The use of a repertory grid technique with siblings of autistic children: How they see themselves, their siblings and their peers.

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Using a repertory grid technique, 15 siblings of autistic children were asked to describe themselves, their siblings and their peers. Siblings of Downs Syndrome (N=15) and nondisabled (N=15) children were also interviewed to control for the effects of having a 'disabled' sibling and to examine the types of constructs generated in relation to normal sibling and peer relationships. The children's ages ranged from 8 to 19 years. A large number of constructs were generated using the dyadic sort method, and these were subject to a preliminary content analysis. The children's generated constructs were also analysed using the GRAN computer program. A number of supplied constructs were included at the end of each child's grid to facilitate comparisons between the element ratings made by siblings in each of the three groups. Following the grid administration, a short semi-structured interview was conducted to explore the nature of the relationship with the target sibling in more detail. The findings of these multiple data sources were then compared using the process of triangulation. The results suggest that whilst children with autistic and Downs Syndrome siblings both use characteristics relating to their target sibling's 'disability' to distinguish them from the other children being rated, the autistic child is discriminated further on the basis of constructs pertaining to their low levels and impaired style of social interaction. The potential consequences for the social and emotional development of the nonautistic child are considered and suggestions for clinical interventions with this client group are presented. Methodological considerations suggest that by allowing children to respond freely, using their own language and construct systems, valuable insight can be gained concerning the unique *and* shared experiences of these children.

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INTRODUCTION

I. Autism: A Family Perspective

In every family, the birth of a new child brings with it new challenges to the structure and roles of the family unit. Prior to the birth, some changes may already have taken place within the home with respect to finances, living arrangements, and areas of parental responsibility. The family will have been able to anticipate many of these changes on the basis of their previous child bearing experiences or from advice given by friends, relatives and professionals. Nevertheless, there are always unexpected effects that the new child will bring, but few with such a dramatic impact as the birth of a child with disabilities (Norton & Drew, 1994).

There is a long standing debate about the extent to which a family containing a handicapped child is likely to be a handicapped family. Until the mid 1970's, most research in this area adopted a 'pathological' approach, which assumed that such families are subject to high levels of stress which could lead to psychological impairment among some, if not all, family members (Schonell & Watts, 1957; Worchell & Worchell, 1961). Proponents of this model have devoted a great deal of effort to scoring the amount of guilt and shame, rejection, depression and over-protection shown by parents of disabled children.

However, in recent years, researchers have begun to recognise that there is greater heterogeneity in psychological responses among families with a disabled child (Drew et al, 1992). Each type of disability and each child is unique, and every family will have evolved their own style of coping with stressful events. In contrast to the 'pathological' approach, a 'normal' model of families with a disabled member is being advocated. According to Wilkin:

> "Where the normal family model is used, the fact that problems are experienced by the family is not denied, but the assumption that one should always look for harmful effects is questioned". (Wilkin, 1979, p.33).

This approach recognises that all families with a disabled member are unique in their response style. For some families, the arrival of a child with disabilities will weaken family relationships whereas for others it can become a source of unity for the family (Shelton et al, 1988).

"Why focus on Autism ? "

Several authors have noted that certain characteristics of the handicapped child, such as social responsiveness, temperament, repetitive behaviour patterns, and additional or unusual caretaking demands may amplify the amount of stress experienced by a family (e.g. Beckman, 1983). One such disability - which presents extreme variations in ability and behaviour - is autism.

In autism, the core deficit is believed to be social in nature (Rutter, 1983; Wing & Gould, 1979). This means that whereas a learning disabled child can be sociable, relative to his or her mental age, the autistic child, regardless of intellectual ability, will have observable social impairments. If the family is viewed as a 'social group', whereby the actions of one member will have an effect on the other members, what would be the impact on the family unit, and each of its members, of having an autistic child within the family ? If Beckman (1983) is correct, one might expect a family with an autistic child to face particular forms of stress due to the specific social impairments of the child with autism.

DeMyer (1979) described families of autistic children as a "lonely minority". Despite the burgeoning literature concerning the 'general effects' of having a disabled member within a family, systematic research concerning the specific effects which autism may bring to family functioning is still in its infancy.

There have been a number of poignant accounts written by parents (e.g. Grandin & Scariano, 1986; Greenfeld, 1986; Lovell, 1978), and clinicians and researchers have become increasingly interested in the impact of autism on the family (e.g. Cantwell et al, 1978; DeMyer, 1979; Morgan, 1988; Norton & Drew, 1994; O'Moore, 1978; Rutter & Howlin, 1987; Schopler & Mesibov, 1984). Nevertheless, a detailed literature search in this area revealed very few contemporary findings relating to the effects of autism on family functioning.

There have been several studies which have explored the impact of having a 'disabled' child on parent's psychological well-being, with mixed results. Some authors indicate that parents of children with disabilities are unlikely to have increased psychological problems, and that the problems which do exist are likely to be limited to mild forms of depression (e.g. Carr, 1988). Other researchers claim that parents of disabled children are more vulnerable to serious emotional problems, such as enormous guilt (particularly on the part of the mother) and heightened sensitivity to criticism (Featherstone, 1980).

There have also been mixed findings concerning the impact that having a disabled child has on the marital relationship. Some researchers have noted high levels of marital conflict (e.g. Gabel et al, 1983), whereas others claim that there is no more stress in these marriages than in those without children with disabilities (Seligman & Darling, 1989).

Families with an autistic child

In the late 1970s, an investigative team (Cantwell et al, 1978) drew attention to the severe stress experienced by parents in their struggle to deal with their autistic child's behaviour. Following the diagnosis, the family with an autistic child may go through a process similar to that experienced by families of children with other forms of disability. In many ways, the response is akin to a bereavement reaction, with the family progressing through the stages of shock, realisation, anger and finally acknowledgement of the disability (Shontz, 1965). However, this process is complicated in the case of autism, because a diagnosis is often not made until after infancy, and frequently follows the parent's persistent requests for assistance and assessment (Norton & Drew, 1994). The family is therefore left searching for a reason for their child's problems, with many claiming to feel "alone in their worry" (DeMyer, 1979, p.35). Consequently, these parents are often left to fully experience and manage their grief at a much later date.

Rutter and Howlin (1987) present examples of difficulties commonly reported by parents of autistic children. These children are frequently described as unresponsive and unrewarding to be with, difficult to play with, and demanding in their need for supervision, structuring and control. Therefore, in addition to the continuing sense of sorrow, loss and guilt they share with parents of other disabled children, the families of autistic children often experience feelings of rejection as a result of having a child who shows little or no emotional attachment to them.

Some parents describe feeling as though they are being used as conveniences. As one mother puts it:

> "He can do without most anybody. He won't respond to our love. My husband misses his companionship and he is a good father. I miss being able to cuddle and comfort him". (cited in: DeMyer, 1979, p.107).

Newson and Davies (1992, p.150) quote another mother as saying "I think I'd rather have a *normal* abnormal child, if you can see what I mean".

Several studies were undertaken in the late 1970s to mid-1980s comparing the psychological responses of parents with autistic children with the levels of coping amongst parents of children with other forms of disability.

In one of the earlier studies, Holroyd and McArthur (1976) examined the levels of stress reported by mothers of autistic children, Downs Syndrome children, and children being seen in an outpatient clinic. Mothers of autistic and Downs Syndrome children shared a number of problems, including poor health, depressed mood, excessive time demands, excessive dependence of their children upon them, pessimism about their children's future, and limits on family opportunity. The mothers of autistic children, however, generally reported more embarrassment and disappointment than the mothers of Downs Syndrome children and experienced more difficulties when taking their child to public places.

A more recent study by Koegel et al (1983) failed to detect elevated stress levels in parents of autistic children when they were compared with parents of nondisabled children or children with other forms of disability. On a variety of personality assessment scales and measures of marital satisfaction and family environment, the scores from the parents of autistic children did not differ significantly from the normative group scores. The authors did note, however, that there was more individual variation in the scores from the parents with a disabled child than amongst the group of parents with nondisabled children.

"Why focus on the effects on siblings ? "

Until relatively recently, research exploring the effects of having a handicapped child on family functioning has focused almost exclusively on the psychological responses of the mother. Few studies have examined the effects on siblings, and there have been even fewer reports of the psychological well-being of fathers, grandparents and other members of the extended family. Even in those few studies where effects on siblings have been examined, this has tended to be done by asking the mothers rather than the siblings themselves ! Consequently, there is very little information on the experience of living with a handicapped sibling from the point of view of the brothers and sisters directly involved (Bågenholm & Gillberg, 1991).

This lack of research is surprising considering the current move towards 'care in the community', which has meant that most handicapped children are growing up in the context of the family, at least until they reach adolescence (Andersson, 1988; McHale et al, 1986). While parents are typically the primary care providers, the sibling(s) of the child with a disability may have to assume additional care taking responsibilities, and learn to cope with the behavioural and cognitive limitations of their brother or sister.

Theoretical interest in exploring the sibling relationship

None of the classical theories of personality or psychological development portrayed siblings as important agents of socialisation. Traditionally, psychological theories have emphasised parental influences on child development. However, siblings have now become important subjects of study in their own right (Dunn, 1985; Werner, 1986), and as members of a broader family system (Brody & Stoneman, 1987; McHale & Pawletko, 1992). There has been a growing appreciation that families are complex systems, comprising a network of relationships (Bronfenbrenner, 1979). Consequently, rather than continuing to focus on studies of children with disabilities in isolation, or on the mother-child dyad, researchers have begun to look at the entire family system - the target child, mother, father, and siblings (Blacher, 1993).

Piaget (1932) and Sullivan (1953) both supported the notion that each type of relationship a child forms serves significant but distinct functions in his or her social development. They proposed that it is through children's interactions with one another, in contrast to interactions with adults, that they are most likely to develop mutual understanding, interpersonal sensitivity and intimacy.

The sibling relationship is usually the longest lasting one across the lifespan (Cicirelli, 1982), and for the majority of children, it is likely to be the first extensive social relationship they have with another child (McHale et al, 1984). It has been argued that this relationship provides important mechanisms for learning how to negotiate, co-operate, support and reward one another (Minuchin, 1985). Given the general intimacy of this relationship, siblings have been shown to affect each other in many domains (Sutton-Smith & Rosenberg, 1970), including intelligence (Zajonc, 1976) and affective and attitudinal development (Dunn & Munn, 1986). Furthermore, several researchers (e.g. Stewart et al, 1992) claim that sibling relationships are likely to influence many social interactions in later life.

The question then arises: What are the consequences, in terms of the social and emotional development of the non-autistic child, when the reciprocal and complementary nature of the sibling relationship is compromised due to the autistic child's impaired social behaviour ?

Siblings of autistic children

Seltzer & Krauss (1993) review the literature on sibling relationships where one sibling has a disability. Although much of their discussion is directed at the 'generalities' of the experience of being a brother or sister to a child with a disability, it suggests a number of issues which should be taken into account when considering the experiences of siblings of children with autism.

The authors draw on three theoretical models to explore the impact of having a sibling with a disability: (1) Lifespan Development, (2) Attachment, (3) Exchange Theory.

(1) Lifespan Development This model looks at the extent to which behaviour is constant or changing across the lifespan, and seeks to discover the factors that lead to either stability or discontinuity in human development. Among these factors are normative and nonnormative events. Normative events are seen as predictable by most people, and tend to be governed by biological maturation (e.g. puberty), or by sociocultural timetables (e.g. entering school). Conversely, nonnormative experiences are unpredictable, unplanned, often unwanted, and are largely unshared (Seltzer & Krauss, 1993). While having a sibling is a normative experience for 85-90% of the population (Cicirelli, 1982) having a sibling with a developmental disability is not.

The normative experience of having a sibling has been conceptualised in developmental terms, with attempts being made to account for later development by examining earlier statuses or experiences (Beardsall & Dunn, 1992; Goetting, 1986;

Stillwell & Dunn, 1985). Goetting (1986) described the lifetasks of the siblingship from childhood and adolescence, through early and middle adulthood, to old age. During childhood, the relationship is characterised by companionship and emotional support. Intense patterns of involvement are witnessed, and siblings may be involved in delegated caregiving roles. During adulthood, sibling ties are generally loosened and become more diffuse. The relationship tends to be less intense, and may be characterised by a passive sense of concern. In old age, the tasks of companionship and emotional support represent a reintensification of the emotional bond between siblings.

In contrast to this developmental model of normal sibling relationships, there has been very little theoretical analysis of the developmental consequences of nonnormative sibling relationships. Most studies of sibling relationships where one sibling is disabled have been cross-sectional rather than longitudinal. The lifelong developmental sequelae of having a sibling with a disability have yet to be investigated (Seltzer & Krauss, 1993).

(2) Attachment Whilst in the past the concept of attachment was linked almost universally to infancy and tended to refer to the mother-child bond, in recent years theorists have attempted to examine the implications of attachment across the lifespan (e.g. Murray Parkes et al, 1991). Ainsworth (1989) gives the sibling relationship as one example of affectional bonds which persist throughout the life course.

As with Goetting's (1986) conceptualisation, although attachments between siblings can persist from childhood until old age, the behavioural manifestations of attachment change from stage to stage in age-appropriate ways (Seltzer & Krauss, 1993). Proximity seeking, a hallmark of attachment, may be achieved through joint play and physical signs of affection in childhood, whereas in later life the same function is met through letters, visits and phone calls. Seltzer & Krauss (1993) claim further research is needed to clarify patterns of continuity and discontinuity in attachments across the lifecourse, and to examine the ways attachment differs from the norm when one sibling has a lifelong disability.

(3) <u>Exchange Theory</u> The third theoretical perspective discussed by Seltzer and Krauss (1993), is perhaps the most relevant for sibling relationships when one sibling is disabled. Exchange theory focuses on the interactions among people and explains social relationships in terms of give-and-take (Blau, 1964).

Sahlins (1965) described three types of reciprocal relationships: (1) *generalised reciprocity* (in which individuals give without the expectation of repayment, typically characteristic of the parent-child relationship), (2) *balanced reciprocity* (characterised by an equitable pattern of exchanges, typically characteristic of sibling relationships), and (3) *negative reciprocity* (in which the support given by one person is never reciprocated, even though reciprocity is expected).

In the long run, sibling relationships are generally balanced in their reciprocity (Avioli, 1989). In situations where there are long-term inequalities in the sibling relationship, one of two consequences may occur. The siblings may become estranged from one another, as in negative reciprocity, or alternatively the siblingship takes on the characteristics of generalised reciprocity, as with a parent-child relationship. Such shifts in patterns of interaction when one sibling does not reciprocate have implications for the analysis of the sibling relationship when one sibling has a disability (Seltzer & Krauss, 1993).

Implications for the study of siblings of autistic children

While normal sibling relationships are conceptualised as evolving over time, the relationship a child has with his or her disabled sibling may become 'fixated' at a particular developmental level. In autism, the opportunities for the sibling relationship to develop at a social and emotional level are drastically reduced, as a result of the autistic child's impaired social communication and understanding. Companionship and emotional support, which are seen as constants in the sibling relationship according to Goetting's conceptualisation, may have a lesser role to play in the quality of a siblingship with an autistic child. In particular, the lack of reciprocity in the interactions with an autistic child may have significant consequences for the other children in the family.

Before examining the research which has attempted to assess the impact of autism on the sibling relationship, a more detailed description of the symptomatology of autism and the current thinking concerning its etiology, may aid the reader who is less familiar with this rare and unusual condition.

II. Autism: Diagnostic criteria and epidemiology

The first description of autism was published by Leo Kanner, a child psychiatrist at The John Hopkins University, in 1943. He reported on 11 children whom he had worked with over a period of eight years. In his article, he writes:

> "Since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits and, I hope, will eventually receive a detailed consideration of its fascinating peculiarities. (cited in: Frith, 1989, p.8).

Despite being written over half a century ago, Kanner's description is still valid and highly instructional today (Sullivan, 1994). While some aspects of the Kanner syndrome have been modified by empirical research, certain parts of his definition are still used. These features, which collectively have been referred to as the "Triad of Social Impairment" (e.g. Wing & Gould, 1979), include: (1) extreme aloneness and impaired social relationships, (2) disordered language and impaired social communication, and (3) insistence on repetitive behaviours, with upset when such behaviours or routines are interrupted.

(1) Extreme aloneness and impaired social relationships

Kanner described the 'autistic aloneness' of the child as follows:

> "He has a good relation to objects; he is interested in them, and can play with them happily for hours ... the child's relation to people is altogether different ...Profound aloneness dominates all behaviour." (cited in: Frith, 1989, p.9)

The autistic child is frequently described as "living in a world of his own". Autistic aloneness has nothing to do with being physically alone - the child is alone mentally. Frith (1989) uses the classic fairy tales of 'Snow White' and 'The Sleeping Beauty' to convey the quality of the experience familiar to those who are closely involved with an autistic child. One theme present in these tales, is that of a 'life-like' death. The glass coffin or the hedge of thorns can be used as a metaphor for the impossibility of reaching the autistic child - capturing the feeling of being so near, yet so far. The normal healthy appearance of the autistic child would appear to indicate that he is 'awake', yet, his social isolation makes us painfully aware that he is not ('asleep').

Social withdrawal is seldom total, and varies depending upon the situation the child is in, his age, and the identity of the people trying to relate to him (DeMyer, 1979). Problems in social relatedness are usually most severe around 21/2 -3 years of age. By the time the child is 4 or 5 years old, they may show signs of relating to people both inside and outside the family. However, they will always experience difficulties in this area of functioning.

(2) Disordered language and impaired social communication

In babies, there is typically no babbling. Initial utterances show little variation, and tend to emerge as a high-pitched squeal. There is less imitation of pre-speech sounds than in normally developing infants. In many cases, speech begins normally around the end of the first year, but tends to disappear by about 18 months - for reasons not yet understood. 50% will never speak. Sullivan (1994) comments on the 'strange silence' in classrooms in which there are only students with autism. This is in stark contrast to classrooms with normal, same-age children, or even those with children with other disabilities.

For those who can use spoken language, speech patterns are likely to be peculiar. Language disorders include echolalia; pronoun reversal, using "you" instead of "I"; and "revved up" speech. Some sing, others may talk backwards. More often than not the tone of their conversation is flat, and there is little or no commensurate body language. An autistic individual's understanding of language can be extremely literal. Frith (1989, p.5) relates one mother's experience of casually remarking to her autistic son that his sister was "crying her eyes out". His response to this innocent comment was to anxiously scan the floor to see where her eyes had fallen ! Although such incidents may provide some amusement for onlookers, the autistic child's inability to understand the subtleties of social communication can be a frustrating and unhappy experience.

(3) Insistence on repetitive behaviours

This characteristic is often referred to as "preservation of sameness". People with autism may display stereotyped bodily movements such as hand-flapping, rocking or spinning. They may have a persistent preoccupation with parts of objects e.g. spinning wheels of a toy car, or show a high level of attachment to an unusual object e.g. insisting on carrying around a piece of string. Some may insist on following routines in precise detail, such as taking the exact same route on each shopping expedition. Minor changes to the environment or to a routine can create significant resistance, and may be met with verbal or physical aggression. Consequently, any form of spontaneous activity can prove to be a challenge for people with autism and can interfere with learning and independent living.

Diagnostic criteria today

On the basis of international collaboration, experts have agreed to use certain behavioural criteria for the diagnosis of autism (Frith, 1989). The most detailed and recent scheme is the one outlined in the Diagnostic and Statistical Manual (DSM-III-R) of the American Psychiatric Association. A similar diagnostic scheme is available in the International Classification of Diseases (ICD-10) issued by the World Health Organisation. The essential criteria are specified by concrete examples under the following headings:

- Qualitative impairment in reciprocal social interaction.
- Qualitative impairment in verbal and non-verbal communication and in imaginative play.
- Markedly restricted repertoire of activities and interests.

Etiological factors

Kanner (1943) reported that the parents of autistic children were unique in that they were highly educated and professionally successful. He wrote:

> "In the whole group, there were very few really warm-hearted fathers and mothers. For the most part they are strongly preoccupied with abstractions of a scientific, literary or artistic nature, and limited in genuine interest in people" (p.250)

Following this observation, throughout the 1950s and early 1960s, the parents of autistic children were studied for their presumed role in the cause of the disorder. Influenced by the psychoanalytic teachings of that time, it was proposed that separation from the parents (either physical or emotional), during the "critical periods" of ego formation resulted in the development of autism. The evidence for these claims was weak and was based heavily on retrospective reports of a biased nature.

"Deviant personality" in parents of autistic children was also postulated as a primary causal factor in the development of autism. Parents, were described as emotionally cold, introverted, obsessive, lacking in empathy, overprotective, 'Refrigerated', and in some cases downright mentally ill (Cantwell & Baker, 1984). In 1967, Bettelheim, went so far as to claim that the only potential for the autistic child's improvement was to remove him from his family in a "parentectomy". Comparison studies using standardised measures, however, have consistently shown no evidence for the assertions of parental pathology as a primary cause of autism (Koegel et al, 1983;

McAdoo & DeMyer, 1978) and this hypothesis is no longer considered seriously in the literature.

From the mid-1960s, investigators have increasingly reported finding neurobiological irregularities in autistic individuals. Family and twin studies have provided strong evidence for genetic factors operating in autism (August et al, 1981; Folstein & Rutter, 1978). These findings have significantly influenced how the child with autism and his family are treated. Parents and siblings, not just the autistic child, are now being recognised as victims of the disorder.

Prevalence and sex ratios

The earliest, and to date the largest, epidemiological study of autism was conducted by Lotter (1966). From a massive survey of 78,000 children between the ages of eight and ten living in a geographically defined area (Middlesex), he found an incidence of 4.5 per 10,000 of the population. His sample was initially contacted by means of a postal questionnaire sent to teachers and other professionals concerned with children of that age. Using this process, he identified those children who might conceivably be autistic, and followed these cases up by consulting medical records and conducting individual interviews. Lotter had used Kanner's criteria to identify a core group of children who showed autistic features to a marked degree. However, a large number of less typical cases were also identified. These cases might well be diagnosed as 'autistic' by clinicians employing criteria less strictly based on Kanner's notions (Frith, 1989).

This was the case in a recent well controlled study in Nova Scotia (Bryson et al, 1988). Drawing on a sample size of 20,800 children aged between six and fourteen years, these researchers reported an incidence of 10 per 10,000 which doubled the previous estimate.

An excess of autistic boys over girls was noted by Kanner, and this finding is now well established (Frith, 1989). The male:female sex ratios in the two studies described above were 2.6:1 and 2.5:1 respectively, demonstrating a remarkable consistency in observations.

