudice. For example, Vidal (2000) studied the discussion of racial oppression within families, he found that parents only approached the subject after children had initiated the discussion. Shakespeare's (1996, cited in Fawcett, 2000) work in the field of disabilities gives further insight into this position. He rejects what he terms the reductionist perspective of the social model which views prejudice and stigma as a purely social relationship, instead he highlights the importance of the role of the individual's personal experience of disability. Therefore when applied to the process of disclosure it may be that any discussion of the issues may only become possible once it becomes relevant to the child's own experience, that is once they themselves have begun to notice the differences and make social comparisons.

Another area where social stigma is apparent is in parental disclosure of their own, or their child's HIV positive status to the affected child or other members of the family (Nehring, 2000). Parents often choose not to disclose their, or their children's, condition in order to avoid negative reactions and discrimination against them and their families. The decision to disclosure information to children within this area was judged against perceived threats and expected benefits, both for themselves and for significant others (Thampanichawat, 2000).

The studies cited in this section provide the reader with some insight into the disclosure process. They have highlighted the siblings need for information as well as the potential benefits of sharing information with children, particularly in terms of it serving a protective function leaving the child less vulnerable for misunderstanding and fear. However, when applied to the field of learning disabilities it seems that by also acknowledging the influence of social prejudice parents, and professionals, may gain a greater awareness into the child's experience of living with a person who has a

learning disability. Notably, there remains a lack of knowledge about the exactly how parents should endeavour to engage non-disabled children in the disclosure process.

## 1.7    Disclosing to Children with Learning Disabilities

Two studies, which have looked specifically at disclosing information about learning disabilities (Cunningham, Glenn & Fitzpatrick, 2000; Todd & Shearn, 1997) to children, have done so in relation to discussing the issues with the affected person themselves. The usefulness of these studies is that they have gone beyond the initial stage of deciding whether or no to disclose to actually examine what is involved in the process. Todd and Shearn (1997) have also incorporated the dimension of "social significance", mentioned earlier, within their discussion about the disclosure of learning disabilities. They go on to examine the impact of this disclosure on the development of self-identity in the affected person, and therefore one could speculate on the identity of other family members. They found that living with a learning disability posed identity problems not only for the affected individual but for other family members too. In particular the stigma extended beyond the disabled individual to affect the whole family. Todd and Shearn (1997) described the role of parents as significant in facilitating the construction of their disabled child's self-identity, and in shaping their views of the world and their relations to it. They stress that identity construction was an active process, and as such involved people close to the individual. This sense of self incorporated social and moral meanings associated with learning disabilities. If this is an accurate description of the mechanisms involved, then the meaning and values that parents assign to living with a person with learning disabilities must also affect non-disabled siblings, and the construction of their self identity as they live within the same family unit and are therefore open to the same parental influences.

Research has identified two key elements which help to develop an awareness of the meaning of living with learning disabilities. These are an open system of discussion within the family (Cunningham, Glenn & Fitzpatrick, 2000; Hames 1994; Powell & Ogle, 1985), and parental sensitivity to the child's ability to understand information (Cunningham, Glenn & Fitzpatrick, 2000; Todd & Shearn, 1997). Parents accurately estimated their child's understanding of the definition and aetiology of their sibling's

disability, but they consistently overestimated their child's ability to understand the implications of the disability (Glasberg, 2000). This highlights the need to re-present information to the child over time, in order to allow them to develop a more complete understanding of their siblings' disability.

Cunningham, Glenn and Fitzpatrick (2000) identified two strategies of disclosing. Firstly reactive strategies, where parents waited until their child showed some awareness of their brother or sister's disability, and secondly proactive strategies, where parents sought opportunities to discuss issues with their non-disabled child. An advantage of employing a pro-active strategy is that parents are able to have more control over the information presented to their child. For example, preventing the affected children and their siblings from learning about disability from others outside the family in what may be a negative or misinformed way. Furman's (1993) advocates a strategy he called "anticipatory management" this combines open discussion and a pro-active approach, in order to foster positive, and decrease negative, sibling interactions. For example, it was found that open discussion about the needs and intentions of a new-born baby were found to increase the positive interactions with older siblings (Dunn & Kendrick, 1981). An open style of communication within the family is important because siblings of children with disabilities are very curious (Grossman, 1972). Research (e.g. Beardslee, 1981; Lavine, 1977) has found having the opportunity to discuss a child's disability fosters adjustment of both the disabled child, and the non-disabled sibling.

The onset of disclosure was often associated with questions from affected child, from siblings, or from other children (Cunningham, Glenn & Fitzpatrick, 2000). Initially children's questions and the resulting discussions focused on concrete aspects of disability such as the facial features of Downs Syndrome. However, it was social triggers which are grounded in individual child's experience that were more likely to be associated with ongoing discussion of disability over time. This involved parents answering questions about issues such as "why are people staring?" (Cunningham, Glenn & Fitzpatrick, 2000).

Parents stated that their reasons for not disclosing included fears that the child would not understand or may get upset. Neither of these claims have been substantiated in

the literature (Cunningham & Shearn, 2000; Hames, 1994). Another reason parents cited for not disclosing is provided by the work of Goffman (1968, cited in Todd & Shearn, 1997). He found that parents often construct a "protective capsule" around the disabled child. They did this by controlling the information received by the child, both in terms how much information they provided, and how they interpreted information, which often involved filtering out negative associations. However, this was shown to offer only time-limited protection becoming less robust as the child aged and became aware of societal attitudes, and the discrepancy between their lives and that of their siblings and peers (Todd & Shearn, 1997). The scope of the "protective capsule" could be extended to surround non-disabled siblings, as parents attempt to protect them from the reality of living with a person with a learning disability. Goldberg et al. (1995) hypothesised that the act of protection is not confined to parents. All family members, including siblings and the disabled person, try to protect each other against the sense of loss and other perceived consequences of the disability.

## 1.8 Summary and Rationale

This discussion of the literature has outlined the effects of living with a person who has a learning disability on both parents and non-disabled siblings. This includes the impact on their social, emotional, and financial future as well as more general effects on their plans for their own future. Whilst studies report inconclusive findings, there is little doubt that there is potential for the situation to act as a significant life stressor, and therefore may be detrimental to the non-disabled siblings well being. However, research has shown that an individual is not merely a passive victim of stressors in their environment, but rather an active agent who can influence the impact stressors have on them. Indeed, it is interesting to consider why some families appear to deal with the situation of having a learning disabled child better than others, or why siblings from the same families report different experiences and may present with somewhat divergent outcomes.

In an attempt to answer this question research has moved from examining static variables, such as gender, birth order, or the severity of the disability to look at the role of more dynamic variables. Stamp (1991) stated that the key to understanding the extent of a families well being, or their pathology, lies within our understanding of

real-life conversations and family interactions. Researchers have also begun to examine concepts such as resilience, and are attempting to identify other potentially protective factors. One such example, suggests that the provision of information could act as a buffer against the negative effects of a stressful situation such as living with disability. Indeed, by presenting children with the facts, parents could guard against the potentially harmful effects of misunderstanding. This information could also help negate the effects of differential parenting, minimise the impact of social stigma often associated with learning disabilities, and finally by providing non-disabled siblings with accurate information parents could facilitate the development of a meaningful understanding of the situation for the non-disabled child.

It can be argued that a thoughtful presentation of the facts should begin at the earliest stage of information giving, as research has shown the value of a positive initial disclosure interview for parents. It was also found that the way this early situation is handled can have long term implications in a parent's relationship with their disabled child. The same could also be true for non-disabled siblings.

Research is beginning to suggest that providing accurate and meaningful information about a child's learning disability could be a potentially protective factor, not only for parents but for the non-disabled sibling too. If this is true it is vitally important to fully understand how children receive this information and define the factors which are involved in a making the disclosure of their brother or sisters learning disability as positive an experience as possible for the non-disabled child. Only then may it be possible to examine the influence of the way this information is presented on the non-disabled sibling's ability to positively adapt to the situation of living with a brother or sister who has a learning disability.

The importance of the non-disabled sibling adapting positively to the situation of having a disabled brother or sister goes beyond their own wellbeing to how it affects both their parents and the learning disabled person. Research has shown the longitudinal nature of the sibling relationship, and highlighted their potential role as future caregivers to their disabled brother or sister. Also their role in supporting and understanding their parents as carers cannot be underestimated. Finally, the way in which the non-disabled sibling perceives and interacts with the disabled child can

impact on the self-esteem of the disabled child. This provides further evidence for the need to facilitate a positive relationship between a learning disabled child and their non-disabled siblings.

Current clinical practice advocates the importance of open and honest communication with children across a range of sensitive situations, from discussing health problems to divorce and bereavement. Whilst talking to children is often clinically recommended, the potential benefits of this practice has yet to be substantiated by research. However, parents have voiced concerns that the child may not understand the information given or may become upset by it. The assumption that misconceptions and confusion are an inevitable consequence of cognitive immaturity have been challenged, instead it is hypothesised that a lack of information may be potentially damaging especially in young children given their egocentric thinking style. This review of the literature has shown that even young children have the potential to understand complex concepts such as disability if they are exposed to the ideas over time, and their learning is appropriately facilitated.

For parents deciding that they would like to talk to their non-disabled children about their brother or sisters' learning disability is often the first step. But what parents have asked clinicians is how do we talk to our children, when do we talk to them, what do we say? Research into the specific components involved in the disclosure process is lacking. To date research has focused on addressing the questions of whether children should be told and at what age. The question of exactly how to disclose this sensitive information remains unanswered, and is the focus of this study.

## 1.9    Aims of the study

The present study aims to investigate the disclosure process in order to build a frame of reference for parents and professionals seeking guidance on how to share sensitive information with non-disabled children in the family.

The aims of the study are as follows:

- To discover the specific factors involved in the disclosure process

- To build a frame of reference for parents which will inform them about how to manage the process of disclosure

- To provide professionals with a guide which will enable them to inform and support parents through the disclosure process

- To develop a model of disclosure that will enhance the current literature's understanding of the process

# 2.    METHOD

The aim of this chapter is to provide an overview of qualitative research and a rationale for using grounded theory as a methodology for data collection and analysis in this study. Furthermore, a description of the specific procedures employed in this study will be provided, followed by a discussion of how the issues related to reliability, validity, generalisability and reflexivity were considered.

## 2.1    Qualitative Research

Psychological research has traditionally adopted the positivist epistemology of the natural sciences, concerned with testing hypotheses based on logico-deductive theories, and establishing objective and reliable methods of investigation emphasising the use of quantitative methods (Madill, Jordan & Shirley, 2000). Stevenson and Cooper (1997), argue that by adopting a positivist position, researchers in psychology have maintained 'scientific' credibility in the production of knowledge.

Qualitative methodologies tend to adopt a constructionist epistemology which points to the ways in which knowledge is generated within networks of social activities and systems of socially constituted meanings (Henwood & Pidgeon, 1995a). Qualitative researchers aim to explore the subjective experience and the meaning given to this experience, being sensitive to the multiple interpretations which may be placed upon thought and behaviour when viewed in their full complexity (Henwood & Pidgeon, 1995a). Madill et al. (2000) argue that constructionists view enquiry as a process in which findings represent a culmination of both the participants' and researchers' meaning systems interacting and they suggest that a dominant theme within qualitative research is the understanding of linguistic meaning within textual material. However explication of meaning requires a certain level of inference, and qualitative approaches have been criticised for the space that they afford the subjectivity of the researcher. There is a general assumption that the person having an experience is in a better position to know it's meaning. However it may also be the case that experience is inchoate (i.e. underdeveloped) for the person experiencing it and may be difficult to articulate, in these circumstances an external person may be helpful as an aid to articulation (Rennie, 2000).

Stevenson and Cooper (1997) contend that there are problems with both positivist and constructionist approaches. Positivism entails a narrow definition of good science which serves to distance the researcher from the researched. The relativism implicit in the constructionist approach could be said to suggest that all accounts of the world are equally good, and all research positions are equally good. The author argues that positivists maintain that their interpretation is a representation of reality, whereas constructionists interpretation is viewed as one of the many possible realities, as researchers are discursively constructing the very contexts that render their data meaningful (Stevenson & Cooper, 1997).

The above discussion summarises basic distinctions between the positivist and constructionist perspectives. Of late, due to the dramatic increase in the use of qualitative research methods (Elliot, Fischer & Rennie, 1999), the debate has moved away from the qualitative/quantitative divide to focus on questions of epistemology and rigour within qualitative methods.

Madill, Jordan & Shirley (2000) state that there are a number of epistemological positions within which the qualitative researcher can work, and many different methods of analysis. They have identified three broad epistemological strands within qualitative methods: realism, contextual constructionism, and radical constructionism.

Realism emphasises that there is a reality outside the enquirer that can be studied, and that the task of research enterprise is to strive to know the subject matter from an objective standpoint (Kidd, 2002). Content Analysis is an example of a qualitative methodology within the realist context (Silverman, 2000). In contrast other epistemologies assume that there is not one reality that can be revealed through inquiry. Contextual constructionism is the position that all knowledge is local, provisional, and situationally dependent (Jeagar & Rosnow, 1988). This perspective contends that results will vary according to the context in which the data was collected and analysed. All accounts, whether by participant or researcher, are understood to be imbued with subjectivity, and therefore are not invalidated by alternative perspectives. However, work within a contextual framework values "grounding the results" within participant's actual descriptions (Madill et al., 2000), and therefore fits well with the Grounded Theory Methodology. This position is of

particular relevance to the human sciences where the researcher and the subject of research are both conscious beings interpreting and acting on the world around them within networks of cultural meaning (Giorgi, 1995).

At the far end of the continuum, the radical constructionist position is characterised by a profound distrust of the idea that language can represent reality. Rather than consider objects to be the foundation of representations, representations are understood to construct the objects that come to populate our world (Madill et al., 2000). Hence knowledge is considered a discursive construction, and therefore questions of absolute truth and falsity are put to one side, and the spotlight turned towards ways in which knowledge claims function and are legitimated within overarching "regimes of truth" such as the discourses of science (Madill et al., 2000). Discourse Analysis usually takes the radical constructionist approach (Potter, 1997 cited in Silverman, 1998)

## 2.2. Grounded Theory

Grounded theory was first described by Glaser and Strauss (1967) who proposed that within sociological research, conducted at that time, there was an over-emphasis on the verification of a few existing theories. This led to dissatisfaction with the inability of the research to capture lived experience, and little generation of new theory (Madill et al., 2000). Glaser and Strauss (1967) argued that in order to generate new theory qualitative data, aimed at capturing meaning and understanding of experience, could be used to build theories from within the data itself. Rather than continuing to employ the traditional positivist approach which conceptualised theory before testing it with data (Rennie, 2000).

Grounded Theory is a suitable methodology for use with any form of unstructured material, including interview transcripts, documentary evidence, and fieldwork observations, (Henwood & Pidgeon, 1995b). It allows for the original research question to be initially broad, then refined as data is collected and analysed (Henwood & Pidgeon, 1995b). The process of Grounded Theory involves the systematic application of a range of methodological techniques which are outlined briefly below, and in more detail in the section on Grounded Theory Analysis later in the chapter.

In essence data analysed using Grounded Theory is coded using categories that are derived from the data rather than imposed upon it. A process of comparative analysis is employed to check and adjust these categories against other emerging themes within successive chunks of data. (Strauss & Corbin, 1990).

Throughout this process, memo writing is used to explicate and fill out categories, and to explore links between the categories. This is all done from the perspective of a deep immersion in the data. Finally, the generation of a justifiable model using the derived categories and memo-ed links provides a traceable audit trail through the analysis. Hence, Grounded Theory consists of a set of inductive strategies for analysing data, aimed at developing theory. Analysis begins with individual cases or experiences and develops progressively towards a more abstract and conceptual level (Charmaz, 1996). The models developed represent a form of theorisation or at least conceptualisation (Charmaz, 1995) that necessarily goes beyond the data itself (Madill et al., 2000).

When conducting a study using Grounded Theory the researcher is simultaneously engaged in both data collection and analysis (Charmaz, 1995). This allows the researcher to use the emerging categories to inform the process of data collection itself. Underpinning the analytic process is the need for theoretical sensitivity (Glaser & Strauss, 1967). This process refers to the capacity of the researcher to interact with and understand the data, to be sensitive to subtle meanings and able to recognise salient themes when trying to make meaning from the data. Such insight is achieved through drawing upon a background knowledge arising from a familiarity with existing literature and drawing from personal and/or professional experience. Theoretical sensitivity is a creative and imaginative skill but one which needs to be firmly grounded in data in order to ensure that hypotheses are both justified and explainable (Strauss & Corbin, 1990; 1998).

### 2.2.1 Revisions of Grounded Theory

Since the original description of grounded theory (Glaser & Strauss, 1967) there has been considerable debate regarding epistemological and inductive positions within grounded theory (e.g. Charmaz, 1990; Henwood & Pidgeon, 1995a). Madill et al.

(2000) state that the early articulation of grounded theory utilised the language of realism, thus implying that "the phenomena exist out there, awaiting discovery, like a fossil in a stratum" (p.322, Madill et al., 2000). Henwood and Pidgeon (1995a) describe an inherent contradiction in Glaser and Strauss' original Grounded Theory, they feel that the inductivist idea that theory simply emerges from the data does not fit with the active encouragement of the researcher in the creative and interpretative processes involved in generating new theory.

The original Grounded Theory method was also criticised for being difficult to operationalise given its dense theoretical explication, and this lack of explanation of the precise role of the researcher's interpretations in theory generation (Morse, 1994). Strauss and Corbin (1990) attempted to make the method more accessible and rigorous by introducing more steps in the data collection and analysis and by incorporating hypothesis testing directly into the method itself. However, Glaser (1992) argued that this new proceduralised version of the method had lost the essential elements of grounded theory, as it placed the importance of procedure over the value of the meaning able to emerge from the data. Therefore, shifting Grounded Theory away from being an inductive process back towards a methodology with increasing deductive features. Furthermore, Rennie (2000) argued that Strauss and Corbin's (1990) refined method of data analysis, from text fragment to fragment, was tedious to conduct. It seems that their attempt to answer the problem of validation was made at the expense of the discovery-based orientation of the original methodology.

Some researchers have argued that grounded theory cannot be purely inductive and have advocated a constructionist revision of grounded theory (e.g. Charmaz, 1990, 1995; Henwood & Pidgeon, 1995a). Charmaz (1990) argues that the researcher does not approach the data as "tabula rasa", indeed they have their own perspectives and experiences from which they actively seek to build their analyses. Hence, constructionist revisions of Grounded Theory acknowledge the interplay of various forms of subjectivity and interpretation. Whilst some state that this interpretation is a feature of all forms of scientific practice (Henwood & Pidgeon, 1995a), it is actively foregrounded in qualitative research. Henwood and Pidgeon (1995a) cite the feminist position as one which can move Grounded Theory away from induction and pure phenomenology, here the researcher adopts a position of "conscious subjectivity".

They recognise an interdependence of the subjectivity of the researcher and her participants in the research process, at a wider level they acknowledge that experiences are constructed as meaningful within cultural frameworks, social and power relationships.

Grounded theory may also be applied within a contextual epistemology. Charmaz (1986) argues that the approach is ideally placed to bridge positivist and interpretative methods. The difference is the extent to which findings are considered to be discovered within the data or the result of the construction of inter-subjective meanings (Madill et al., 2000). Rennie's (1998; 2000) work highlights the double hermetic involved in qualitative research. He states that the process of interpretation is not only present on the part of the researcher but respondents also choose the way in which they represent their experience. Rennie acknowledges that this interpretation is influenced by the individual's interests, beliefs, and values. In this sense people are made to be interpreters of their experience and their account is then re-interpreted by the researcher.

## 2.3     Reasons for Using Grounded Theory in this Study

Bryman (1988, cited in Henwood & Pidgeon, 1995a) identified two routes that may influence a researcher's decision to choose to employ a qualitative methodology; these are technical and epistemological. The technical route involves choosing between qualitative and quantitative methods in terms of which approach is most suited to the research question. The epistemological route asks more fundamental questions regarding the nature and practice of science, and the generation of legitimate knowledge.

Henwood and Pidgeon (1995) cite two reasons for choosing qualitative methods. First, over reliance upon theory testing can lead to a neglect of strategies for the systematic generation of new theory. Minimally, this is necessary where theory is non-existent, such as within a new domain of enquiry as in this study. Secondly, there is a need in human sciences research to be sensitive to people's own understandings as seen from their local frames of reference, or from inside their own socially situated

phenomenal worlds. This equates to grounding research in participants' own experiences, accounts and worlds.

Qualitative research methods were thought to be appropriate for this study for the following reasons. First, there is a scarcity of research in the area of understanding disclosure between parents and children. Qualitative methods have been shown to be particularly useful where psychological phenomena have not been extensively investigated (Turpin, Barley, Beale, Saige, Slade, Smith & Walsh, 1997; Henwood & Pidgeon, 1995). Hence, the broad aims of this study were considered to be more appropriate to theory generation than theory testing. Secondly, Elliot et al. (1999) argue that qualitative research is able to reconcile objectivist and relativist positions by accounting for factors that relativise the data whilst grounding interpretations of the subject matter empirically.

Grounded Theory is a qualitative method whereby data is used to ground analysis in the findings which aims to provide transparency between the data that is presented and the claims made upon it (Charmaz, 1995). Grounded theory was chosen as a research method for this study as it has been shown to be a particularly useful method for investigating action and processes and is therefore relevant to the study of disclosure (Rennie, 2000; Charmaz 1996). Finally, a recent article in the APA Monitor reported that a group of editors interested in research taking place within the field of child development were calling for an increase in the recognition of qualitative research (Kidd, 2002). Grounded Theory was therefore perceived to be appropriate methodology to address the questions asked in this study.

## 2.4    Epistemological Position

Qualitative researchers rarely assume that there is one reality that can be revealed through the application of the correct methodology (Madill et al., 2000). Charmaz (1990) asserts that the researcher has a perspective from which they interpret and construct meaning within the data. Therefore, they have a responsibility to make their epistemological position clear, conduct their research in a manner consistent with that position, and present their findings in a way that allows them to be evaluated

appropriately. This is particularly important for approaches such as Grounded Theory which can be applied in a realist or constructionist context (Rennie, 2000).