III. Review of the literature: Siblings of autistic children

As outlined earlier, the majority of studies which have considered the impact an autistic child may have on the other children in the family have tended to rely on reports given by mothers and occasionally by fathers. Many of these parents have expressed the fear that their normal children may be at particular risk of developing problems because of the autistic child's lack of social and communicative skills and their often very severe behaviour problems (Howlin, 1988). It has also been suggested that the greater complexity, unpredictability and inexplicability of the symptoms exhibited by children with autism place their siblings at an even higher risk for poor psychological adjustment than siblings of children with other disabilities (Morgan, 1988; Rodrigue et al, 1993).

In DeMyer's (1979) landmark study of families with an autistic child, parents were asked how they thought the presence of the autistic child had affected their normal children. One mother described how the tension and worry she and her husband experienced had inevitably affected the siblings:

> "I think the whole problem has been a terrible strain on all of us - to our other children. We can't sleep right or enjoy our meals together or go out much. I feel sorry for us all" (p.169)

The most prominent negative effect, which was reported in 30% of the families, was that one or more of the normal children in the family felt neglected because of the disproportionate amount of attention paid to the autistic child. One family experienced a dramatic change in their normal five year old daughter's behaviour towards her autistic brother. Her parents described how she had changed from being loving and accepting of her brother, to resenting him because:

> "He has gotten too much attention - I don't blame her for resenting it, but we literally have no choice right now" (p.170)

18% of the parents reported that at least one sibling appeared worried and upset regarding the autistic child's condition:

> "One of my children continually asks me why she won't talk, and why she doesn't like him" (p.170)

15% reported regression in habit training (toileting and eating), which they attributed to the autistic child's effects on the sibling. Other effects described by a minority of families included, teasing from school friends, almost complete ignoring of the autistic child, and an unusually high level of jealousy.

The parents' descriptions of the behaviour of each sibling were rated by a psychiatrist who made a judgement as to whether there was evidence of emotional disturbance in the sibling. The ratings for the 59 siblings of autistic children were then compared with descriptions given by parents of 67 siblings of normal controls. Remarkably few major differences were found between the two groups, with only 9 children in each group being described as emotionally disturbed. DeMyer suggests that more accurate estimates of the levels of emotional disturbance in siblings could be achieved by conducting face to face interviews with the children themselves, and obtaining reports on the child's behaviour from outside sources such as teachers.

About half the parents (54%) in DeMyer's study felt that the specific problems encountered in day-to-day life with the autistic child had also brought out the helpful side in at least one of the other children. Some siblings gave assistance in the physical care of the autistic child, and many were described as being "understanding" when the autistic child received preferential or special treatment from the parents. Finally, it was noted that a number of siblings had pursued careers in medicine, teaching or psychology, in part spurred by the desire to help.

The findings from DeMyer's study raise a number of important issues for the study of siblings of autistic children. Firstly, it suggests that the experience of having an autistic sibling is neither unequivocally positive or negative. Siblings differ in their coping mechanisms and in their attitudes towards their autistic brother or sister. This implies that there are certain ‘mediating factors’ which influence the level of adjustment a particular child will achieve.

Whilst there have been no studies which have specifically looked at factors which mediate the effect of having an autistic brother or sister, there have been several studies which have explored factors which may influence the level of adaption made by children who have a 'disabled' sibling in general. McHale et al (1984) provide a summary of these findings and these are presented in Table 1.

The mediating effects of the 'family' and 'nondisabled child' characteristics are likely to have a similar impact irrespective of the nature of the disability. However, certain characteristics of the disabled child described in this summary table appear to have particular relevance for the adjustment of siblings of autistic children. Firstly, the ambiguous nature of autism and the frequently delayed diagnosis of this condition might make it more difficult for the siblings to adjust. A second factor relates to the autistic child's lack of social and communicative skills and their often very severe behaviour problems (Howlin, 1988).

Table 1: Correlates of adjustment in children with disabled siblings (adapted from McHale et al (1984), p. 334).

Characteristics	Impact on level of adjustment
Family:	
1. Size	Children from large families are better adjusted, provided their families have sufficient financial resources
2. Socio-economic status	Families of low SES have the problem of limited finances. Families of middle or upper SES must adjust their high expectations for the disabled child's achievements
3. Parental acceptance	When parents are more accepting of the disabled child's condition their other children are better adjusted
4. Marital relationship	With a positive marital relationship, both parents and children adjust better
Nondisabled child:	
1. Birth order	Older children tend to be better adjusted, particularly when here is a span of 10+ years between the nondisabled and disabled siblings
2. Gender	Oldest girls in the family are most adversely affected
Disabled child:	
1. Age	As the disabled sibling grows older, other children in the family experience more problems
2. Gender	Children of the same gender as the disabled sibling experience more problems, except for the oldest female, who usually experiences the most difficulties
3. Type of disability	When the sibling's disability is ambiguous or undefined, children tend to be more poorly adjusted, especially in higher SES families
4. Severity of disability	When the sibling's condition is severe (and the child requires a lot of care), children experience more problems, especially in low SES status families

A second issue, made apparent by DeMyer's study, concerns intra- as opposed to inter-individual variability. Each sibling may cope with the presence of the autistic child in different ways at different times. In the example given above, the young girl changed her style of responding from being affectionate and understanding towards her autistic brother to resenting him for receiving what she felt were the 'benefits' of parental attention. This view of sibling adjustment, as a continuous developmental process, was outlined in the Lifespan Development and Attachment models earlier.

Thirdly, by reading between the lines of DeMyer's discussion, it would appear that the autistic child can influence the functioning of siblings both directly and indirectly. In the first quote, the mother describes how the tension felt by the marital pair in response to bringing up an autistic child had meant that they were less 'available' to do certain activities with their other children. In this example the effect the autistic child had on the sibling(s) was *indirect*. In contrast, the third quote describes how the sibling's concern regarding his autistic sister's lack of social communication had a more *direct* influence on his adjustment.

From a wider review of the literature, there appears to be several influences autistic children have on their siblings which are common to much of the research (Simeonsson & McHale, 1981). Among the effects of a negative nature are identity problems and physical and psychological demands, whilst the positive effects include a greater maturity of attitudes and behaviour.

Identity problems

Several studies have shown that siblings may experience problems in establishing self-identity (Fromberg, 1984; Grossman, 1972; White, 1993). Howlin (1988) suggests that the normal child may harbour secret fears that he/she might also be affected in some way. For the younger sibling, these concerns might be based on the child's knowledge that in many ways they *are* similar to their autistic brother or sister e.g. they share the same home, parents, and perhaps the same colour of hair and eyes. The question they then grapple with is "how many characteristics do I share with my autistic sibling ? Am I somehow defective too ?". As the sibling grows older, these doubts may be redefined as a fear of having a defective child and passing on the disorder to the next generation (Simeonsson & McHale, 1981).

Physical demands

Extra demands are frequently placed upon the normal siblings in families with an autistic child, with respect to childcare and household tasks. Farber and Rychman (1965) describe the 'role tension' that characterises siblings of handicapped children when:

> "regardless of his birth order in the family, the severely handicapped child essentially becomes the youngest child socially, and other siblings are expected to care for him and subordinate their needs to him".
> (cited in: Simeonsson & McHale, 1981, p.156)

Many parents are aware of the pressures these siblings face, but feel at a loss as to what to do about the situation. In "A Client Called Noah", Josh Greenfeld describes his awareness of the sacrifices his normal son Karl has made to accommodate his autistic brother Noah:

> "It must be awfully hard trying to leave your own childhood behind when your sibling's childhood is perpetual" (1986, p.265)

Psychological demands

Psychological stress is frequently reported, with siblings feeling they need to over-achieve or 'make up' for the limitations of the impaired child. Such demands, whether real or imaginary, can result in at least transitory feelings of resentment or hostility on the part of the siblings (Howlin, 1988).

A number of studies have attempted to assess whether siblings of autistic children are at a greater risk of psychological disturbance than siblings of children with other forms of disability. McHale et al (1986) compared 30 siblings of autistic children with 30 siblings of mentally impaired and 30 siblings of nonhandicapped children. Each child was questioned about their sibling relationship in an open-ended interview, and in the two groups where there was a handicapped sibling, the children were also asked questions about the types of problems they faced with regards to their brother or sister. In addition, mothers were asked to complete a behaviour rating scale which described the positive and negative aspects of their child's behaviour towards the sibling.

Overall, the children and their mothers rated the sibling relationship positively. Group comparisons revealed no significant differences between the children with autistic and mentally impaired siblings on any self-report measure. Children with nonhandicapped siblings reported that their family relations were slightly more cohesive, but otherwise did not differ from the other two groups in terms of their self-reports. These group comparisons, however, focused on each group's mean scores, and the authors noted interesting findings when the data was examined more closely.

A high degree of variability was revealed in the experiences of children with an autistic or mentally impaired sibling. Not all the children in these two groups described their sibling relationships in positive (i.e. socially desirable) ways, and they showed a wide range of responses to the interview questions. In comparison, the responses of children with a nonhandicapped sibling clustered around the mean on each interview scale item. These findings imply that comparative studies which present their results simply in terms of group averages may in fact be concealing high levels of individual variability within sample groups; differences which may well be of theoretical and clinical significance.

Gold (1993) compared 22 siblings of autistic boys (11 sisters and 11 brothers) and 34 siblings of nondisabled boys (17 sisters and 17 brothers) on measures of depression and social adjustment. She found that the siblings of autistic boys scored significantly higher on the Children's Depression Inventory (CDI; Kovacs, 1980-1981) than the siblings in the comparison group. However, the two groups did not differ in terms of their 'social adjustment' scores, as measured by the Parent Report form of the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1981). The author related this finding to the results of other studies which have demonstrated that siblings of disabled children are more likely to manifest *internalising* symptoms than externalising symptoms (e.g. Ferrari, 1984). Gold (1993) claims that her findings highlight the importance of using self-report measures when assessing the psychological state of these siblings, as opposed to relying solely on reports from parents or teachers.

Partial support for Gold's findings emerged in a study published around the same period by Rodrigue et al (1993). These authors compared 19 siblings of severely autistic children with 20 siblings of children with Downs Syndrome and 20 siblings of nondisabled children. Their results also revealed more internalising problems in the group of children with an autistic sibling. In contrast to the findings of Gold's study however, the siblings of autistic children also displayed more externalising behaviour problems (as rated by their parents using the CBCL; see above) than the children in the two control groups. The authors qualify this result, however, by stating that although the mean scores for the siblings of autistic children were higher on these two dimensions, their scores still fell within the normative range. They conclude that siblings of disabled children in general, and siblings of autistic children in particular, are not especially vulnerable to adjustment difficulties.

Maturity of attitudes and behaviour

A number of studies have shown that, far from being harmed by their experiences, siblings of autistic children are often remarkably well-adjusted and frequently show greater maturity, less hostility and more responsibility than their peers (Cantwell & Baker, 1984; McHale et al, 1986; Sullivan, 1979). They have also been reported as having positive self-concepts and as being more altruistic and tolerant generally (Berger, 1980; Howlin, 1988; Mates, 1990).

In one of the few studies which have relied solely on reports given by brothers and sisters of autistic children, Sullivan (1979) invited five siblings to write down some of their own experiences. Although she readily admits that her collection of 'sibling stories' is a modest sample, she claims it gives us some "tone" as to what it is like to be the brother or sister of an autistic child and how this disorder manifests itself throughout the family's environment.

Although each sibling candidly described the stressful aspects of living with the autistic child, as the following selection of statements demonstrates, they were all able to reflect on their experiences and consider some of the positive gains they had also made as individuals:

> “Being in a family with someone “special” to take care of not only makes you mature faster but gives you more experiences and a better understanding of how to handle people as well". (p.290)
>
> "Looking back, it seems to me that what got the family through difficult times was a special talent of responding to the small but wonderful things .... living with Chris made us aware of the little things one hardly ever notices.... We quickly learned the meaning and value of individual differences". (p.292)
>
> "I consider myself to have had a very special upbringing. I learned so much from my brother, indirectly". (p.294)
>
> "I used to think about how nice it would be if I had a normal brother and our family was "normal" like all my friends' families. But after a while I realised that everyone thought that their families were weird ..... In the long run, I am and will be a better person because of him". (p.296)

Some researchers may dismiss these biographical accounts as interesting but anecdotal, biased and lacking in the 'scientific rigor' to warrant serious attention. Others, however, may view such personal descriptions as a rich source of information concerning the experiences of children who live with an autistic sibling; data valid and insightful enough to justify careful consideration. The writer subscribes to the latter point of view, and has chosen a theoretical and methodological framework which endorses the "individual's frame of reference" as a valid point of departure for scientific enquiry.

It was noted earlier, that a number of investigators (e.g. DeMyer, 1979; Sullivan, 1979), have acknowledged the value of face to face discussions with siblings of autistic children in order to gain 'first hand' accounts of their experiences. The present study is an attempt, from within a psychological frame of reference, to add to the small body of systematically gathered commentary regarding the personal experiences of siblings of autistic children.

IV. Theoretical and methodological framework

> "Psychologists, of course, repeatedly involve people in their experiments, but relatively few experimenters seem concerned with them as individuals, preferring generally to see each one as part of a fairly anonymous subject pool. So widely accepted is this view that some may not think it very important that there are striking features of individual people as we know them from everyday experience to which 'experimental' or 'scientific' psychology pays little heed. My own belief, however, is that whatever else it may concern itself with, psychology should be concerned centrally with defining and elaborating individual experience and action".
> (Mair, 1970, p.245)

Mair's comments echo those made by a growing number of psychologists who question the traditional focus of inquiry within psychology. These critics claim that 'traditional psychology' has achieved a rather inadequate and miserable statement of its subject because it has declined to use the idea of 'a person' (Bannister, 1970).

Several philosophers and historians of science have discussed what they see to be as psychology's self-conscious concern with scientific respectability, and its emphasis on appearing scientifically rigorous (e.g. Kuhn, 1970; McWilliams, 1988). The belief among the followers of such a scientific endeavour, is that behaviour alone is "real"; the fear being that unless psychology clings steadfastly to behaviour, the whole discipline may turn out to be a ghastly, ghostly and above all, unscientific misadventure (Bannister & Fransella, 1986). Measurement, according to this approach, consists of making observations of behaviour which are then quantifiable and subject to mathematical and statistical analysis.

Morris (1977) posits, however, that a large portion of psychological research using human subjects relies on subjective reports of what they are thinking, perceiving, hearing, or emoting. She claims, therefore, that the argument as to whether it is acceptable or not to include subjective experience within empirical research is becoming ridiculous. We cannot proceed without it !

In an endeavour to take account of personal meaning, some researchers have adopted the methods of "grounded theory" (Glaser & Strauss, 1967). Such methods have the advantage of leading the researcher in unanticipated directions (Charmaz, 1990; Jackson, 1993), and as such allow the researched some power in determining the content of the data. Yet, whilst

> "personal meaning must not be sacrificed to scientific method"

neither must

> "scientific method be abandoned in the pursuit of personal meaning"
> (Wright, 1970, p.221).

One approach within traditional psychology which rests in the notion that the individual is the 'maker of meaning' yet provides the structure and tools to explore that sense-making in a systematic, methodological and replicable fashion, is Personal Construct Psychology (Kelly, 1955). It is this theoretical paradigm which will be used throughout the present study.

Personal Construct Psychology

Personal Construct Psychology (PCP) is a constructivist approach which emphasises the role each individual plays in constructing his or her own 'subjective reality'. In setting out his theory of personal constructs, Kelly writes:

> "What we think we know is anchored only in our assumptions, not in the bedrock of truth itself, and that world we seek to understand remains always on the horizon of our thoughts" (Kelly, 1977, p.6).

Kelly uses the expression ***constructive alternativism*** to refer to the idea that everything we believe to exist appears to us the way it does because of our present constructions of it. It is not a solipsistic theory, in that it accepts that there is a reality 'out there'. However, PCP argues that we cannot apprehend reality directly. Rather, a person's view of this universe is obtained "through transparent patterns or templates which he creates and then attempts to fit over the realities of which the world is composed" (Kelly, 1955, p.89); in other words, he construes. Construing is an active, ongoing process in which we each try to give meaning to our world and predict future events. For each individual, there is a huge range of alternatives, bounded only by the rules he imposes on the system itself.

A "construct" is

> "... a way in which some things are construed as being alike and yet different from others" (Kelly, 1955, p.105).

That is, whilst they allow definition of what something ***is***, they allow concomitant definition of what something ***is not***.

These ideas are reflected in the Fundamental Postulate of his theory; that

> "a person's processes are psychologically channelized by the way in which he anticipates events" (op cit, p.46).

This statement is elaborated by eleven corollaries, and used together, this structure forms the blueprint for understanding how a person construes and operates within the world. Whilst each corollary has relevance for any work carried out within this framework, of particular importance to the present study are the Individuality, Commonality and Sociality corollaries.

The Individuality corollary

> "Persons differ from each other in their construction of events". (op cit, p.55)

That is, although people may share common ways of organising constructs, the meaning they each attribute to all experience will be personal and unique.

The Commonality corollary

> "To the extent that one person employs a construction of experience which is similar to that employed by another, their psychological processes are similar to those of the person". (op cit, p.90).

It is the Kellian view that no two people ever have an identical construction of experience. However, in terms of cultural experience, Kelly suggests that similarity between people be understood as a similarity in what they perceive to be expected of them. It is also important to bear in mind that Kelly is referring here to similarity of construing and not the verbal labels individuals place upon their constructs (Dalton & Dunnet, 1990).

The Sociality corollary

> "To the extent that one person construes the construction processes of another, they may play a role in a social process involving the other person". (Kelly, 1955, p. 95)

That is not to say that one person, in order to understand another, should construe things in the same way; rather, he/she must be able to construe the other's outlook.

There is now strong evidence from researchers examining the fundamental cognitive deficits in people with autism, that it is this ability to attribute independent mental states to self and others in order to predict and explain actions which is lacking in autistic individuals (e.g. Baron-Cohen et al, 1985; Bowler, 1992; Happé, 1994; Leslie, 1987). The term commonly used in the literature to refer to this process of "mentalising" the cognitive states of others is "Theory of Mind" (see Happé, 1994 for a comprehensive review).

The Repertory Grid

This technique is perhaps the most widely used approach within this framework. Essentially, it is an implementation of the Dichotomy corollary; the assumption being that all construing is bi-polar. Kelly argued that both similarity and contrast are essential to the meaning we give events. Thus, he assumes that we cannot understand what is 'good' without having some idea about what is 'bad', nor 'saints' without 'sinners', nor 'order' without 'chaos' (Fransella & Dalton, 1990, p.9).

Construing goes beyond dictionary definitions. It is more than words. Frequently it is in the opposites that the truly personal meaning of construing becomes evident. For example, for one person the opposite of 'friend' might be 'an acquaintance', whereas for another the contrast pole would be 'enemy'.

A grid has three main components: elements, which define the areas to be investigated; constructs, which reflect ways in which the person groups and differentiates elements; and the linking mechanism, which show how elements are judged on each construct (Beail, 1985). Grids have been used in diverse clinical and research areas, including: eating disorders (Button, 1983; Marsh & Stanley, 1995); depression (Sheenan, 1985); and monitoring change in psychotherapy (Gibson, 1995; Winter, 1985a). However, to the writer's knowledge there is no published work documenting the use of grids with siblings of autistic children.

Before moving on to discuss the present study, it is important to mention the concept of ***reflexivity***. Personal Construct Psychology treats scientists as persons and persons as scientists. Kelly (1955) states the psychology is the study of people by people, and therefore whatever you say or do should be applicable to you the 'researcher'. In contrast, traditional psychology has tended to prefer the paradoxical view that:

> "Psychologists are explainers, predictors and experimenters, whereas the organism, God bless him, is a very different kettle of fish" (Bannister & Fransella, 1986, p.157).

The concept of reflexivity has important implications for our notions concerning empirical research. Whilst the aim of research is still to gain an understanding of some facet of the participant's behaviour or experience, it is essential not to lose sight of the fact that the research question is necessarily part of the researcher's own construct system. Hence, the framework chosen to explore these questions, and the type of data reflect one person's account of several people's stories. As Viney (1989) says of her own work:

> "Some psychologists seek for truth when they carry out their research. Others are not looking for truth but for meaning. This research is of the latter kind". (Cited in: Jackson, 1993, p.29)

V. The present study

A review of the literature concerning siblings of autistic children revealed a dearth of studies which had examined this siblingship from the point of view of the brothers and sisters actually involved. It was Kelly's opinion that:

> "If you do not know what is wrong with someone, ask them, they may tell you" (cited in: Fransella & Dalton, 1990, p.53).

It is from this premise, that the present study was borne.

The decision to adopt a Personal Construct framework was made for a number of reasons:

(1) The findings of McHale et al (1986) highlighted the risk of potentially important individual differences being obscured in group based research. In contrast, a Personal Construct framework emphasises the uniqueness of how each person construes or makes sense of their world.

While a Personal Construct approach is highly idiographic, it also offers the scope to explore commonalities between the construing processes of different individuals. The Commonality corollary states that, as the result of shared cultural and social experiences people may use similar constructs in similar ways. In particular, the repertory grid methodology goes some way towards the integration of 'idiographic' and 'nomothetic' procedures (Bannister, 1985). That is, whilst the grid permits individuals to work with material drawn from their own experience, systems of grid analysis can be used to make comparisons between individuals and to test out hypotheses.

(2) Rather than simply launching in with numerous open-ended questions, the repertory grid technique provides a systematic method for gathering information concerning the child's ways of construing themself and others. It enables the researcher to access each person's own 'language' or construct system, and also allows the researcher to look beyond the words into entire conceptual frameworks.

A further advantage of the repertory grid is that it does not force people into making artificial or meaningless choices, which is sometimes the case when structured questionnaires (which principally reflect the construct systems of the researcher), are used.

(3) Related to this latter point is the finding that people are often intrigued when the researcher demonstrates an interest in their views and is open to their use of language (Loveday-Sims, 1992). From initial consultations with professionals and the parents of autistic children, there was a clear indication that the brothers and sisters of the autistic child felt they were seldom given the opportunity to discuss their own experiences. With little empirical research available to help anticipate the types of issues that might be important to this group of children, a method which allowed them to describe their relationships, "in their own words", was felt to be appropriate.

(4) Finally, the repertory grid technique provides a way of directly assessing the issue of ‘identity problems’ discussed earlier. Constructs are elicited in a process which requires the child to consider ways in which they are both ‘similar to' and ‘different from' the other elements (i.e. siblings and peers). Thus it would be possible to determine which children they feel similar to and different from, and on the basis of which characteristics (constructs).