In this study the researcher adopted the position of contextual constructionism (Madill et al., 2000). Giorgi (1995, cited in Madill et al., 2000) stated that this epistemological stance is of particular relevance to the social sciences where the researcher and respondent are both conscious beings, who interpret and act upon the world around them within networks of cultural meaning. This position acknowledges that neither the researcher, nor the respondent can be completely objective in their accounts. Indeed, Lincoln and Denzin (1994) state that in order to successfully implement Grounded Theory the qualitative researcher needs to know about the methodological issues rather than conform to detailed instructions.

The interviews are contextually based and therefore are affected by the dynamic between the researcher and the interviewee. Indeed, had the data been collected and analysed in another context the outcome may have been different (Kvale, 1996). For example, knowing that the researcher was a professional would have shaped the story that people felt comfortable sharing, for some it may have inhibited their accounts whilst for other they may have been reassured by this. Equally the researcher's background of being a parent and having had foster brothers with learning disabilities, will have influenced the questions asked, and the interpretation of the stories received.

Given the context dependent understanding of the data the findings are not considered to be generalisable. Rather they are understood to be transferable and as such can inform both theory and clinical practice, whilst not claiming to be representative of all experiences of disclosure. This transparency and acknowledgement of the uniqueness of each account is seen as a strength, particularly in the area of clinical work where it is important to acknowledge the uniqueness of the individual narrative.

## 2.5   Participants

Six adults participated in the study, they all have a sibling with a learning disability. The demographics of the participants, as well as those of their learning disabled sibling are presented in the Table one below.

**Table 1: Details of Participants and their Disabled Sibling**

| | Gender of participant | Gender of disabled sibling | Participants age in relation to their disabled sibling | Number of siblings in participants birth family | Diagnosis and severity of siblings disability | Placement of disabled sibling |
|---|---|---|---|---|---|---|
| 1 | F | M | Younger by 4 years | 3 (3/3)* | Downs Syndrome (severe) | Resides with participant |
| 2 | F | F | Older by 5 years | 2 (1/2) | Autism (moderate) | Resides with parents |
| 3 | M | F | Twin | 3 (2/3) | Non specific (severe) | Residential care |
| 4 | M | M | Younger by 2 years | 5 (5/5) | Non specific (moderate) | Resides with participant |
| 5 | F | F | Older by 11 years | 4 (1/4) | Downs Syndrome (mild) | Independent living scheme |
| 6 | F | F | Older by 8 years | 4 (2/4) | Downs Syndrome (moderate) | Residential care |

*Bracketed numbers represent the participant's place in the birth order over the number of siblings in the family, with 1 standing for the eldest.

There were four female and two male participants. Their birth order in relation to their learning disabled sibling was evenly spread and included two older siblings, two younger siblings, one middle sibling and one twin. The age difference between the participant and their learning disabled sibling ranged from none (twin) to 11 years, with a mean of five years difference. The number of siblings in the participant's birth family, that is their family of origin, consisted of between two and five children (mean number = 3.5 children per family). The number of children in the participants own families were generally smaller ranging from one to three children per family (mean number = 1.6 children per family). The type and level of the sibling's learning disability was described by participants, and included three siblings with a diagnosis of Downs Syndrome, one with a diagnosis of autism, and two with a non-specific diagnosis. The level of their disabilities ranged from mild to severe, as defined by the Nottingham learning disability service. At the time of inclusion in the study two of the participants lived with their learning disabled sibling, one was living with her parents,

two were living in residential care and one was placed in an independent living scheme.

Table two provides details of the participant's own children.

**Table 2: Details of Participants Own Children**

|   | Number of children | Gender of children | Ages of children (years) |
|---|---|---|---|
| 1 | 1 | F | 24 |
| 2 | 3 | M<br>M<br>F | 5<br>10<br>14 |
| 3 | 2 | F<br>F | 3<br>5 |
| 4 | 1 | F | 45 |
| 5 | 1 | M | 15 |
| 6 | 2 | M<br>M | 8<br>10 |

## 2.5.1 Sample Frame

The broad aim of the research was to conduct a study which examined the process through which children become informed about their sibling's learning disability. The study focused specifically on the role parents play in communicating this information to their non-disabled children. The sample frame allowed the purposeful sampling of individuals in order to generate data meaningful to the research question asked.

In this study the participants were required to fulfil three criteria. Firstly, participants had to be adults, defined as over the age of 18 with no upper limit. Secondly, all participants must have a sibling with a learning disability, and finally all participants were required to be parents themselves. No restrictions were placed on the level or type of learning disability, or on the place of residence of the participants learning disabled sibling. However, sampling methods, described later, were used to ensure that an appropriate range of disabilities and care placements was achieved. Similarly no restrictions were placed on the age or number of the participants own children.

## 2.5.2 Exclusion Criteria

The researcher excluded participants if they did not give their consent. In line with recommendations from the Ethics Committee potential participants were also excluded if their learning disabled sibling, when able to be informed of the proposed study, did not consent to their brother or sister taking part.

## 2.5.3 Number of Participants

Turpin et al (1997) recommended that a minimum of five participants were targeted for a qualitative research study when it was undertaken as part of the Doctorate in Clinical Psychology. Traditionally, in Grounded Theory the number of participants is determined by a process of saturation (Glaser & Strauss 1967). This occurs when subsequent analyses of additional data sets reveal no new categories, themes or relationships. Saturation was not achieved in this study, the implications of this are considered in the discussion.

## 2.5.4 The Use of Adult Siblings as Research Participants

Adult siblings of people with learning disabilities were chosen as participants for this study as it was felt that each participant was able to embody multiple perspectives. This enriched the data available to the researcher as it facilitated the generation of additional narratives, thus building a more comprehensive account of the disclosure process.

In this study the participants are able to answer the research question from three different perspectives: the child, the adult and the parent. The retrospective perspective represents the participant as a child with a sibling who has a learning disability. The adult position can be viewed as an idealised perspective where the participant is able to reflect on how they made sense of their family's situation and how, as a child, they would like to have been informed. The final perspective is that of the participant as a parent, here the participant is able to use their experience to help shape the way they inform their own children. It is now that their adult, idealised

perspective may be modified by the practicalities of conversing with children at different developmental stages.

By choosing adult siblings as participants the researcher was acknowledging their expertise in this situation. That is they have real-life experience of being both the receiver, and the provider of information in the process of disclosure. That is they have been in the position of both the child and the parent.

## 2.5.5 Recruitment

Two strategies were employed to recruit participants. Firstly, potential participants were identified from a database of a previously surveyed cohort of learning disabled school leavers, who were engaged in a longitudinal study in Nottingham (Cromby et al 1994). The researcher together with the Headmaster, who was known to the families, sent an introductory letter and information sheet to parents named on the database, see Appendices One and Two. It was requested that details of the research was passed on to adult non-disabled siblings who may be interested in taking part in the study.

The second recruitment strategy involved accessing potential participants via the Community Learning Disability Teams, in the Nottingham Healthcare NHS Trust. Here case managers directly approached adult siblings with details of the study and asked for permission to allow the researcher to contact them.

Once identified potential participants met with the researcher and were provided with additional information about the study. Before the person agreed to participate a discussion about their siblings learning disability took place. The potential participant was asked to decide if it was appropriate to seek the consent of their learning disabled sibling before proceeding. Principally, only those who it was felt had the capacity to understand were asked to give consent for their brother or sister to be interviewed. Finally written consent was gained from the participant.

## 2.5.6   Sensitivity to the Research Question

The researcher experienced difficulty in recruiting participants for the study. This was most apparent when using the first recruitment strategy of contacting participants via their parents. It may simply be that the direct approach of a request from a key-worker to the adult sibling was more a appropriate method. However, feedback from responses and from several people who dropped out of the study suggested that the research question had the potential to touch on deeper issues. Parents may have felt some reaction to the research topic, perhaps asking themselves questions such as "How did I share this information?" or "Did I do it correctly?". They may have been afraid of exposing themselves to potential criticism from both professionals and family members, for not having managed disclosure appropriately. The fact that many parents have asked for guidance on how to speak to siblings on this topic shows it is an area of worry for some parents.

An alternative explanation could be that the research question may have been somewhat ambiguous. It hinted at disclosure being a more contained process than the analyses revealed it to be, and therefore the initial research question have asked about a topic that was somewhat unrecognisable to parents and siblings.

## 2.6   Ethical Approval

Ethical approval for the study was gained from the Queens Medical Centre in Nottingham. It was granted on 31$^{st}$ October 2000. A copy of the letter granting approval can be found in Appendix Three.

It was acknowledged that whilst participants would be focusing primarily on their own experiences they could potentially be discussing issues closely related to their learning disabled siblings. Therefore, the Ethics Committee requested that where possible, and dependent on the individual's capacity to understand, the learning disabled sibling should be asked about their brother or sister's inclusion in the study.

A number of procedures were employed to ensure that participants and all members of their families were protected. These included;

1.  Confidentiality – Data was stored securely, this included all the audiotapes and transcripts of interviews. Transcripts were presented in a way which preserved anonymity, all names and any identifying details were changed. Transcripts were viewed only by a small number of people involved in the study.
2.  Participants were asked for their written consent prior to the interview and were reminded that they could withdraw their consent at any time and stop the interview.
3.  The interviews did not last more than 90 minutes. They would have been terminated earlier if the participant had become distressed, though this situation did not occur.

## 2.7     The Use of Interview Data

The data generated through the use of interviews can be useful when a researcher is interested in the consideration of complexity and/or process (Smith, 1996), both of which are issues pertinent to the phenomenon of disclosure. Smith goes on to argue that the material gained through interview allows access to both the world outside of the person (e.g. the factual record) and their internal world (e.g. beliefs, attitudes, and values). This idea is in line with the epistemological stance of contextual constructionism (Madill et al., 2000) taken in this study, this is more fully discussed in the sections on qualitative research and epistemological stance.

Given the sensitivity of the topic area, interviews were considered an appropriate method through which to create a safe environment for the respondent to share their personal story. The researcher's clinical skills were employed in order to provide respectful sensitivity and generate trust, the importance of which is highlighted by King (1996). This allowed the interviewer to use empathy as a research tool to more fully access an understanding of the participant's accounts (Stiles, 1993).

## 2.7.1 Interview Design

The researcher devised an interview schedule which was used to guide the interview, rather than dictate it. The role of the interviewer was to facilitate the respondent's articulation of their experience, rather than to direct exactly what happened during the interview (Smith, 1996). As such the ordering of specific questions is not viewed as important, resulting in the interviewer being freer to probe pertinent themes as they arise. Therefore, it is quite possible that that the interview may enter an area that had not been predicted by the researcher prior to the interview, but which may be relevant and enlightening of the study's overall question. Indeed, these novel avenues are often the most valuable (Smith, 1996).

The initial interview schedule was devised by the researcher in accordance with the relevant literature, as well as issues from the researchers own clinical and personal experience. In the first interview schedule the questions were open and curious about whether disclosure had occurred and how the respondents had understood the process in terms of the child's readiness for information and their ability to understand information when it was presented to them. Open coding of these first interviews led to the evolution of the interview schedule, see Appendix Four. Later interviews focused on questions addressing: the on-going nature of the disclosure process, the value of the child's lived experience, non-verbal modes of sharing information, and the management of societal values and attitudes towards disability.

## 2.7.2 Interview Procedure

Five participants choose to be interviewed at home, one was interviewed at their place of work. The interview procedure was similar at each location.

Prior to beginning of the interview the participants were reminded of confidentially and that they were free to withdraw from the interview at any time, they were also given the opportunity to ask any questions they had about the research study and the subsequent use of the data. Finally, their permission for the interview to be audio taped was sought and a consent form signed, see Appendix Five. The interview then took place and lasted no longer than 90 minutes. After the interview participants were

debriefed and encouraged to ask the researcher about any concerns or questions they may have.

### 2.7.3 Audio-taping

Audiotaping of research interviews is recommended because of what may be lost if you do not record using this method. This allows the interviewer to concentrate on the interview process, and provides a much fuller record than field notes (Smith, 1996). The process of transcription is described in the section below.

### 2.7.4 Data Corpus

The final data corpus was comprised of six audiotaped interviews, all of which were transcribed verbatim in accordance with Strauss and Corbin's (1990) description. Pauses and verbal hesitations were not included. As recommended by Charmaz (1995) the researcher transcribed the first four audiotaped interviews. Charmaz stated that the process of transcription allows the researcher to closely study the emerging data and become aware of any implicit meanings. However, due to time constraints a secretary transcribed the last two interviews, these were then checked and amended as necessary by the researcher.

The transcripts of the six interviews are included in an addendum which is bound separately. All names have been changed to ensure participants anonymity and any potentially identifying information has been altered.

### 2.8 The Grounded Theory Analysis

The method of data analysis employed within this study is based upon that described by Charmaz (1995). However, ideas both from the original source Glaser and Strauss' (1967) and others such as Rennie et al. (1988), Henwood and Pidgeon (1995) and Madill et al. (2000) were also incorporated.

A basic principle of Grounded Theory analysis is that researchers should engage in the close inspection and analysis of their data, in order to generate new theory. Thus

grounding any emerging theory within the context of the interview data. Henwood and Pidgeon (1995) state that this process requires an openness and flexibility on the part of the researcher. They argue that data handling strategies should be used as aids rather than "methodological prescriptions", thus the analysis should simultaneously liberate and discipline the theoretical imagination.

Grounded theory analysis involves a systematic coding of the interview material where the categories are derived from the data rather than imposed on it. Categorisation proceeds through several stages of abstraction. Initial categories remain close to the language of the text, such categories are termed descriptive by Glaser and Strauss (1967), an example of this level of open coding can be seen in Appendix six. The process of Constant Comparison (Henwood & Pidgeon, 1995b) is used, both within and across accounts, in order to fully explore the complexities of the data. Here meaningful chunks of data are compared to emerging codes to fit as many as possible. When data does not fit an existing code a new category is created to represent it. Therefore, the researcher is continuously checking and adjusting derived categories against successive chunks of text (Strauss & Corbin, 1990).

Throughout the process of coding memos were used to consider the properties of the categories, the name of codes, relevant themes, and the way in which categories relate to each other. This aids the development of codes from the descriptive level to a more abstract and theoretical level of analysis. The use of memos also provides a traceable audit trail through the analysis.

Once emerging codes were identified in the early transcripts data that would fit and expand upon those codes were sought out in the latter transcripts, Charmaz (1995) refers to this process as Focused Coding, an example of this can be seen in Appendix seven. This process only took place once the codes had moved to the more abstract level and as they moved towards saturation, that is few new themes were emerging from the data. In this study saturation of the data was not completed although the categories demonstrated a diversity of data.

The aim of the process of categorisation is to conceptualise "higher order" or more abstract categories that will eventually subsume the initial descriptive categories.

The pinnacle of the conceptualisation is the recognition of a supreme or core category that gathers together all the other categories. This is best achieved through the sorting of theoretical memos made about the interpreted relations between the lower-order categories (Rennie, 2000). Appendix eight shows an example of a theoretical memo. Rennie argues that this process should involve an element of creativity on the part of the researcher, this would fit with the constructionist stance taken in this study.

This process of increasing abstraction involves the use of negative case analysis, which refers to those aspects of the data where things "go differently" (Perakyla, 1997), that is they do not fit into the emerging categories. Such cases are valued in Grounded Theory analysis and are incorporated within the model rather than disregarded as outliers, because they are viewed to add depth to the overall theoretical understanding. In this study the use of negative cases was sought out and used particularly within the theme of "Creating Protection", this will be illustrated in the results and discussion section.

Ideally, the end result of Grounded Theory analysis is the generation of a complete theory through the linking together of categories. Henwood and Pidgeon (1995) recognise that it might not be possible to realise such an ambitious goal, an issue they feel to be particularly relevant to novice qualitative researchers at undergraduate or post-graduate levels. However, they outline a number of other useful research outcomes which can be achieved though the use of grounded theory. In this study theory generation was not achieved, instead a working model which can be used by parents and professionals was developed.

## 2.9    Methods to Enhance Quality

The way in which the relative merits of the outcomes of qualitative research are assessed, or the question of how to ascertain the validity or goodness of qualitative research is a difficult one (Henwood & Pidgeon, 1995). However, the way in which scientific rigour is addressed in qualitative research is informed by the epistemological stance taken by the researcher (Madill et al., 2000). There are a number of qualitative methodologies, and both within and across those methodologies different epistemological stances can be taken. This study takes a contextual

constructionist stance and therefore the ways of addressing the issues of reliability, validity and reflexivity have been considered within that context. The following sources have informed the ways in which issues of scientific rigour have been considered in this study; Henwood and Pidgeon (1992), Turpin, Barley, Beale, Saige, Slade, Smith and Walsh (1997), Elliot, Fischer and Rennie (1999) and Madill et al. (2000). Each issue and how it has been addressed is outlined below.

## 2.9.1 Validity

Whilst not concerned with concepts of truth and objectivity the issue of validity still exists within contextual constructionism. Elliot, Fischer and Rennie (1999) described the addressing of validity as the carrying out of creditability checks to access the trustworthiness of the interpretation or conclusions drawn from the data. Glaser (1992) maintains that validation in a Grounded Theory study comes about through the checks and balances which constitute aspects of the method itself, such as the constant comparative method and theoretical memoing. The following credibility checks were also incorporated into this study:

1.  The findings are grounded within the data so demonstrating a close fit (Elliot, Fischer & Rennie, 1999)
2.  The use of open coding of fully transcribed accounts ensured that each aspect of the data was included in the analysis (Silverman, 2000). This was further supported by the use of negative case examples, that involves incorporating data that initially did not fit emerging codes. This aims to generate a more conceptually rich account (Henwood & Pidgeon, 1992).
3.  The use of constant comparison encouraged the researcher to become immersed in the data, thus ensuring grounding in the data when interpreting the findings.
4.  The inclusion of transcripts and quotations to support the generated categories allow the reader to assess the fit between the actual data and the researchers interpretation of that data.

A common form of validation is Respondent Validation (Smith, 1996). This involves the "checking out" of the end analysis with the original participants. This was not carried out in this study due to time constraints. Also Henwood and Pidgeon (1995b)

argue that we cannot hold up a mirror to reality. So no matter how well grounded our account, validity claims in qualitative research cannot be based solely on appeals to the correspondence between the researchers own account and participants experiences and views as meanings are situationally based. Therefore, a second interview becomes another data stream that can be incorporated into the final data set but it cannot offer a superior check of validity.

Triangulation (Mason, 1996) is another commonly used form of validation. However, this is most often associated the realist stance (Rennie, 2000) where results are thought to be substantiated when different perspectives converge, the assumption being that convergence provides evidence of accuracy and truth (Silverman, 2000). When applied in a contextual framework the goal of triangulation is to provide completeness rather than convergence (Feilding & Feilding, 1986, cited in Madill et al., 2000). Triangulation was not employed in this study, however the process of accessing the multiple perspectives available to each respondent enriched the data. This is explained in more detail in the section on the use of adult siblings as research participants.

## 2.9.2 Reliability

The three epistemological positions outlined earlier (realist, contextual constructionist, and radical constructionist) carry different implications for the evaluation of research carried out under their auspices (Madill, et al., 2000). Many researchers have tried to transfer notions such as objectivity and reliability directly into the evaluation of qualitative research. However, Madill et al., (2000) argue that this is only achievable if the qualitative analysis has been conducted within a realist epistemology. Even then the notions of objectivity and reliability have been critiqued. For example, Collins (1975, cited in Madill et al., 2000) shows that what counts as replication, or reliability of findings may actually just represent a shared interpretative framework, subject to argument and negotiation between scientists, rather than an ultimate truth. Research within a radical constructionist framework does not claim to be replicable. Parker (p. 11, 1994) states *"It is certainly possible to repeat the work that has been described but that repetition will be a different piece of work"*

Constructionists feel that the application of traditional notions of objectivity and reliability to assess their research is inappropriate (Madill et a.,l 2000). It is suggested that qualitative analyses should be assessed on their own merits. Henwood and Pidgeon (1995) suggest that generativity should be considered when assessing the usefulness of research outcomes – that is the extent to which the findings generate further questions for research. Potter (1996) suggests alternative criteria for assessing quality of constructionist research. These include the extent to which the theory has internal coherence, that is how the analysis hangs together with no abhorrent contradictions, and how the theory explains deviant cases. Rennie (2000) measures the outcome by asking how much the overall formulation resonates with its audience, as well as its ability to promote understanding and action. These issues will be addressed in relation to this study in the discussion section.

### 2.9.3 Reflexivity

Contextual constructionism accepts the inevitability of the researcher bringing their own personal and cultural perspectives to bear on their research projects (Madill et al 2000). Therefore, this epistemological approach embodies a strong rationale that requires researchers to articulate the perspective from which they approached their material (Madill et al., 2000).

In order to acknowledge, and manage the impact of the researcher's values and assumptions within the research process, the following procedures were employed:

1. Regular supervision was used to question the perspective taken by the researcher
2. A reflexive journal was kept throughout the process (Lincoln & Guba, 1985, cited in Stevenson & Cooper, 1997). This documented the research process including the researchers observations, perceptions of the interviews (pre and post), and the impact of the researchers values on the data analysis.
3. A qualitative peer support group allowed the researcher opportunity to discuss the experience of the research process, and facilitated insight into the ways in which one's views may impact on the findings.

Qualitative researchers (e.g. Webb, 1992; Henwood & Pidgeon, 1995a) recommend the presentation of the reflexive material to the reader, alongside unedited chunks of data, sufficient for the reader to evaluate the researchers conclusions. Therefore, I have included the transcripts of the interviews as an addendum, and examples of coded text, and memos in Appendices Six and Seven.