Having chosen a research methodology, and given the relatively small sample size and time limitations, the aims of this exploratory study had to be considered carefully. It was decided to focus on the following areas:

- 1) To explore the system of constructs siblings of autistic children use to describe themselves and significant others (in this case siblings and similar aged peers), and also to evaluate how they see themselves in relation to these significant others on the same dimensions.

- 2) To compare the nature of the constructs generated by siblings of autistic children with the types of constructs generated by siblings of children with a different form of disability (Downs Syndrome controls) and siblings of nondisabled children (nondisabled controls).

- 3) To use a number of supplied constructs to compare the ways siblings of autistic children view themselves and significant others, with the ratings made by siblings in the two control groups.

- **4)** To compare the repertory grid data with information gained through a short semi-structured interview, in order to assess whether the same core constructs are elicited using these two different methodologies.

METHODOLOGY

VI. Research participants

In all, 45 **nondisabled** children and adolescents between the ages of 8 and 19 years participated in this study (mean age = 13, SD = 3.4). These 45 children belonged in one of the following three groups:

Sib A Group: 15 children who had brothers or sisters who had been diagnosed as mildly, moderately or severely autistic by at least one mental health professional. One female in this group had one older autistic sister and two younger autistic twin brothers. Another boy had two younger autistic brothers. The remaining children had only one sibling with a diagnosis of autism.

Sib DS Group: 15 children who had brothers or sisters who had been diagnosed as suffering from Downs Syndrome.

Sib ND Group: 15 children who had siblings with no apparent physical or cognitive disabilities.

With regards to the choice of comparison groups, siblings of Downs Syndrome children were chosen to control for the effects of having a 'nonnormative' sibling relationship, and siblings of nondisabled children were included in order to examine the types of constructs generated in relation to normal sibling and peer relationships.

Due to the rarity of cases of autism relative to other kinds of disorder, and because the writer's primary interest concerned the effects of this condition on siblings, participation of children in the Sib A group was solicited first.

A clinical psychologist known to the writer and a family support worker from the National Autistic Society approached two parent support groups with details of the study. Subsequently, the writer attended several group meetings and described the study in more detail. Participation in the study was entirely voluntary, and informed consent was obtained from the parents and the siblings.

The parents were given two separate information sheets, one for themselves and one for the sibling of the autistic child (see Appendix A). Parents who believed that one of their autistic child's siblings might be interested in taking part signed a consent form agreeing that the child could be contacted. However, the decision of whether to participate or not was left to the sibling him/herself.

Having recruited the children for the Sib A group, children in the Sib DS and Sib ND groups were chosen to match children in the Sib A group on the basis of gender, family size, and relative birth order (i.e. whether the Sib A, Sib DS, or Sib ND was older or younger than the target child). Children in the Sib DS group were also recruited from parent support groups, and children in the Sib ND group were from local primary and secondary schools. The informed consent procedures described above were undertaken with both comparison groups.

Most of the children came from families of middle socio-economic status (as assessed by their father's occupation). Only one child (a female in the Sib ND group) was non-Caucasian. Table 2. provides data on participants' characteristics in each of the three groups.

Table 2: Proportion (number) of participants with specific individual and family characteristics.

Characteristics	Sib A Group (N = 15)	Sib DS Group (N = 15)	Sib ND Group (N = 15)
Age in years			
8 - 10	.33 (5)	.27 (4)	.27 (4)
11 - 13	.20 (3)	.27 (4)	.27 (4)
14 - 16	.27 (4)	.33 (5)	.27 (4)
17 - 19	.20 (3)	.13 (2)	.20 (3)
Gender			
Male	.53 (8)	.47 (7)	.47 (7)
Female	.47 (7)	.53 (8)	.53 (8)
No. of children in the family Two	.27 (4)	.40 (6)	.20 (3)
Three	.53 (8)	.47 (7)	.53 (8)
Three+	.20 (3)	.13 (2)	.27 (4)
Birth Order			
Firstborn	.47 (7)	.53 (8)	.33 (5)
Middle	.27 (4)	.20 (3)	.53 (8)
Lastborn	.27 (4)	.27 (4)	.13 (2)
Socio-economic Status Lower	.27 (4)	.13 (2)	.27 (4)
Middle	.73 (11)	.87 (13)	.73 (11)

The decision to cover such a wide age range deserves some comment. It has not been uncommon in studies of autistic children, whether considered alone or in relation to comparison groups, to include siblings ranging in age from early childhood to late adolescence (e.g. Bågenholm & Gillberg, 1991; Gold, 1993; Knott et al, 1995; McHale et al, 1986; Rodrigue et al, 1993).

For the purpose of the present study, it was hoped that by involving children of different ages, some limited insight may be gained as to the nature of the constructs generated by siblings at different developmental stages. Findings relating to this variable might then highlight potentially fruitful areas for future research. Finally, it should be stated that a lower age limit of 8 years was set on the basis of research which suggests that children below this age may find verbally labelled constructs too abstract (e.g. Butler, 1985).

VII. Procedure

The data was collected during one visit to the children's homes. These visits were typically between 60 and 90 minutes in duration, and the children were interviewed privately.

At the beginning of the interview, the children were provided with a brief rationale for the study. They were informed that the researcher was interested in how children describe their relationship with their autistic (or Downs Syndrome or nondisabled target) sibling, and also whether they see this relationship as being the same or different to the kinds of relationships they have with other children, for example, other brothers or sisters and other children of their own age. It was explained that there were no right or wrong answers to the questions and that it was what the child themselves thought that was important. When the researcher was certain that the child understood the procedure and was willing to participate, informed consent was obtained.

Interview structure: The children were first asked to complete the repertory grid, which took approximately 30 to 40 minutes to administer. The grid format was presented as a way of making sure that all the children taking part in the study were asked the questions in the same way. It was emphasised, however, that the content of each grid would be different for each child and therefore no two grids would be identical. Following the grid administration, the children were asked a number of open-ended questions which explored further their relationship with the target sibling.

This semi-structured interview lasted about 20 minutes, although this time varied according to the length of time each child wished to discuss the questions.

Measures:

I. GRIDS:

In general, the administration of repertory grids occurs in 5 stages (Beail, 1985):

(1) Eliciting elements
(2) Eliciting constructs
(3) Completing the grid
(4) Analysis
(5) Interpretation

Stage 1: Eliciting the elements

One of the aims of this study was to explore the nature of the constructs generated by siblings of autistic children with regards to their relationships with significant others (siblings and peers). Ideally then, the elements of the grid would represent ***relationships between pairs of individuals*** e.g. 'my relationship with my brother', 'my relationship with my best friend' etc. This form of grid is known as the 'dyad grid' (Ryle & Lunghi, 1970). Constructs can then be generated by asking the individual to compare different relationship pairs, saying in what way they are similar and in what way they are different. However, although immediately relevant to the research question, asking children as young as 8 or 9 years old to compare different relationships was felt to be too complex a task.

An alternative, and in many respects simpler, format of grids is to have each element representing an ***individual person*** e.g. 'myself'; 'my brother'; 'my best friend' etc. The children were therefore provided with the following elements:

(1) Self as I am now
(2) 'Target' sibling (either autistic, Downs Syndrome, or nondisabled)
(3) Other nondisabled sibling(s)
(4) Two liked peers
(5) Two disliked peers
(6) Ideal self

Thus, the minimum number of elements present in any grid was seven (self; target sibling; peer like 1; peer like 2; peer dislike 1; peer dislike 2; and ideal self). A grid would have eight or more elements if the child had other nondisabled siblings in their family. The unequal numbers of elements between grids was important to bear in mind during the analysis stage, when comparisons between different grids were made.

Stage 2: Eliciting the constructs

(A) Generated constructs

Regardless of the number of elements in a grid, the procedure for construct elicitation was the same. For simplicity, each element (representing an individual child) was written on a separate piece of card. Two element cards were then selected, and the child was asked whether they were similar/different in any way. The style of questioning was as follows:

> *"Is there any way you think you and X are like each other ?"*

followed by

> *"Can you think of any way you and X are different ?"*

In order to seek the contrast pole for each description, the child was then asked:

> *"How would you describe someone who wasn't like that ?"*

This process of dyadic comparison continued until every element pair had been contrasted with each other, or until the child could no longer generate any further constructs. The dyadic, as opposed to the traditional triadic sort method advocated by Kelly (1955), was used in this study due to the young age of the children participating in this study.

(B) Supplied constructs

A wide range of idiosyncratic constructs were elicited from the children using the above approach, and this helped to maximise the individual relevance of the task. However, as outlined earlier, the repertory grid technique can also allow for comparisons between individuals, provided a number of standard constructs are included in each grid.

As the third aim of this study was to compare the element ratings of siblings of autistic children with the ratings made by siblings of Downs Syndrome and nondisabled children, 10 constructs were supplied. These constructs were chosen by the writer as being representative of characteristics commonly reported in the sibling and peer literature. It was decided to include these constructs at the end of the grid, so as to encourage the children's spontaneous responses initially.

Four of the supplied constructs were positively framed, three were phrased in a negative way, and three could be considered either positive or negative. The constructs chosen are outlined below, with the numbers referring to the order of presentation which was the same for all the children:

Positively framed	Negatively framed	Positive or Negative
1. Is friendly	3. Annoys me	2. Likes to be alone
6. Tells the truth	5. Is bad tempered	4. Knows what I'm feeling
8. Is someone I like to be with	10. Is selfish	7. Acts silly
9. Is helpful		

The supplied constructs were presented in a unipolar form, and the children were asked to generate their own contrast pole. Thus it was possible to examine how the children were using these constructs by exploring the opposite poles they produced.

Stage 3: Completing the grid

A large sheet of card was laid out in front of the child. Along the top were written the numbers 1-7 (1 being on the far left-hand side, and 7 being at the extreme right-hand side). These numbers were at an equal distance from each other.

Both poles of the generated and supplied constructs were then written on separate pieces of card. The child was asked which pole of each construct he/she would most like to be at; this pole is referred to as the 'preferred pole'. For example, if the construct 'Good at sport vs Not sporty' was generated by a child, and they stated a clear preference for being good at sport, this construct pole would be labelled as the preferred pole. The opposite pole in this example i.e. 'Not sporty' would be seen as the contrast pole. The preferred pole of each construct was placed above the number 1, whilst the contrast pole was placed at the opposite end, above the number 7. This presented the child with a visual rating scale on which to rate each element.

The child was given his/her element cards, and was asked to place each card under the number which best described that element. It was explained that he/she could use any number for any element card and that more than one element could be given the same number on a construct. This process was repeated with all the constructs.

It was anticipated that this procedure would make the grid completion task easier for the younger children, by providing them with a concrete indicator of their ratings. It also made the scoring process easier for the researcher in that elements clusters could be seen at a glance. An example of a completed grid is given in Fig. 1.:

Fig. 1.: An example of a completed grid: Data from child no. 8 in the Sib A group when asked to rate elements 1-8 (E1-E8) on the construct 'Loves cuddles'(preferred pole) vs 'Hates being touched' (contrast pole).

Loves cuddles						**Hates being touched**
1	**2**	**3**	**4**	**5**	**6**	**7**
[E1]	**[E3]**	**[E7]**			**[E2]**	
[E5]	**[E4]**					
[E6]						
[E8]						

Stage 4: Analysis

The completed grids were analysed using a computer program called **GRAN** (Leach, 1988, see Appendix B). This carries out cluster analyses of elements and constructs, and produces a rearranged version of the grid with similar elements and constructs close together. Thus, it is possible to examine which elements (children) are construed as similar and which dissimilar, and also which constructs are considered to be important in distinguishing these relationships.

This study produced 45 grid matrices, and whilst the uniqueness of each child's grid was recognised and respected, there was also an interest in exploring whether there were any commonalties and/or differences in grid structure both within and between each group. According to Bell (1990):

> "Not only have multiple grids caused problems in the amount of data generated, they have also been confronted with a scarcity of methods available to represent them" (p.39)

Multiple grids need to have some feature in common to enable their analysis. When multiple-grid data allow both the elements and constructs to vary, there is no common feature to be represented, so only summary measures can be used (Marsh & Stanley, 1995). To decompose multiple grids in terms of elements, constructs, and grids, it is necessary to supply both the elements and constructs (Bell, 1985). To this end, the 10 supplied constructs were extracted from the grids, and the number of elements within each grid was equalised by removing the 'other nondisabled sibling(s)' elements. This produced 45 10x7 grid matrices which were analysed using the multidimensional scaling (MDS) option of SPSS for windows.

Stage 5: Interpretation

Going beyond the grid: Beail (1985) advocates the use of caution when using computer programs to analyse grid data. He claims that the complexities of analysis are often so elaborate that it becomes difficult to see the connection between the final scores and the original thoughts of the person who completed the grid. A further concern about the interpretation of grids, is that the 'words' used by the person (especially a child) to denote a construct, may have a very different meaning from how an adult (researcher) might interpret them.

In order to minimise such misinterpretations, it is advisable to explore the *meaning* behind each construct in more depth. However, due to the time limitations of the interview, it was not possible to conduct this "construct elaboration" process in the present study. This issue will be addressed when recommendations for future research are considered.

II. SEMI-STRUCTURED INTERVIEW

Following completion of the grid, the children were asked a number of open-ended questions pertaining to their relationship with the target sibling. The format for these questions was adapted from a booklet written by Davis (1992), and similar questions have previously been used in various support groups for siblings of autistic children. The responses made by the children to each question were recorded verbatim by the researcher.

The questions given to the children in the Sib A group were as follows:

(1) What are the most difficult things about having an autistic brother/sister ?

(2) Are there any good things (things you like) about having an autistic brother/sister ?

(3) What things do you enjoy doing with your autistic brother/sister ?

(4) What things would you like to change to make things better for you ?

(5) What things would you like to change to make things better for your autistic brother/sister ?

(6) How do you explain your brother/sister's problems to your friends ?

For the children in the Sib DS group, the same six questions were given, substituting 'Downs Syndrome brother/sister' where appropriate. Children in the Sib ND group were only asked the first three questions, and the name of the target sibling was inserted in place of 'brother/sister'.

III. PARENT QUESTIONNAIRE

Whilst not part of the main study, the writer was interested in whether the levels of problem behaviour exhibited by the autistic child had any effect on how their brother or sister rated them in relation to the other children in the grid. The rationale for gathering this information was the finding that various characteristics of the disabled child may influence the level of adjustment made by their siblings (see pp. 22-23 and Table 1.).

Several authors have investigated the impact of a disabled child's challenging behaviours on family functioning (e.g. Beckman, 1983; Dunlap et al, 1994; Fong et al, 1993; Gold, 1993; Koegel et al, 1983; Rodrigue et al, 1992; Simeonsson & McHale, 1981). The findings suggest that it is the behavioural style characteristics of the disabled child (e.g. temperament) which influences the sibling's behaviour more than the type or severity of the disability.

No short-form measure of problem behaviours in autistic children was available, so the writer devised a checklist of 20 problem behaviours commonly witnessed in autistic children. The items were selected from the subscales of The Childhood Autism Rating Scale (*C.A.R.S*) (Schopler et al, 1988). Hence, this checklist has not been standardised. However, its intention was to provide a general indication as to the level of behavioural disturbance displayed by the autistic child. A copy of the Parent Questionnaire can be found in Appendix D.

If one parent was available during the interview time they were asked to complete the questionnaire. For those who were not available or who did not have the time to fill out the questionnaire immediately, they were asked to send the forms back in a stamped addressed envelope. The response rate to these requests was 100%.

Parents in all three groups were asked to complete sections A and C. Only parents of children with autism were asked to provide information regarding the child's diagnosis in section B.

VIII. Treatment of the data

This study drew upon multiple data sources in order to build up a detailed and richer picture of the experiences of children who have a brother or sister with autism. This process of looking at a question from different sources is sometimes referred to as ***triangulation*** (Fielding & Fielding, 1986; Smith, 1995).

An attempt was made to adhere to an idiographic approach which valued the uniqueness of each child's responses and resisted the temptation to make sweeping generalisations about this sample population by presenting group composite scores. Some comparisons across cases were attempted, but these should be viewed with a degree of caution. The inclusion of the two comparison groups enabled a limited amount of quantitative analysis to take place, but again no firm conclusions concerning between-group differences can be made.

Sources of data and types of analyses chosen

(A) GRIDS

i) Generated constructs: Content analysis and GRAN

Themes were identified and connections between them were examined. Related themes were put together and given a general category heading. For the purposes of this study these categories remain very close to the content of the children's constructs, rather than representing higher level theoretical speculations. Each category was given a code by the writer, and the inter-rater reliability of these codes was assessed by asking a colleague to code a sample of the constructs generated by each group.

By using this process, the first two aims of this study i.e. to explore the nature of the constructs generated by siblings of autistic children and to compare these with the types of constructs generated by the siblings in the two comparison groups were achieved.

The sibling's generated constructs were also analysed using the GRAN computer program. The clustering of elements on each of these constructs were examined and are presented using summary measures. Statistical comparisons between individuals and groups were not possible due to the unequal number of constructs generated by individual children and the differing content of the various constructs produced. However, with regards to the cluster analyses carried out by GRAN, two general predictions can be made for the children in the Sib A group:

Research Hypotheses

(1) Current research in the area of autism would suggest that the autistic child will have observable social impairments. It is therefore not unreasonable to suppose that their brother or sister would have incorporated these aspects of the autistic child's behaviour into their construct system, and may use these characteristics to distinguish their autistic sibling from their nondisabled sibling(s) and peers.

By examining the element tree produced by the grid analysis, such discriminatory processes can identified. The tree shows clusters of elements considered similar or dissimilar. It also highlights 'outliers' i.e. elements which are seen as separate or unique in some way from the other elements. One might then predict that the siblings of autistic children may rate the autistic child as an 'outlier', sharing few characteristics with themselves or with similar aged peers.

(2) The second major hypothesis concerns the nature of the constructs used to discriminate between the autistic sibling and others. The prediction would be as follows: Those constructs which discriminate most between the autistic sibling and others would be expected to be broadly *social* in nature.

Concerning the two comparison groups a number of tentative predictions can be made:

(3) Children in the Sib DS group may also rate their Downs Syndrome sibling differently from their nondisabled sibling(s) and peers on certain dimensions. These may include differences in physical appearance, given the frequently noticeable facial characteristics of individuals with Downs Syndrome. However, due to the Downs Syndrome child's capacity to engage in reciprocal social behaviour, they may be expected to share many of the same characteristics with the other elements.

(4) Siblings of nondisabled children would be expected to show a more even spread in terms of their element ratings, with the target sibling being seen to share many of the same qualities as the other elements.

ii) <u>Supplied constructs</u>: Multidimensional Scaling (MDS)

As outlined earlier, the third aim of this study was to compare the element ratings of the three groups using a number of supplied constructs. This was achieved by extracting the 10 supplied constructs from each child's grid and standardising the number of elements across grids. The 45 10x7 grid matrices were then analysed using the ALSCAL (MDS) option of SPSS for windows.

MDS programs construct geographical representations of the data's structure, usually in Euclidean space of relatively low dimensionality. These representations allow interpretation of the relationships within the data based on the distances between the points representing, in this case, elements and constructs. Thus it is possible to explore how each group use the supplied constructs and how they rate the elements accordingly.

(B) <u>SEMI-STRUCTURED INTERVIEW</u>: Content analysis

To satisfy the study's fourth aim, the recorded responses of the children to each interview question were subject to a content analysis. Themes were extracted, and these were compared with the categories identified for the generated constructs. Comparisons are made at a descriptive level and quotations from the children's statements are provided to illustrate the range of ideas and feelings expressed. In order to keep the assurances of confidentiality, some details which would have exposed the identity of the children had to be changed.

(C) PARENT QUESTIONNAIRE: Descriptive & Correlational analyses

The demographic details from section A of the Parent Questionnaire are shown in Table 2. (p. 44). The analysis of the data collected in sections B (Diagnosis) and C (Problem Behaviours) can be found in Appendix D.

Information concerning the diagnosis is presented at a descriptive level. A total severity score for problem behaviours was computed for each target child, and a correlational analysis between this variable and the grid structures obtained in the GRAN analysis of the generated constructs was undertaken.

RESULTS

IX. THE GRIDS

i) GENERATED CONSTRUCTS

(A) *Content analysis*

Using the process of dyadic comparison described earlier, a large number of heterogeneous constructs were generated by the 45 children taking part in this study. This produced a wealth of data which are here subject to a preliminary content analysis.

The total number of constructs generated by the children within each group are shown in Table 3. below:

Table 3.: Total number of constructs generated by each group.

Group	Total N =	Mean	SD	Range
Sib A	190	12.7	2.64	8 - 16
Sib DS	200	13.3	2.66	6 - 17
Sib ND	182	12.1	1.55	10 - 15

On average, the children generated between twelve and thirteen constructs, although a degree of individual variation within each group is evident when the measures of dispersion are examined; with some children generating as few as six constructs while others produced as many as sixteen or seventeen.

Of interest to the present study, however, is not the number but the ***nature*** of the constructs generated by the children; that is the content and meaning of the constructs they use to describe themselves and their siblings and peers.

In order to analyse this data, one has to first interpret it. This involves a process of "abstracting from the immense detail and complexity of our data those features which are most salient for our purpose" (Dey, 1993, p.94). However, it is essential to remember what we are abstracting from. As the Taoist Chung Tzu wrote:

> "Fishing baskets are employed to catch fish; but when the fish are caught, the men forget the baskets; snares are employed to catch hares; but when the hares are got, the men forget the snares. Words are employed to convey ideas; but when the ideas are grasped, men forget the words".
>
> (Cited in Dey, 1993, p.94)

An attempt was made in the present study to remain close to the content of the children's constructs ("the words"), when organising the data for the purpose of group comparisons. It was anticipated that this would fulfil the dual aims of reducing the vast number of generated constructs into a coherent structure for comparison purposes, whilst retaining a strong link with the original data from each child's grid. The process of categorisation will be described in more detail below.

Categorising the constructs

The very quality of qualitative data - its richness and specificity - makes it difficult to make comparisons between the various items of information collected (Dey, 1993). Typically, comparisons are made by categorising the items according to their similarities or differences; with each category being allocated a separate code for identification purposes. There are three main operations in this process: (1) noticing relevant phenomena, (2) collecting instances of these phenomena, and (3) analysing these phenomena in order to find commonalties, differences, patterns, structures etc. (Seidel & Kelle, 1995).

(1) Noticing relevant phenomena

This is the central task of the researcher who enters an empirical field without ready-made hypotheses (Seidel & Kelle, 1995). As previously discussed, the rationale for adopting a Personal Construct framework in this study was the lack of information in the literature concerning the nature of the relationships children have with their autistic brother and/or sister. Thus it was not possible to begin this study with a set of pre-arranged categories or responses.

However, this should not imply that the writer had no theoretical preconceptions as to the types of constructs which would be generated. As Dey (1993) argues, an open mind does not mean an empty head. Seidel and Kelle (1995) refer to these conceptual networks as perspectives rather than 'hypotheses' or 'theories'. These perspectives help the researcher to select relevant phenomena, and of course different researchers with different perspectives will select different phenomena.

All the constructs generated by the children were read through carefully by the writer, and common themes were noted. Related themes were put together and given a category heading. Using this procedure, four major categories were identified (these will be referred to as superordinate categories). A description of each category is given below:

I. Characteristics of the Person: This is a broad category capturing those constructs which describe some characteristic of the person (element) him/herself. This superordinate category is divided into 10 subcategories, each referring to a more specific quality of the person. Each subcategory is given a separate code number (1-10). These categories are displayed in Fig. 2(a).

II. Characteristics of the interaction between the Person and Others: A large number of constructs refer to characteristics of the interaction between the person described and other people. This superordinate category is divided into 3 subcategories; two of which refer to the ***level*** of interaction between the person and others (quantitative aspects - codes 11 & 12), whilst the third refers to the ***style*** of the person's interactions with others (qualitative aspects - code 13). This set of categories is shown in Fig. 2(b).

III. Attitudes and responses of Others to the Person: Although every construct generated using the repertory grid technique reflects the attitudes of an 'other' (i.e. the individual completing the grid) towards the person, it was clear that many of the constructs refer to attitudes of people 'in general' towards the person. Examples of the criteria for inclusion in this category (code 14) are given in Fig. 2(c).

IV. Family characteristics/circumstances: This superordinate category is divided into 4 subcategories (codes 15-18); each pertaining to a different characteristic of the person's family. These categories are shown in Fig. 2(d).

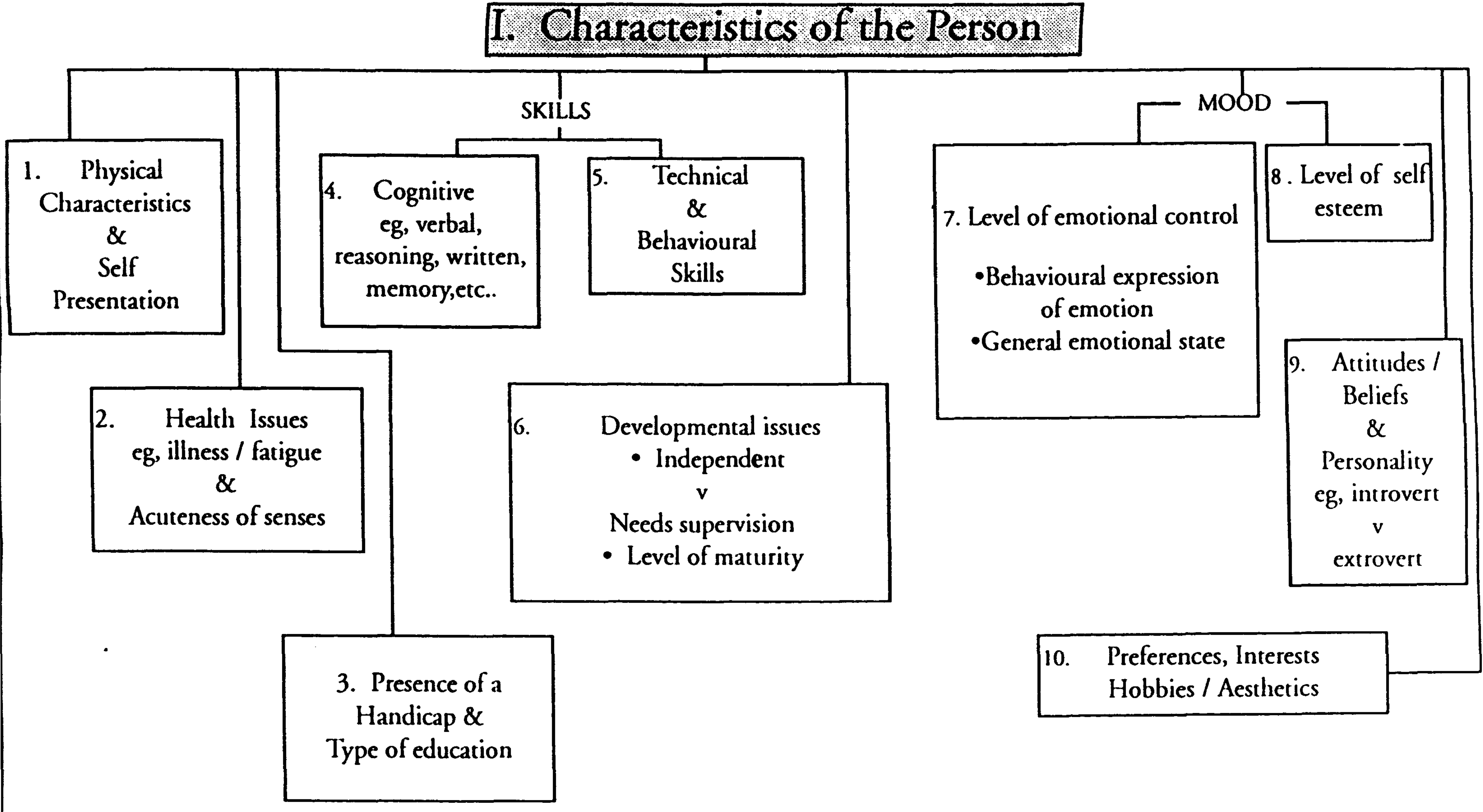


Fig 2.(a) Category I : Characteristics of the person. Breakdown of the 10 subcategory codes. Inclusion criteria are given in each box.

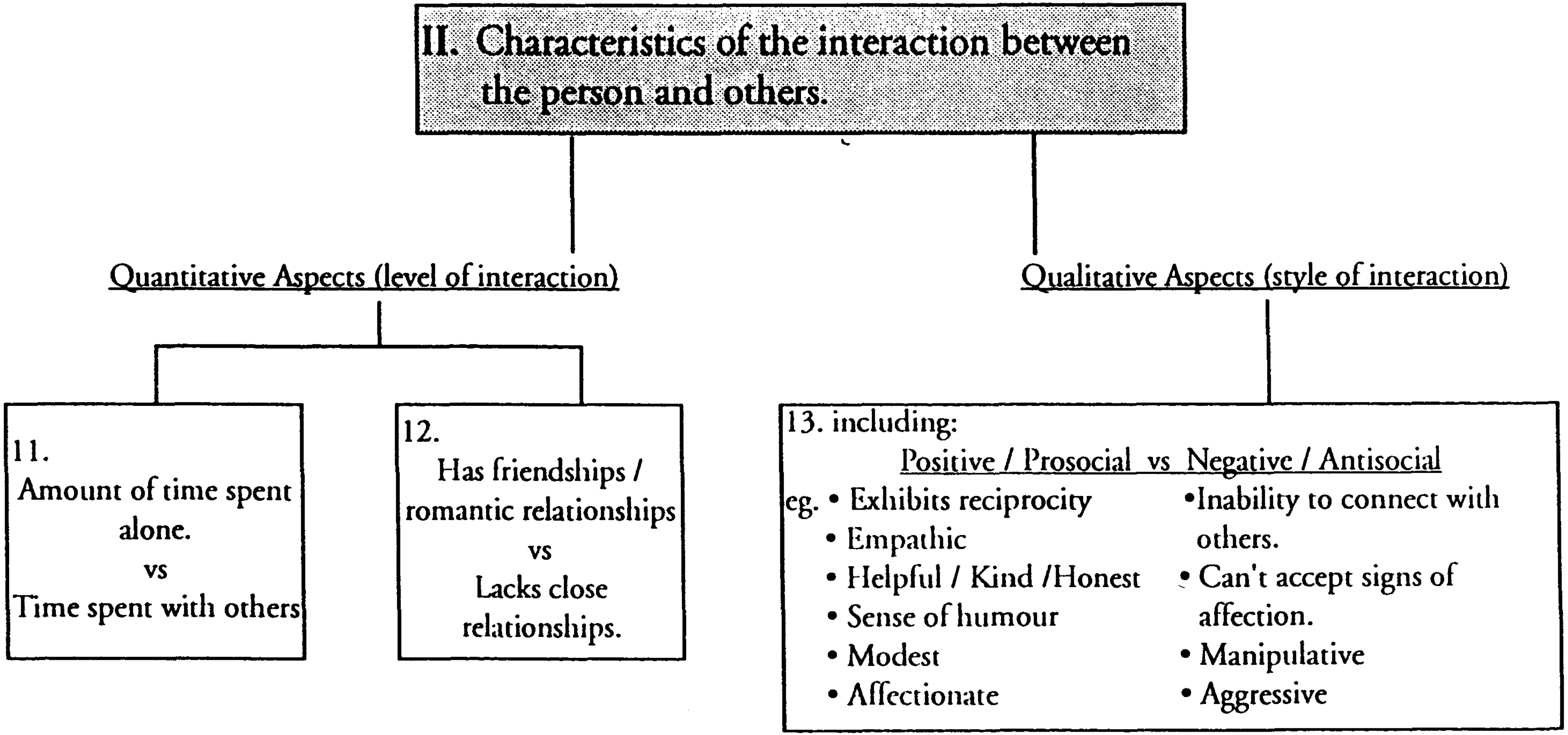


Fig 2.(b) Category II : Characteristics of the interaction between the person and others. Breakdown of the 3 subcategory codes. Inclusion criteria are given in each box.

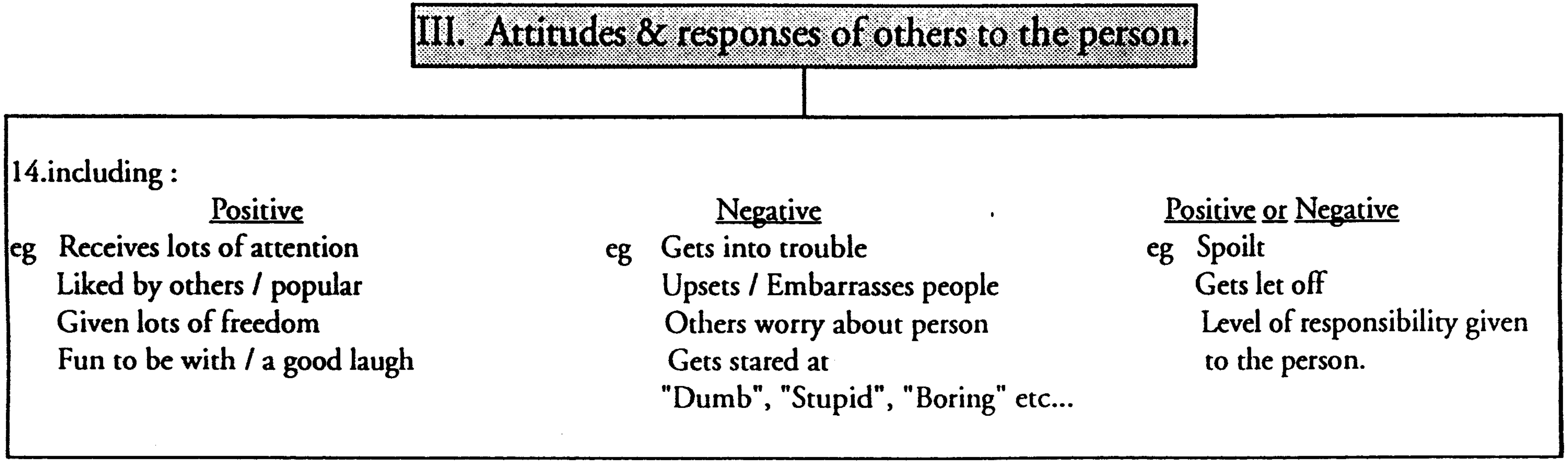


Fig 2.(c) Category III : Attitudes and responses of others to the person. Inclusion criteria are given in each box.

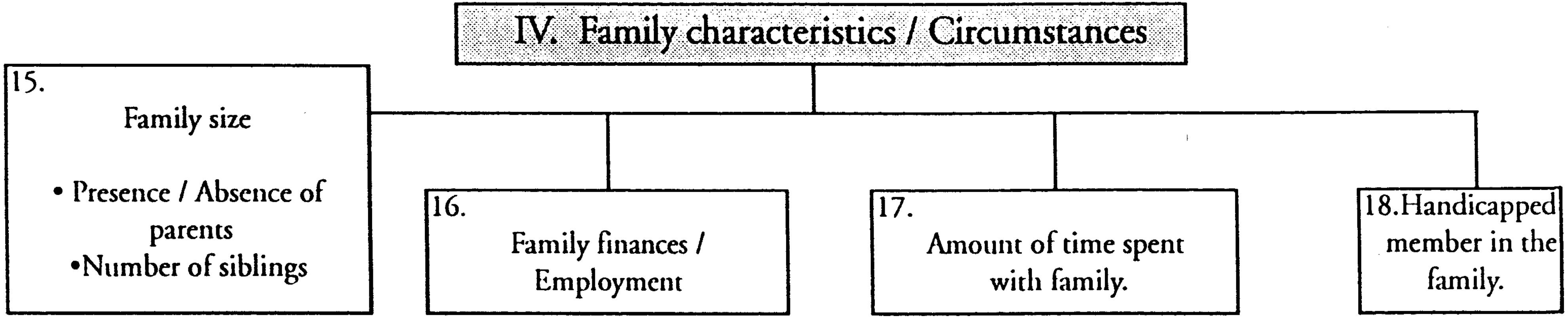


Fig 2. (d) Category IV : Family characteristics / Circumstances - Breakdown of the 4 subcategory codes. Inclusion criteria are given in each box.

(2) Collecting instances of relevant phenomena

The constructs generated by the children in all three groups were categorised using the 18 codes outlined in Figs. 2 (a)-(d). A brief description of the criteria for inclusion in a particular subcategory is given in each code-box. Each construct was given a single code number by the writer.

Bearing in mind the point made by Seidel and Kelle (1995), that the perspectives of one researcher may differ from those of another, a colleague was asked to independently code a random sample of the constructs generated by each group using the writer's system of categories (see Appendix C for a more detailed description of this analysis). This process produced inter-rater reliability (kappa) scores of .809, .724, and .791 , for the constructs generated by the Sib A, Sib DS, and Sib ND groups respectively. Bakeman and Gottman (1986) recommend kappa scores of .7 ; and so with the high agreement between raters using the same categorisation system, it was felt that the analysis of these constructs could proceed with greater certainty.

Table 4. shows the percentage of constructs generated by each group of siblings which fall into each subcategory. No attempt was made to determine whether the number of constructs generated by each group within each category were significantly different (e.g. a 3x4 analysis of variance; Group x Superordinate category), due to the small number of constructs within each category.

Table 4: Percentage of generated constructs falling into each category for each sibling group.

Category	Sib A N = 190	Sib DS N = 200	SibND N =182	Total
I. Characteristics of the person				
(1) Physical characteristics & Self presentation	5.8	2.5	8.8	5.7
(2) Health Issues & Acuteness of senses	3.2	3.0	1.1	2.4
(3) Presence of a handicap & Type of education received	3.2	3.0	0.6	2.3
(4) Skills - Cognitive	4.7	3.5	6.6	4.9
(5) Skills - Technical & behavioural	3.2	5.0	7.1	5.1
(6) Developmental Issues	4.7	8.5	1.1	4.8
(7) Mood - level of emotional control etc.	11.1	10.0	6.0	9.0
(8) Mood - level of self esteem	3.2	1.5	1.6	2.1
(9) Attitudes / Beliefs & Personality	10.5	13.0	17.6	13.7
(10) Preferences / Interests etc.	4.2	6.5	9.9	6.9
II. Characteristics of the interaction between person & others.				
(11) Amount of time spent alone vs with others	1.1	0.0	0.0	0.4
(12) Has/Doesn't have close relationships	2.6	1.5	1.1	1.7
(13) Style of interaction	23.1	26.5	27.5	25.7
III. Attitudes & responses of others to the person				
(14)	15.8	14.5	9.3	13.2
IV. Family characteristics / circumstances				
(15) Family size	2.1	0.5	0.6	1.1
(16) Family finances / employment	0.5	0.0	1.1	0.5
(17) Amount of time spent with family	0.5	0.5	0.0	0.3
(18) Handicapped member in the family	0.5	0.0	0.0	0.2

This summary table shows that the most frequently used subcategory by children in all three groups was "the style of interaction between the person and others" (code 13). Perhaps the large number of constructs falling into this subcategory is not surprising considering the grid task was presented to the children as a way of finding out about their 'relationships' with other children - implying an interest in their ***interactions*** with others.

Within the first major category, "characteristics of the person", the children in this study generated a large number of constructs pertaining to the "attitudes/beliefs and personality of the person" (code 9). Constructs describing the person's affective state (code 7); their preferences, interests and hobbies (code 10); and their physical appearance (code 1) were also frequently employed. The two subcategories which displayed the greatest group differences were code numbers 3 and 6 i.e. "presence of a handicap/type of education received" and "developmental issues". These codes were used more by children in the Sib A and Sib DS groups.

The Sib A group was the only group to generate constructs relating to the amount of time spent with others (code 11). Although the numbers are small, this finding may well be significant if one considers the "autistic aloneness" described by Kanner (see Frith, 1989, p.8). The autistic child's avoidance of social interaction may be an important characteristic which has become incorporated into the construct systems of some siblings.

There was a slight tendency for children in the Sib A and Sib DS groups to use code 14, "attitudes and responses of others to the person", more often than children who had a nondisabled sibling. Of interest to the present study would be the element(s) to which these constructs are applied, and also the specific nature of these constructs. For example, are the constructs relating to the attitudes of others to the person generated more in response to the target sibling as opposed to the other elements, and if so, are the target siblings in these two groups the recipients of positive or negative attitudes from others ?

The numbers of constructs generated in the fourth major category "family characteristics/circumstances" were small across all groups.

(3) Analysing the phenomena

There are various systems of analysis available to analyse repertory grids which are able to reveal important features of the grid that might not be obvious at first sight. The computer program **GRAN** (Leach, 1988, see Appendix B) was used to test out the research hypotheses described earlier (pp. 58-60). The results of this analysis will be presented below.

(B) *GRAN analysis*

GRAN produces a matrix of distances between elements. These element distances were used to explore Hypothesis 1:

> (1) That the siblings of autistic children will rate their autistic brother or sister as an 'outlier', sharing few characteristics with themselves or with similar aged peers.

GRAN also produces a rearranged grid, which allows the second major hypothesis to be evaluated:

> (2) Those constructs which discriminate most between the autistic sibling and the other elements will be broadly *social* in nature.

Hypothesis 1: Element Distances

The self-other element distances were extracted from each child's element distance matrix. For the two children in the Sib A group who had more than one autistic sibling, an average self-target sibling rating was calculated. Mean self-nondisabled sibling ratings were also taken for those children who had more than one nondisabled sibling.

Table 5. shows the average self-other element distances for children in each of the three sibling groups. Small values indicate that the two elements are viewed similarly

across the constructs. For brevity, the following abbreviations will be used to denote the elements in all tables and diagrams throughout the results section:

T. Sib = Target sibling; ND Sib = nondisabled sibling; PL1/PL2 = Peer like 1/2; PD1/PD2 = Peer dislike 1/2; IS = Ideal Self.

Table 5: Average self-other element distances for children in each group. (using inter-element distances arising from GRAN's output)

Group	T. Sib	ND Sib	PL1	PL2	PD1	PD2	IS
Sib A							
$\bar{X}$	36.5	13.9	10.1	11.0	26.3	22.8	10.4
SD	9.8	5.7	6.9	8.1	13.9	12.8	6.6
Sib DS							
$\bar{X}$	23.1	17.9	6.7	6.7	30.4	25.2	6.1
SD	9.1	9.0	5.6	5.3	13.5	12.8	5.4
Sib ND							
$\bar{X}$	10.7	11.8	7.9	9.0	33.9	32.2	4.9
SD	7.4	4.6	6.1	4.9	12.3	14.9	3.9

On average, children in all three groups see themselves as closest to the two peer like elements and to the ideal self. They also see themselves as being similar in many respects to their nondisabled sibling(s). The self-peer dislike element distances are greater across all groups, indicating that the children in this sample see themselves as sharing few characteristics with disliked peers. However, a degree of caution should be exercised when interpreting these results due to the high levels of variability in the self-other element ratings (min-max. SD = 3.9-14.9).

From the data shown in Table 5., the main focus of interest are the self-target sibling distances. These are analysed further below.

'Identification' with the target sibling

Fig. 3. shows a stem-and-leaf display of the self-target sibling distances for each of the three groups. This presentation has the advantage of preserving the original data, whilst presenting it in a visually meaningful way.

Fig. 3.: Stem-and-leaf display of the self-target sibling element distances for children in the Sib A, Sib DS and Sib ND groups.

Stem width = 10.0
Each leaf = 1 case

	Sib A	Sib DS	Sib ND
6	0		
5	0		
4	0 1 2 3	5	
3	0 1 1 1 1 3 6	5	
2	0 9	2 2 2 4 6 6 7 8	4 7
1		0 1 4 5 9	0 0 0 0 5 8
.			2 3 4 4 7 8 8

A Kruskal-Wallis one-way analysis of variance demonstrated highly significant differences in the self-target sibling distances of each group ($X^2_{(2)} = 29.02$, $p<.001$). Pairwise comparisons using the Mann-Whitney U test, with an adjusted significance level of 0.05/3 = 0.017 (as recommended by Leach, 1979), demonstrated that the self-target sibling distances in the Sib A group were significantly higher than the self-target sibling distances in both the Sib DS ($z = 3.5$, $p<.005$), and the Sib ND ($z =$

4.6, p<.001) groups. The self-target sibling distances in the Sib DS group were also significantly greater than the distances in the Sib ND group (z= 3.5, p<.006).

It can therefore be stated with a high degree of confidence that there is less identification with the target sibling in the Sib A group than in the two control groups. Furthermore, although the self-target sibling distances are smaller in the Sib DS group, these children identify less with their target sibling than do children in the Sib ND group. This would support the view that siblings of children with some form of disability are less likely to identify themselves with the disabled child. From the results of this analysis, having a sibling with autism appears to accentuate this perception of being "different from" the disabled child than does having a sibling with Downs Syndrome.

A visual inspection of the stem-and-leaf display highlights individual variability in the levels of identification with the target sibling within each group. The highest levels of variation occur in the Sib A group, where it can be seen that whilst one sibling places himself at a great distance from the autistic child (60), another identifies relatively closely with their autistic sibling (20).