## 2.9.4   The Researcher in Context; Owning One's Own Perspective

In a contextualist framework it is expected that researchers will identify different codes depending on, for instance, their training, research and personal experience. By articulating their position the researcher allows the reader to evaluate the inevitable contribution of their experience on the interpretation of the data (Marshall, 1986).

Good interpretation involves living inside and outside the experience and monitoring the degree of fit between the two aspects, that is analysts work with their own experience to attempting to understand others experience. Too much caution, results in a reluctance to give rein to subjectivity and can result in missing the life experience of the experience of those under study. Alternatively when given undue rein the life of the analyst may be represented more than that of the respondents (Rennie, 2000). Therefore, it is important for the reader to understand the context the author comes from. At the time of conducting this study the researcher was working as a Clinical Psychologist within both a Child and Adolescent Mental Health Service and in an Adult Learning Disability Service. The researcher is female, and a parent to a young family. Both in her private and professional life she often deals with the dilemma of how to talk with children, of different ages, about sensitive or difficult topics. When growing up the researcher lived for several years with two foster brothers both of whom had a learning disability. She has also had the experience of living with situations that were socially sensitive, such as the break up of her parents marriage within a catholic community, and her mothers homosexuality.

# 3. RESULTS

This chapter provides an account of the analysis of the six interview transcripts. One core category and six main categories were derived from the analysis of the data. The categories are divided into three sections: Foundation categories, mediating categories, and the core category. The categories are named in figure one. A model of the factors involved in the disclosure process was developed based on these seven categories, see figure two.

**Figure 1:** The Seven categories which Describe the Factors Involved in the Disclosure Process

| |
|---|
| **Foundation Categories** |
| • Changing Experience into Involvement |
| • Family Dynamics |
| **Mediating Categories** |
| • Engaging in a Lifelong Conversation |
| • Normalising Difference |
| • Challenging Social Values |
| • Creating Protection |
| **Core Category** |
| • Building Acceptance |

The model proposes that disclosure is a process which originates within the foundation categories of family dynamics and experience. The processes described in the two foundation categories shape the content and delivery of any information shared with the non-disabled child. Disclosure occurs when parents and children perform the activities described within the mediating categories. In this model one function of the mediating categories is to serve to create a sense of protection for the non-disabled child. Once established this enables the non-disabled child to move towards the core category of acceptance, which is the desired outcome of the disclosure process.

48

**Figure 2**: A Model of the Factors Involved in the Disclosure Process
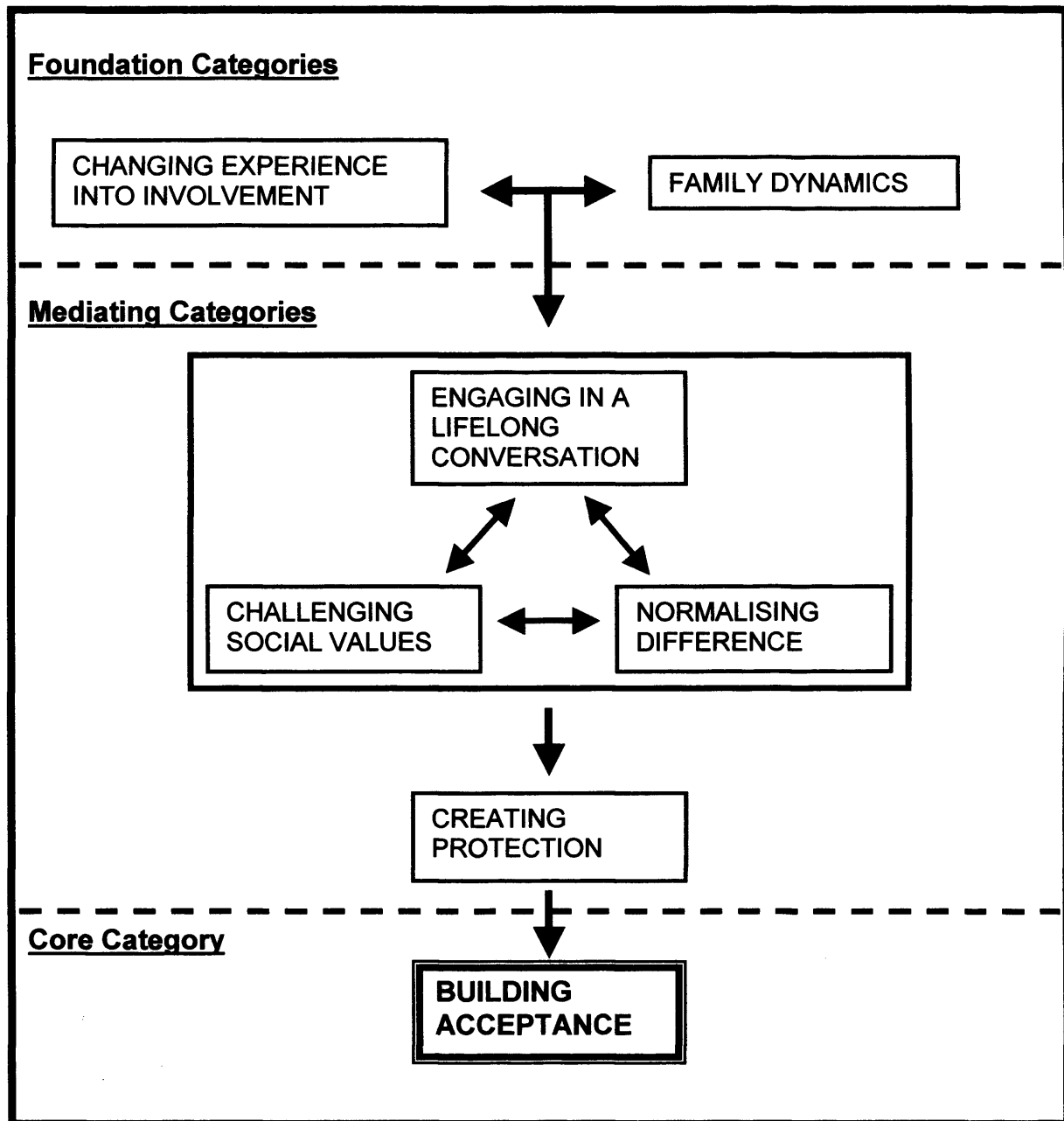


In this chapter the three sections of the model will be discussed in turn. Throughout the text distinctions between different levels of analysis (e.g. Main Category, sub-category, and theme) can be made by the style of the section title. Each main category title will be written in capitals, with bold text and underlined. Sub-categories titles will be written in lower case, with bold text and underlined. Any further themes

within either the main or sub-categories will be written in lower case, with bold text. Sub-categories and themes represent issues that expand the understanding of the main category. Interview data is presented throughout this section, in the form of quotes. The majority of these are shown as indented paragraphs, written in italicised text. Data in the form of shorter phrases is also italicised but is placed within the body of the text. Each extract is followed by a reference to its location in the transcripts.

## Section one: The Foundation Categories

### 3.1 CHANGING EXPERIENCE INTO INVOLVEMENT

Figure 3: Changing Experience into Involvement

```
┌─────────────────────────────────────────┐
│  CHANGING EXPERIENCE INTO INVOLVEMENT    │
└─────────────────────────────────────────┘
                    │
                    ▼
        ┌───────────────────────┐
        │  Knowing & Not-Knowing │
        └───────────────────────┘
                    │
                    ▼
   ┌───────────────────────┐        ┌──────────────┐
   │  Experience           │ ═══▶   │ Involvement  │
   └───────────────────────┘        └──────────────┘
              ↕                            ↕
        ┌───────────────────────┐
        │ Observation to Modelling │
        └───────────────────────┘
```
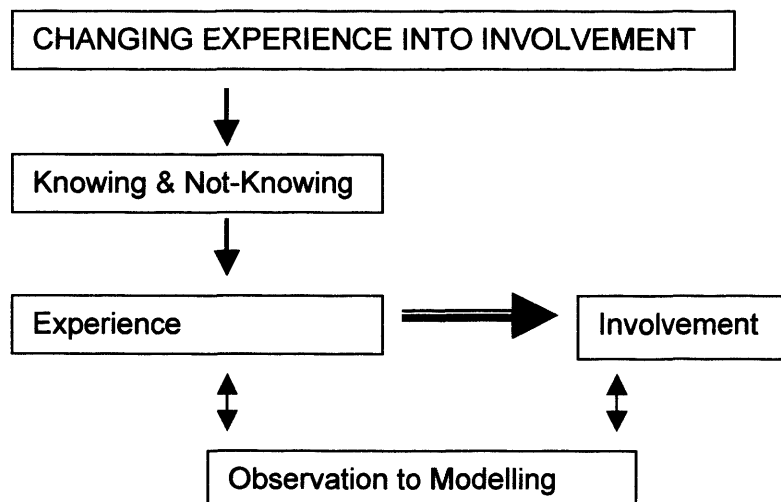
This category highlights the central role of experience in helping the non-disabled child gain insight into the issues surrounding a family member's learning disability. It goes on to describe how parents can enhance their child's experience by making it into a more active process. By doing this parents are helping to develop the child's knowledge, and understanding of disability. The sub-category of "knowing-not knowing" shows how the non-disabled child can gain an awareness of their brother or sister's disability, or difference, without being directly told about it. They develop this through their experiences, and by observing the situation and the interactions that happen around them:

*"It's a bit like learning on the job, the apprenticeship isn't it really, because if they've seen it, yes they've not had a direct course on it, but because it's been in the family they've seen"*

<div align="right">

*(Pat, lines 477-479)*

</div>

### 3.1.1 <u>Knowing & Not Knowing</u>

From a young age non-disabled siblings develop an awareness that there is something different about their learning disabled brother or sister. This knowledge is not gained via a direct conversation with parents, but from the experience of having lived with a learning disabled person in the family. This information challenges the assumption that parents can decide whether or not to tell their non-disabled children about their brother or sister's learning disability:

*"Well I've been brought up with him haven't I? I know what it is...I know"*

<div align="right">

*(Finn, line 166)*

</div>

Whilst children may be aware that their learning disabled relative is different, they may not be able to understand that difference. Therefore, parents play an important role in helping to develop their non-disabled child's understanding, though they cannot choose whether to give or withhold the basic concept that their learning disabled brother or sister is different, as the non-disabled child gains some of this information though their own observation and experience. The following quote describes the level of knowledge in two pre-school children:

*"If we have conversations about Aunty Chloe you know they'll have observed everything about her. You know they'll have observed how she holds her hands, or the way she might shriek from time to time, and you know we can just have a very normal conversation...because we know that they've sussed her...they really have got her"*

<div align="right">

*(Peter, lines 96-100)*

</div>

Children's knowledge about their brother or sister's learning disability can stand independently of the knowledge presented to them by their parents, or even of the knowledge held by their parents. For example, one respondent told how as a child she

felt she had accepted her sister's learning disability before her parents had come to terms with it:

> "I realised that she wasn't learning in the same way that other children of her age should learn. And I knew that my parents, well my father in particular, were fighting against everything, he wanted her to be normal"
>
> *(Pat, lines 171-174)*

This shows that children not only observe the differences between themselves and their disabled brother or sister, but they are also aware of their parent's reactions to the situation. Indeed, a denial or lack of information from the parents does not prevent the children from knowing about the disability, or noticing their difference. Rather it may prevent them from making sense of the situation as opportunities to discuss issues are blocked:

> "The conversations always came back to well 'there's nothing wrong with her'. I knew it was wasted conversation because I tried for so many years to talk to them about Vicky"
>
> *(Pat, lines 669-671)*

In the absence of factually correct information the child may construct their own understanding of the situation, or look to other sources outside the family. The danger here is that the child may receive confusing information (Pat, lines 271), or they may create a story that is inaccurate. This could have a long-term impact. For example, one respondent described how, for many years, she had felt responsible for her sister's learning difficulties:

> "She wriggled and she fell off (the child's knee), you know, she fell onto the floor. And I know that for quite some time I felt very guilty, that that was what had caused her difficulties....It was only really until I got married that...I realised that it couldn't have really been that, or other people made me realise that it couldn't be that"
>
> *(Pat, lines 73-81)*

### 3.1.2 Experience

Siblings report that the experience of having lived with a person with a learning disability provides them with an insight into the reality of the situation; This insight came not only from their own perspective, but also from that of the affected person

and other family members. For example, they see their personal care needs, the implications of their speech difficulties, and the reactions they receive from other people outside the family home. Siblings know the *"reality, it's day to day"* life (Diana, line 374). They know about the hard work, and the difficulties the family have experienced. One respondent talked about this in relation to the positive reactions her sister, who has Downs syndrome, received as an adult:

> *"She (sister-in-law) sees somebody wonderful...and they think oh isn't she lovely, and she's dead clever, 'you must be really proud of her', well yeah, yeah, dead right. But there's been a lot gone on to get her to that point that people don't see....You have all the processes to go through that brings you to that point. And they're the things that people don't see"*
>
> *(Diana, lines 493-506)*

Siblings feel that it is as a direct result of having experienced the intensity of living in close contact with the person with a learning disability, which allows them to gain a deeper understanding of the issues involved:

> *"I suppose that until you've lived it you can't understand. I honestly believe that you can't. I think you can educate people, you can tell people, but until you've lived the experience then I don't think you can understand"*
>
> *(Diana, lines 369-372)*

> *"I think if it (the learning disability) was sort of further removed within the extended family then it might have been different...people aunts and uncles have said things to their children in the past things that just aren't reasonable....and it's about not knowing isn't it?"*
>
> *(Diana, lines 189-194)*

This understanding incorporates an awareness of the reality of the situation. It is this understanding coupled with an awareness of the reality of disability which contributes to the development of acceptance in the non-disabled child. This is discussed further in the sub-category "A different type of acceptance":

> *"If we hadn't had somebody in the family with a learning disability maybe they wouldn't have been so tolerant and so acceptable of it"*
>
> *(Becky, lines 118-120)*

Another way in which having this experience may help facilitate the process of building acceptance and understanding, is by making the person with a learning disability real for the non-disabled child *"making sure she's a live person for them"* (Peter, line135). This allows the non-disabled child to view that person as an individual unrestricted by stereotypes or unnecessary fear:

> *"It breaks downs barriers and the stereotypes doesn't it, it breaks down the 'oh Downs people are very loving', because he's seen her in a temper and he's seen her throw things and she is a real person. It's not about Downs Syndrome people, it's about my Aunty Lucy"*
> *(Diana, lines 213-216)*

> *"They wanted to sit on her lap and, you know, stroke her hair, and they realised she wasn't going to do anything to them or hurt them in any way"*
> *(Peter, lines 269-271)*

For two groups of people there was a sense that disclosure and getting to know and accept the person with a learning disability may be more difficult. These were people who come into contact with a learning disabled person for the first time at an older age, and people who have limited contact with the disabled person:

> *"I think it's harder to take on board when you suddenly become aware of it, than when you've never known any different"*
> *(Becky, lines 134-135)*

> *"I think for people who come in, people on the outside, I think that's different"*
> *(Diana line 614)*

Siblings younger than the learning disabled person have had a relationship with that person from birth, so their everyday experience has involved living with difference. People who are older on their first encounter with someone who has a learning disability, such as a non-disabled siblings spouse or a teenage sibling may struggle to achieve this level of experience. For those who are not a part of the immediate family unit, it may be difficult achieve this level of experience at all.

The importance of regular contact with the learning disabled person was stressed in all accounts. However, where this is limited other modes of maintaining contact can be

useful, for example the use of photographs, telephone calls, or by talking about the person in an everyday conversation:

> " My mum...if she's gone and seen Chloe she'll send photos to the girls or, you know, the home send Christmas presents and Birthday presents to the girls from Aunty Chloe"
>
> (Peter, lines 136-138)

The more removed a person is from the situation the greater the need for a more formal approach to disclosure. However, as discussed later in the "Acceptance" category this is akin to education and as such the understanding it provides is not thought to be comparable to the insight gained from the experience of living in close proximity to someone with a learning disability:

> "I suppose with children from the wider family then it's more of an issue, you need to perhaps sit and say, this is...(name disability)"
>
> (Diana, lines 196-197)

### 3.1.3 Involvement

Further analysis of the "Experience" category revealed a co-construct of "Involvement". Experience and involvement lie along a continuum where experience occurs without effort, through living in close proximity to a person with a learning disability. Involvement has to be created by presenting the non-disabled child with opportunities through which they can become actively engaged in a relationship with the learning disabled person. Therefore, involvement is an active form of experience, and as such can be utilised by parents throughout the disclosure process to strengthen the relationship, and help the non-disabled child to develop an understanding of the issues:

> "The best interaction is working with Chloe, I mean that's where they've learnt, you know, it's actually, you know, my parents (saying) 'you want to help feed Chloe, that would be brilliant, she'd love you to'....she gets eye contact with them and she seems to enjoy it, you know, their company, seems to sense their presence, and you know 'brush her hair, fine do join us when we're having a bath', so that's almost the best role play because it's reality"
>
> (Peter, lines 643-649)

Involvement provides a way of focusing the non-disabled child's experience, in order to facilitate the relationship between the non-disabled child and the person with learning disabilities. This level of experience can almost negate the need for a more formal, or verbally based, process of disclosure:

> "I never found it easy to talk to mum and dad....but mum did make us feel involved, I can remember from quite an early age feeding Angela of an evening when we came in from school....I suppose in that way we accepted it....and a bond did start to form and I got very protective of her"
>
> (Becky, lines 177-193)

Non-disabled children were often described as having a "willingness to get involved and just muck in" (Peter, line 88). Involvement on a practical, day to day level is particularly important:

> "They...very much want to be hands on, and er, and are hovering around my mother particularly, you know, "can we help, can we feed Chloe?"
>
> (Peter, lines 75-77)

Going beyond the realm of the caring practical tasks, respondents demonstrated how they facilitated the non-disabled child's involvement in a range of aspects involved in living with a learning disability. Examples cited included attending appointments with the learning disabled person, going on hospital visits, and thinking about the person's future care needs:

> "My younger one has actually been with us when we actually went to see a home...and he said 'oh this looks nice what are we going to do here?'"
>
> (Pat, lines 591-593)

As described in the quote above, involvement in this type of activity can lead to "one or two conversations on the way home" (Pat, line 570), and can be used as a tool to prompt discussion, and information giving across a range of issues. The accounts showed that through active involvement children are able to process experiences which they may initially find daunting. This exposure to different situations can contribute to their understanding and prevent them having any "fantasies or...fears" (Peter, line 394), it also allows them to process information to the extent where they feel more able to communicate to others. One respondent spoke of taking his young

children to visit his learning disabled sister while she was staying in a long stay hospital:

> "She's got very serious epilepsy and she was in hospital for a long-time...so the girls visited her there, that puzzled them a lot ...they visited her a few more times, after that it's 'no that's fine', they knew where they were going, to tell their friends"

> (Peter, lines 373-386)

## 3.1.4 Observation to Modelling

Respondents noted how observant non-disabled children were of the situations around them. They felt that the children noticed the similarities, the differences, and the interactions that constitute everyday experience within their family unit:

> "You take on board, the environment and the relationships and everything else that are real to you, that are your experience"
>
> (Diana 225-227)

In a process similar to that described in "Changing experience into involvement", respondents showed how parents could utilise a child's naturally occurring observational skills to model appropriate ways of interacting in relation to the learning disabled person. It seems that by observing family relationships the non-disabled children can learn how to interact with their learning disabled relative. Respondents clearly felt that parents act as models for their children:

> "I just think it's something that comes....from the way that everybody is and the way that we live, and the way that Lucy has been treated"
>
> (Diana, lines 286-289)

> "I think children pick up things very quickly in that my five year old now without my sort of sitting him down and telling him about Vicky....will go and fetch the coat for her and he will try and fasten it for her....he wouldn't do it to me, and he doesn't do it to his brother and sister or to his dad...so he may have taken some, quite a lot of those cues from what my mum does, what I do"
>
> (Pat, lines 427-437)

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For some siblings the visible characteristics of their brother or sister's disability immediately identify them as different. For example, it may be their personal care needs, a speech impediment or a differential ability level that set them apart. These visible signs are usually those which are easily observable by others outside the family, and siblings often witness, and have to deal with, the public's reactions:

> *"Adam (who has Downs Syndrome) walks up the road and you can see kids looking at him"*
>
> *(Erica, line187)*

Respondents cited several examples of how non-disabled children had internalised their parent's strategies of coping with public reactions to their learning disabled brother or sister. These included sticking up for them in fights, talking to their friends about disability before they visited the family home, and challenging some of the unacceptable language used:

> *"I mean he, he would challenge people now himself...he says 'somebody's called her a Mongol this afternoon', he says 'I've told them she's British'"*
>
> *(Diana, lines 261-265)*

For non-disabled children observation is an effective mode of learning. Therefore, parents can pass information to their children through modelling positive relationships with the learning disabled person. A similar method is also used to teach the non-disabled child strategies for interacting with the outside world, this is discussed further in the "Challenging social values" category.

In summary, this category has described how children gain an understanding of disability through their own lived experience, and by observing the interactions around them. Parents play a key role in helping the child make sense of this information. The discussions of "Involvement" and "Modelling" highlight how parents employ alternative ways of sharing information with the non-disabled child, ways that may actually be more fundamental to the disclosure process than a purely verbal conversation.