In the Sib DS group, the self-target sibling distances of most children are somewhere in the region of 10-28. However two children in this group draw a sharper distinction between themselves and the target sibling; producing distances of 35 and 45. There is a more even spread of self-target sibling distance scores in the Sib ND group, but a degree of variation is still present.

The results of the previous analysis clearly show that the children in the Sib A group (and to a lesser degree in the Sib DS group) see their target sibling as sharing few characteristics with themselves. However, the question remains as to whether the autistic child is generally rated as an 'outlier' i.e. as being different from the other elements in the grid. A similar analysis to the one undertaken with the self-target sibling distances was therefore conducted to assess the outlier status of the target sibling in each group.

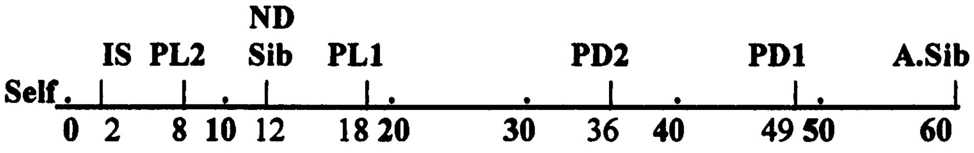
'Outlier' status of the target sibling

The first problem encountered in this analysis was deciding how to define an 'outlier'. A conservative estimate of outlier status would be to take this as the distance between the target sibling and the next closest element. However, this measure was not felt to be appropriate considering the high self-peer dislike distances. Had these been used as a sole marker of outlier status, this would have resulted in an underestimation of the distance between the target sibling and the majority of elements; which tended to form a tight cluster i.e. self, liked peers, ideal self and nondisabled sibling(s).

In order to give a more accurate estimate of how different the target sibling was seen to be from the majority of elements, it was decided to use the distance of the target sibling from the ***median*** self-other element distance, that is the value which lies in the middle of the distribution.

Fig.4. demonstrates how the outlier status of the target sibling differs when each of these methods is used. The example given uses the element distance matrix from one of the children in the Sib A group.

Fig. 4.: Self-other elements line distribution for child no.15 in the Sib A group (using inter-element distances)



This child's self-other elements distances show that they perceive themself to be similar to their ideal self, the two liked peers and their nondisabled sibling, but dissimilar to both peer dislike elements and their autistic sibling. If the outlier status of the autistic sibling in the above example was defined as the distance from the next closest element, this distance would be 60-49 = 11. However, if the measure of outlier status is calculated using the median value of the self-other distances (15 in the above example), the outlier status would become 60-15 = 45. The latter value gives a more accurate reflection of the distance the target sibling is from the core group of elements.

The stem-and-leaf display in Fig. 5. shows the outlier status of the target sibling in each of the three groups. Smaller values indicate that the target sibling is seen as closer to the core group of elements. Negative values would place the target sibling in the midst of the core group.

Fig. 5.: Stem-and-leaf display of the 'outlier' status of the target sibling in the Sib A, Sib DS and Sib ND groups.

Stem width = 10.0
Each leaf = 1 case

	Sib A	Sib DS	Sib ND
5			
4	5		
3	1 3 8	0	
2	0 2 2 4 9	0 4	
1	0 1 3 7 7	1 1 6 6 6 8	0 1
.		1 3 7 9	0 4 5
0			
-.	2	5 9	1 1 2 2 3 5 5 6 6
-1			4
-2			

A Kruskal-Wallis one-way analysis of variance demonstrated highly significant differences in the outlier status of the target sibling in each group ($X^2_{(2)} = 22.15$ $p<.001$). Pairwise comparisons using the Mann-Whitney U test, with the adjusted significance level of 0.05/3 = 0.017, showed that the outlier status of the target sibling was significantly greater in the Sib A group than in both the Sib DS ($z = 2.4$, $p<0.015$), and Sib ND ($z = 4.3$, $p<.001$) groups. The target sibling was also seen as more of an outlier in the Sib DS group than in the Sib ND group ($z = 3.1$, $p<.002$).

These findings support the first hypothesis; that the autistic child is seen as an outlier, sharing few characteristics with the other children being rated. The target sibling in the Sib DS group is also seen as being different to the other elements, although from the positioning of the leaves in Fig 5., a degree of overlap is evident between the ratings made by this group and those given by the siblings of nondisabled children.

There is less overlap in the outlier status scores of the Sib A and Sib ND groups. This suggests that it is not the presence of a 'disability' which sets the autistic child apart from the other children being rated. Had this been the case, the outlier ratings would have been similar in the Sib A and Sib DS groups. Thus it appears that there are some characteristics of the autistic child which obviously distinguish them from the other elements.

Identifying the types of constructs which discriminate most between the autistic sibling and the other elements was the aim of the second stage of the GRAN analysis.

Hypothesis 2: Discriminatory constructs

Fig. 6. shows an example of a rearranged grid produced by GRAN. This example uses data from the analysis of a grid produced by a child in the Sib A group. Some construct labels are abbreviated.

In this example grid, it is clear that a number of constructs can be identified which distinguish the autistic sibling from the other elements. The autistic child is seen as an outlier on the constructs "Doesn't have many obsessions vs Has lots of obsessions" and "Able to have their own life when an adult vs Isn't able to have a life of their own". Having obsessions and being dependent on others are two characteristics which are seen to be applicable only to the child with autism.

Fig. 6.: Example of the rearranged grid output from GRAN. Data from child no.5 in the Sib A group.

Elements								
Self	**ND Sib**	**IS**	**PL2**	**PL1**	**PD1**	**PD2**	**A Sib**	**Constructs**
1	1	1	1	1	1	1	7	Doesn't have obsessions / Does have
1	1	1	1	1	1	1	5	Able to have own life when adult /Isn't
3	2	2	2	3	3	1	6	Chatty / Doesn't talk to many people
2	4	1	2	2	2	2	6	Can take care of self / Can't
3	4	1	2	3	1	1	6	Confident / Quite shy
3	4	3	4	2	5	5	1	Very tidy / Messy
1	1	1	1	1	6	4	4	Not a bully / Bullies
2	1	2	4	4	5	5	7	Likes cuddles / Doesn't
2	1	1	2	2	4	4	6	With others most of the time / Alone
3	3	1	3	2	5	6	6	Well behaved / Naughty

Although the elements differ in how "chatty" they are, the autistic child is still perceived as being different on this construct. The issue of lacking independence is again used to discriminate the autistic child from the other elements in the construct "Can take care of themself vs Can't look after themself". The child with autism is also considered less confident than the other elements.

There is less discrimination between the autistic child and the other elements on the constructs in the lower half of the grid. Although the autistic sibling tends to remain at the contrast pole of each construct, so too are the peer dislike elements. The autistic child thus becomes part of a "cluster" of elements rather than being seen as completely different. They are included in element clusters at both the preferred pole i.e. "Very tidy vs Messy", and the contrast pole e.g. "Well behaved vs Naughty".

This process of examining the rearranged grid in order to identify the constructs which discriminate most between the autistic sibling and the other elements was undertaken with the data from the other children in the Sib A group. The same procedure was followed using the rearranged grid data from the two control groups. The findings from these examinations are described below.

Analysis of the rearranged grid data

Only those constructs which clearly differentiated the target sibling from the other elements will be discussed i.e. the constructs where the target sibling is seen as an outlier and is not included in any cluster of elements. A distance of 3 or more rating points was used as an estimate of outlier status e.g. the target sibling is given a rating of 6 on a particular construct whilst the nearest other element(s) had a rating of 3 or less. The pole where the target sibling is placed is indicated in **bold** print.

Sib A Group

Of the 190 constructs generated by the children in this group, 49 (i.e. 25.8%), clearly discriminated the autistic child from the other elements. Using the 18 subcategories developed during the content analysis stage, these constructs were each given a code number. The discriminatory constructs were found to fall into ten of the subcategories. These are presented below:

Code 3: Presence of a handicap & Type of education received

Six discriminatory constructs fell into this subcategory. Examples of these constructs are given below:

Normal ---- **Handicapped**
Normal ---- **Autistic**
Normal ---- **A bit odd**

Goes to normal school ---- **Goes to a special school**

It is interesting to note that the contrast poles of the constructs pertaining to the presence of a handicap differ in their specificity. Whereas one child uses the general term 'handicapped' to describe their autistic sibling, another is more specific about the nature of the disability. If the contrast pole in the third example was taken out of context, there would be little indication that it relates to the presence of a handicap. This meaning only becomes apparent when it is seen that this characteristic is used to distinguish the autistic child from the other elements.

Code 4: Skills - Cognitive

The autistic child was discriminated on six constructs in this subcategory:

Can speak well ---- **Can't speak well**
Can talk ---- **Can't talk (x2)**
Understands what things mean -- **Doesn't understand what things mean**

Can write ---- **Can't write**
Intelligent ---- **Not intelligent**

The autistic child is seen to lack various cognitive skills which the other elements possess, particularly to do with language. Two children used constructs referring to a general lack of intelligence/comprehension to describe their autistic sibling.

Code 6: Developmental Issues

Eight discriminatory constructs fell into this subcategory; which refers to the person's level of independence and/or maturity. The nature of these constructs were as follows:

Goes out on own ---- **Doesn't go out on own**
Able to have their own life when adult ---- **Not able to have a life of their own when adult**
Can take care of themself ---- **Can't look after themself**
Acts right ---- **Acts funny**
Mature ---- **Like a kid**
Streetwise ---- **Naive**

It is clear from these findings that the autistic sibling is considered less mature and more dependent when compared with the other elements. The distance between the autistic child and the other elements was greatest on the construct which anticipated the future dependency needs of the autistic child (i.e. when an adult). No other element was seen to require ongoing care.

Code 7: Mood - emotional states and behaviour

There were seven constructs within this subcategory on which the autistic sibling was seen as an outlier. These included:

Patient ---- **Loses it**
Patient ---- **Gets frustrated**
Laughs a lot -- **Doesn't laugh much**
Not scared ---- **Gets frightened easy**
Happy ---- **Sad**
Doesn't have many obsessions --- **Has obsessions**

While some of the other elements were seen to be slightly impatient, fearful, and unhappy, the ratings for the autistic child placed them at a great enough distance on these constructs to be considered an outlier. Obsessional behaviour was seen as unique to the autistic child.

While the writer considered obsessional behaviour to be a sign of poor emotional control, others might construe this characteristic as either a handicap or a personality trait. The permeability of the categories developed in this study will be discussed later.

Code 8: Mood - level of self esteem

Four constructs in this subcategory were used to distinguish the autistic siblings:

Confident ---- **Shy (x3)**
Not shy ---- **Lacks confidence**

Although some of the other elements were perceived as being somewhat shy, the autistic sibling tended to be placed at the extreme end of the contrast pole.

Code 9: Attitudes/Beliefs and Personality

Five constructs discriminated the autistic child from the other elements in this subcategory:

Emotional ---- **Practical**
Talks a lot ---- **Very quiet**
Outgoing ---- **Shy**
Outgoing ---- **Quiet**
Loud ---- **Quiet**

The autistic child was perceived as being more introverted than the other elements. They were also seen by one child as being less emotionally led.

Code 11: Amount of time spent alone vs with others

One child distinguished their autistic sibling from the other elements using the construct:

With other people most of the time ---- **On their own a lot**

This construct appears to capture the characteristic "autistic aloneness" described by Kanner (see Frith, 1989, p.8).

Code 12: Has close relationships vs Lacks close relationships

Another child used the following construct to distinguish their autistic sibling from the other elements:

Has friends ---- **Doesn't have many friends**

This child sees their autistic sibling as lacking in the close relationships the other elements form with people.

Code 13: Style of interaction between the person and others

Seven discriminatory constructs fell into this broad category. The content of these constructs are given below:

Can tell jokes ---- **Not funny**
Affectionate ---- **Doesn't show emotion**
Loves hugs ---- **Hates being touched**
Chatty ---- **Doesn't talk to many people**
Can be with others ---- **In a world of their own**

The style of interaction between the autistic child and others is seen to be qualitatively different on these constructs. A poor sense of humour is noted in the autistic child. They are also perceived as being less able to give and receive overt signs of affection. There is a general sense of the autistic child being "separate" from the people around him.

Code 14: Attitudes and responses of others to the person

Four constructs in this subcategory discriminated between the autistic child and the other elements:

Reliable ---- **Can't rely on**
Popular ---- **Not popular**
Doesn't upset people ---- **Upsets people**
Has lots of freedom ---- **Parents watch everything you do**

These constructs see the autistic child as being the recipient of negative responses from other people. One child felt that their autistic sibling was given little freedom by their parents.

Sib DS Group

From the GRAN analysis using the element distance matrices, it was shown that the target siblings in the Sib DS group were rated as being less of an outlier than the target siblings in the Sib A group. Of the 200 constructs generated by the children in the Sib DS group, only 24 (i.e. 12%) were found to discriminate the Downs Syndrome child from the other elements. These constructs fell into five of the 18 subcategories developed in the content analysis stage. These findings are summarised below:

Code 3: Presence of a handicap & Type of education received:

Five discriminatory constructs fell into this subcategory, and the content of these constructs was similar to those generated by the children in the Sib A group. For example:

Normal ---- **Handicapped**
Doesn't have learning disabilities ---- **Has learning disabilities**
Doesn't look Downs ---- **Has a special look; Downs**
Attends normal school ---- **Attends special school**

For one child in this group, the noticeable physical characteristics of the Downs Syndrome child were incorporated into their construct system relating to the presence of a handicap.

Code 4: Skills - Cognitive: Only two constructs in this subcategory were used to distinguish the Downs Syndrome sibling from the other elements:

Can speak ---- **Can't speak**
Learns lots of things ---- **Doesn't learn things well**

A lack of speech was identified as a discriminatory characteristic by only one child in the Sib DS group. Another child considered their Downs Syndrome sibling to be less able to learn things than the other elements.

Code 6: Developmental Issues: This was the most commonly used subcategory to discriminate between the Downs Syndrome sibling and the other elements (10 constructs). The nature of the constructs relating to levels of independence and maturity were similar to those generated by children in the Sib A group. Examples include:

Independent ---- **Needs looking after**
Will do own thing ---- **Needs lots of security**
OK on their own ---- **Needs looking after**
Acts age ---- **Immature**

Code 13: Style of interaction between the person and others: There were four discriminatory constructs in this subcategory:

Forgiving ---- Holds grudges
Chats the guys up ---- Doesn't chat up guys
Shows affection ---- Feels uncomfortable showing affection
Affectionate ---- Not a warm person

Whilst the target sibling in the Sib A group was placed at the extreme end of the contrast pole on the discriminatory constructs in this subcategory, the target sibling in the Sib DS group was perceived to be *more* affectionate and sociable than the other elements on the constructs shown above.

Code 14: Attitudes and responses of others to the person: Three constructs in this subcategory were used to discriminate the Downs Syndrome sibling:

Has lots of freedom ---- **Doesn't have much freedom (x2)**
Doesn't get stared at ---- **Get's stared at**

As was the case in the Sib A group, the child with a disability is distinguished from the other elements on the basis of their lack of freedom. One child was aware of their Downs Syndrome sibling being stared at (negative attention).

Sib ND Group

The target siblings in the Sib ND group were not seen as outliers on any of the constructs generated by the children. On a number of constructs they were discriminated from the cluster of elements at the preferred pole. However, on these rare occasions, they formed part of a cluster of elements towards the contrast pole of the construct.

Summary: Generated Constructs

The two analyses using the children's generated constructs have provided some insight into the nature of the constructs which are important to siblings of children with autism, and have enabled comparisons to be made between these constructs and the types of constructs generated by children with Downs Syndrome or nondisabled siblings. Using the computer program GRAN, it was possible to explore the ratings of each element on each construct, and to determine which constructs are most useful in discriminating between the target sibling and the other elements.

Whilst each child's grid is valid in its own right, and deserves to be examined closely for its unique features, the writer was also interested in examining whether there were any common features in the grid structures generated by the children in the Sib A group which could distinguish them from the children in the two control groups.

The analysis of multiple grids can take several grid structures (Bell, 1994), but the structure which offers the least restriction is when the grids are comprised of the same elements and the same constructs. This was achieved in the present study by supplying 10 standard constructs and equalising the number of elements in each grid by removing all nondisabled sibling elements. The 45 10x7 grid matrices were then analysed using the ALSCAL (MDS) option of SPSS for windows. The results of this analysis will now be presented.

ii) SUPPLIED CONSTRUCTS

Multidimensional scaling (MDS): ALSCAL

The ALSCAL (for Alternating Least Squares SCALing) program of Takane et al (1977), belongs to the family of multidimensional scaling (MDS) techniques. All the methods of analysis in the MDS family construct spatial representations of the data's structure. The term MDS has been used broadly to describe a variety of techniques, including factor analysis, analysis of variance, and test theory (Clark, 1984). In the present study, the term is limited to spatial distance models for proximities obtained from ratings of the similarity between pairs of stimulus objects, in this case, elements and constructs.

The similarity judgements made to all possible pairings of the different stimulus objects by each subject are organised into half matrices. The output of these matrices is a geometric configuration of points, as on a map, where each point corresponds to one of the stimulus objects. The larger the dissimilarity (or the smaller the similarity) among the stimulus objects, the greater is their distance on the map (Clark, 1984).

The distances between these points, organised usually in Euclidean space of r-dimensions, reflect the relative similarities among the stimuli along the various dimensions. This map is known as the ***group stimulus space***, since judgements are combined over subjects. The ordering of the stimuli amongst these dimensions allows inferences to be made about the structure of the group's underlying perceptual world.

No *a priori* knowledge of the attributes or dimensionality of the stimuli is required by either the researcher or the subject. Insight into the meaning of the configuration or dimensions is based on the arrangement of the labelled stimulus objects.

INDSCAL (for Individual Differences SCALing), was first developed by Carroll and Chang (1970), and is available as a model option within the ALSCAL procedure. In addition to the group stimulus space, INDSCAL generates a subject space in which the output of the analysis is a set of dimension weights for each subject, one point per subject. These individual subject weights portray the relative importance or saliency of each stimulus dimension to each subject (Clark, 1984). These subject weights can then be related to other individual measures such as the subject's age, gender, or other potential mediating variables.

The group stimulus space and the derived subject weights from the ALSCAL analysis of the children's grids are described below.

The Group Stimulus Space

For each dimensional solution, the ALSCAL program provides details of stress values (Kruskal's stress formula 2; see Young, 1987) and squared correlations averaged over all matrices. These values act as indicators of the maximum number of dimensions to be viewed as the best representation of the data's structure (Marsh & Stanley, 1995; Schiffman et al, 1981).

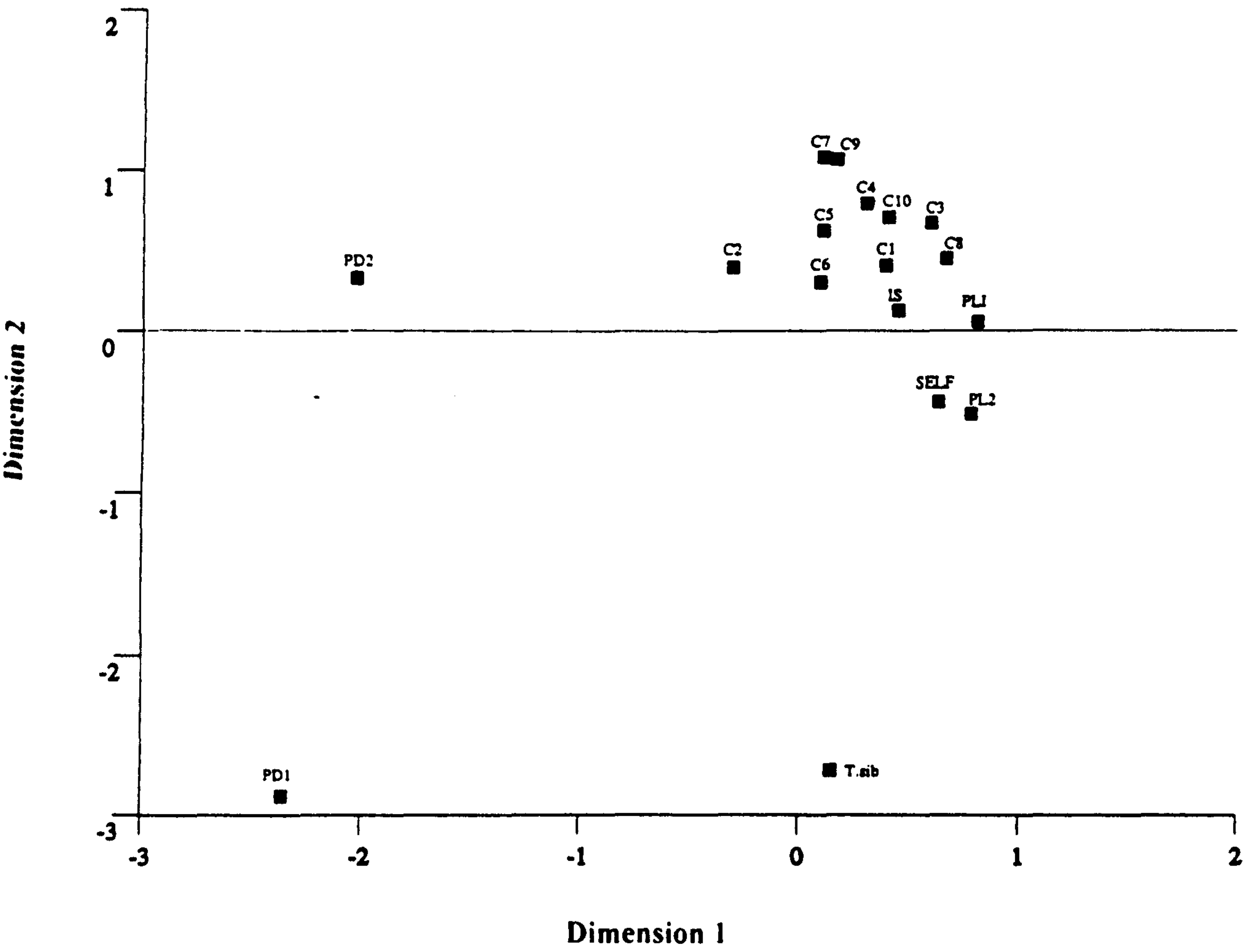
Examination of stress values and squared correlations indicated that no more than the two-dimensional solution was appropriate in explaining the variance in the ratings made by the children in the three sibling groups.

Fig. 7. presents the derived two-dimensional configuration of the children's stimulus ratings. When interpreting this diagram, it is important to bear in mind that each co-ordinate point represents the ***combined*** judgements of the children in the three sibling groups. Differences in the way each group use the elements and supplied constructs will be explored in the next stage of the ALSCAL analysis.

This plot shows a tight clustering of the constructs; which tend to load relatively equally on each dimension. The positioning of the elements on the two dimensions shows an interesting pattern. There is a clustering of the self, peer like and ideal self elements close to the construct weightings. The two peer dislike elements are separated from this core group by their low ratings on Dimension 1.

Whilst the peer dislike 2 element receives a similar rating to the core group on Dimension 2, the peer dislike 1 element is again seen as different from these elements in terms of its loading on the second dimension. The position of the target sibling shows the reverse pattern to the peer dislike 2 element; by loading highly on Dimension 1 but receiving low ratings on Dimension 2.

Fig. 7: Derived Stimulus Configuration.
Individual differences (weighted) Euclidean distance model.



Construct labels

Key: C1 - Is friendly
C2 - Doesn't like to be alone
C3 - Doesn't annoy me
C4 - Knows what I'm feeling
C5 - Isn't bad tempered
C6 - Tells the truth
C7 - Doesn't act silly
C8 - Is someone I Like to be with
C9 - Is helpful
C10 - Isn't selfish

As outlined earlier, the meaning of the dimensions can be inferred from the arrangement of the labelled stimulus objects within the group stimulus space.

Table 6. shows the elements and constructs that loaded at the opposite ends of each dimension. The positively weighted data points are shown in the top half of the table, and the negatively weighted points in the bottom half. Entries at the extremes indicate the heaviest weightings in each direction.

Table 6: Elements and constructs that loaded positively and negatively on each dimension of the two-dimensional ALSCAL solution for the children's grids.

Dimension 1	Dimension 2
Is someone I like to be with	Doesn't act silly
Self as I am now	Is helpful
Doesn't annoy me	Knows what I'm feeling
Peer like 1	Is not selfish
Peer like 2	Is not bad tempered
Likes to be alone	Peer dislike 1
Peer dislike 1	Target sibling
Peer dislike 2	

Given the tight clustering of the supplied constructs, the interpretation of each dimension was not an easy task. The positive pole of Dimension 1 is defined by the constructs "Is someone I like to be with" and "Doesn't annoy me". The self and peer like elements also load highly on this dimension. In contrast, the negative pole of Dimension 1 is clearly defined by the two peer dislike elements. This dimension was labelled "Like vs Dislike".

The second dimension proved more difficult to interpret. The positive pole of this dimension is defined by the constructs "Doesn't act silly" and "Is helpful", whereas the negative pole is defined by the peer dislike 1 element and the target sibling. Bearing in mind the bipolar nature of construing, the finding that the preferred pole of each supplied construct loaded positively on Dimension 2 makes it reasonable to assume that the contrast pole of each construct would load negatively on this dimension. If not acting silly and being helpful are seen as signs of positive social behaviour, negative signs of social behaviour would weight negatively on this dimension. Consequently, Dimension 2 was tentatively labelled "High vs Low sociability".

Referring back to Fig 7., the following observations can now be made. Firstly, the children in this study tend to place more emphasis on Dimension 1 (Like vs Dislike) when distinguishing between elements. In general, they draw a sharp distinction between elements they like (self, ideal self, peer like and target sibling) and those they dislike (peer dislike).

Whilst they like their target sibling (high Dimension 1 rating), they also see this element as lacking in sociability. It is interesting to note that while both peer dislike elements are in fact 'disliked' , it appears that they are disliked for different reasons. For the peer dislike 1 element, this may be due to their negative social behaviours (Low Dimension 2 rating), whilst for the peer dislike 2 element the dislike occurs for some other reason.

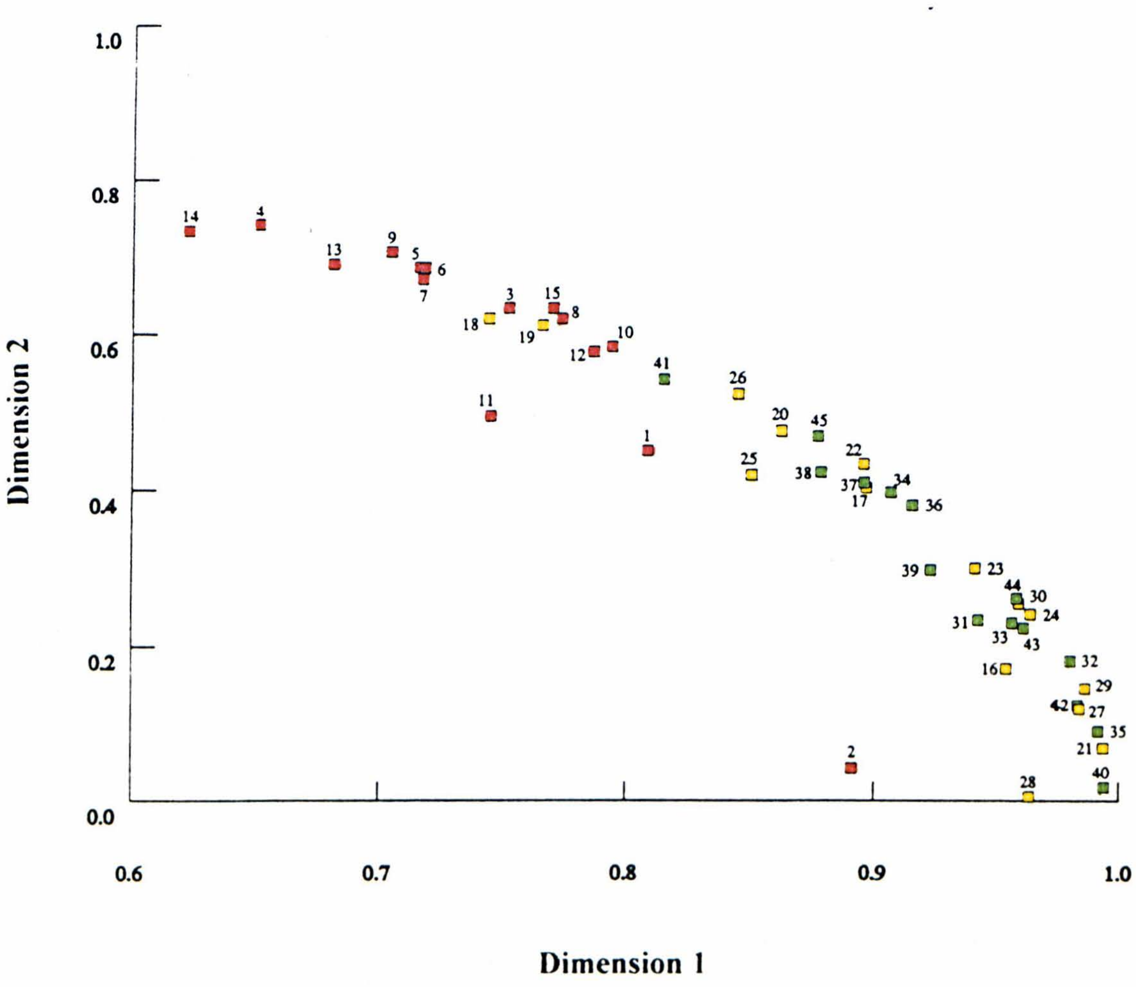
Derived Subject Weights (individual differences)

The group stimulus space provided a general indication as to how this group of children, as a whole, used the elements and the constructs in their grids. Whilst this information is valuable in gaining an insight into the underlying dimensions of the children's perceptions, the presentation of a composite group configuration may mask important individual differences in construing processes. The INDSCAL model was therefore used to examine the relative importance each subject placed on each dimension. Fig. 8. displays the derived subject weights from this analysis.

The results of this analysis demonstrated a marked difference in the relative weightings on each dimension by the children in the three sibling groups. Children in the Sib A group (with the exception of child number 2) loaded highly on Dimension 2 (High vs Low sociability). About half the children in the Sib DS group gave weightings of .4 or more on Dimension 2, which indicates that this dimension has some relevance to these children, but less so than in the Sib A group. Most of the children in the Sib ND group had ratings below .5 on Dimension 2 (with the exception of child number 41).

These findings suggest that while the "Like vs Dislike" dimension is a powerful one for all the children, the second dimension, possibly pertaining to levels of sociability, is of most relevance to children who have an autistic sibling. These results will be considered in more depth later.

Fig. 8: Derived Subject Weights.
Individual differences (weighted) Euclidean distance model.



Key: No's
🟥 1 - 15 = Sib A. Group
🟨 16 - 30 = Sib DS. Group
🟩 31 - 45 = Sib N.D. Group

X. SEMI-STRUCTURED INTERVIEW

Content analysis

All the children taking part in this study produced answers to the first three interview questions. Only the children in the Sib A and Sib DS groups were asked to respond to the final three questions. The recorded responses to the interview items were read through by the writer and emerging themes were extracted.

The following presentation will focus primarily on the responses made by the children in the Sib A group. Comparisons with the responses made by children in the two control groups are made at a descriptive level. All names have been changed to guarantee the confidentiality of the children taking part in this study.

Sib A Group: Emergent Themes

Question 1: What are the most difficult things about having an autistic brother / sister ?

Having a nonnormative sibling relationship: Three children made comments which conveyed their awareness that the relationship they had with their autistic sibling(s) was different from a normal sibling relationship:

> "I can't have a normal relationship with him no matter how hard I try, there's just no way to get close to him".

> "I can't relate to them like proper brothers and sisters ..... I can't tell them things and go out with them and stuff".

> "I would like a normal brother my age. It's hard to play with them because they're younger but also because they're autistic too".

Problems with social interaction: Most children described facing some difficulties when interacting with their autistic sibling(s). Problems occurred in a number of areas:

Communication:

> "Because he is so quiet it means it's hard for us to communicate with him. His speech is really bad, but it's got a lot better since he's had help with it at school .... It's hard to get through to him sometimes, well most of the time actually, and it can get really frustrating when I can't understand what he means or he doesn't listen to what I say".

> "There's things I'd like to talk to him about, but I can't because of the way he is. I just try to accept it, but it's hard sometimes".

Play:

> "He never wants to do the things I do, so it gets boring sometimes ..... sometimes I try to play a computer game with him, but he wants to do it on his own and sometimes he'll push me away".

> "When we try to play together or arrange to do something, he always has to get his own way. If he doesn't he might have a tantrum and then everyone gets upset, so it's easier to do what he wants in the first place".

Lack of reciprocity:

> "It's hard to share things with him".

Lack of affection:

> "I feel frozen out sometimes and it's a horrible feeling to see someone you really care about flinch when you try to touch them".

Difficult behaviours: Several kinds of problem behaviours were mentioned; including - tantrums, poor sleeping habits; damage to personal belongings; aggression, and obsessional behaviours. Examples of the difficulties experienced are given below:

> "It's hard having to cope with his awkward behaviour especially in public places. It gets really embarrassing if you're with him and you get all the curious looks. There's been times when I wished I could walk away or wished that the ground would just swallow me up, but I know he can't help how he is and then I feel guilty for wanting to leave him".

> "What upsets me most is that he is really noisy at nights and I don't get much sleep. We share a room so when he wakes up, I do too".

> "Loads of my clothes have been ruined....she ripped the pocket off my favourite shirt that I wanted to wear to a party. I didn't think it was fair that my mum told me not to get mad with her".

> "She's always winding me up. She doesn't say anything, but I can just be sitting there and she'll come up and hit me. She never say she's sorry".

> "His obsessions get on my nerves the most. He has to watch the same TV programme every week and gets really worked up if he misses it. He also has to have the same kind of cereal and not just for breakfast, but for lunch and dinner too".

Sibling's lack of social relationships: A number of children expressed concern and sadness that their autistic sibling lacked close relationships. As one child put it:

> "I feel really bad for him because he doesn't have many friends ..... I think he must be lonely, but my mum says he likes to be on his own because that's how people who have autism are".

'What might have been': One child described how she often wondered what things would have been like for her autistic brother if he was able to develop normally:

> "I feel like he's missing out on so much of the world and will miss out on growing up in a normal way, like I will".

Differential treatment: Some children felt that they were treated differently to their autistic sibling:

> "I get told off more than him, even if it's not my fault. He gets away with things because he's autistic".

Reduced parental attention: One young boy said:

> "Mum and dad have to spend a lot of time with him and my younger sister and I don't get to talk to them much".

Concern about parent's well-being: One girl was worried about the effect that looking after her autistic brothers and sister had had on her mother:

> "There's no really bad times for me .... things are more difficult for my mum. She didn't know whether to put the boys into full time care ... she's really upset about it all".

Question 2: Are there any good things (things you like) about having an autistic brother / sister ?

Appreciation of sibling's 'different' personality: Although most children in the Sib A group found the autistic child's behaviour puzzling and frequently stressful, many were also able to construe these behaviours in positive terms:

> "I would definitely say he keeps the house "lively" .... he's always up to something and you have to be on the lookout. I think he has a really unique personality which makes him special and fun to be with".

> "It's good to watch him draw and make models because he's really good at doing that. Sometimes I show my friends things that he's made, and they're really impressed".

> "He makes me laugh and does funny things. Dad is trying to teach him about jokes, but he can't really understand. It's funny to hear him try".

Avoiding some of the negative sides to normal sibling relationships: A number of children felt that the relationship they have with their autistic sibling avoided some of the negative aspects to normal sibling relationships:

> "We don't fight with each other or argue like I argue with my other brother. A lot of my friends don't get on as well with their brothers or sisters and sometimes slag them off, but me and my brothers don't say nasty things about each other".

Positive influence on own development: Some children felt they had benefited from the experience of having an autistic sibling in terms of gaining a more mature attitude:

> "People have said that I've always been quite mature and grown-up for my age ... I think they're right in some ways. When Alex has problems, it makes me think about things more carefully. I think I've learned a lot from listening to what the Drs have had to say and watching how my mum and dad cope".

> "I suppose it means that I have to learn to be patient and I don't get as worked up about small things like my friends do. I think I'm able to see how lucky I am too; seeing how hard things are for Mike makes me see that my problems aren't so bad".

> "Having Thomas as a brother has made me more aware of disabilities and made me more sensitive to other areas of problems".

> "It feels good to teach Robert things - a bit like I'm the "big brother" instead of him".

Recognition of effort by others: One child spoke of her pleasure that the effort she had made in looking after her autistic siblings had been acknowledged by others:

> "I was "Child of Achievement" when I was younger. My aunt sponsored me for helping my mum to look after my brothers and sister. I went to London

> and got to meet lots of famous people. It was a special way to show the effort I've made".

Positive impact on family interactions: Whilst having an autistic child in the family was seen to cause a degree of stress, one child felt that the experience had brought the family closer together:

> "We do more as a family; I think because of the way Brian is. We talk about his problems and try to think of ways round them. I don't think any of my friends talk to their mum or dad as much as I do".

Value of a sibling relationship: One child felt that having a brother with autism was better than having no brother at all:

> "It's nice to have a brother even if he isn't a proper brother because I can do lots more things than he can. I think if I didn't have a brother at all, it would be strange to be on my own".

Question 3: What things do you enjoy doing with your autistic brother / sister ?

Doing activities together: The children in this group described a number of activities they enjoyed doing with their autistic sibling. From their descriptions, it was clear that these joint activities were often dependent on the mood of the autistic child:

> "I like playing on the computer or playing football with Matthew, but only when he's in the right kind of mood. If he's in one of his tempers, he might kick the ball too hard and hurt someone or else break something".

> "I like drawing and reading with him. We both go horse riding and Sam loves it ... he's got lots of confidence being on a horse which is a bit strange because he's quite frightened of a lot of other things".

> "I like being on the computer with him because it's about the only time he'll let me sit close to him for more than five minutes. I think he concentrates so hard that he forgets I'm there".

Family outings / holidays: Family activities were considered special occasions by a number of the children:

> "It's usually good fun when we go away on holiday together. Last year we went to France. Mum was worried that Tony wouldn't like it, but he loved it ! In a couple of years dad says we might go back there again".

Involvement in sibling's school activities: Several children found it enjoyable taking part in the autistic child's school activities:

> "I like to know how he's getting on at school and I think he seems very happy there. It's good to go to his prize-giving at the end of the year. Last year he won a prize for his project and I was really proud of him".

Question 4: What things would you like to change to make things better for you ?

Improved communication: Some children felt things would be easier for them if they could communicate with their autistic sibling more:

> "If I could talk to Tony more it would make me happier. I'd like to be able to talk to him as much as I talk to my other brother and my friends".

> "I'd make it so my brothers could talk, so I could have a conversation with them like I can with my sister. It would make it easier to know how they feel, so I could either stay with them or leave them alone".

> "Scott keeps saying the same things a lot of the time. Like when I play football and have to wear shorts he doesn't like it and keeps saying "you'll get cold", "you'll get cold". I don't like it when he keeps saying this".

Less problem behaviours: Reducing the levels of difficult behaviours in the autistic child would have made things easier according to a number of children:

> "I'd like it if she didn't ruin all my things, especially my clothes because it gets me embarrassed if my friends see I have dirty or spoiled clothes".

> "I'd probably change the fact that he's noisy at night which interrupts my sleep. It might help if I had my own room .... I hope he'll sleep a bit more when he gets older because I'll have more homework and exams then and it won't do any good if I'm tired all the time".

More attention / support from parents: A number of children felt that receiving more attention from their parents would help. One child was concerned about burdening her parents with her problems:

> "I'd like it if Steve and my little sister didn't get all the attention. I feel left out sometimes, and go off and play with my friends instead".

> "It would be good if mum and dad weren't so tired all the time. It's hard work for them looking after Liam and I think they need a break sometimes; then maybe they could do things with me too".

> "It helps when I can talk to my mum and dad, but usually I try not to bother them too much with how I am".

Knowing more about autism and what the future holds: Several children expressed the desire to learn more about autism and also what the future might hold for themselves and their autistic siblings:

> "I'd like to know more about autism and what things will be like for Simon in the future - how much he'll be able to live an independent life or will we always have to take care of him. If I'll have to take care of him, I'd like to know what kind of help I'd get".

> "I think I'd like to know more about what things will be like for me and Mark when we're both older. I know I'm only 13 but I do worry about what will happen to Mark when he's older. I don't like to ask my parents because I think it would worry them".

> "I wish I knew more about autism and what causes it. I did a project at school once and read loads of books and leaflets. I think that helped me a lot. If I knew what caused it then I might be able to help him more".

Having a normal sibling relationship: Some children wished that their autistic sibling could become normal, whilst others felt that the presence of another nondisabled child in the family might make things better for them:

> "Sometimes I wish we could be like two normal sisters, and I could talk to her about things and she would know what I meant".

> "I've sometimes thought it would be nice to have another brother who could do things with me ... then it wouldn't matter that Matthew doesn't".

Question 5: What things would you like to change to make things better for your autistic brother / sister ?

Changing their difficult behaviour: Some children felt that reducing the autistic child's level of problem behaviour might help them live a more normal life:

> "If he didn't have such a temper then people might like him more".

> "It would be good if he wasn't as frightened of people. We all care about him and wouldn't hurt him at all, but I don't think he understands that".

Increasing social contacts: A large number of children wished that their autistic sibling had more close friendships:

> "If he had people of his own age to go out with that would be good, but it's hard because he always has to have an adult with him".

> "I feel sorry for her that she doesn't have friends. My mum and dad say that she doesn't know any better, but I still think it's a real shame".

> "If he could join in with me and my friends more. I think he gets lonely sometimes".

Improving educational services: Two children were concerned at the lack of educational facilities for their autistic siblings:

> "Things would be easier for my brother if he could go to a school nearer to where we live. It takes ages for him to get to school at the moment and I think this stresses him out. He doesn't get home until late, so we don't have much time together before he goes to bed".

> "It would be good to get a school for him to go to when he's past 11 years. I worry that we'll not find a good enough place for him where he can learn to be independent".

Changing people's reactions to the autistic child & increasing public awareness of autism: Some children were concerned by the reactions of other people towards the autistic child. One child felt greater public awareness of autism might help his brother.

> "I don't like the way people can be to him, they can be right mean".

> "Most people would say that they would change him to normal, but not me, I wouldn't change him for the world. Instead, I'd change the way people stop and stare at him .... It used to make me embarrassed, but now I just get mad and feel sorry for Brian".

> "I hate it when people stare at us if he makes loud noises. I'd like the government or the newspapers to write more about autism, so that people would know more about it and wouldn't be so shocked when they see Sam".

Question 6: How do you explain your brother / sister's problems to you friends ?

There were a wide variety of responses to this question; with different children explaining their sibling's condition in different ways. Some of the issues which emerged from this investigation are outlined below:

General explanations concerning a 'handicap':

"I say that she's handicapped; mentally handicapped. People know she's not in a wheelchair".

"I tell them that he's not well and that his brain doesn't work properly. He looks normal but he isn't normal. It's hard to explain".

Fairly detailed descriptions of autism:

"When I did my project at school, my friends were really interested and asked lots of questions. I explained that people with autism find it hard to get on with other people; that they can't understand language as well as we can. I said that Doctors thought it was caused by brain damage".

"I usually say that my brother is autistic, and that autism is a number of things. Not all autistic people suffer from the same things, and Simon has got learning disabilities and speech problems".

Using descriptions of problem behaviours:

"I say he can't communicate very well and that if he doesn't speak to you, he's not being rude ... he's been like that all his life and it can't be cured".

"I tell them that he has problems communicating and socialising with other people".

Using 'images' of autism from the media:

"Usually they think it's got to do with people who are really good at remembering numbers, like the guy in "Rainman", but I don't think Angela will ever be as smart as he was".

"My friend's brother says Gary is like the man in "Rainman"; but he could talk to people a bit better than Gary can, but maybe that's because he was a bit older than Gary".

Difficulty in explaining autism:

> "If people pick on him, I say it's not his fault ... he's younger and he's autistic. It's hard to explain to them what autism means and I can't. I try sometimes, but they don't understand".

Getting advice from family members about what to say:

> "My friends ask me why Brian is always in a bad mood. I say it's because he has a handicap and doesn't like being with people - that people make him scared. That's what my mum told me autism means".

> "My other brother tells me a lot about what autism is, so when my friends ask me a question and I don't know the answer I can ask him or my parents".

Not discussing it with friends:

> "I don't talk to them about it. Some of my friends don't know I have a brother, it's none of their business".

Sib DS Group: Emergent Themes

Question 1: ***Difficult things .....***

The themes emerging in response to this question were similar to those generated by the children in the Sib A Group. The extracts below illustrate the range of feelings expressed:

> "It feels like I've been cheated (became tearful) ..... that I've not had the experience of having a normal brother".

> "His speech is really hard to understand and I feel sorry for him because he gets frustrated when we can't work out what he wants to say. If my friends come round, they don't understand what he's saying so I have to translate".

> "The way she acts sometimes makes it hard for us to play together. If she has a maddy, then the game's basically over".