## 3.2 FAMILY DYNAMICS

**Figure 4**: Family Dynamics

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              ┌──────────────────────┐
              │   FAMILY DYNAMICS    │
              └──────────────────────┘
                          │
                          ▼
┌──────────────────┐          ┌──────────────────────────────┐
│ Unique Character │ ◄──────► │ Reciprocity of relationships │
│ of the Family    │          └──────────────────────────────┘
└──────────────────┘                ╱              ╲
                          ┌──────────────┐  ┌──────────────┐
                          │ Parent & Non-│  │ Sibling      │
                          │ disabled child│ │ Relationship │
                          └──────────────┘  └──────────────┘
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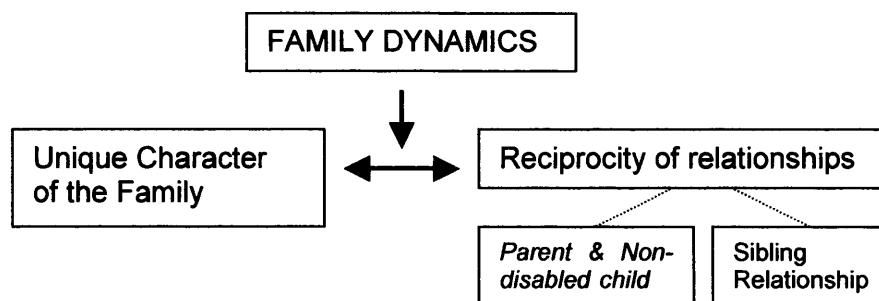
A child lives within, and is dependent upon, the family system. It is within this system that the process of disclosure operates. Therefore, the factors described in this category have a strong effect upon all the processes which occur within the other categories. For example, the family dynamic will decide how much information the child will be given, it will shape their experiences of living with their disabled brother or sister, and facilitate their level of involvement. Respondents particularly recognise the central influence of parents, describing it as:

> "*Fundamental, in terms of just complete acceptance and integration and erm, you know, complete openness*"
>
> *(Peter, lines 316-317)*

Similarly, the way children perceive their parents to manage day-to-day issues can affect their relationship with their learning disabled brother or sister:

> "*She got blamed for everything....me being the youngest I got away with a little bit, but her being the eldest it was her that always got chased and she got smacked*"
>
> *(Erica, lines 212-217)*

> "*I said to her did you feel as if you were shoved out on odd occasions? And she said 'yeah'*"
>
> *(Erica, lines 271-272)*

There are two themes within this category. The first highlights the unique character of each family, the second discusses the nature of the relationship between family members.

### 3.2.1 Unique Character of the Family

A family is made unique by the amalgamation of the personal characteristics of each individual family member. In each family it is the parents who hold this knowledge, therefore, they can be viewed as experts in the family situation:

> *"You know your own children, you've got to be the judge of when it's right for your child"*
>
> *(Becky, line 642)*

Parents and siblings are aware of individual differences within the family, such as how a person reacted to the situation, or how much information they require. For example, when comparing her own and her non-disabled sister's relationship with their brother, who has Downs Syndrome, one respondent described the difference in their reactions:

> *"She's entirely the opposite to me...she does resent Adam...whereas I've been too protective"*
>
> *(Erica, lines 203,226,232)*

Other reasons cited for differences between siblings were: the non-disabled child's temperament (Pat, line 976; Peter, line 92), their developmental ability in comparison with siblings at the same age (Becky, lines 395-400), how curious individual children are (Erica, line 742), and age gap between the sibling and the disabled child (Becky, lines 222-226). Some older siblings experienced the loss of the wished for brother or sister:

> *"It saddens me really that she is the way she is, and that although I've got a sister I haven't had a sister I can talk to, you know, I haven't had this sisterly sharing make-up ideas, or talks about boyfriends, or going out together...in a way I'm an only one... in that there is a person there but it isn't a person that I can have a real meaningful relationship with"*
>
> *(Pat, line 916-921).*

The family is also affected by the nature of the person's disability. A more visible disability such as the use of a wheelchair, speech difficulties or the facial shape characteristic of Downs Syndrome has *"its blessings and its drawbacks"* (Diana, line 588). The visibility of the disability provides concrete cues about that person's

difference which parents can utilise when explaining disability to their non-disabled child. They are also observable to strangers and so allow them to adjust their expectations of the person accordingly. Whilst this reduces the risk of having too high expectations of the disabled person, it can lead to low expectations or dismissal (Diana, line 586). Less visible disabilities may be harder to put into words, which may make explaining the disability to children more difficult (Peter, line 524). However, less prominent overt characteristics (e.g. as with some autistic people) means that sometimes there is no need to have to explain their difference to others outside the family (Pat, line 494). When the person's disability involves them engaging in a negative behaviour, such as violence, this can have a profound effect upon the sibling:

> "I never stayed in the house...it used to frighten me. I used to have nightmares all the time"
>
> (Finn, lines 603-605)

This situation was exacerbated, as disclosure was not adequately addressed in Finn's family. Therefore, whether challenging and violent behaviour will always have a negative impact needs further investigation. The differences within, and therefore between, each individual family means that they will need to approach the process of disclosure in the way that is most appropriate to both the family's and the siblings unique character:

> "I don't necessarily think that what's right for one family would be right for another family"
>
> (Becky, lines 360-361)

> "You can't generalise, you can't say living with Down's Syndrome person is like this, you can't say having a Downs Syndrome brother or sister will be like this, because you can't say that"
>
> (Diana, line 385 – 387)

### 3.2.2 Reciprocity of Relationships

Analysis showed that parents are fundamental in facilitating the sibling's experience of living with a person with a learning disability (Peter, line 316). However, the accounts also highlighted the bi-directional nature of family relationships. This was

discussed in terms of the relationship between parents and their non-disabled children, and the relationship between the siblings and their learning disabled brother or sister.

**Parent and Non-disabled Child:** The longevity of the sibling relationship was apparent throughout all the interviews, particularly in relation to siblings becoming carers for their disabled brothers and sisters as adults. This taking on of caring tasks had cast the siblings into the role of *"second mother"* (Becky, line 47). The sibling's willingness to take on some, or all of the responsibility of caring provided the parent with some peace of mind as to the long-term welfare of their disabled child (Erica, line 385). Interestingly, in the second generation of these families, two of the parents refused offers from their own children to continue caring when they were no longer able to:

> *"No way. I said I'll write it in the will and everything. I said there's no way that you're having Adam"*
>
> *(Erica, lines 429-430)*

It seems that having reflected on their experiences of caring for the learning disabled person, siblings recognised the impact this had on their lives and wanted to protect their own children from experiencing similar feelings:

> *"I've been sort of thinking did I do the right thing? You know would our lives have been a lot different? Yes they would, but you can't turn the clock back so there's no point dwelling on it"*
>
> *(Erica, lines 399-402)*

> *"Why should I give up my life for someone, I know it's sounds horrible don't it? ....I don't really think I should be living other peoples lives"*
>
> *(Finn, lines 725-736)*

> *"I don't want her to feel guilty. That she has a mountain of responsibility on her shoulders"*
>
> *(Pat, lines 374-375)*

Having lived within the family non-disabled siblings are able to empathise and understand the situation and their parents reactions to it. This is true even if the siblings don't agree with the way their parent has chosen to bring up the disabled

person (Pat, lines 693 & 743, Erica, line 325). As the non-disabled child grows older there are examples of them taking the role of confidante or advisor to their parents. For example, one young woman suggested that it was now time that her mother let her learning disabled brother go and live in residential care (Erica, line 405).

In these ways siblings provide their disabled brother or sister, and their parents with practical and emotional support. Siblings may also try to challenge their parent's perspectives on disability, or their choice of caring styles.

**Sibling Relationship:** Several parents noted that their children's relationship with the learning disabled person was strengthened by the recognition of the many similarities between them. This occurred particularly when the non-disabled children were younger:

> *"I think they've almost got...a natural empathy for Chloe, because the things that we're having to do with our daughters...the whole gamut of personal care, Chloe needs doing for her as well, and they see that"*
>
> *(Peter, line 68-72)*

Siblings acknowledge the unique qualities of their learning disabled brother or sister, and they recognise the contribution they make to maintaining the sibling relationship:

> *"Absolutely, I value that (difference) because she's got so much that I haven't"*
>
> *(Diana, line 366)*

> *"She (my wife) needed to sort of see for herself what...Chloe needs and also what Chloe gives as well, and I think that's been an important part of seeing what Chloe provides, what Chloe in her own way can, you know, give back to people"*
>
> *(Peter, lines 202-205)*

Respondents recognised the positive impact of living with a person who has a disability. They felt that this had helped their non-disabled children to develop positive qualities, and more tolerant social values:

> *"They seem to have a lot of expression of compassion and care, you know, they're both very caring children"*
>
> *(Peter, lines 551-553)*

In summary, this category described how each family, and indeed each sibling is unique, this stresses the need for disclosure to be tailored to meet needs of each individual. Parents are seen as the experts within their own family system. However, this category also highlights what non-disabled sibling offers to the family, showing disclosure to be somewhat less of a uni-directional process than previously envisaged.

**Section two: Mediating Categories**

**3.3 ENGAGING IN A LIFE LONG CONVERSATION**

**Figure 5**: Engaging in a Life Long Conversation

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│      ENGAGAING IN A LIFE LONG CONVERSATION        │
└─────────────────────────────────────────────────┘

┌──────────────────┐  ┌──────────────────┐  ┌──────────────────┐
│  Luxury of Time  │  │ The Relationship │  │ A Child Initiated│
│                  │  │ between Curiosity│  │ Process?         │
│                  │  │ & Questions      │  │                  │
└──────────────────┘  └──────────────────┘  └──────────────────┘

┌──────────┐ ┌──────────┐ ┌──────────┐ ┌──────────┐
│ Curiosity│ │Techniques│ │Non-disabled│ │Usefulness│
│          │ │for answering│ │Sibling's │ │of a label│
│          │ │questions │ │questions │ │          │
└──────────┘ └──────────┘ └──────────┘ └──────────┘

              ┌──────────┐ ┌──────────┐
              │ Direct   │ │ Indirect │
              │ questions│ │ questions│
              └──────────┘ └──────────┘
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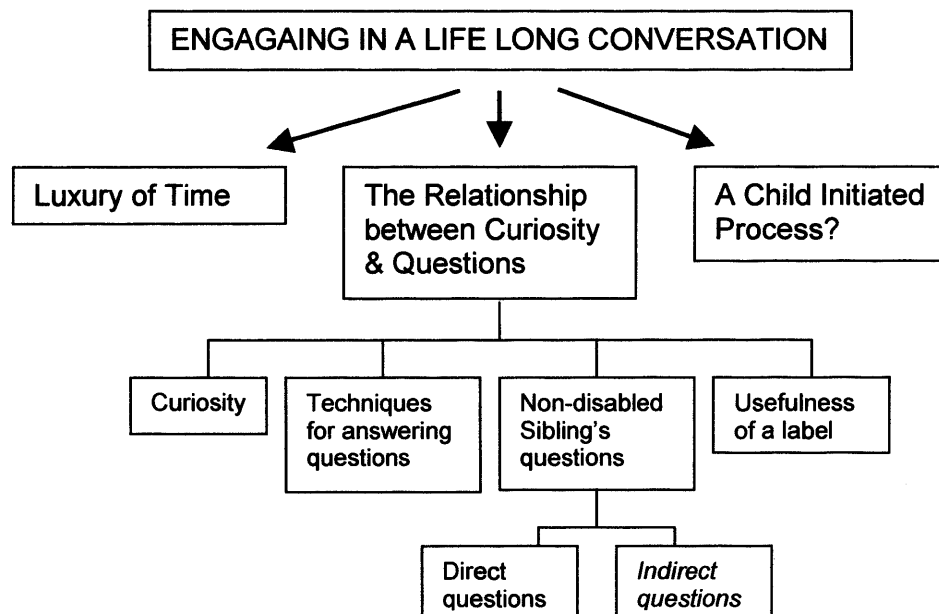
This category outlines the process of information exchange, where parents and children create and use opportunities to discuss issues relating to living with a person with a learning disability in the family. This is done through the mechanism of a lifelong conversation that occurs between parents and children. The term lifelong because it is a conversation that begins when the non-disabled child is young and continues into adulthood, though it changes shape and content.

Many respondents referred to the absence of a formal disclosure process, that is they did not recall a time when they sat down with their children and told them about their

learning disabled relative's difficulties. Instead they described conversations that had *"just come up in passing"* (Peter, line 317) often as a result of questions from the non-disabled child. It was the use of questions that they identified as the primary vehicle through which most information was shared:

> *"We never sort of made a point of actually sort of bringing it up as a big issue and telling them and just sitting them down and telling them. I answered the questions as they arose"*
>
> *(Becky, lines 59-61)*

Questioning works in tandem with experience to allow the non-disabled children to establish an active role for themselves in the acquisition of knowledge:

> *"You've got to get that mixture of telling and informing them but letting them inform themselves"*
>
> *(Peter lines, 451 –452)*

Respondents reported that the process of sharing information with non-disabled siblings was not qualitatively different to other conversations that take place between parent and child. Examples of comparative conversations included sex education (Peter, line 237), drugs awareness (Becky, line 544), and bereavement (Peter, line 398). Interestingly, the topics chosen by respondents to illustrate this point are ordinary, in that they routinely occur in most families, yet they refer to sensitive, and sometimes contentious issues. By aligning the disclosure process with this type of conversation, respondents highlighted the potential complexity involved when discussing disability:

> *"These issues just roll by don't they, it's just life and it's living and you deal with each issue as it comes"*
>
> *(Diana, lines 450-451)*

### 3.3.1 Luxury of Time

Respondents unanimously identified disclosure as a long-term process, a conversation which is returned to many times over the lifetime of the family. Respondents

identified that non-disabled children were able to engage in this process from a young age:

> *"It's been a natural progression across his formative years"*
>
> *(Diana, line 221)*

> *"It sort of was a gradual procedure, probably from being about three I would say the first question came"*
>
> *(Becky, lines 335-336)*

The non-disabled child needs time to process information shared throughout disclosure, and will frequently return to questions when necessary. This has the advantage of keeping the dialogue open, allowing parents to build the child's understanding step by step:

> *"With a child they'd perhaps have to think 'Oh what's she mean by that?' and go away, and come back"*
>
> *(Erica, lines 641-643)*

Taking time to process information is particularly important for those children who feel overwhelmed. In this case quoted below the respondent was confused after receiving contradictory information:

> *"I was confused...so well I thought well I'm too, you know, I'll think about it later because I think I couldn't cope with it at that particular time"*
>
> *(Pat, lines 263-266)*

Her strategy in dealing with her confusion highlighted that disclosure occurs over time. Indeed, there is rarely an immediate need to be addressed. Respondents generally felt that parents should wait for disclosure opportunities to occur *"naturally"* (Becky, line 341), though an exception to this may be with much older siblings:

> *"It depends what age your children are...maybe with an older child you do need to introduce something straight away and tell them straight away"*
>
> *(Becky lines 341-344).*

Whilst acknowledging that throughout the process of disclosure there will be many opportunities to address the issue of disability, respondents noted that there are some situations where you "*sometimes you really feel...I need to seize this moment*" (Peter, line 251). The word "sometimes" in this quote indicates that these opportunities to initiate discussions happen more than once, indeed respondents suggested that parents will have multiple opportunities to raise these issues with their non-disabled children.

There is a developmental aspect to the nature of this disclosure conversation between parents and their non-disabled children, as the disclosure process continues into adulthood. The content of the conversation changes from creating an awareness of the person's difficulties to other related issues. Such as considering care options for their learning disabled person as an adult (Pat, line 245), indeed, some siblings took over as the primary point of contact for professional services (Erica, line 377), for others it raised concerns about disability when thinking of starting their own family (Diana, line 394). It seems that once the conversation has begun it is open, it lasts a lifetime, and covers a wide range of changing issues.

### 3.3.2   The Relationship Between Curiosity and Questions

This sub-category discusses what respondents termed as, the non-disabled child's natural inclination for curiosity and questions. It demonstrates how parents can work to provide an environment that will encourage the child to ask questions. In the later part of this section techniques which respondents felt were useful when answering a child's questions are outlined.

**3.3.2.1 Curiosity**: Respondents reported that their children were naturally curious and observant about many aspects of their life (Becky, line 398). When living with a learning disabled person in the family children are particularly "*inquisitive*" (Erica, 652) about disability:

> "*They've both shown an acute fascination in Chloe when they meet her*"
> "*They were fascinated with her wheelchair*"
>
> *(Peter, lines 65 & 271)*

Respondents described children as less self-conscious than adults (Erica, line 657) and therefore were more likely to openly show their curiosity or puzzlement, usually by asking questions, which often related to the issue of difference:

> "They only ask questions that you know genuinely puzzle...they just come out with 'why is somebody different?' or you know something that's immediately struck them...they just ask a very direct question"
>
> *(Peter, lines 155-160)*

The "*inevitability*" (Peter, line 595) of the non-disabled child's questions, stems not only from their curiosity, but also from their experience. This implies that the process of talking about a brother or sister's learning difficulties would begin naturally with little need for preparation. However, effort is needed to maintain and develop this process, as an environment unresponsive to the non-disabled child's enquiry may, in time, prevent the child from overtly asking questions, but it will not stop them from being curious:

> "I can remember thinking to myself, why?"
>
> (Pat, line 42).

Analysis revealed that the phenomenon of curiosity was most active within the initial developmental phase of the relationship, or when a new situation was encountered. These are times when the non-disabled child is experiencing something novel, something which they have not yet made sense of:

> "It was possibly sort of a puzzle to them initially but now they take it for granted"
>
> *(Peter, lines 74-75)*

However, respondents noted individual differences in the non-disabled child's level of curiosity, when it emerged, and how the child chose to express it. Answering the non-disabled child's questions and allowing them to experience the different parts of the learning disabled person's life, such as showing them their special school, tended to satisfy the child's curiosity:

> "Once they've had an explanation it really doesn't puzzle them"
>
> *(Peter, line 150)*

*"I don't think there's many more revelations for them to see...there's not that many areas of her life where I think they would be even more curious about"*

*(Peter, lines 122-125)*

**3.3.2.2 Non-disabled Sibling's Questions:** Overall respondents said that the questioning by non-disabled children was relatively unobtrusive, in that it occurred occasionally, and therefore was not a constant feature of the relationship between the learning disabled relative and the non-disabled child. One respondent remarked *"actually it's amazing how much they don't (ask)"* (Pat, line 946). In a similar process to curiosity, most of the non-disabled child's questions came in the early stages of the relationship, or at times of significant change.

Analysis identified two question types, "Direct questions" specifically related to the child's learning disabled relative, and "Indirect questions" which were asked about other people outside the family.

**Direct Questions:** This type of question was concerned with specific and observable factors. These were the type of questions most frequently asked by the non-disabled child:

*" 'Why does Aunty Chloe wear a funny hat in the bath?'...once they'd asked this once they didn't really seem to come back to it"*

(Peter, lines 282-284)

Direct questions required a simple answer and children were unlikely to ask the same question again:

*"It's just an odd quick question and an answer seems to satisfy them and that's it"*

*(Pat, lines 947-948)*

*"Once you give an explanation that's fine, you know, they can make sense of that"*

*(Peter, lines 114-115)*

Another level of direct question was identified, these involved asking about more abstract concepts:

*"I used to say to my mum 'why doesn't she play with me, or why can't she play with me, or why doesn't she smile, or why does she sit there so still?'"*

*(Pat, lines 31-33)*

This type of question was viewed as being more complicated, both to answer and to understand. This was shown by the increased likelihood of the non-disabled child to ask the same question at a later point.

**Indirect Questions:** This type of question stemmed from the non-disabled child's interest in people with disabilities whom they encountered outside of the family. Analysis showed that non-disabled children use direct questions to help satisfy their initial curiosity, after which they become relatively infrequent. Whereas indirect questions are less frequent, but occur more consistently over time:

> *"They know that I work with children with special needs, they ask more about my children actually....They asked about Sarah whom I teach, you know, in fact sometimes they have said what's wrong with Sarah or what are Sarah's difficulties...I've just told them the condition...and then they'll just say well what does that mean, and what can't she do and so they're fairly curious about people that I teach"*
>
> *(Pat, lines 469-471)*

> *"The questions I had which I may not be able to articulate about Chloe necessarily, but I might have been then asking about that little Downs Syndrome child...other disabled people that I came across, I guess maybe I had those, I'd sort of find out and ask questions about that and then 'oh right, oh yeah and I've go...my sister's similar as well', some parallels"*
>
> *(Peter, lines 320-326)*

It is possible that by asking indirect questions non-disabled children were protecting their parents feelings, or perhaps it felt safer to address the issue of their relative's disability indirectly. However, the data suggested that these indirect questions originated from the non-disabled child ability to see disability more easily in others than in their own relative. This phenomena is explained further in the "Acceptance" category, under the theme of "Seeing the person first":

> *"Thinking about other people's siblings or together people's children or other people's brother or sisters can sometimes be more of a challenge or more of a debate because it is, you know, Chloe is Chloe"*
>
> *(Peter, lines 465-468)*

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It is the more complicated questions that the child is likely to repeat as the answers are more involved and therefore, the child may require time to process or supplement the information. The explanation they receive in answer to their questions help to build an understanding of the person's disability:

> *"All you can really do is wait until the question comes up again...children do repeat and affirm what they thought they knew and will ask you days, weeks, minutes whatever later the same question and I suppose the trick is to try and give the same answer or be consistent"*
>
> *(Peter, lines 254-258)*

Whilst children do refer primarily to their parents, they may also ask questions of other members of the family:

> *"They just ask a very direct question and they ask very direct those questions of me, my wife Joy, of grandma, grandpa as well"*
>
> *(Peter, lines 159-161)*

**3.3.2.3 Techniques for Answering Questions**: Of central importance to respondents was the manner in which disability is discussed with their non-disabled children, rather than the content. Respondents unanimously agreed that parents need to be open to the child's questions and answer them as honestly as possible, this included admitting when you don't know:

> "Whatever questions they're asking you just try and answer them the best you can"
>
> *(Erica, lines 507-508)*

Being honest and open with non-disabled children not only provided them with information they asked for, but it also modelled a way in which they could approach the subject with their friends. This allowed them to take control of the conversations:

> *"By being open and honest at least she's gone out and said to her friends that Adam is Downs"*
>
> *(Erica, lines 807-808)*

> *"She's talked about it before she's brought her friends here, whereas the friends would have probably been firing twenty bullets at her...what's the matter with him"*
>
> *(Erica, lines 816-818)*

Other techniques for answering questions included; Using simple language that is appropriate to the non-disabled child's developmental level, both in terms of both their cognitive ability (Peter, line 211) and their language skills (Peter, line 495). Giving answers that are consistent over time (Peter, line 258) and consistent across different members of the family (Pat line 264). Offering the child a long-term perspective to show that the learning disabled child would have these difficulties *"for life"* (Erica, lines 509). One way to reinforce this is by naming the disability, or giving the non-disabled child a story that explains the difference.

### 3.3.2.4 The Usefulness of Having a Story or a Label: The non-disabled child used labels when referring to the learning disabled person's difficulties. These consisted of generic terms such as *"disability"* (Becky, line 86) or *"handicapped"* (Erica, line 52). The use of these labels seemed to signal that the child had begun to make some sense of their relative's difference. Respondents agreed that finding a way to describe the disability may be *"quite a difficult subject but I still thought it was worthwhile saying"* (Peter, line 515). The benefits of endeavouring to explain the condition to the non-disabled child were enough to encourage the parent to try to find an appropriate level of language:

> *"Is it unwell this or is it, you know, something's broken inside her, I mean these are the words we try to weave our way through"*
> *(Peter, lines 371-373)*

In cases where the aetiology of the disability is uncertain, providing a story about the problem that is meaningful is enough to begin to facilitate a child's understanding:

> *"Q: she'd got no formal diagnosis?....No just brain damage. No it was I believe it was a mismanagement at birth"*
> *(Peter, lines 44-45)*

A lack of a story, leads to uncertainty about the causes and effect of the person's difficulties, and can contribute to preventing the non-disabled child from accepting of the situation. For example, one respondent felt guilty for having caused her sisters disability following a fall (Pat, line 73), another felt ambivalent about his relationship with the learning disabled person as he was frustrated by the intentions he perceived to be behind his brother's behaviour (Finn, lines 62-64).

Disabilities with a visible component, such as a wheelchair or distinct facial features seem easier for a child to understand. This suggests that providing the non-disabled child with some concrete elements, when explaining the disability may help to facilitate the child's understanding:

> *"It is more visible what Chloe needs doing for her, and I suppose that might be a better way of actually trying to explain to people, actually what the needs of the person are"*
>
> *(Peter 524-526)*

### 3.3.3  A Child Initiated Process?

Questions were identified as playing a crucial role in the disclosure process. Parents characteristically waited for children to ask questions before they felt they had begun the process of disclosure. This led them to believe that disclosure was a child initiated process, *"yes it has been more prompted by them"* (Peter, line 162). However, analysis of the data showed that behind the surface parents were very active in creating the right environment. An environment within which they could to both stimulate, and receive questions from their non-disabled children:

> *"Give them opportunities to understand Chloe themselves"*
>
> *(Peter, line 454)*

> *"Until you've actually encouraged them to spend time and get to know her, you know, it's hard to have a discussion"*
>
> *(Peter, lines 449-450)*

These quotes illustrate how parents can work to create opportunities and encourage their non-disabled children to become involved with the learning disabled person, and that this can happen prior to any discussion of the issues. This act of facilitation also occurs when the parent is engaged in the process of normalising difference, that is they are encouraging the non-disabled child to notice and question aspects of their environment.

Providing environments that facilitate the questioning process is particularly useful in the connection with the use of indirect questions. Here, parents can give the non-disabled child the chance to experience environments where they may observe issues

relating to their sibling's disability that may be more difficult to see, or ask about in their home situation. One respondent described how he gained "*a lot of exposure...getting involved...in support groups and other networks*" (Peter, line 317-320).

Accounts also showed how parents utilise the opportunities provided by the child. For example, when the non-disabled child asked a question parents interpret this as a signal that the child may be receptive to information, and often made use of this by answering beyond the scope of the question:

> "*I tended to answer the questions each time and then sort of expand a bit on them*"
>
> *(Becky, lines 71-72)*

> "*I think that the approach, you know, that myself and my wife have taken, Joy, is to try and give, to use that as a lead in, you know, to talk a little more broadly*"
>
> *(Peter, lines 163-165)*

Children are very good at controlling the amount of information they want to hear, and will clearly state this to their parents. Therefore, the danger of overwhelming, or under-informing them is minimised:

> "*She would say oh well I don't want to hear any more or that's enough, or if you stopped and they wanted a bit more I think they'd follow it with another question*"
>
> *(Erica, lines 569-571)*

> "*She asked a question you give her the answer if she weren't happy she perhaps would have said 'well what do you mean by that'*"
>
> *(Erica, lines 616-619)*

In summary, this category shows that children are active participants in the disclosure process, they ask questions and are curious about their relative disability. It is this curiosity that acts as the staring point of the disclosure process. Whilst it may begin naturally, parents are working hard to develop this process. They do this by creating an environment that is both stimulating, and responsive to the child's question.

## 3.4    NORMALISING DIFFERENCE

The process described in this category shows how parents help their children to explore the meaning and value of difference. This is associated with the sibling having acknowledged that having a learning disability makes their brother or sister different from other children, and that this in turn makes them and their family different.

The accounts showed that siblings lived with contradiction in that they acknowledged the difference was integral to their brother or sister's identity, but this difference constituted their only experience of family life, therefore one which they accepted as their "norm":

> *"I mean it is, it is very different, but it's not different to you and your experience. This is it, this is your family, this is what you're living"*
>
> *(Diana, lines 621-622)*

The aim of this process of normalising difference is to guide the child to see difference as something ordinary, something that is all around them in their daily life:

> *"Accept that lots of people have disabilities of some degree and it's nothing out of the ordinary but that's how people are, that everybody's made different"*
>
> *(Becky, lines 115-116)*

Respondents felt that children are naturally curious about difference, and that they will spontaneously ask questions across a range of different situations:

> *"If it's not Chloe it would be somebody else in their class, or it would be someone else in the street...you know, 'why have they not got a house, why are they asking me for money, why have they not got a daddy?'"*
>
> *(Peter, lines 574-578)*

By facilitating the process of exploring difference with the child, parents can have some control over the development of the child's attitudes towards difference. This will make it more likely that the values the child develops about difference are similar

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to those held by the parents, and more positive towards their relative with a learning disability:

> *"Ignorance...could mean that they have misconceptions about Chloe's humanity, and other people that are different to them, so I think that would worry me"*
>
> *(Peter, lines 554-556)*

Parent's encouraged their non-disabled child to notice difference across a range of situations, from different hair colour to homelessness and single parent families. By doing this, the child develops a broader concept of difference, one that goes beyond disability to incorporate other forms of difference:

> *"(We) make reference to other situations, maybe other people they've met, or children at school, or people in the street, other people with disabilities, other people who are different"*
>
> *(Peter, lines 171-173)*

Viewing difference as ordinary was seen to benefit the child in three ways; Firstly it enables them to minimise their sense of their learning disabled brother or sister's difference, this in turn protects them from the isolation they may otherwise have felt by living in a "different" family. Finally, viewing difference as ordinary provides the non-disabled child with the opportunity to become more tolerant of difference in the wider context, and so contributes to the development of their social values.

Respondents reported that many of the opportunities for discussion about difference occurred in very ordinary situations. Indeed parents used everyday activities to contribute to the exploration of difference, such as television programmes, books or the use of play:

> *"They have got books and....they've got a dolly who's got a wheelchair and things like that, so again, that's another route in"*
>
> *(Peter, lines 177-181)*

Parents can use these ordinary situations to prompt or extend a conversation about disability with the non-disabled child:

*"We watched the Hunchback of Notre Dame and...we ended up having a discussion about whether this cartoon character is disabled or not"*

*(Peter, lines 462-464)*

*"You occasionally stumble across a really good episode of Sesame Street, one of them, you know, one of the presenters or one of the children in the street is a wheelchair user or whatever...and that may or may not be a route for talking about disability and making some links we wouldn't always do that it's not always necessary, but it might be"*

*(Peter, lines 618-623)*

The above quote says that disability need not be discussed at every opportunity. Respondents noted that to over-emphasise difference directly in relation to the relative's learning disability could be detrimental to the relationship as it may result in alienating the non-disabled child. By discussing difference in the wider context rather, than exclusively to learning disabilities, the relationship was felt to be protected as difference became an ordinary feature of everyday life:

*"We've never sat him down and said "Lydia's Downs"...(Q:so there's no special attention to this issue?)...No because I think that in itself can be alienating. I think for people coming in from outside I think it's different. I think when it's your experience, when you're living with it, when it's your other children, siblings, close family, I think it needs to be dealt with in the same way as everything else"*

*(Diana, lines 604-617)*

Further protection against possible alienation was gained by accompanying talk about difference with references to similarities. By reflecting on the similarities between the non-disabled child and their learning relative, the child sees the similarities as well as the differences, and realises that their learning disabled relative is not too different from them:

*"We understand it, that clearly there's differences and...so many similarities"*

*(Peter, lines 66-78)*

In this category the non-disabled child acknowledges the difference of their learning disabled relative. By noticing a range of difference in the world around them the impact of living with difference, caused by disability, is minimised. Therefore, viewing difference as ordinary serves a protective function for the child.

## 3.5 CHALLENGING SOCIAL VALUES

**Figure 6**: Challenging Social Values

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          │   CHALLENGING SOCIAL VALUES      │
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          ┌────────────────┴────────────────┐
┌──────────────────────┐      ┌──────────────────────┐
│ Developing Social    │      │ Non-disabled siblings as │
│ Values               │      │ Ambassadors          │
└──────────────────────┘      └──────────────────────┘
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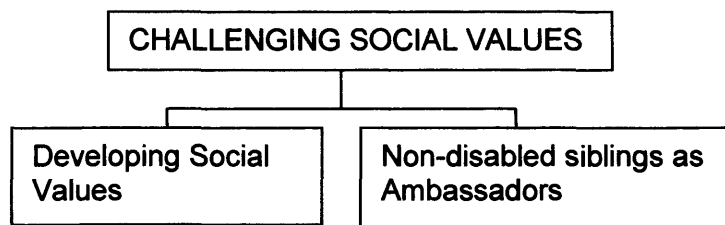
Respondents acknowledged that non-disabled children *"can't live in a cocoon"* (Peter, line 594). They will at some time encounter negative reactions from other people as a result of living in a family with a learning disabled person. This category describes how parents can prepare their non-disabled children to deal with these reactions by developing a foundation of social values that are more positive towards disability.

Respondents reported that it was strangers, that is people who did not know their relative, or who had not had any previous contact with people with learning disabilities, who were identified as the source of the most hurtful reactions. Respondents felt this was not as a result of malice but was *"just about ignorance"* (Diana, line 353). In contrast people who had a level of regular contact with the learning disabled person, such as neighbours, behaved in a more tolerant manner, again indicating the important role of experience:

> *"Not the ones that knew him, the ones that knew him and grew up with us none of them ever did. But if you got strangers in the area they'd say 'oh look at that Mongol' you know and go up and sort of torment him and kick him, and he'd come down home and I'd have to paste 'em"*
> *(Erica, lines 136-140)*

Respondents spoke of the personal impact of experiencing negative reactions:

> *"I've heard things said, as a child myself, I heard things said that were very hurtful, things that people had said, throw away comments, that had upset me, because this was like me and my family that you were talking about. And people were quite dismissive of some of the things"*
> *(Diana, lines 245-248)*

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*"It was 'oh he's handicapped' or 'you're a Mongol' that's the worst thing
I think that used to stick in my mind"*

*(Erica, lines 179-180)*

Non-disabled children live within wider social systems; for example they attend school and have friends. Therefore, they will be affected by the reactions towards disability and difference, of those people around them. The value they assign to the opinions expressed by others will depend on their relationship with the speaker. For example, siblings who are considerably older (e.g. teenagers) than the disabled child may already have a strong affinity to their peer group, and may therefore invest in their perception of the situation:

*"My awareness at that point was of the fact that this child was very
different...I suppose you haven't got the knowledge, you haven't got the
understanding, you've not had that experience. Your friends' are very
important, you're part of a wider peer group at that age and your friends
perceptions of what is happening and what's going to happen all have an
effect on you"*

*(Diana, lines 233- 239)*

Living primarily within the protected family environment gave younger children the opportunity to gain experience and begin to develop their own values, before being exposed to the perspective of others outside the family. The impact of external values, such as the learning disabled child having to attend a different school, made the learning disabled child's difference more concrete and real, both for parents and siblings:

*"Reality doesn't hit them...reality doesn't see them until their child's
perhaps say five or six and going to school, you know, and the
implications from there"*

*(Erica, lines 895-898)*

The intrusion of an influential social system, such as education, into the family system meant that parents' values are no longer the only views that their children are exposed to, indeed their views may even be challenged:

*"That element of control that you've got is taken away really because it,
it's somebody else is involved in the equation then"*

*(Diana 333-335)*

### 3.5.1 Development of Social Values

To enable the non-disabled child to cope with the likely exposure to multiple value systems, parents can help their children to begin to form their own values. These are values which can facilitate the relationship, and a build a more positive attitude towards disability. Examples cited included "*teach(ing) him not to be judgmental*" (Becky, line 98), and "*to be tolerant of any disability*" (Becky, line 254). One way in which parents achieve this is by modelling values that are "*socially acceptable within our family unit*" (Diana, line 277). This provides non-disabled children with a framework of values against which they can measure alternative views:

> "*All these really difficult questions are clearly the material about where they make sense of the world and hopefully generate their own values, so hopefully you're sort of laying the foundations*"
>
> *(Peter lines 579-581)*

Many of the values that parents espouse in relation to their learning disabled child, are generalisable to other disadvantaged groups:

> "*Inculcate your children with the values that, you know, you feel you hold true and, you know, I think this is quite key, a key value in terms of acceptance...that people are worth an equal amount regardless of their situation*"
>
> *(Peter, lines 562-567)*

A positive consequence of the non-disabled child adopting these values, and of gaining insight into the issues of difference, is that they may develop a more tolerant position in relation to other forms of difference in the wider social context. This is a similar process to that discussed in the "Normalising difference" category.

### 3.5.2 The Non-disabled Sibling as an Ambassador

Respondents recommended that parents communicate with their non-disabled children about the values held by society towards disability issues:

> "*(Don't) evade the issue...so that they are wise and when they're going out on the street*"
>
> *(Erica, line 513)*

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The term making the child "wise" had a double meaning. Firstly, it prepared the non-disabled child to deal with the personal impact of negative reactions, as discussed earlier. Secondly, being wise ensured that the non-disabled child was correctly informed and therefore would not perpetuate stereotypes and prejudice when they saw disability, or other forms of difference around them. Indeed respondents and their families characteristically took an active role in challenging this prejudice in other people:

> *"I've challenged it in his friends and said, you know, why are you using that language, that's...that's not appropriate, you shouldn't be saying that, that's quite hurtful"*
>
> *(Diana, lines 257-259)*

Families use their expert knowledge of living with a person who has a learning disability to inform and change the attitudes of an ill informed wider society, becoming ambassadors for the rights of people with learning disabilities to be accepted in society:

> *"These...young people are so much more a part of our lives and our society that you're more accepting and also I think as we push the boundaries, as we challenge the stereotypes and the images than things will continue to improve"*
>
> *(Diana 529-532)*

Through this active challenging parents are modelling the strategies they use to challenge prejudice. They are also teaching their non-disabled children about their values regarding difference and disability, in relation to societal attitudes. Many respondents found that the non-disabled child began to challenge negative reactions as they had witnessed their parents do. This highlights the fundamental influence of parents, and is indicative of the non-disabled child having developed value system which is more accepting of difference and disability:

> *"He's got quite...not so much hurt but I think it upsets him, I think he feels that that's unfair and you shouldn't be doing that"*
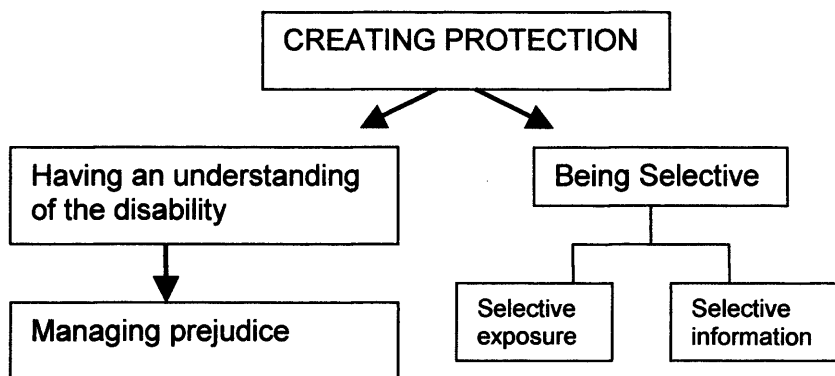>
> *(Diana, lines 269-270)*

In summary, this category describes how parents can help to build an awareness of social values in their non-disabled children by modelling appropriate behaviour and challenging existing prejudice. This is done to prepare, and therefore protect the child

from negative reactions they may experience outside the safety of the family. Children internalise many of these values and become ambassadors for people with learning disabilities by continuing to challenge prejudice.

## 3.6    CREATING PROTECTION

**Figure 7**: Creating Protection

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          │     CREATING PROTECTION     │
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┌──────────────────────────┐   ┌──────────────────┐
│ Having an understanding  │   │  Being Selective │
│ of the disability        │   └──────────────────┘
└──────────────────────────┘            │
              │                ┌─────────┴─────────┐
              ↓          ┌───────────┐      ┌───────────┐
┌──────────────────────┐ │ Selective │      │ Selective │
│ Managing prejudice   │ │ exposure  │      │information│
└──────────────────────┘ └───────────┘      └───────────┘
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When parents engage in the processes outlined in the mediating categories, they are able to foster feelings of protection in their non-disabled children. This feeling of protection allows children to accept the differences and difficulties they experience when living in a family with a person who has a learning disability. This category describes the specific elements that contribute towards creating this sense of protection.

### 3.6.1    Having an Understanding of the Learning Disability

Respondents stated that providing the non-disabled child with an explanation about the disability, was protective (Fred, line 850). Indeed, by "Engaging in a lifelong conversation", and therefore giving the non-disabled child information about their brother or sister's disability, the parent is protecting them against developing any fears or misconceptions (Peter, lines 394 & 555). When a child has an understanding of their sibling's disability they able to protect themselves, and others. For example, one respondent described how her daughter told her friends about her uncle's learning

disability before she brought them to the house. This reduced the likelihood of negative or embarrassed responses (Erica, lines 531, 656, 794), and not only protected her from being placed in an awkward situation, but also her disabled uncle, and her friends.

### 3.6.2 Managing Prejudice

In the "Challenging social values" category it was reported that non-disabled children are likely to experience negative reactions in relation to their learning disabled relative due to social stigma and prejudice:

> "I've heard things said, as a child myself, I heard things said that were very hurtful...throw away comments, that had upset me"
>
> *(Diana, lines 247-247)*

Parents try to protect the non-disabled child from these attitudes by preparing them to deal with these situations. This is done through the development of a foundation of social values within the family unit, which the child then uses to judge the value of any alternative perspectives they may encounter:

> "These really difficult questions are clearly the material about where they make sense of the world and hopefully generate their own values, so hopefully you're sort of laying the foundations"
>
> *(Peter, lines 600-603)*

Parents also model ways of challenging prejudice:

> "I've challenged it in his friends and said, you know, why are you using that language, that's not appropriate, you shouldn't be saying that, that's quite hurtful and ...he (son) would challenge people now himself"
>
> *(Diana. Lines 257-262)*

Protection in these forms make the child "*wise*" (Erica, line 502) and develops their ability to deal effectively with interactions in the wider world outside of their family.

Part of this development of social values concerns the family's attitude towards difference. In the "Normalising difference" category the value of seeing difference as

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ordinary was highlighted. It is proposed that this minimises the negative impact of living with difference, and so protects the non-disabled child from feeling isolated or alienated.

Having accurate information about disability and a value system that is positive towards disability, allows both non-disabled children, and parents to act as ambassadors for people with learning disabilities. Therefore, they are protecting the rights of their relative, and the wider group of disabled people. However, holding this value system can result in the child sometimes feeling "*hurt*" (Diana, line 267) by the injustice their relative is exposed to.

### 3.6.3   Being Selective

Parents were found to be selective in the information and experiences that they offered to the non-disabled child. This developed from an awareness that some information about a person's disability can be "*quite troubling*" (Peter, line 346). By being selective parents were trying to protect their child. For example, by managing the child's fear, or preventing them from being overwhelmed by complicated information, or the implications of the situation. These processes are described below.

**Selective Exposure**: Experiences which parents feel may potentially be difficult for the non-disabled child are minimised. This is done to prevent them from being exposed to situations that may have a negative effect on their relationship with the person with learning disabilities. Therefore, selective exposure is a process that serves to protect the relationship. For example, one respondent regularly invited his learning disabled brother to his home rather than expose his daughter to a house which he felt she might find difficult to cope with due to it being ill maintained:

> "*I wouldn't take...I never took Anna down to see them because it was pathetic*"
>
> (Finn, lines 342-343)

This suggests that while more difficult experiences are minimised, they can be replaced by other experiences that are more appropriate.