> "I can't eat with Sarah because she always messes up everyone's food by putting salt in it .... there's always a bad atmosphere at teatimes. It's easier if I just go into my room to eat".

> "It's hard to see that he hasn't got many friends .... I wish I could change that".

> "Not knowing what it would be like to have a normal brother or sister. I try to imagine how things would be different if I had a brother I could really talk to, a lot of what I talk to Michael about is superficial".

Two further themes emerged from the responses of the children in the Sib DS group:

'Burden' of responsibility:

> "I find the responsibility of looking after Hannah hard. Although I'm not forced to by my parents, I just feel I *should.* I feel bad that I don't have more time to spend with her".

> "I feel like I'd like more freedom to do my own thing, rather than look after George all the time".

'Overtaking' the disabled sibling developmentally:

> "The hardest thing is that I know she's my older sister but at the same time she acts younger than me ... I don't know if she'll grow up , I hope so, but I don't know yet".

***<u>Question 2</u>*: Good things .....**

Most children described the positive effects that having a Downs Syndrome sibling has had on their own personality. One teenage boy felt his greater sensitivity was recognised by the girls in his class:

> "I think the girls in my class feel that they can talk to me more because I'm more caring and don't do stupid things like the other guys. They think Adam is really cute".

Many of the children spoke about the positive social qualities their Downs Syndrome sibling possessed:

> "She's very loving and generous, so we don't fight much".
>
> "Susan is really nice to me, nicer than my friends' sisters are to them, so I'm quite lucky in that way".
>
> "She's got a great sense of humour and is really sociable. She's very happy and will mix with anyone".
>
> "Gareth is kinder than other children and we don't ever argue. We do things together, and when he goes to bed at night I go in to say goodnight. He says he loves me and that makes me feel really good".

***<u>Question 3</u>*: Things you enjoy doing .....**

The children in this group also enjoyed doing activities with their sibling. In contrast to the accounts given by the children in the Sib A group, however, these joint activities were less conditional on the Downs Syndrome child's mood or behaviour.

Reciprocity was evident in the relationship; with activities being characterised by 'give-and-take':

> "It's good because we'll help each other tidy our rooms. He also helps my dad in the garden".

Whereas the children in the Sib A group primarily watched their autistic sibling doing different activities; there was a more *active* quality to the interactions between the sibling dyads in this group:

> "We do gymnastics together and practice our singing. We also go to a drama club together, and a lot of the time we'll just sit and chat".

Question 4: ***Changes for yourself.....***

Over half the children in this group said they couldn't think of anything they'd like to change, and were happy with the way things were:

> "There's nothing at all I'd like to change. I think I'm really lucky to have a brother like Stuart, and I'm very, very, very happy. I don't think I'd like to make him normal because he's nice the way he is".

> "I don't think I'd necessarily want a brother who didn't have Downs Syndrome because there are things about me which were made by him, for example, the way I think about people".

For the children who did wish for some changes, these tended to relate to the problem behaviours of the disabled child and the levels of responsibility they had for their care:

> "If we could make his speech better then I'd be able to understand him more and I think we'd have a closer relationship".

> "If his attention span was better he wouldn't get so bored. When he gets bored he might have a tantrum".

> "I wish I didn't always have to wait to do things. I have to wait until Sarah has gone to bed to do my homework".

> "I'd like to feel I didn't have to do things with Hannah. My parents don't nag me, but I can usually tell there's a pressure on me to help out".

Question 5: ***Changes for your brother / sister .....***

Three principal themes emerged from the children's responses to this question; increasing the Downs Syndrome child's level of independence; increasing the number of friendships and social activities for the sibling; and changing other people's attitudes towards the sibling:

> "If he could be a bit more independent he might be able to make more friends of his own and have more of a social life".

> "It hurts me to see how his "normal" friends outgrow him. It never used to matter when he was younger ...but now they've moved on and he can't keep up".

> "I wish he could have more friends. He's really warm and caring and loves being with people. I think because of his handicap people feel a bit awkward being around him, but if they just took the time to get to know him, they'd see what a great person he is".

> "I would like to change people's ignorance. Kate should get the equal opportunity everyone else gets".

> "I'd like to give every family around here James for a week, to see how they cope. It would make them understand him more and make them more sympathetic".

Question 6: *How you explain to your friends .....*

Almost all the children used the term 'Downs Syndrome' to describe their sibling to their friends. A few said they didn't need to describe what was wrong with their sibling because of the characteristic physical features of the Downs Syndrome child:

> "Most of my friends know that Carly has Downs Syndrome and it's pretty obvious when you look at her because she's got the Downs features. Carly usually tells them more about herself than I do. Ever since she was little, she's learned to say "I'm special, I've got Downs".

> "I tell them that she's got Downs Syndrome and has problems learning and that's why she has to go to a different school".

> "All my friends are pretty clued up about Downs Syndrome so I don't feel I have to discuss it; but I'm not embarrassed to talk about it if they ask".

> "I've never been that bothered about Hannah having Downs, so people accept it because I do. When I gave a talk about it at school, I gave my class a lot of the jargon and technical information, e.g. about the extra chromosome. When I talk to my close friends I just say that she's got Downs Syndrome but she's all right.... she isn't severely handicapped and can hold a reasonable conversation with people. I say she's a bit behind and that we don't know how things will even out".

Sib ND Group: Emergent Themes

Question 1: *Difficult things .....*

Most children in this group described their sibling's annoying habits, such as being lazy, messy, cheeky, and having a bit of a temper. In contrast to the siblings of children with disabilities, there was no mention of having a nonnormative sibling relationship; experiencing communication problems; concern over their sibling's lack of social relationships; or a sense of 'what might have been'. Examples of their thoughts are given below:

> "He makes a mess around the house and we're always having to go around picking up his things".

> "He can be quite cheeky at times and always answers back to my mum and dad. He always has to get the last word in".

> "It feels like we're walking on egg shells sometimes. My mum says it's because she's a teenager, but she's always been a bit touchy".

> "He gets on my nerves because he follows me around and hangs about when my pals come round to the house".

> "She can be like any little sister, annoying - acting silly, always coming into my room, putting on stupid voices and messing with my things. If you tell her to get out she goes whining to mum, and I get told not to be so mean to her".

<u>Question 2</u>*: *Good things .....

All the children were able to describe some positive aspects of their relationship with their target sibling:

> "We share a lot of hobbies like dancing. Rachel is a very caring sort of person and is always wanting to help people. She's got a lot more patience than I have".

> "Lots of things. He's brilliant to talk to if I have a problem and gives me advice and stuff about boys. I think he's quite mature for his age, I trust him with my secrets".

> "She's always full of ideas about things to do and has a great imagination even though she's only six".

Question 3: ***Things you enjoy doing .....***

The children cited a number of activities they enjoyed doing with their sibling:

> "Going to the pub or dancing. We're both into fashion, so we'll go shopping together. We've got quite similar tastes in clothes".

> "It's good to stay in with him sometimes and watch a video. Our dinner table is always lively and I think it's nice that we try to eat our meals together as a family. It means we get to know what everyone has been up to. I think we're quite a close family".

One child commented that they didn't spend much time with their sibling due to the large age gap:

> "He's too young to come and hang out with my friends, so we don't spend that much time with each other".

DISCUSSION

XI. Discussion of the findings: The logic of triangulation

This study set out to examine the nature of the constructs generated by siblings of autistic children when they are asked to describe themselves, their siblings and their peers. Siblings of Downs Syndrome and nondisabled children were also interviewed to control for the effects of having a 'nonnormative' sibling relationship and to examine the types of constructs generated in relation to normal sibling and peer relationships.

Due to the social impairments of the autistic child, it was predicted that he/she would be rated as an outlier; sharing few characteristics with the other children (elements) in the grid. Furthermore, it was anticipated that the autistic children would be perceived as being "most different" on constructs which are broadly *social*, as opposed to physical, in nature.

While each source of data collected in the present study (i.e. Grids and Interview), and each type of analysis conducted (Content analysis, GRAN, and Multidimensional scaling), have provided valuable insight into the construing processes of these three groups of children; comparing the findings from each type of analysis would be expected to promote a greater understanding of the data. This process can be thought of more simply as looking to see whether the different types of data "tell the same story". In the event that each separate data source produces similar findings, any generalisations one wished to make concerning these sample groups could then be made with a greater degree of certainty.

This process of convergent validation is the principle which underlies the concept of ***triangulation*** described earlier. Bryman (1988) claims that researchers usually follow one of two different goals when they apply such a strategy:

(1) Either they try to find further evidence to confirm or disconfirm previous research findings by using a different research methodology. The underlying assumption being that the validity of research results is enhanced if there is a convergence of findings about the same empirical domain produced by using different methodological approaches (Padilla, 1992).

(2) Or they attempt to establish a more complete picture of the investigated phenomena by combining different research strategies. Typically, these different strategies represent an integration of qualitative and quantitative methods which are seen to represent different perspectives, and can therefore be employed to investigate different aspects or levels of reality (Fielding & Fielding, 1986).

Comparing the findings from each type of analysis in the present study would be representative of the latter approach, whilst drawing comparisons between the present findings and the findings from similar studies would reflect the former strategy. In the present study it was decided to adopt both methods of triangulation; to build up a richer picture of the experiences of children who have a brother or sister with autism.

The two main hypotheses concerning the outlier status of the autistic child and the nature of the discriminatory constructs will first be examined by drawing upon the multiple data sources used within the present study (Method 2 above). These findings will then be compared with the results of other studies which have explored the experiences of siblings of autistic children (Method 1 above). Following these explorations, the theoretical and clinical implications of the findings will be discussed.

Comparing the findings of each type of analysis

Outlier status of the autistic sibling

Two forms of data were used to explore this hypothesis. Firstly, the element distance matrices produced by GRAN were analysed to determine which elements are considered similar and which dissimilar on the generated constructs from the children's grids. The second method examined the children's ratings of each element using ten constructs supplied by the writer. This data was analysed using the ALSCAL (MDS) program.

GRAN - element distances: Although there was a degree of individual variability in the outlier ratings within each group, pairwise comparisons using the Mann-Whitney U test found the outlier scores of the autistic children to be significantly greater than the ratings given to the target siblings in the two control groups. This finding indicates that on constructs generated by the children themselves, there are certain characteristics of the autistic child which clearly distinguish them from the other children in the grid.

ALSCAL: In Fig 6, the analysis of the children's element ratings using the ten supplied constructs also depicts the target sibling as an outlier. There is a relatively tight clustering of the self, peer like and ideal self elements in the upper right-hand quadrant of the group stimulus space. The two peer dislike elements are separated from this core group of elements by their low scores on Dimension 1 (Like vs Dislike). The target sibling is placed in the lower right-hand quadrant - separate from the other elements.

Although the group stimulus space represents the *combined* judgements of the children in all three sibling groups, the derived subject weights shown in Fig. 7 indicate that the outlier status of the target sibling is most strongly influenced by the weightings of the children in the Sib A group on Dimension 2 (High vs Low sociability). Had the stimulus co-ordinate points from this group been removed from the analysis, the target sibling would be placed closer to the core group of elements.

Summary: Both analyses consistently show that the autistic child is rated as an outlier by their siblings. This discrimination occurs when the constructs being used originate from the children themselves and also when they are provided by another person.

The nature of the discriminatory constructs

The finding that the outlier status of the target sibling was greater in the Sib A group than in the Sib DS group suggested that the perceived "difference" between the autistic child and the other elements could not be fully accounted for by the presence of a 'disability'.

The nature of the constructs which discriminated most between the autistic child and the other elements were examined using the rearranged grid output from GRAN. The category labels developed during the content analysis stage were mapped on to the construct ratings in the grid to facilitate a qualitative understanding of the mathematical grid data. The nature of the constructs generated in relation to the autistic child were also assessed using the semi-structured interview which followed the grid administration.

GRAN - the rearranged grid: The constructs which discriminated most between the autistic child and the other elements were found to fall into ten of the eighteen subcategories. These are shown below:

- Presence of a handicap & Type of education received
- Skills - cognitive
- Developmental Issues
- Mood - emotional states and behaviour
- Mood - level of self esteem

- Attitudes / Beliefs and Personality
- Amount of time spent alone vs with others
- Has close relationships vs Lacks close relationships
- Style of interaction between the person and others
- Attitudes and responses of others towards the person

The types of constructs generated by the children in the Sib A group in the first three categories above did not differ from those generated by the children in the Sib DS group. Characteristics relating to the target sibling's disability were used by a number of children in these groups to distinguish the autistic and Downs Syndrome child from the other children being rated. Deficits in cognitive skills, particularly to do with language, and a lack of independence and/or maturity were mentioned by children in both groups.

Some children in the Sib A group used the autistic child's emotional state and level of self esteem as distinguishing features. The child with autism was considered more impatient, fearful, obsessional and less confident than the other elements. They were also discriminated on a number of constructs relating to attitudes / beliefs and personality. In contrast, children in the two control groups did not use constructs from within these categories to differentiate their target sibling.

Two children in the Sib A group used constructs relating to low *levels* of social interaction to distinguish their autistic sibling from the other elements. The target siblings in the Sib DS and Sib ND groups were not construed in this manner.

The nature of the constructs in the category "the *style* of interaction between the person and others" produced interesting group comparisons. In their relationships with other people, the autistic child was seen to lack a sense of humour and was considered less affectionate than the other elements. Whilst the Downs Syndrome child was also seen as an outlier on a number of constructs within this category, the nature of these constructs differed markedly from those generated by the children in the Sib A group. The child with Downs Syndrome was considered more affectionate and sociable than the other elements.

The final category used to distinguish the autistic child related to the "attitudes and responses of others towards the person". These constructs described the autistic child as being the recipient of negative responses from others and as having little freedom. Children in the Sib DS group also distinguished the Downs Syndrome child from the other elements on the basis of their lack of freedom.

Semi-structured interview: While the repertory grid methodology sampled the children's constructs concerning themselves, their siblings and their peers, the interview questions focused primarily on the relationship they have with their target sibling. The responses to these questions were recorded by the writer and emerging themes were extracted. Comparisons between these themes and the constructs generated using the grid technique are made at a descriptive level in an attempt to assess whether the same core constructs are elicited using these two different methodologies.

The discriminatory constructs relating to the presence of a handicap, language problems and dependence on others were evident in the responses made by the children in the Sib A and Sib DS groups to the interview questions. Having a nonnormative sibling relationship, experiencing communication problems, and having to look after their dependent sibling were examples of the responses made when the children were asked to describe the most difficult things about having a brother or sister with autism/Downs Syndrome.

These constructs also emerged when the children were asked about the things they would like to change to make things better for themselves and/or their autistic/Downs Syndrome sibling. Having a normal sibling relationship, improving their sibling's communication skills and increasing their sibling's level of independence were viewed as changes which would make the situation easier.

The autistic child was described as fearful and obsessional by a number of children in the interview demonstrating the use of constructs relating to the emotional state of the autistic child. Whereas the discriminatory constructs in the "attitudes / beliefs and personality" category in the GRAN analysis placed the autistic sibling at the extreme end of the contrast pole, the interview elicited responses which showed that some children in the Sib A group were able to construe these 'different' personality traits in positive terms. One child described his autistic brother as "special" , "unique" and "fun to be with", while another responded "He makes me laugh and does funny things".

The style of interaction with the target sibling was described in different terms by the children in the three groups. Children in the Sib DS and Sib ND groups described having positive relationships with the target sibling. Examples of joint activities were given, and these interactions were generally characterised as being reciprocal in nature. In comparison, a number of children in the Sib A group commented that they found it difficult to play with their autistic sibling, and the few activities they did together were often conditional on the autistic child's mood or behaviour.

When asked to describe the good things about having a brother or sister with Downs Syndrome, the affectionate nature of the child was mentioned by a large number of children. This is in contrast to the child in the Sib A group who described her sadness at being "frozen out" by her autistic brother who found it difficult to accept her signs of affection.

Children in the Sib A and Sib DS groups expressed concern that their sibling lacked close social relationships. Implicit in the children's descriptions, however, was the suggestion that the target siblings in these two groups lack close relationships for different reasons. In the Sib A group, the autistic child is seen to be alone because "that's how people who have autism are". Some children used this characteristic to describe their autistic sibling to their friends e.g. "people with autism find it hard to get on with other people" and "he has problems socialising with people".

The descriptions given by the children in the Sib DS group suggest that although the Downs Syndrome child is capable of forming close relationships with people, their social networks are limited for other reasons. One child described how her brother's normal friends had "out grown" him. Another child felt that other people's awkwardness about his brother's disability meant they never got to find out what a warm and caring person he is.

The attitudes and responses of others towards the target sibling were mentioned by a number of children in the Sib A and Sib DS groups. Concern was expressed about the negative reactions their sibling faced from members of the public. One child in the Sib A group felt things would be better for his autistic brother if he could change the way people stopped and stared at him.

<u>Summary</u>: The nature of the constructs generated using the repertory grid and interview strategies revealed a number of common themes. The findings suggest that while children in the Sib A and Sib DS groups both use characteristics relating to their target sibling's disability to distinguish them from the other children, the autistic child is discriminated further on the basis of constructs pertaining to their levels and style of interaction with others. This finding supports the second hypothesis, that the constructs which specifically discriminate the autistic child relate to their lack of social communication and interaction.

The similarity of the constructs generated using the repertory grid and interview methodologies demonstrates that, whilst each method is capable of accessing unique and personal constructs, they also provide insight into some of the shared constructs and experiences of siblings of autistic children. The common themes which emerged from the Sib A group will now be compared with the findings from other studies which have explored the experiences of children who have an autistic brother or sister.

Comparing the findings with previous research on siblings of autistic children

Outlier status of the autistic sibling

The majority of children in the Sib A group see themselves as being similar to their liked peers, ideal self and nondisabled sibling(s) and different from the peer dislike elements and their autistic sibling. In most cases, the autistic child was rated as an 'outlier'; sharing few characteristics with the other children in the grid.

To the writer's knowledge, there have been no other studies which have asked siblings of autistic children to compare and contrast the types of relationships they have with other children. Hence, it is not possible to comment on whether the element ratings made by the children in the Sib A group are representative of the manner in which siblings of autistic children tend to view these different relationships. However, the self-target sibling distances produced by the GRAN analysis does permit the issue of ***'identification'*** with the autistic sibling to be assessed more closely.

Several studies have shown that siblings of autistic children may experience problems in establishing self-identity (Fromberg, 1984; Grossman, 1972; White, 1993). A number of authors have suggested that these identity problems arise in response to the normal child's fear that he/she might also be affected in some way (e.g. Howlin, 1988).

On the basis of information obtained in discussion groups of adolescents with autistic siblings, Grossman (1972) found high levels of overidentification with the autistic brother or sister. This 'overidentification' can be witnessed in the personal account given by Fromberg (1984). In his article he describes how the experience of caring for his autistic brother on a day-to-day basis had led him to behave in an "autistic-like" manner. For several years he adopted odd habits, such as watching a certain weatherman every night on the 10 o'clock news, and going to the record store every day for no reason. This immersion in ritual had only dissipated once his brother moved into residential care.

Other studies have found no evidence of identity problems among siblings of autistic children. Berger (1980) explored the self-concept of 20 siblings of autistic children. His findings revealed no detrimental effects on the sibling's self-concept as a result of having an autistic brother or sister. The study by McHale et al (1986) also found that, on average, siblings of autistic, mentally impaired or nonhandicapped siblings had positive self-concepts. However, on closer inspection the data revealed a high degree of variability in the self-concepts of children who had a disabled sibling.

In the present study, the levels of identification with the target sibling were found to be significantly lower in the Sib A group than in the Sib DS and Sib ND groups. This suggests that for the siblings of autistic children taking part in this study, there are certain characteristics which they use to clearly differentiate themselves from their autistic sibling. However, as in the McHale et al (1986) study, a degree of individual variation was present in the levels of identification within the groups of children who have a disabled sibling.

The nature of the discriminatory constructs

The nature of the constructs used by children in the Sib A group to discriminate the autistic child related to: the presence of a handicap; cognitive deficits; a lack of independence; emotional states; personality characteristics; low levels and impaired styles of social interaction; and negative responses from other people. These characteristics will now be compared with the responses made by siblings of autistic children in other studies.

Many of the ideas and feelings expressed by the siblings of autistic children in the present study can be found in the 'sibling stories' presented by Sullivan (1979):

The presence of a handicap: Confusion concerning the nature of autism was evident in a number of the children's accounts. One child described the turmoil her family had faced in their pursuit of her brother's elusive diagnosis:

> "The family shared in the knowledge that "something" was wrong - he didn't talk, didn't seem to hear, yet he loved music and could keep the rhythm, he would only eat bananas and never wanted a cuddle .....Knowing all these things made it even more difficult when the professionals sought out gave confusing and conflicting messages: "He's just slow", "He's severely retarded", "He's deaf", and finally, "He's autistic". For that, there was no explanation" (p. 291)

This uncertainty concerning the etiology of her brother's condition resulted in a childhood spent searching for answers to the question "Why ???" :

> "As a child, it's hard to live with someone who has difficulty learning, gets upset, and acts strangely when no-one seems to know why. Children expect adults to have the answers, but so often in the case of the autistic child, the siblings are left on their own to grapple with this question. What could have gone wrong ? Did the hospital stay harm him ? Was it the fever ? Is his diet OK ? Can he hear ? Is it our fault ? Anyone's fault ? Does he know we love him ? Yes, a lot of questioning, and anger - anger that a helpless beautiful child could be so inexplicably damaged" (p. 292)

Although there is now a greater understanding concerning the biological factors operating in autism than at the time of Sullivan's study, similar sentiments concerning the inexplicability of the autistic child's disability were expressed by a number of children in the present study. These children felt that knowing more about the causes and prognosis of autism would enable them to anticipate the future needs of the autistic child and would also help them to explain their sibling's condition to other people.