**Selective Information Giving:** In a process similar to that of selective exposure, parents also decide what is an appropriate level of information to share with their non-disabled children. They aim to answer the child's question in a way that will reinforce, rather than undermine the relationship. In cases where the information is sensitive parents gradually release it in *"little bits as we went along"* (Erica, line 577), or choose not to share it at all:

> *"I'd never say that to the girls at all, you know, it wouldn't be appropriate there's no point putting fear into their mind"*
>
> *(Peter, lines 219-220)*

### 3.6.4 Lack of Protection

Where parents failed to provide a sense of protection children sought to protect themselves:

> *"I was a great reader anyway so I used to like to shut myself off and read, so it probably didn't affect me as much"*
>
> *(Pat, lines 53-54)*

> *"When I was old enough to go, let's say, 9, 10 years of age, I used to go to me Aunty's ... I never stayed in the house one day. I realise now I must have been a bloody nuisance to keep on going, I loved her dearly, and she was the same to me, but I must have got on her nerves. I just, er, I went to be out of there. As soon as I got home from school I used to get changed and I'd go"*
>
> *(Finn, lines 602-612)*

However, the child's attempts at self-protection could have negative consequences, such as leaving them with feelings of guilt, or causing them to withdraw from family life:

> *"I probably didn't interact with her as much as I probably ought to have done"*
>
> *(Pat, line 55)*

> *"All I wanted to do was to get out of the home life"*
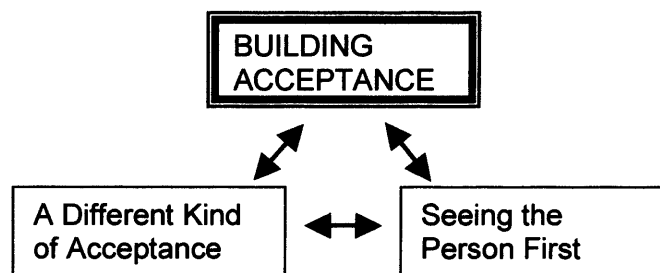>
> *(Finn, line 483-484)*

In summary, this category describes how whilst facilitating the activities involved in the mediating categories parents act to create an atmosphere of protection around the

non-disabled child. It is the creation of this feeling of protection and the security, or safety it provides that enables the child to move forward into the outcome category of acceptance. By having an open system of discussion and information giving the parent helps the non-disabled child build an understanding and value system about disability which can protect them from fear, misconception, and negative attitudes. Parents were found to be aware of their child's needs and developmental level in that they presented opportunities and information at an appropriate level, one which they felt would strengthen the sibling relationship rather than undermine it. In the absence of a protective element being introduced by parents children sought to create this for themselves, though this was achieved in less adaptive ways.

**Section three: Core Category**

**3.7    BUILDING ACCEPTANCE**

**Figure 8**: Building Acceptance

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                    │ BUILDING       │
                    │ ACCEPTANCE     │
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                        ↙        ↘
     ┌──────────────────┐      ┌──────────────┐
     │ A Different Kind │ ←→   │ Seeing the   │
     │ of Acceptance    │      │ Person First │
     └──────────────────┘      └──────────────┘
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This category represents the primary aim of the process of disclosure. The building of acceptance refers to the generation of a tolerance and understanding of the learning disabled person by the non-disabled child, rather than having gained a more, purely, cognitive type of knowledge about learning disabilities (Finn, line 388).

All of the respondents used the term "acceptance" throughout the interviews. It was presented as a resolution or outcome of the disclosure process, as something that the child developed through their relationship with the disabled person.

Analysis of the data showed that acceptance was a multi-faceted concept which is represented by the following two sub-categories: "A different kind of acceptance" and

"Seeing the person first". These are inter-linked because in order for a non-disabled sibling to see a sister rather than a learning disabled person, she has to know the person very well. This involves accepting the disability as an integral part of their disabled relatives' identity, as well as of the identity of the non-disabled child and the family.

### 3.7.1 A Different Kind of Acceptance

The data showed that the process of acceptance operated on a different level for those people who have experienced living with a learning disabled person within the family. Their experience had allowed the person to develop a deeper awareness of the meaning and impact, of having a learning disability:

> "I think people who haven't had close contact with people with learning difficulties learn to accept... and I think people who have had close contact, and when it's as close as immediate family it's just very different, there's an awareness, it's not something that you can learn it's just something that is"
>
> (Diana, lines 176-178)

Siblings felt that it was very important to acknowledge their brother or sisters learning disability, as this was an integral part of that person's identity:

> "It's like saying I see a black person but I don't see the black skin, well that's a negative then isn't it then, because you should see the black skin. I see a Downs Syndrome person but I don't see her as a person with learning disabilities, I see my sister"
>
> (Diana, lines 361-364)

To deny the disability would be to denigrate an important part of both the individual's, and the family's, identity:

> "Excluding such a significant part of my identity, and our families identity would I think be very potentially damaging"
>
> (Peter, lines 581-583)

This level of awareness involved the non-disabled sibling acknowledging how having a learning disability makes their brother or sister different:

*"It's not just acceptance of the fact I don't think, I think part of it is an awareness of the fact that she's different"*

*(Diana, lines 155-156)*

By acknowledging this siblings also become aware of how their learning disabled brother or sister's difference has an impact on them and their family, making them different too:

*"Well they are different aren't they...they're not as normal as what me and you are, they're not able to go out and get jobs that's something Adam's never been able, so they are different to you. But I mean I'm not saying that's that wrong or anything but they are different people to you, you know, I mean like Adam wouldn't be living with me at 53 would he?"*

*(Erica lines 843-848)*

Siblings spoke of the dilemmas this had presented them with at different times in their lives, such as when deciding whether or not to care for a learning disabled bother or sister. In another example which was cited by two respondents, both acknowledged that whilst siblings can accept and love their learning disabled brother or sister it is not a situation they would choose to be in. They would not choose for their lives or their children's lives to be so different. Their decision to try to avoid the possibility of having a disabled child stemmed from their knowledge of the sometimes harsh reality of living with a person with a learning disability:

*"I had amniocentesis, and was determined that if this baby that I was carrying was going to be Downs Syndrome then I was going to terminate this pregnancy. Because I love Lydia, she's part of the family, but I did not want a Downs Syndrome child for myself because I'd seen the things that happened with Mum and Dad and the fact that it's not easy. It's not the same as having another child, it's very different and it's difficult... and I don't want that, I didn't want that for my child or me"*

*(Diana, lines 394 – 401)*

Interestingly, this respondent's sister also had amniocentesis, but her sister-in-law chose not to have the test (Diana, line 488), further highlighting the different perspectives of those who have, and those who haven't grown up with a person with a learning disability in the family.

Respondents clearly felt that having an awareness of the person's differences does not make those differences more apparent rather it allows them to be minimised and therefore reduced the distance between siblings:

> *"Just the fact that there are differences but it doesn't make a difference"*
>
> *(Diana, lines 180-181)*

> *"They've noticed she can't do things and I think they've taken as being very natural, probably because she's part of the family"*
>
> *(Pat, lines 439-441)*

### 3.7.2  Seeing the Person First

Despite being aware of the learning disability and difficulties of living with that in the family, siblings described being able to see the person first, before or regardless of the disability. Through growing up alongside the person with a learning disability, non-disabled siblings had developed an intimate knowledge of that person which allowed them to see and respond to their disabled brother or sister as an individual. As shown above siblings acknowledge the difference, but it's regarded as one part of their siblings personal identity, not separate, but not foregrounded:

> *"Why is he different?...that doesn't really matter and he's still a human being and he's still got feelings"*
>
> *(Peter, lines 469-470)*

The person with the learning disability is regarded simply as another member of the family. It's the role that the learning disabled person occupies within the family that is important, rather than their limitations due to their disability. This is the information that is foregrounded by the family members:

> *"To them she's just Aunty Andrea and that's it, they know she's different, they know what disability she's got, but she's still their Aunty. Just to include her in the family and the position that she is, she's my sister, she's their Aunty"*
>
> *(Becky, lines 272-274)*

Whilst acknowledging the disability, non-disabled children appear not to consciously attend to it in the way others outside the family might. Two respondents spoke of their decision to ask their learning disabled sisters to be bridesmaids at their weddings:

*"Someone said what about your photos?...I genuinely think that people who say things like that don't realise that it's not an issue for you"*

*(Diana, line 349-354)*

*"I mean to me she's my sister and I didn't hesitate to have her as a bridesmaid at my wedding, and my younger brother didn't either...It didn't occur to us not to have her, you normally have your sister as your bridesmaid and that was it"*

*(Becky, lines 276, 296)*

On a day to day basis much of the child's sibling relationship is based on engaging in ordinary activities with their disabled brother or sister, it is this ordinary contact that builds the relationship between them:

*"I remember...being quite excited about this other little girl arriving and enjoying doing all the "I'll bring the nappies, can I make her bottle" type activities"*

*(Diana, lines 307-309)*

The process of building this level of acceptance is not exclusive to those people who grow up in a family with a person with learning disabilities. Adults entering the family who may have no prior experience of learning disabilities, such as spouses of non-disabled siblings, are able to gain their knowledge of the real person through involvement with the learning disabled person in a meaningful context:

*"It's through exposure, through family events and you know just spending time with her that Joy's come to know her as a sister-in-law, or as my twin sister"*

*(Peter, lines 206-208)*

In summary, this category shows that acceptance is developed after the non-disabled child has acknowledged the person's learning disability and become aware of how this makes them, and their family different. In doing this the power of the difference is minimised which allows the non-disabled child to get to know the person behind the learning disability. This was demonstrated by the child's ability to see the role the person with the learning disability takes, such as sister or Aunty, before their disability.

In conclusion, this results section has guided the reader through the various elements involved in the disclosure process. Beginning in the Foundation Categories which

examine the context from which the child comes, then moving into the Mediating Categories which address the mechanisms of disclosure, this includes some activities that both the parents and child engage in throughout this life-long process. Finally, the overall aim of the disclosure process is discussed in the Core Category of Building Acceptance.

# 4. DISCUSSION

This chapter will seek to discuss the results of the study, and critically examine the research process. Initially the findings will be considered in reference to the existing literature, however, as noted in the introduction this is a new area of investigation and therefore, the literature on this topic is somewhat sparse. The discussion then continues by considering the clinical implications of the findings, and presenting areas for further research.

Before moving into the main body of the chapter the reader is reminded of the aims of the study.

## 4.1 Aims of the Study

The aims of this study were to develop an account of how best to inform non-disabled children about their siblings' learning disability. The intention was also to inform parents, research, and clinical practice about the specific factors and mechanisms found to be useful when sharing this sensitive information. The aim was to present a model that would act as a frame of reference that could guide parents, and professionals, through the disclosure process.

Data was obtained from interviews with six adult participants, all of whom had a learning disabled brother or sister. The sibling's perspective explored in this study had not previously been investigated. The data was analysed using a Grounded Theory methodology in order to produce significant themes, and a model of the disclosure process.

## 4.2 Interpretation of Results

A discussion of the results of this study will take place in three sections. Firstly, the three stages of the model will be examined, this will be followed by a discussion of the individual categories, then the predominant themes within the model will be summarised.

### 4.2.1 The Three Stages of the Model

The model developed during analysis divides the categories into three stages, namely Foundation Categories, Mediating Categories and the Core Category. The model aims to organise the categories into meaningful sections which seek to give a structure to the process of disclosure, a process that has not been previously defined, in order to render the process more understandable for parents and professionals. However, as with all working models any attempt to describe a phenomenon can imply that the process is far simpler than may actually be the case. In practice the different phases of disclosure are not likely to be so distinct. They may not exist as separate entities, instead they may overlap, occur out of sequence and may be repeated. For example, involvement could be described as a mediating activity, but it's close association with experience results in it being placed within the foundation stage where it acts as a bridge into mediating categories. Similarly, the protection category occurs as a result of well managed mediating activities and therefore could be described as an outcome rather than a mediating activity. However, the finding suggest that a developing sense of protection facilitates engagement in the mediating activities, and is a necessary step before progressing onto the core category of Acceptance. It is also likely that the disclosure process may not be as linear as the model presents. There may be more movement backwards and forwards across categories, perhaps as a result of the individuals changing developmental level (e.g. peer pressure as a teenager), or due to significant transitions in their life (e.g. leaving home or marriage). In many ways disclosure is a journey that parents and children make together because often parents are simultaneously discovering the impact that disability has on their lives too.

The Foundation Categories represent the starting point of the disclosure process. They represent the context from which the child emerges and are fundamental to the disclosure process as all the other categories emerge through these cateogries. For example, all activities that the child will engage in are effected by the dynamics of their individual family. Foundation categories are initially rather static occurring with no effort from the parent or child. However, as the disclosure process continues they become increasingly interactive.

In contrast the Mediating Categories describe a range of more dynamic processes. These categories involve a wide range of activities, both verbal and non-verbal, through which parents and their children are able to co-construct an understanding of what it means to live with a person who has a disability. Initially, the parent provides much of the structure and content for their child's narrative, but as the child's understanding increases they take more personal responsibility for their own story, and therefore, require less scaffolding from their parents (Wahler & Castelbury 2002). It is this early co-authorship between parent and child that is critical in developing the child's understanding of disability. Through it the child develops a foundation of beliefs and values which they can then build upon. Vygotsky (1962) represents this process of storytelling as a shift from an inter-psychological process of co-construction to one that is intra-pychological. Therefore, learning which first appears on a social plane gradually becomes part of the individual's own store of abilities (Vygotsky 1978). The author feels that the information derived within the Mediating Categories Section of the model is particularly innovative. It begins to answer parents questions of exactly how to disclose to their children, an area not previously investigated.

Reaching the core category of Acceptance represents the internalisation of the messages given to the non-disabled sibling throughout the disclosure process. It is hypothesised that this is a very personal level of understanding that is meaningful to the non-disabled sibling. An intra-psycholgical state that allows the person to accept their situation and live more comfortably within it.

### 4.2.2 Discussion of Categories

The pertinent information provided by each category will be discussed, followed by a look at how that category relates to other categories and the research literature.

### Changing Experience into Involvement

This category is based in the Foundation Stage of the model. It is similar to the category of Family Dynamics in that initially, it does not require any action by family members in order to occur. However, as the category develops, evolving from this

passive level of experience into active involvement, it becomes increasingly dynamic and so bridges the divide from the foundation categories into the more interactive mediating categories.

Two pertinent themes arise within this category. Firstly, this category highlights the many different mediums through which a child can learn about their brother or sister's disability. Therefore, the emphasis in the literature on disclosure as a fundamentally verbal process seems to represent only a fraction of what actually occurs in the family disclosure processes. Secondly, the discovery of how much children learn simply by being a part of a family with a learning disabled child has significant implications for the process of disclosure. It renders the decision whether or not to tell children about a siblings disability redundant as the model suggests that the process begins through the child's own observation and experience rather than being based upon the parents' decision of whether or not to disclose.

The sub-category of experience describes the day to day exposure a child gains whilst living with a person who has a learning disability. Children in families with a learning disabled sibling clearly derive knowledge about their brother or sister's disability from this experience. Through this they begin to build their understanding of disability and difference, and develop their values towards the issue of disability. This substantiates Liveresley and Bromley's (1973) work which stated that gaining experience alone significantly enhances a child's understanding of disability.

As the category goes on to discuss observation it highlights the social nature of a child's learning in line with Vygotsky's work (1962; 1973) which advocated the use of social interaction to support a child's learning. Involvement, observation and modelling could be said to represent methods of scaffolding referred to by Vygotsky. These can be employed during disclosure to develop the child's learning about disability in a way that is more meaningful to them than a purely verbally based discussion. These less verbal based mediums of information exchange also have the advantage of being more readily incorporated into an ordinary family's daily life than a more formal verbal discussion. In addition they may minimise parental concerns about the child's ability to understand information provided as it is more practically presented.

The findings of this study show that parents can play a vital role in shaping their child's understanding but they cannot withhold information or protect their child from noticing differences that result from their brother or sisters' disability. This fits well with the research which states that children need the help of a competent person to interpret the information they observe or they may be vulnerable to misinterpreting the situation (Lobato, 1993). Indeed, communication between parents and children has bee shown to help a child to deal with aversive situations (Shulmans, 1988).

The category concludes in a discussion of involvement, which is presented as a co-construct of experience. Experience represents a passive phenomenon that occurs without effort, in contrast at the other end of the continuum lies involvement, which requires some action by a family member in order to occur, and is therefore viewed as a more dynamic construct. The sub-category of involvement requires the parent to present the child with opportunities to actively engage in a relationship with the disabled person. This is done in order to strengthen the relationship between them and to facilitate the child's understanding of disability.

**Family Dynamics**

In contrast to the other categories in this model the Family Dynamics category describes a relatively static phenomenon. It emphasises the unique character of each family, in terms of their unique mix of individual characteristics (e.g. temperament, I.Q., birth order, severity of disability), and the ways in which family members interact with each other (e.g. levels of responsiveness, warmth, cohesion). The model views consideration of these factors as important as it encourages the reader to think carefully about the context from which the child originates and about their personal attributes.

The model cites the parents as experts within their family system. They have the best access to this unique knowledge specific to their own family system. This information is viewed as a baseline, rather than an explanation in its own right. Indeed, Furman (1993) stated that the examination of static factors alone was not enough to gain insight into the processes that are at work within a family with a learning disabled child.

Family dynamics is a foundation category as it represents the context from which the child emerges, and is therefore fundamental to the model as it will influence how all other categories will function.

## Engaging in a Lifelong Conversation

One of the main findings of this study was that disclosure is a process, a long-term dynamic process that continues between parents and the non-disabled siblings into adulthood. Analysis revealed that parents were unlikely to sit down and formally discuss their child's disability with the non-disabled sibling. Instead, the disclosure process took a far more naturalistic approach occurring through multiple mediums, such as observation, modelling, and the use of questions initiated by the child. As such the process is probably not recognised by both parents and professionals as "a disclosure" in the way it was previously described in the literature (e.g. Cunningham et al., 1984). Therefore, it could be assumed that by the time parents are asking professionals for advice about how and whether to disclose, the process has already begun.

Disclosure is a process that changes over time. The child's level of curiosity is greater early in the disclosure process and as such the amount of active questioning they engage in is higher at this time. This is associated with their rapidly changing developmental capacity and their ability to increasingly understand the issues. The model hypothesises that in the early stages of the disclosure process the child concentrates on building a framework which will allow them to understand more about their siblings disability and deal with the differences and difficulties this presents them with. As the child's internal framework becomes established their need to ask questions diminishes. However, when the child is faced with new challenges, or reaches a significant transition (e.g. leaving home, becoming the main carer) their existing framework may be challenged and as such may need to be revised to accommodate these life changes. This may work in a similar way to Olshanky's (1962) concept of Chronic Sorrow. He said that at times of transition or significant life events the initial sense of grief at having discovered your child is disabled may be re-experienced and the parent may need further input at these times to help them deal with their feelings. Similarly, disclosure may need re-addressing at these significant

points in the non-disabled siblings' life. This re-evaluation is possible within this extended disclosure process identified in this study.

This framework that the child gradually develops by engaging in the disclosure process could be said to function in a similar way to a coherent story. The child needs to develop a coherent story to help them make sense of a difficult situation and to help them understand their part in it. However, unlike many of the situations with which this technique is commonly associated, such as past childhood sexual abuse, the situation of having a disabled person in your family in a long-term situation. This requires opportunities for some adjustment of the story in order to deal with new challenges as time progresses.

There are many advantages to disclosure being a long term process: firstly, parents will be reassured that here is no critical period within which they should divulge crucial information to their non-disabled child, instead they are likely to encounter multiple opportunities to address these issues. Secondly, a child needs time to process information and will often return to parents for further explanation. Developmental changes mean that the child's cognitive ability will change and with it the type of information they require, therefore a one-off information session will never be appropriate to meet the non-disabled child's needs. Finally, a long-term process allows for the many transitions that the child goes through to be incorporated into their understanding. It is important to note that throughout this process respondents felt that it was crucial to acknowledge the difficulties involved in living with, and caring for a person with a disability. Findings suggest that it is only by acknowledging this dimension of the child's experience that they would be able to fully accept the disabled person. Parents need to be aware of this and give their non-disabled children the opportunity to discuss the negative aspects of living with a person who has a disability.

An important finding within this category is that the child is seen as an active participant in the disclosure process. This concept began to emerge in the "Experience and Involvement" category with the discovery of the role of experience and observation in knowledge acquisition. However, in this category it is expanded upon. The child is naturally curious and therefore driven to actively question the parent. It is

important to note that children are able to regulate the flow of information, for example by asking more questions or walking away when they've heard enough. Reassuringly for parents this negates their concerns about overwhelming, or indeed under-whelming the child with information.

Whilst parents were acutely aware of their child's input into the disclosure process, they were less observant of the crucial role they played. Firstly, analysis found that parents worked hard to create an environment that allowed the child to ask questions. Secondly, parents made excellent use of the opportunities the child presented to them, for example to expand the discussion beyond the question.

## Normalising Difference

This category explores the meaning and value that the concept of difference has in the non-disabled child's life. Through engaging in the activities entailed in this and other categories the child begins to understand their relative's difference. The non-disabled siblings' acknowledgement of their disabled relative's difference, as well as how this makes their family different and therefore, themselves different too, is seen by the model as an essential part of working towards an acceptance of their situation.

This study found that the process of exploring and acknowledging difference actually allowed differences to be minimised and encouraged the non-disabled sibling to see the person behind the label more clearly. Wendall (1996, cited in Fawcett, 2000) advocated positive reframing of disability as "embodied difference", a concept which fits well with the findings of this category. However, for the concept of difference to be meaningful to the child they must have frequent exposure to disability. As is emphasised in several other categories this occurs primarily within naturalistic settings.

The aim of this category is to help the non-disabled child minimise the negative impact of living with difference. Therefore, the process of Normalising Difference serves a protective function for the child. By seeing difference as ordinary, that is something that frequently occurs all around them the child may be protected from feeling isolated by their difference, or from overemphasising the difference of their

disabled relative. Another advantage of normalising difference is that the child may develop more tolerant attitudes and beliefs towards a range of disadvantaged groups. The apparent contradiction of seeing difference as ordinary is embodied in the non-disabled siblings' life experience. To the non-disabled child the difference caused by their brother or sisters disability is ordinary because it is their only known experience of that person. Finally, so as not to fragment the child's world, talk of difference should be balanced by talk of similarities.

**Challenging Social Values**

All the respondents interviewed in this study referred to the issue of social stigma. It became apparent that it is important to recognise the impact of wider social values on the non-disabled child and their family. Particularly as all respondents felt that they had at some time experienced negative reactions towards learning disabilities in public, an inevitability according to Todd and Shearn (1997). This is associated to the earlier discussion of the importance of acknowledging the difference and difficulties incumbent with living with a person with who has a learning disability, and reiterates the need to acknowledge both the positive and the negative aspects of disability.

The analysis in this study substantiated Charmaz's (1987) findings that it was possible to resist some of the social stigma through the support of one's family. The model presented outlines how support is given in the early stages of the disclosure process. It views the family environment as a protective bubble within which parents have the opportunity lay down a foundation of attitudes and beliefs about disability, that it is hoped will act as a guide for the child. However, like Goffman's (1968) concept of the protective capsule, the protective bubble is acknowledged to exist only in the short term and will be challenged when the child horizons expand and they move further into the wider public arena. As the child becomes older other's attitudes, such as peers, extended family, schoolteachers and the media become increasingly important and may challenge the child's established view. However, having developed a strong foundation of beliefs it is hoped that the child is more able to accurately interpret the messages they receive from other sources.

The nature of the framework of beliefs and attitudes developed within the protective bubble of the family has parallels with concepts outlined in the literature review. For example, Todd and Shearn (1997) describe the significant role parents play in facilitating the development of their child's self-identity, one which in this situation could incorporate adaptive messages about disability which will guard the child's sense of self against the pressure of social stigma. This is a similar process to the child developing a coherent story about their life experiences. Children were found to be more resilient if they had developed a coherent story of their experiences and were therefore able to understand what had happened to them, and reflect on the meaning of that situation (Gilligan, 2002).

The other face of this category is that by having a tolerant and well informed value base the non-disabled child can move beyond protecting their own feelings to being an advocate for their sibling with a disability, able to challenge negative and ill-informed attitudes. The positive benefits were seen to extend further, the non-disabled child can become increasingly sensitive and tolerant towards a wide range of oppression and disadvantage. Indeed, many respondents felt that their children had gained a healthy perspective on what is important, and of value in life.

This discussion highlights the close relationship between the categories of Challenging Social Values and the Creating Protection. The way in which parents prepare the child to accept their disabled brother or sister, also serves a protective function that may minimise the impact of any negative or difficult reactions they may encounter.

**Creating Protection**

The model presented hypothesises that by engaging in the processes outlined in the three other mediating categories, namely A Lifelong Conversation, Normalising Difference and Challenging Societal Values, a feeling of protection is created for the non-disabled child.

The protection category is placed away from the other mediating categories, as it emerges from engaging in the interactive processes involved within these other

categories to become a more intrinsic concept embedded within the child. It is hypothesised that the safety resulting from feeling protected is vital in making the child robust enough to be able to move on towards a position of acceptance. However, it must be noted that one account, from Pat (Interview two), showed that it possible to gain acceptance without feeling protected. It seemed that this was a longer and more complex process, and whether the nature of the acceptance gained in this situation is different from that gained through a successful disclosure remains unanswered.

The protection described in this category is an active type of protection; this supports the work of Cunningham and Fitzpatrick (2000) and Furman (1993) who advocated a pro-active style of disclosing. However, the findings of this study go one step further to encourage the parent to provide the opportunity for the child to acknowledge all aspects, both the positive and negative, involved in living with disability. This is seen as necessary in order for the child to develop a meaningful and holistic understanding of disability, one which may guard against fear and misunderstanding. This active protection contrasts with the type of protection where the parent endeavours to prevent the non-disabled child from being affected by the issues by employing an avoidant style of information giving. For example, Goffman (1968) described a "Protective Capsule" that parents created in order to attempt to filter out negative messages associated with disability, this was found not to be a robust method of protection in the long term. In contrast the protective bubble described in this category uses the family environment to create a type of protection that can withstand negativity as it has been previously acknowledged within this safe environment. These findings indicate that accurate information is itself protective to the child and not damaging, or frightening, as many parents had feared.

Parents were found to be able to strike a balance between giving the child enough information whilst at times being selective about what they chose to tell them. Exactly what stops a parent being over selective, and thus inhibiting the process of disclosure is unclear. The researcher hypotheses that the answer comes from viewing the child as an active participant in the disclosure process. Findings indicate that children are able to find ways to inform parents of their needs and a responsive parent will be able to interpret these messages and be guided by them. Finally, the child is not the only

target to be protected, the child themselves were found able to be protective of the disabled person, their parents and of their peers.

**Building Acceptance**

Building Acceptance is the Core category of this model. All respondents in this study talked about acceptance. It is the main aim of a successful disclosure, and was presented as a resolution to the disclosure process. All the other categories in the model relate to acceptance as they all act to move the non-disabled child towards this position of acceptance.

The finding that acceptance is the desirable outcome of the disclosure process is perhaps unsurprising. However, it was the nature of this acceptance that was interesting. The model developed in this study viewed acceptance not as a passive resignation to living with the person's difficulties, instead rather like protection it is seen as an active process. A process that involved the non-disabled sibling gaining a true understanding of the learning disabled person. This includes knowing their strengths and their difficulties, gaining some positive experiences from living with them but also being able to acknowledge the loss and negative impact that living with a person who has a disability presents them with. Building Acceptance involved an intra-psychological change within the non-disabled sibling in order to accommodate what the concept and reality of disability means to them and their family. It involved the non-disabled person accepting disability as a part of their own life, rather then something that was external to them existing only in their brother or sister.

The siblings route to acceptance can be linked to the processes of Fragmentation (Todd & Shearn, 1997) and Transformation (Reinders, 2000) described in relation to parents in the literature. A significant difference between parents and siblings is that children have less strongly developed life expectations and self identity. This has the advantage of giving non-disabled siblings the opportunity to accommodate disability much earlier into their developing expectations and self identify. Which may in turn result in fragmentation and transformation being a less dramatic process for them than it is for parents, in that they may not experience the initial acute phase of distress experienced by parents. However, at times of developmental change or transition non-

disabled siblings may experience a gradual realisation of the implications placed upon them or their disabled brother or sister, as a result of living with a disability. At these times they may experience a stronger sense of fragmentation, which they need transform. This could be a similar process to that of Chronic Sorrow as described by Goldberg et al (1995), where the child may need to grieve for what could have been. Interestingly, being able to accept the disability is one of the three elements Scorgie (1997) identified as being involved in the transformation process. She described this acceptance as allowing the person to be free to express their emotions rather than being captivated by them. This fits with the findings in this study that non-disabled siblings need to acknowledge both the positive and negative aspects of living with disability in order to accept their position.

Gaining acceptance marks the completion of the non-disabled child's coherent story. This does not necessarily involve achieving a cognitive type of knowledge about disability, but is closely associated with the individual exploring the meaning and value that disability has in their life. The completion of coherent stories in families where disclosure is not adequately facilitated may inevitably take longer, at times it may not be sufficiently developed until the non-disabled sibling is an adult and able to find alternative ways in which to inform themselves about disability. In this situation the coherent story may include a narrative about the fallibility of the parents.

This presents the question of what benefits are gained from achieving this level of acceptance. Is it beneficial for the mental health of the non-disabled sibling, does it lead to improved self-esteem, increased familial cohesion, or a higher level of involvement between siblings? These are all questions to be addressed in future research.

### 4.2.3 Main Themes Identified During Analysis

**Disclosure is a Long-Term Process**

The existing disclosure literature refers primarily to parents and is weighted towards the beginning or early part of disclosure where they first hear that their child has a disability (e.g. Cunningham et al., 1984). This inevitably comes as a shock, which has

the potential to shatter their known world. The researcher hypothesises that this may not be the case with non-disabled siblings as living with disability is often their only known experience, also they may not have the understanding or cognitive capacity to realise the implications this will have on themselves or their family. Therefore, disclosure to children may not be as initially traumatic as adults may have anticipated. Instead, disclosure needs to be seen as a longer-term process in order for it to incorporate changes within the child's developmental capacity, allowing them to gradually engage with increasingly complex information about disability.

The findings from this study highlighted that disclosure between parents and children is not confined to childhood. Many respondents spoke about renewed conversations with their parents which occurred in adulthood as the family or individual faced new challenges, such as how to manage the on-going care needs of the disabled person. The long-term nature of the disclosure process was outlined in the category named Life Long Conversation. This category described disclosure not as a situation where the parent shares a singular fact with the non-disabled child, rather it is a process that aims to create a context of meaning for the non-disabled child. This will involve exploring the many aspects the child's life affected by the fact that they live with a person who has a disability.

**The Use of Multiple Mediums to Share Information**

The analysis found that there are many ways in which a child learns about their brother or sister's disability. Of course children ask questions and the ensuing conversations are undoubtedly an essential part of the information exchange process between parents and their non-disabled children. However, the findings of this study show that other modes of exchange are also employed and are equally important in the disclosure process. These include modelling, observation, and hands on involvement. It could be argued that when disclosing to children there may be times when these non-verbal mediums are more appropriate vehicles for information exchange than verbal discussions as they provide a better match for the child's developmental level, rendering the information exchanged more understandable to the child. What is clear from this study is that disclosure in this situation is not the purely verbal process identified in the literature.

The findings of this study highlight the qualitative difference between a disclosure that takes place between professionals and parents, as it has been studied in the literature, and the conversations that occur within families. Professionals see families for short and infrequent amounts of time; therefore the process of sharing information is distinct as it is clearly situated within these short sessions. In parent-child disclosure information giving is more diffused by the sheer amount of interaction between family members and the intimate knowledge they have about each other. There is also more scope for other mediums to be involved, such as the child observing how their parent interacts with the disabled person. It is understandable then that most disclosure related exchanges within the family take place in naturalistic settings, like when watching television or when out shopping and do not appear to exist as clearly defined, separate periods of time.

The long-term nature of the disclosure process combined with the use of non-verbal mediums to share information, and the naturalistic settings within which these exchanges occur may be disguising the fact from parents that they are actually engaging in the process of disclosure. Respondents in this study appeared to have expected disclosure to have taken the form of a more formal and contained discussion. Which may explain why many parents feel concerned that they haven't yet "told" their non-disabled children about their brother or sister difficulties, when in fact the disclosure process (as outlined in this model) has already begun using other, more appropriate and child friendly mediums of communication.

These findings call into question some of the samples used in existing studies, such as Hames (1994) "not told" group. The author would postulate that these children are likely to have begun to develop an understanding of their siblings disability or difference. Therefore, the divide between groups in such studies is more likely to be a reflection of the parents perception of their role and their understanding of the act of disclosure.

Finally, the use of multiple mediums in the disclosure process results in minimising the parents dilemma about whether or not to tell children about their brother or sisters disability. The findings from this study show that children observe similarities and differences for themselves perhaps before the parent chooses to confront the issue,

and as such the parental choice not to disclose is rendered defunct. This may be a similar process to the situation some parents experience when they report knowing something is wrong with their child before the doctor speaks to them (Murdoch, 1983). Interestingly when parents report being told at this stage they say it feels too late, they would have preferred an earlier discussion (Quine & Pahl, 1987). The same could then be true for non-disabled siblings, and if so this highlights the need for there to be an openness about the disability from as early as possible.

## The Active Role of the Child

In this model the child is not viewed as a passive recipient, but an active agent who interacts with their environment to facilitate the information exchange. That is the children play an active role in their own acquisition of knowledge. Children have been shown to be able to gain information without being formally told, they can also regulate the flow of information they receive and even strive to protect other family members from difficult feelings or situations. However, it is important to note that the child operates most effectively in this way within a facilitative environment, one that encourages their curiosity and responds appropriately to their advances. An advantage of the child being an active participant in the disclosure process is that they are able to access information they want to know about (e.g. by asking questions) and are not reliant on the parents perception of what they think a child would want to know. This is an important feature as adults are often unaware of some of the connections made in a child's immature and egocentric mind (Lobato, 1993).

## Social Influences

The literature has described disclosure in terms of an individualistic process, where the parent struggles to come to terms with difficult information, and the impact it will have on their life. It has not acknowledged that some of the familys' struggle may be associated with the prejudice, ignorance or social stigma surrounding the concept of learning disability within our society. The model presented in this study acknowledges the impact of these cultural views on the family, and stresses the need for children to be equipped to deal with any potentially negative reactions they may

experience towards their brother or sisters condition. This is in line with the position held by the social model of disability (Fawcett, 2000).

In the protection category it was discussed how younger siblings are encased within the protective bubble of the family for enough time to potentially allow them to build a strong framework of values about their siblings disability. The child can then draw upon these values to challenge, or measure, any negative reactions they may encounter. However, the model does not explain so neatly how older non-disabled siblings develop this sense of protection, as due to their age they may not have had the opportunity to exist solely within this protective family bubble. Instead, the importance of a realistic and honest outlook is cited as crucial. The model advocates that parents must discuss both the positive and the negative aspects of living with a person who has a disability. This involves acknowledging the impact on both the individual and the family, and the stigma that exists in our society. Overall, it does not seem possible to protect the child from experiencing some negative feelings whether they are self generated, about loss or embarrassment, or occur as a result of prejudice. Instead the model stresses that the key to dealing with these feelings is acknowledging them as this allows the sibling to incorporate all aspects of the disabled person into their acceptance.

**Non-facilitation of the Disclosure Process**

The absence of an active parental figure during disclosure doesn't initially change the processes that the non-disabled child will attempt to go through. For example, they may still try to ask questions but be rebuffed and in time learn that this is not a worthwhile activity. However, their curiosity will remain and they may attempt to answer their questions in other ways, for example by asking teachers or members of their extended family, or by reading or observing what occurs around them. Indeed the model shows how a child can access some information through non-verbal mediums, as discussed earlier. However, the way they interpret this information is questionable and may not reflect the reality of the situation. Two respondents in this study felt that their parents had been unable to answer their questions. In adulthood one remained ambivalent about his brother disability and his role as carer, he also lacked a cohesive understanding of the situation. The other respondent had studied

and searched for answers as an adult in order to try to understand her sisters' difficulties, as well as to try to rid herself of the guilt she had felt since being a young child that she had somehow caused her sisters' disability. This highlights the danger that without parental facilitation of the disclosure process the child cannot easily access good quality, accurate information, and so is increasingly vulnerable to fear and misconception.

## 4.3 Clinical Implications

When thinking of disclosing to their non-disabled children parents ask professionals two main questions, namely should we disclose and how do we do it? Clinically there is anecdotal agreement that adults should talk to children about sensitive topics that may affect them. However, until now, the question of "how" to engage in this process had not been answered. The model of disclosure presented in this study will act as a guide for parents and professionals to refer to. It aims to provide a general map of the territory of disclosure, which can be refined to suit individual differences within, and between each family. By having this model new parents, who may be overwhelmed by their own feelings when coming to terms with devastating news of their child's diagnosis, have a structure to refer to. For example, the framework allows parents to reflect upon the context that their family provides, then through the mediating categories, breaks down the task of disclosure into manageable activities. It is hoped that by having this frame of reference both the parent and the professional will feel more in control of the disclosure process and thus be able to manage it better, so supporting the non-disabled child. The model aims to demystify the "how" of the disclosure process.

As the model presented is concerned with parent-child disclosure, the primary role of the clinician is to support parents in understanding and managing this process. Initially, the clinician may have to explain aspects of the model in order to dispel fears about upsetting the non-disabled child or them not being able to understand the information. Parents may also require help to decide what is developmentally appropriate information. For example, Glasberg (2000) found that whilst parents were able to match information appropriately to their child's age, they often overestimated the child's understanding of the implications of this information. By emphasising

disclosure as a long-term process clinicians can encourage parents to provide developmentally appropriate information upon which they can build over time. Therefore, more accurately reflecting changes in the child's developmental ability and understanding. Further reassurance for parents comes from seeing the child as an active participant in the disclosure process. One that, to some degree, is able to influence the process to suit their individual needs. For example, by regulating the flow of information they receive. This will help to allay parents concerns about overwhelming their child when presenting information (Potter & Roberts, 1984).

The model also alerts parents to consider some factors that may not readily occur to them during the disclosure. Issues such as the importance of creating an environment that will encourage the child to ask questions, and the need to focus on disability as a challenge that is not only internal to the family but also acknowledges external influences, such as wider societies social values. It is also as important for parents to allow space for the non-disabled sibling to acknowledge the difficulties and the loss associated with living with someone who has a disability, as it is to promote positive coping strengths.

Dissatisfaction with disclosure between parents and professionals is highlighted in the literature on this topic, and as such professionals are under pressure to improve the process. Some of these anxieties could inappropriately be transferred to the parent-child disclosure, and whilst there will be some similarities between these two types of disclosure there are also many important differences (e.g. see the multiple mediums section in the discussion). The most fundamental difference is the longevity of parent-child disclosure process. This has the potential to be reassuring to parents and act to reduce the pressure to "get it right" as they will have multiple opportunities to address the necessary issues.

The findings of this study may also provide an insight into disclosure to children in other settings, particularly those where the role of social stigma is active, such as in parental mental health. Here the mediating categories of Challenging Societal Values and Normalising Difference may be particularly beneficial.

For the profession of Clinical Psychology the findings of the study raise many interesting issues. It challenges our assumptions about the disclosure process. When disclosing to children this is not the previously described discreet, observable conversation, but a long-term somewhat more pervasive process that becomes entwined into the families day to day activities. This has interesting implications for a psychologist's therapeutic work with children, both within and outside the field of disclosure. It highlights that the therapeutic setting does not have access to the varied and multiple opportunities for information exchange that naturally occur within the family setting. Therefore, optimising the parents' skills to address their child's difficulties over time and create an environment that encourages discussion and questions from the child may be most beneficial. The model highlights that the child is an active participant within their environment. Therefore, when working primarily through the parents it is important for the psychologist to remember that the child may have made their own sense of events, and may know more than the parent realises, for example through he processes outlined in the "Knowing and not knowing" and "Observation and modelling" categories.

Finally, whilst developing our understanding of psychology we need to consider the usefulness of our investigation. Sometimes there is a need to go beyond gaining an understanding of an event (e.g. Yes, we need to disclose), to address the practical application of how a process will actually occur, that is there is a need to keep psychological investigation, especially within the clinical field, grounded and useful. The development of the mediating categories is an exciting example of this. They describe activities that parents may engage in with their child during the disclosure process, they also highlight the naturalistic settings within which disclosure occurs.

## 4.4 Evaluation and Critique of the Study

The use of the non-disabled siblings' interviews generated a rich data set which led to the development of some innovative categories. The findings provided insight into the needs of non-disabled siblings during the disclosure process and answered some of the "how" questions relating to the disclosure process not previously addressed. However, there are several points to be addressed before being able to fully evaluate the quality of the findings.

**Generalisability of the Findings:** Unlike new parents of a disabled child, the adult siblings interviewed in this study were not entering the disclosure arena unprepared. Their life experiences had provided them with a wealth of information to offer, they had lived with a person who has a disability and had not only been the recipients of a disclosure they had also disclosed this information to their own children. The author feels that the non-disabled sibling perspective used in this study gave access to an expert view of disclosure, a view which embodied the learning that had taken place over a lifetime. Whilst this has provided valuable information about disclosure, it is questionable how generalisable this perspective is to parents who themselves may be in the process of coming to terms with the information about their child's disability and the impact it will have on their lives.

Indeed, the model developed in this study has high expectations of parents. It does not take into account the parents' own distress. In fact it may be the case that dealing with their own distress may effect the parents' ability to engage in the necessary mediating activities. However, factors within the model begin to indirectly address this problem. For example, the long-term nature of the disclosure process allows time for parents to address their own issues. Crucially, disclosure involves discussion of both the positive and the negative aspects of living with disability. Therefore, the pressure for the parent to always be positive, and have resolved their own possible ambivalence towards their situation is minimised, it may even be appropriate at times for the parents' own distress to be visible to the non-disabled child.

The application of these findings to all non-disabled siblings is questioned. This study asked participants how they had informed their own children about disability, and therefore accessed the perspective of children who had known the disabled person all their lives, which more accurately mirrors the role of younger siblings within the family than the experiences of older siblings. Whilst some participants were able to reflect on their own experiences as older siblings the disclosure process for older siblings requires further investigation.

**Sample:** The sample employed in this study fulfilled the requirements for a Doctorate in Clinical Psychology project (Turpin et al., 1997). However, the author acknowledges that a larger sample would have been advantageous. The current

sample included a good cross section of variables; older and younger non-disabled siblings, a range of different care options for their disabled brother or sister, and variation in the quality of information and relationships the respondents had with their parents. The author acknowledges the difficulties with volunteer bias in this study. This is reflected in the sample which consists of non-disabled siblings who were all highly involved with their disabled brother or sister. In future research it would be interesting to include siblings who have little or no contact with their leaning disabled brother or sister, or those who have a much more limited input into the disabled siblings care giving. This would enable the researcher to investigate alternative routes to acceptance, or begin to address the question of whether this lack of contact occurred as a result of a poor disclosure. It would also allow the researcher to begin to look at the impact on the non-disabled person's well being and level of adjustment to the situation.

**Analysis:** The pragmatic limitations resulting from difficulties with recruitment of participants, (see Sensitivity to the Research Question p.38) meant that that Theoretical Sampling was not employed within this study. This has implications for the model developed, as this technique helps to fill out categories and discover variation between them (Charmaz, 1995). Expanding the sample (see Ideas for Future Research p.114) would also lead to an enriched data set where the categories could achieve saturation and negative cases could be explored more thoroughly. The lack of Saturation and Theoretical Sampling meant that the model may not be as conceptually dense and complete as it could have been had these strategies been engaged. Also it is worth noting that it was the researchers first time using Grounded Theory and as such the role of her interpretations in the model development are somewhat difficult to gauge. The availability of the transcripts in the addendum permits the reader to examine whether the claims made by the researcher are reasonable. Due to time constraints Respondent Validation was not undertaken, which is unfortunate as this may have helped to further clarify this issue.

Overall, the qualitative approach used in this study accessed commentaries from respondents that were rich in personal meaning and conveyed the vast experience of non-disabled siblings, where more quantitative methods may have provided largely inconclusive results. Using the grounded theory approach gave voice to the sibling

perspective not previously heard and added to our understanding of the disclosure process. The researcher believes that the quality of the findings in this study support the use of qualitative methodologies when investigating complex processes.

## 4.5 Ideas for Future Research

This was an exploratory study of an area not previously considered in great detail. The completion of the study has highlighted several pertinent issues requiring further research. These include revisions and elaboration's of the current study, as well as ideas for new areas of investigation.

### 4.5.1 Expanding the Sample

Developing the sample to be interviewed could expand upon the present findings of the study. Initially, interviewing larger numbers of participants would allow the researcher to achieve saturation, and may result in the possible expansion of categories, both of which would provide a richer data set for analysis and any subsequent theory development.

Future studies would also benefit from interviewing siblings who were much older (e.g. teenagers) at the time of the learning disabled child's birth. This would provide further information about the process of disclosure with older siblings, particularly as this was identified as a potential gap (e.g. see the "Creating Protection" category) in the model devised in this study.

### 4.5.2 Interviewing Non-Disabled Siblings Whilst Still Children

This study has explored the disclosure process from the perspective of the non-disabled sibling for the first time. The use of adult siblings allowed the researcher access to multiple perspectives, discussed earlier, in order to gain an overview of the disclosure process. However, the difficulties with retrospective studies are well known. For example, Senapati and Hayes (1988) state that they are subject to a range of bias including selective recall, and an ability to reflect with more maturity and objectivity than was available a the time. In order to further expand our understanding beyond the realms of the current study the researcher feels that it would be beneficial

to interview non-disabled siblings whilst they are still children, living at home with their disabled sibling and their parents. This would allow access to their present time voice, and insight into their current day-to-day lived experience.

### 4.5.3 Investigating the Age of Onset of the Disclosure Process

The model developed in this study identifies disclosure as a life long process. However, it would be useful to explore whether there is a critical time period within which disclosure should begin in order to be most effective. For example, is disclosure more or less successful with older children? Previous research implies that disclosure may be easier with older children as they have the cognitive capacity to understand the information they are being told. However, the findings from this study cite that younger children gain much of their information through non-verbal mediums, and this is a fundamental mechanism of the disclosure process which helps facilitate the child towards gaining an acceptance of the situation. Findings revealed that the disclosure process is about creating a personal context of meaning rather than having a cognitive understanding of factual information. Both of these factors negate the need to postpone disclosure until the child is thought to be old enough to understand the information presented. In contrast to the assumptions of previous research into parent-child disclosure this studies findings imply that it may be harder for much older siblings (e.g. teenagers) to experience many of the mediating activities necessary to promote the building of Acceptance. For example, they will have a more developed self identify and value base and will not be able to exist within the protective bubble of the family available to younger siblings. Similarly, their level of involvement with their disabled brother or sister may be less intense as they are likely to be out of the house more, they is also the influence of their peer group to consider.

### 4.5.4 Investigating Alternative Routes to Acceptance

The findings of this study raise a question about other possible routes to acceptance. Two respondents in this study reported difficult or non-existent disclosure processes between themselves and their parents, and yet were highly involved with their disabled sibling. This highlights that it may be possible for the non-disabled sibling to achieve acceptance even if parents have not managed the disclosure process well,

perhaps because they themselves are in denial about their child's disability, or lacked a clear understanding of the disability. Certainly respondents viewed a disclosure facilitated by responsive parents early on in the non-disabled sibling life to be the most straightforward, and least damaging route towards an adaptive relationship with their disabled sibling. However, parental disclosure is unlikely to be the only way of achieving acceptance. Further research could enlighten us further on this topic.

### 4.5.5 Assessing the Effects of Disclosure

Once the process of disclosure is clarified researchers can begin to investigate the impact of having a positive disclosure. For example, its effect on relationships within the family, on the non-disabled child's well being, on parental well being, on levels of involvement, and on the disabled and non-disabled child's self-esteem could be investigated. More generally beginning to answer the question of whether information giving has the potential to act as a protective factor for non-disabled siblings and other family members, in families where one child has a learning disability.

### 4.5.6 Disclosure in Other Areas

Another area for further research is looking at the process of parent-child disclosure across a range of other settings. In the introduction it was noted that clinically there is a growing belief that children should be more informed about sensitive issues in order for them to best manage these situations, topics such as adoption (Watkins & Fisher, 1993) and bereavement (McGovern & Barrry, 2000) were mentioned. Much of this discussion remains based on anecdotal evidence, exactly how to discuss these issues with children and what benefits may be gained are questions yet to be answered, and could therefore be the focus of future research.

### 4.5.7 Investigating the Cost of Caring

Finally, an issue that arose from many of the interviews was the personal cost to non-disabled siblings of caring for their learning disabled brother or sister. In this study two respondents were full-time carers, and another two managed much of the day-to-day responsibility of their disabled siblings care. This involved a significant re-evaluation and modification of their own future goals, and involved much negotiation

with their parents and families. Also, as the non-disabled sibling moves further into the caring role there was an implication that some essence of the sibling relationship is lost and replaced with something more equitable to a parent/child relationship. Whilst this was beyond the scope of this study it would be an interesting and clinically useful area of research.

## 4.6 Conclusion

In conclusion, this study aimed to provide an account of how parents could best inform non-disabled children about their siblings' learning disability. The study found that disclosure between a parent and child is not a discreet, observable entity as described in the literature between parents and professionals, but rather a more pervasive phenomenon that is entwined within the activities of daily living within family life. The study begins to demystify the disclosure process. For example, the activities outlined in the mediating categories guide parents on how to actively engage in the disclosure process with their child.

For parents the pertinent findings of this study are that disclosure involves a life long conversation between them and their non-disabled child. There will be multiple opportunities in which to address the necessary issues and the majority of these opportunities will arise spontaneously within naturalistic settings. Parent/child disclosure is a conversation in which the child is an active participant, one who is able to gather information through a range of mediums in everyday life and regulate the flow of information to meet their needs.

This study has provided a framework through which clinicians can guide parents. They are able to dispel any fears about upsetting, frightening or overwhelming the child. Indeed clinicians can reassure parents that by directly addressing the issue of disability, including both the positive and negative aspects, the child gains a sense of protection and ultimately achieves an acceptance of the situation.

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# 6. APPENDICES

**N**OTTINGHAM
**H**EALTHCARE
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Clinical Psychology
Learning Disability Service
Highbury Hospital
Highbury Road
Bulwell
NOTTINGHAM
NG6 9DR

Telephone 0115 9770000
Ext: 47855
Or direct dial: 0115 9529462

Learning
Disability
Service
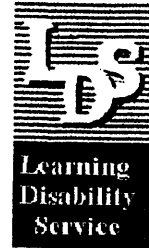
Dear Mr Smith,

My name is Samantha Watson, I am a Trainee Clinical Psychologist working in the Department of Learning Disabilities here at Highbury Hospital. I am currently carrying out some research looking at how to break the news about a childs' learning disability to their non-disabled brother or sisters. This information would be useful for parents (and professionals) in the future, as there is currently very little guidance about how parents should share the news of a child's learning disability with other important people in the child's family.

I am writing this letter to ask you to pass the details of this project to Hadon's brothers and sisters to see if they would be willing to take part. In this study I will be talking specifically to adult brothers and sisters of people with a learning disability. I am particularly interested in talking to those brothers and sisters who have children of their own.

I have enclosed an information sheet for you to give to Hadon's brothers and sisters which explains more about the research and what would be involved if they were to agree to take part in the project.

If one, or more, of Hadon's brothers or sisters are interested in taking part in this study please ask them to complete the slip below the information sheet, and return it in the stamped addressed envelope provided.

If any of you have any questions about the research please don't hesitate to contact me at Highbury Hospital on Tel:(0115) 952 9462. Alternatively I have spoken to Mr Stewart and Mrs Martin at Shepherd School where Hadon used to go and they are happy to discuss the research with you.

Thankyou very much for your help.

Yours sincerely

Samantha Watson
Trainee Clinical Psychologist

Supervised by Dr Jennifer Clegg
Consultant Clinical Psychologist

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INVESTOR IN PEOPLE          Trust Headquarters at: Duncan Macmillan House, Porchester Road, Nottingham, NG3 6AA.

**NOTTINGHAM**
**HEALTHCARE**
**NHS TRUST**

## Information sheet for brothers & sisters

**Title:** What makes a good disclosure? How do families communicate information about a brother or sisters learning disability to non-disabled siblings?

**Researcher:** Samantha Watson (Trainee Clinical Psychologist)
**Supervised by:** Jennifer Clegg (Consultant Clinical Psychologist) and Fred Furniss (Clinical/Academic Tutor)

---

### What is the purpose of the study?
Recently a lot of work as been done to improve how professionals tell parents about their child's learning disability. However, there is still very little research looking at how parents can pass this information on to other important members of the family, especially to brothers and sisters.

I am interested in finding out how best to tell children about their brother or sisters' learning disability, because it is thought that if handled well it will help them to adjust and cope better with the situation. This study asks about the healthy brother or sisters' point of view, it will explore what they feel it is important for children, in families with a learning disabled child, to know about. I am particularly interested in talking to brothers and sisters who have children of their own.

### What will be involved if I take part in the study?
We would like you to help us in this research. If you agree to take part I would come and talk to you at home, or another convenient place. The interview will last no more than one and a half hours. I would like to audiotape this conversation, as this will allow me to get as full a picture as possible, and not to miss anything you might say. If it is appropriate I would also ask your disabled brother or sister for their consent to speak to you.

### Will information obtained in the study be confidential?
Anything you say will be completely confidential, this includes the tapes of your interview which will only be listened to by myself and my research supervisors. All the tapes will be destroyed when the research is completed. No names, addresses or other information which may identify you will be held on computer, or appear in any reports.

### What happens if I do not wish to participate in this study or wish to withdraw from the study?
You do not have to help with this research if you do not want to. If after deciding to take part in the study you later change your mind, then it is okay to withdraw your consent. Whether you decide to take part or not will not in any way affect any care that you, or your brother or sister, may receive in the future.

If you are interested in taking part in this study please complete the slip overleaf and return it in the stamped addressed envelope provided, and I will contact you in the near future. Alternatively you could telephone me on 0115 9529462 or 0789 9744134

Thankyou for your help and your time.

---

Samantha Watson: Dept. of Learning Disabilities,
Highbury Hospital, Bulwell, Nottingham. Tel: (0115) 952 9462

INVESTOR IN PEOPLE

Trust Headquarters at: Duncan Macmillan House, Porchester Road, Nottingham, NG3 6AA.

**Queen's Medical Centre**
**Nottingham**

Research and Development Directorate

Please ask for:    Janet Boothroyd, Business Manager, Ext. 44307
Ruth Doyle, Data Manager, Ext. 44771
Linda Ellis, Administrative Assistant, Ext. 41049
Debbie Cocks, Secretary/Administrator Ext. 35117

Our Reference: EX080004

31st October 2000

Ms S J Watson
62 Paget Road
Leicester
LE3 5HL

Dear Ms Watson

Re:    **What makes a good disclosure?  How do families communicate information about a brother or sister's learning disability to non-disabled siblings?**

The Ethics Committee met on 2nd October 2000 and approved the project subject to your providing of some information, or clarification.  We are now in receipt of this, and the project is now fully approved, including the protocol, patient information sheet and consent form.

The Ethics Committee requires that:

i)      Serious adverse reaction/events, which occur during the course of the project, are reported to the Committee.

ii)     Changes in the protocol are submitted as project amendments to the Committee.

iii)    Yearly reports and a final report on the project to be submitted. (Forms will be sent to Lead Investigator for completion).

Kind regards

Yours sincerely

Dr I M Holland
Honorary Secretary
**Ethics Committee**

University Hospital
Nottingham NG7 2UH
Telephone (0115) 9249924
Fax External (0115 8493295) Internal 35295
*Dr Ian Holland, Honorary Secretary, Ethics Committee*
*Queens Medical Centre, Nottingham University Hospital NHS Trust*

## APPENDIX FOUR(a): First Interview Schedule

### First Interview Schedule

### General, Open questions:
- Have you talked to your children about it?
- I'm interested in how you went about telling your children about your sibling's learning disability?
- I wonder how your experience as a child in a family with a learning disabled sibling influenced how and what you decided to tell your own child?

### Is disclosure a process or one-off conversation?
- Some people approach this area as if it's a one-off discussion, others think about it more as a long-term process, how would you describe it in your experience?
- Is the first conversation more important, or significantly different than subsequent talks?
- I was wondering whether children/young adults etc continue to need or want discussions as they progress through different developmental stages (starting school, teenagers, thinking about having their own family)?

### How do you judge the child's readiness for information?
- How did you/would you know it was a good time to discuss [NAME]'s disability with your children?
- From your experience what advice would you give others about when to start discussing disability with their children?
- How did you know how much to say?
- How did you know what to say?

### How do you determine the child's ability to understand the information?
- How did you know that your child had understood what you were saying?
- How did you know when you'd said enough?

### Adult/Child comparison:
- How does discussing this information with children compare to telling adults?
- What's different or similar?

### Access to resources:
- As a parent having to give sensitive information to their child can you think of anything that would help you?

### The potential benefits of sharing information:
- Do you feel that giving this sort of information, or having these discussions about their relatives learning disability has any positive or negative consequences for the non-disabled child?
- How do you think a child would feel if they never were given the opportunity to talk about their relative's learning disability?

*What makes a good disclosure?*

## Second Interview Schedule

**General, Open questions:**
- Have you talked to your children about it?
- I'm interested in how you went about telling your children about your sibling's learning disability?
- I wonder how your experience as a child in a family with a learning disabled sibling influenced how and what you decided to tell your own child?

**The luxury of time:**
- I have a sense that you don't have to force these (disclosure) conversations. There appears to be no rush, is that what it feels like as a child, and as a parent?
- What are you trying to achieve through having these conversations?

**What is the value of proximity and experience?**
- Spending time with the learning disabled person seems to be important for the child, how does this help?
- Having hands on experience (apprenticeship) also seems important?
- How important is it to have a relationship with the learning disabled person?

**Does knowing the name or cause of the disability help the child?**
- Does this make a difference, how?
- Do the physical and behavioural characteristics of the disabled person affect the process of disclosure?

**Social Comparison:**
- Is this a phenomenon?
- How do people manage this?
- How do you tread the line between developing tolerance and acceptance in the non-disabled child without creating any feelings of guilt or superiority?

**N** OTTINGHAM
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# Consent Form

**Title: What makes a good disclosure? How do families communicate information about a brother or sisters' learning disability to non-disabled siblings?**

**Lead Researcher: Samantha Watson, Trainee Clinical Psychologist**
**Supervised by: Jennifer Clegg (Consultant Clinical psychologist) and**
**Fred Furniss (Clinical/Academic Tutor)**

---

I have read the participant information sheet on the above study and have had the opportunity discuss the study with Samantha Watson and to ask any questions.

I understand that any information I give will be confidential. No names, addresses or other information which identifies me will be held on computer or included in any report of the research.

I understand that my interview with the researcher will be audio recorded, the reasons for this have been explained and I give my consent to the recording of the interview. I understand that the audiotapes will be stored securely and their contents will remain confidential and will be used for this investigation only.

I understand that I am free to withdraw from the study at any time, without having to provide a reason and without it affecting mine, or my brother or sisters', future medical care.

---

I agree to take part in this study and for the interview to be audio taped.

Name (please print)   .............................................

Name (please sign)   .............................................

Date               .............................................

---

If you have any further questions I (Samantha Watson) can be contacted at the Dept. of Learning Disabilities, Highbury Hospital, Bulwell, Nottingham, NG6 9DR Tel: (0115) 952 9462.

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S    quite a difficult thought to live with all those years I imagine

P    yeah

S    I was interested in the thing that you said that almost when ever you got the opportunity that you asked professionals about ▇

P    yes yes

S    can you tell me a bit more about that

P    I went into teaching erm not necessarily special needs teaching I just thought that that's what I would like to do myself and I found myself inadvertently being steered more towards special needs not that I thought it was particularly a career I wanted to that's a particular branch of or specialism that I wanted to do erm in fact the first school I was interested in what they then used to call them the remedial teacher used to do and I used to think to myself how can she ever have the patience you know I was so amazed that she had the patience to work with these students and then I realised that obviously she wasn't having to deal with them in the whole class situation like I was having to deal with them eh and she only had the very worst at that particular time and I know that education changed very much over the years anyway and there are less and less people going into special schools anyway and more and more being educated in mainstream of which I think that's quite a good idea to a certain extent and I think really I used to ask because I was ..' as I got older I became more and more aware that there was something that was not in the normal sense of I don't mean quite right do you know what I mean I realised there was something different about ▇ and I realised that she wasn't learning in the same way that children of her age should learn and I knew that my parents well my father in particular were fighting against everything he wanted her to be normal if you like wanted her to attend a mainstream school wanted her to be in the same class as everyone else in fact if he was here now as a young parent this would be his dream because this is how society has now become you know there is less and less "oh they've this they've got dyslexia so put them here oh they've got Down Syndrome so lets put them here" there's less and less segregation now there is more and more inclusive education and that is really what he wanted he didn't want her to be seen to be any different and whilst I could applaud that I sometimes used to think to myself is it right or is it should she be assessed because he didn't even really want her to be assessed to see how best she could be helped so I used to perhaps think about now what what's going you know what is going to happen because besides this "oh you might have had something to do with her being like this" there's always been an expectation that I'd look after her when they couldn't

how did you now that was the expectation

P    because it's always been said always been mentioned right from me being very small so I thought well you're looking after her in your way I need to know how to look after her in my way because as I got older I began to think "no I couldn't cope with that " and I couldn't or I don't think that's right so I began to realise if I was going if I had got to look after her I needed advice and I need to think what other professional people thought I didn't want tot keep it all within the family I didn't want

*[Handwritten marginal annotations:]*

I am a professional
are / Implicit Link
PLP:

Diff context move conducive 2 Instruction ~ LD.

uncertainty / caution v change

Inc. awareness ~yc of diff ~ ok sib image

Noticing Diff
Child awareness of Parental response / wishes

obs. (of denial)

changing societal attitudes.

struggles ~ difference

rs for future ..

oking to their needs to
coming / Preparation
↓
sponsibility
a caused it
a sort it.

le of oc sib
safety net for parents.

Limits of tolerance

ce expectations.
challenging

13. 
1. ambivalence 2 link ~ S.N
3.
4. ambivalence SP. Needs
5.
6. Changing societal attitudes
7.
9. ce → understanding/identifying diff
10. Noticing Diff
11. Child compared to others.
12. A. Empathy ~ parent/pos/sib.
12.B. understanding of parent position.
13. unvoiced concerns.
16. Child ce + parental Descr or choices
? Need of help
contributing mvs ~ nothing ~ my
Parental expectations - burden of
23. Parental expectations
24. Child ce parents choices/methods
24A. Dev. of sibs own indep. role/pos

27 Seeking help
27. Info seeking - keep in family outside.
27. acc. 2 services
acceptance of diff.
26 Shameful secret

471      say it like this or I might say to them look it's not that she hasn't heard

*Modelling how talk* [handwritten]

472      you you need to get her attention first so there may have been <u>they</u>

473      <u>may know that they've got to sort of say her name first for them to look</u>

*Info re tech* [handwritten]

474      <u>at her to get her attention</u> so they know that they haven't ever said

475      what's wrong with her they've never said that

476    S     haven't they, not even ▉▉

477    P     I don't think she has I don't think they've ever said what's wrong I think

478      <sup>Λ</sup><u>they've realised that she's different and that we need to speak to her</u>

*A awareness of dif* [handwritten]

479      <u>differently they know that I work with children with special needs they</u>

480      <u>ask more about my children actually</u><sup>ᵛ</sup>    <u>Indirect Q's</u> . [handwritten]

481    S     what do they ask

482    P     they asked about Nicola whom I teach in fact they have said what's

483      wrong with Nicola or what are Nicola's difficulties cos they/know I work

484      with special needs children and I've just told them the condition and

485      then say erm eh and then just they'll say well what does that mean and

*(curiosity)* [handwritten]

486      what can't she do and <u>so they're fairly curious about people that I teach</u>

487      <u>▉▉ particularly the middle son</u>

488    S     so that backs up what you were saying earlier that the people they

489      have less contact with they're more direct and questioning about but

490      the people like ▉▉▉ within the family you feel it's more about

491      experience and maybe watching you and maybe the occasional

492      comment. I wonder

493    P     <u>it's a little bit like learning on the job the apprenticeship isn't it because</u>

*Experience not cog.* [handwritten]

494    ᴊQ .    <u>they've seen it yes they've not had a direct course on it but because it's</u>

*not cog. knowledge* [handwritten]

495      <u>been in the family</u> they've seen they haven't even explained it to

Protection.                                          Code EB
              (aim of info giving (?)                          30.4.01

Active protection of L.D. sib · Elusive · beating stranger up (??) ?type some int

Protection/preparation of others · family info family. (warning + = ??)

Protection of DK sib · "wise" - & deal c interaction family/world.

Protect DK sib fr. resp. of caring · (their self) (Gill)

Expl. costs as protection (Fred 76) → guards against misconception (Paul 675)

Protection of L.D. sib self · open dialogue useful · "will get verbal" (Claire 745)

Protection of Parent by sib · takes resp for caring (Claire 376)
                            only indirect co's, respect for feelings (Paul 381, ...)

Lack of protection: fear, stayed away fr. House  (Fred 16, 19, 20)

                                                    Protection ☺

Extends as a
Warning  re: name calling (E 174)
       ∫    : staring    [G 186]

Selective Exposure: Fred didn't take Annette to R's house - Protect fr. ugliness
         + re Sibs                                           of reality.

Selective Info giving: managing fear / this complicated : reinvel not undermine ?
                                                                (P. 35?)
- ve connotation · Protection by denial.

Paul 364 · Selective info giving : some info "quite troubling"

B193 : Protective B - sign of bond
         Protective of sib in her absence (link = ambassador).

See P-C Decip Cyne will
          Older sib protect re, violence..

D 2458: Hearing things people say - hurtful/upsetting, feeling you & your family have been
         dismissed. D protects L fr. that by challenging when she hears it
         - even in his friends.
         - Where fit = peer grp approval?
         - active protection, not stopping hurtful things, challenging them
         - Luke takes that on D268 : "British".

D 267 : L v. protective of L.D. sib, even when she's not bothered by incident he still feels
         "That's unfair + y- shouldn't be doing that"

Paul (?) : protective traits: reading (introversion, escape 2 fantasy?) → regrets re: not interacting c (sib)
      ✓  protecting self took energy → not enough 2 "save" sib → did "damage her?"