The concepts of 'having a nonnormative sibling relationship' and 'what might have been' were also apparent in the responses made by the children in Sullivan's study :

> "I have often wished that my brother were normal. Since we are the only two children my parents have, I really can't imagine what it would be like to have a true brother - one that you could talk to about special things or share secrets with, as most siblings do" (p. 295)

Cognitive deficits: The children in Sullivan's study also experienced communication problems with their autistic sibling:

> "My brother is nonverbal and autistic. The language that most of the world uses for communication is simply not available to him. Yet, he has a desire to communicate. He does not know our method, nor we his" (p. 293)

Lack of independence: The autistic child's need for care and supervision was mentioned in the siblings' narratives :

> "Giving Chris the care he needed was difficult and draining. Progress was slow and at times we were frustrated and disheartened" (p. 292)

Emotional states and Personality: One child spoke of the difficulties they had experienced as a result of their autistic brother's highly strung nature :

> "In my case, stress has been an everyday occurrence during the past 12 years. Wanting to help with my younger brother and yet not being able to withstand the pressure of his impatience and anger has given me tremendous feelings of guilt - guilt that need not have been" (p. 295)

Low levels and impaired styles of social interaction: The feeling of being "frozen out" by the autistic child was poignantly described by one of the children in Sullivan's study :

> "There is a great deal of love in my heart for him, but it is difficult to show it because he is not the kind of child who exhibits or requires a lot of affection. In fact, he is very much the introvert and retreats to his bedroom as much as possible while at home"

Negative responses from other people: One child described how she had learned a lot about other people from observing their reactions to her autistic brother. While she had not been overly concerned about other people's responses, her mother and older sister found these reactions harder to cope with :

> "I could take him to the supermarket, which he loved, and not be bothered or embarrassed if he accidentally knocked down a huge display. My sister would have become nervous and distraught, while my mother would be close to tears. Taking a walk around the beach with him was an education in people. I learned from their fearful expressions, their sympathy, their ignorance ..... some people grimaced, others were shocked or afraid" (p. 294)

Personal accounts written by Fromberg (1984) and White (1993) have also described issues similar to those generated by the children in the present study. Fromberg describes two different kinds of pressure he experienced as an older brother to an autistic child. The first kind was related to the continual need to monitor his brother's behaviour. This required a degree of hypervigilance in order to avoid problem behaviours. The other kind of pressure present in his household was even more difficult to cope with - he described this as the pressure of sadness:

> "This primarily came from my mom's difficulties. As far back as I can remember, I sensed a great sadness about her, and the few times the subject came up she attributed her frustration to the pressures of dealing with Steve and running a household. Throughout my childhood I wished mom could have borne up better to the strain. The sense of my mom's frustration and sadness - not intense but constant - was the greatest hardship of being a brother to Steve" (1984, p. 345)

In a similar vein, a number of the children in the present study expressed concern about their parent's well-being. There was a sense of 'not wishing to burden them with extra hassles'. However, by protecting the parent, the child was often left feeling they had no-one to share their own feelings with. Several children felt that receiving more attention and support from their parents would help them cope to better.

There have been a few larger scale studies which have asked siblings of autistic children to describe the types of problems they face (e.g. Bågenholm & Gillberg, 1991; Gold, 1993; McHale et al, 1986). A Swedish study conducted by Bågenholm and Gillberg (1991) compared the types of difficulties reported by siblings of autistic, mentally impaired and nondisabled children. These authors found that siblings of disabled children had more concerns about the future; with the highest levels of concern being expressed by siblings of autistic children. The siblings of autistic children, 'on the whole', were more negative in their views concerning their sibling relationships than the children in the two control groups. Children in this group also felt more lonely and many of them had peer problems. More than half the children in the 'autism group' felt they had no words to explain why their brother or sister was different from others.

<u>Summary</u>: The themes which emerged from the children in the Sib A group in the present study are similar in many respects to the views expressed by siblings of autistic children in other studies. These studies have ranged from in-depth biographical accounts to large scale group studies and have involved a wide age-range of children from a number of different cultures. In some studies comparisons were made between the responses of siblings of autistic children and the views expressed by siblings of children with other forms of disability and/or normal controls. The remarkable consistency across these studies in terms of the feelings described suggests that whilst each child's experience is unique, there are a number of common concerns shared by siblings of autistic children. The theoretical and clinical significance of these findings will now be explored.

XII. General Discussion: Theoretical and clinical implications

Theoretical considerations

The question raised at the beginning of this study was concerned with the potential consequences for the social and emotional development of the nonautistic child, when the reciprocal and complementary nature of the sibling relationship is compromised due to the autistic child's impaired social behaviour. While it is not possible to draw any strong conclusions from a study of this nature, the strength of the findings in relation to other similar studies enables some theoretically based predictions to be made.

The impact of having a nonnormative sibling relationship

Seltzer and Krauss (1993) draw attention to the lack of research concerning the developmental consequences of having a nonnormative sibling relationship. The responses made by the children in the Sib A and Sib DS groups indicate that whilst there are a number of common factors relating to the experience of having a disabled sibling, there are certain characteristics of the autistic child which further influence the nature of this sibling relationship.

Communication problems with the disabled child were described by children in both groups. A common response to these difficulties was a sense of frustration and sadness at not being able talk to their sibling in an age-appropriate manner. However, for the children in the Sib A group the nature of these communication problems appeared more profound. In addition to verbal comprehension and expression problems, there was a general sense of not being able to "get through" to the autistic child. In contrast, the children in the Sib DS group did not construe the Downs Syndrome child as being so impenetrable.

For many children in the Sib A group, their autistic sibling was seen as a 'mystery'. They had little or no access to the thoughts and feelings of the autistic child and were faced with a range of puzzling behaviours; including obsessions, phobias, tantrums and aggression. In line with the findings of other studies, the children in the Sib A group found it harder to explain their brother or sister's problems.

These difficulties are likely to have implications for the development of social relationships between siblings when one child is autistic. The Sociality corollary of Kelly's theory (see, p. 35) states that in order to engage in social relationships with another person, the individual must be able to understand the other person's perspective. If the nonautistic child is unable to construe the construction processes of their autistic sibling, then they will be less able to "play a role in a social process" involving the autistic child.

Placing these findings in the context of current work being done on the 'Theory of Mind' (or lack of) in autistic individuals, it is interesting to note the apparent bidirectionality of these difficulties. Not only is the child with autism unable to construe the thought processes of their nondisabled sibling, the child without autism also appears to have little or no understanding of the ‘goings-on’ in the mind of their autistic brother or sister. It is hardly surprising, therefore, that such sibling dyads experience problems in social interaction.

Qualitative differences in the 'style of interaction' with the target sibling were obvious when the accounts given by the children in the Sib A group were compared with the responses of children in the two control groups. Constructs generated using the repertory grid technique described the autistic child as having a poor sense of humour and as being less able to give and receive overt signs of affection. The analysis of the supplied constructs also indicated that the "High vs Low sociability" dimension had more relevance to the children in the Sib A group. Poignant descriptions concerning the autistic child's lack of social relatedness were elicited using the semi-structured interview.

The importance of the sibling relationship for the psychological development of the child has increasingly been recognised (e.g. Dunn, 1985; Sutton-Smith & Rosenberg, 1970, McHale et al, 1984). It has been argued that this relationship provides important mechanisms for developing mutual understanding, interpersonal sensitivity and intimacy. Goetting (1986) has conceptualised the normative experience of having a sibling in developmental terms; with the lifetasks of the siblingship being modified as the individual progresses from early childhood to old age. The tasks of companionship and emotional support, however, are seen as constants in the sibling relationship.

In sibling relationships where one child is autistic, the necessary ingredients of companionship and emotional support are sadly lacking. Less interaction with the target sibling was reported by the children in the Sib A group than in the two control groups. Several children described finding it difficult to play with their autistic sibling, and the few activities they did together were often conditional on the autistic child's mood or behaviour.

The absence of play in the sibling relationship may have important consequences for the social and emotional development of the nonautistic child, particularly in families where there are no other normal siblings to act as 'play mates'. While most children below the ages of 3-4 years engage in solitary or parallel play with siblings and peers, the emergence of social and co-operative play tends to take precedence as the child grows older.

Play is not a mindless filling of time or a rest from work; it serves important developmental functions (McMahon, 1992). Through play, children learn how to negotiate, co-operate, support and reward one another. If this medium for social learning is absent, this may have an impact on the nonautistic child's level of social understanding. However, these speculations have yet to be tested empirically, and the findings of the present study gave no indication that the social awareness of the siblings of autistic children had been impaired as a result of having an autistic sibling.

The autistic child's lack of affection and impaired social interaction may influence the nature of the attachment relationship between the siblings. Seltzer and Krauss (1993) note that although attachments generally persist throughout the lifespan, the behavioural manifestations may differ from stage to stage in age-appropriate ways. While the cross-sectional nature of this study does not permit the patterns of attachment to be charted developmentally for the children in the Sib A group, the wide-age range sampled suggests that difficulties in the attachment relationship with an autistic child are pervasive.

While it is possible to assess that the ***nature*** of the attachment relationship a child forms with their autistic sibling is qualitatively different to the bonds they have with other children, this should not imply that the attachment to the autistic sibling is not an important one. Indeed, the responses of a number of children in the Sib A group demonstrate that they are able to see some positive qualities to this relationship e.g. less fighting and arguments. The fondness shown towards the autistic child was also evident in the ratings made using the supplied constructs. Whilst the autistic sibling is seen as being low in sociability, they nevertheless score highly on the "Like vs Dislike" dimension.

Many of the children were also able to describe the positive impact that having an autistic sibling has had on their own development. These children felt they had gained a greater maturity and sensitivity and were particularly pleased when their effort in caring for their autistic sibling was recognised by other people. One child described how the difficulties her autistic brother faced had brought the family closer together.

Other children, however, found the experience of having an autistic sibling more difficult to cope with emotionally. One child described her sadness at being "frozen out" by her autistic brother. Another child spoke of her efforts to get close to her autistic sibling; but her realisation that "no matter how hard I try, there's just no way to get close to him". These descriptions are reminiscent of the analogies drawn by Frith (1989) using the fairy tales 'Snow White' and 'The Sleeping Beauty' - capturing the feeling of being so near, yet so far.

The effort described by the child above in her attempts to connect with her autistic brother also demonstrates the lack of reciprocity inherent in these sibling relationships. The normal child may expend a great deal of time and emotional energy attempting to build a relationship with the autistic child but get very little back in return. This style of interaction is an example of the ***negative reciprocity*** described by Sahlins (1965). According to Seltzer and Krauss (1993), if these inequalities in the sibling relationship persist, one of two consequences may occur: either the siblings may become estranged from each other (i.e. the pattern of negative reciprocity continues), or alternatively the siblingship takes on the characteristics of generalised reciprocity (similar to a parent-child relationship).

Sullivan (1979) identified these two types of response in her collection of 'sibling stories'. Whilst some of the siblings in her study sacrificed almost everything for the sake of the autistic family member, others found their most rewarding life-style was not one of service to the autistic child but one of self expression in other endeavours and other relationships. However, both types of response were accompanied by ambivalent feelings. In the former case, the siblings tended to deny or gloss over strong feelings of anger, sorrow, or jealousy about giving such a large share of themselves to an autistic sibling. For those siblings who chose to remain distant from the autistic child, they often paid a heavy price in terms of guilt and even some family resentment for going their own way.

The children's reactions to the autistic child in the present study did not appear to fall clearly into either of the two response types described by Sullivan. A number of children felt that whilst they had made some sacrifices to accommodate the needs of the autistic child, they had also been encouraged to pursue their own interests and had received support from family and friends. No child expressed complete rejection of their autistic sibling. Characteristics of the sample which may have influenced these findings will be examined when the methodological aspects of this study are considered.

Summary: The findings of the present study support the view that the experience of having an autistic sibling in neither unequivocally positive or negative. The children interviewed differed in their coping mechanisms and in their attitudes towards their autistic brother or sister. A number of researchers have noted that the same life events may have a differential impact on individuals, even amongst children from within the same family (e.g. Beardsall & Dunn, 1992).

The Individuality and Experience corollaries of Kelly's theory help us to make sense of these unique constructions of the same event. Within a family with an autistic child, the experience of each family member will be personal and unique based on each individual's interpretation of events made "in light of their own experiences". Some commonality in construing would be expected, based on the sharing of these experiences, however it cannot be assumed that individuals facing the same experiences will react in the same way.

These findings imply the presence of certain 'mediating factors' which influence the level of adjustment a particular child will achieve. Possible contributory factors will be examined when suggestions for future research are made.

The Lifespan Development model presented by Seltzer and Krauss (1993) facilitates an understanding of the intra- as opposed to inter-individual differences. The issues facing the children in the Sib A group are likely to change over time. Some of the responses made indicate that a number of children were aware that there may be different demands placed upon them as they grow older. One child of 13 years was already anticipating the future needs of her autistic brother and the impact this will have on her own life.

The different response styles of siblings of autistic children have important implications for the manner in which professionals formulate an understanding of the experiences of these children and how they develop strategies to maximise the psychological well-being of this client group. The potential implications for clinical practice will now be explored.

Clinical implications

While there were a number of shared concerns expressed by the children in the Sib A and Sib DS groups, some differences emerged from the experiences of these two groups of siblings which may be clinically relevant.

Most children in the Sib A group expressed some sadness at missing out on a 'normal relationship' with their autistic brother or sister. The impaired social communication and interaction with the autistic child were important issues for these children, and there was a sense of frustration at not being able to connect emotionally with their autistic sibling. While this sibling relationship cannot be 'normalised' due to the autistic child's inherent social impairments, there are several potential strategies which may help the siblings to adjust.

(1) Providing the siblings with a forum to discuss their thoughts and feelings - either individually or in groups - would be likely to serve a number of functions:

- Each child would be able to discuss how the experience of having an autistic sibling has affected them as 'individuals'; with the uniqueness of these experiences being valued and explored in more depth. In group interventions, common experiences could be shared and there would be opportunities for the children to offer support to one another. By sharing these personal experiences, the children may discover that their mixed feelings are a *normal* response to a difficult situation. This might help to relieve some of the feelings of guilt which were so apparent in many of the children's descriptions.

- Individual or group discussions could also promote problem solving strategies. The issues raised by the children may vary according to their age/gender/culture. The concerns expressed by the children in the present study suggest that the following areas of discussion might be relevant: the puzzling nature of autism e.g. the lack of affection and the difficult behaviours associated with the condition; how to explain the autistic child's behaviour to friends; and how to cope with negative responses from members of the public. Some children may also value the opportunity to discuss their hopes and fears for the future and their concerns about the effect the autistic child has on other family members.

- Support groups for siblings could also fulfil an educational role - sharing current knowledge about what is (and is not) known about autism. Information should be tailored to the developmental age of the children in the group and sufficient time should be allowed for questions and concerns to be raised. Advice about coping strategies may be sought from the "experts", and certain issues are likely to require extra sensitivity e.g. children's worries about the genetic risks of having an autistic child themselves. The style of teaching need not always be didactic. A number of children in the Sib A and Sib DS groups had undertaken projects relating to their sibling's disability and this form of self-instruction was seen to be helpful.

A number of clinicians have documented their experiences of being involved with support groups for siblings of disabled children (e.g. Davis, 1992; Lobato, 1990; Meyer, 1993). Meyer (1993) describes siblings as one subsystem of 'overlooked family members'. Other frequently overlooked family members include fathers and grandparents. In his article he describes how peer support and education programmes for these neglected groups can provide an emotional environment that emphasises wellness, mutual encouragement and empowerment.

In Meyer's description of the 'Sibshops' organised by the Supporting Extended Family Members (SEFAM) programme in the United States, the children taking part are encouraged to express the "good and not-so-good" aspects of having a sibling with a disability. Participants can also share strategies to address common sibling concerns such as, what to do when classmates make insensitive comments about people with disabilities or how to respond when their siblings embarrass them in public.

(2) The siblings of autistic children may also benefit from open styles of communication within the family.

The children in the present study differed in how open they were with their parents. One child described how her family had been brought closer together through their open discussions about her autistic brother's difficulties. Other children tended to keep their concerns hidden from their parents in the belief that their parents already 'had enough on their plates'. While such strategies might prove adaptive in the short-term if these patterns persist the child may experience feelings of stress and resentment.

Some children in the Sib A group felt that more support and attention from their parents would make things better for them. If parents and professionals are made aware of the needs of the nonautistic child, attempts can be made to enable the parents to spend time alone with the other children in the family. The availability of respite services provides many families with the extra support needed to care for the autistic child - giving the other family members a welcome break.

(3) Direct intervention to increase the level and style of interaction with the autistic child.

The impoverished style of play between siblings when one child is autistic has already been discussed. There is some evidence that children develop a style of social exchange with their siblings which they subsequently use with their peers (Abramovitch et al, 1982; Knott et al, 1995). The lack of reciprocity in the relationship children have with their autistic sibling might therefore have consequences for the child's attachment relationships with other children.

Whilst there was no indication that the children in the present study had problems forming relationships with other children, there may be children for whom this is a problem. Identifying those children most at risk and providing early intervention should be a matter of concern to professionals working with families with autistic children.

A number of studies have shown that behavioural intervention programmes can help siblings of autistic children to acquire play skills for use in their interactions with their autistic brother or sister (Celiberti & Harris, 1993; Coe et al, 1991; Powell et al, 1983; Schreibman et al, 1983). Many of the children in the Sib A group expressed the desire to interact with their autistic sibling, but were discouraged by a lack of responsiveness, diminished reciprocity and the presence of maladaptive behaviour.

Attempts to improve this area of functioning would therefore be fulfilling an important need for the nonautistic child.

XIII. Methodological considerations and future research

Methodology

This study was an attempt to add to the small body of systematically gathered commentary regarding the personal experiences of siblings of autistic children. The findings have demonstrated that the repertory grid and interview techniques are capable of providing valuable insight into the unique and shared construction processes of children who have an autistic brother or sister. Based on the writer's own experiences of talking to these children, there are several further comments concerning the potential value of this methodology:

- The writer was taken slightly by surprise by how articulate the children were when they were asked to describe their relationship with their autistic sibling. Concern has been expressed by a number of authors about interviewing young children (see Yarrow, 1960). However, there is increasing evidence in the empirical literature that children can give detailed and reliable accounts of their thought processes (e.g. Stillwell & Dunn, 1985). The present study would appear to support the contention that children can be both accurate and uninhibited commentators on their own feelings towards others.

- The candour expressed by the children may have been partly influenced by the methods employed. For many of these children, this was the first time they had been given the opportunity to describe their relationship with their autistic sibling "in their own words". Both techniques allowed the children to respond freely using their own language and construct systems, and it was stressed to the children at the outset that it was *their* thoughts and feelings that were important. The time spent discussing the study with each child and giving assurances of confidentiality was felt by the writer to be essential for the establishment of a safe forum for these children to discuss their experiences.

- Whilst the methods employed were highly idiographic and gained access to a wide range of personal experiences from the children taking part, they also enabled commonalties in the construing processes of different individuals to be investigated. This allowed theoretically based hypotheses relating to the outlier status of the autistic child and the nature of the discriminatory constructs to be explored. Drawing comparisons between the findings of the different data sources and the results of other similar studies added weight to the conclusions drawn.

- The children in the present study quickly grasped the concept of the repertory grid technique. The structured nature of this technique and its strong basis in psychological theory suggests that this methodology can be used as a systematic and replicable tool for assessing the personal experiences of children who have an autistic brother or sister. The findings from each child's grid might also be a useful guide in the development of individually tailored intervention programmes.

Methodological limitations

Interpretation of the findings reported in the present study should be made in light of certain methodological considerations:

The present sample of children was small, primarily middle-class and white. Generalisations should therefore be made cautiously and within the boundaries of these sample characteristics. Moreover, the participants in this study represent a volunteer sample from a population of unknown characteristics. As suggested by a number of researchers (e.g. Cox et al, 1977, Lobato, 1983), people who do not take part in research tend to differ systematically from those who do. It is possible that some parental screening took place during the recruitment process i.e. children who were perceived as being less willing to discuss their relationship with the autistic child were not approached. It is also likely that some children were asked to take part by their parents but declined. In either case, it is not possible to draw conclusions about the perceptions of siblings of autistic children, 'as a whole', on the basis of this sample.

Related to this latter point, is the possible impact that having parents who belong to a support group may have had on the children interviewed. Being part of a support group might be an indication that the families of the children taking part in this study are more aware of the effects that the autistic child has on other family members. Although it is impossible to generalise about the characteristics of this sample, the children's descriptions about feeling supported by their family and friends, would support this view.

The cross-sectional design of this study also limits the conclusions which can be drawn concerning the long-term developmental sequelae of having an autistic sibling. The advantages of longitudinal research in this area is one the suggestions for future research which will now be considered.

Suggestions for future research

- Conducting longitudinal research with siblings of autistic children would enable the consequences of having an autistic sibling to be monitored across the lifespan. It is important to recognise that one cannot assume that because the presence of an autistic child does not have a negative effect at one developmental period that it will not have an effect at earlier or later stages. The reports gained from the children in this study suggest that the issues which affect them often change over time. Professionals working with these families need to be aware of these shifts in focus if interventions are to be timed correctly.

- More research on the factors which mediate an individual's level of adjustment may facilitate a better theoretical understanding of the psychological consequences of having an autistic sibling. Factors which increase or decrease a child's level of resilience should be studied closely and these findings used to target interventions with those children most at risk of developing emotional and behavioural difficulties.

  The mediating variables described in Table 1. (p. 23) suggest some potential areas for study. The mediating effects of the 'family' and 'nondisabled child' characteristics are likely to be similar to findings relating to siblings of children with disabilities 'in general'. However, certain characteristics of the autistic child may specifically influence the level of adjustment of their sibling(s). The results from the analysis using the levels of problem behaviours reported for the autistic children in this study (see Appendix D) suggest that the severity of behavioural disturbance exhibited by an autistic child may influence the way they are construed by their siblings.

- Finally, there are a number of changes to the design of the present study which the writer would make if there was the opportunity to 'do it all over again'.

(1) The inclusion of an 'ideal sibling' element might generate constructs which would give some insight into the children's expectations/fantasies of 'what might have been' had their sibling been nonautistic. Some children may idealise this imagined sibling whilst others might show more realistic expectations.

(2) Although the 'ideal self' element can be used to examine an individual's level of self-esteem (taken as the measure of discrepancy between self-ideal self scores), Bell (1996, personal communication) suggests that 'self at different developmental stages' elements might generate a wider range of constructs e.g. 'self in six months time'; 'self when I was nine years old'; 'self when I'm in my mid-twenties'. The nature of the constructs generated in response to such elements might provide some insight into a child's previous and/or anticipated experiences. Whilst not longitudinal in nature, such an investigation might help the researcher discover the issues of importance at various developmental stages.

(3) In light of the research which has shown that similar experiences can affect children within the same family in different ways (e.g. Beardsall & Dunn, 1992), asking different children from within the same family to rate the autistic child could explore these individual differences in more detail. It would also be interesting to examine the ratings given to the other nondisabled sibling(s) in each child's grid more closely as it is likely that the presence of the autistic child has indirectly affected the nature of the other sibling relationships within the family.

(4) Attempts were made to categorise the large number of constructs generated by the children using the repertory grid. The inter-rater reliability of these categories was assessed to examine whether this system of categories could be meaningfully used by another rater. Although the agreement was high across all eighteen categories, there was nevertheless a degree of permeability in the subcategories developed; with different raters using different categories for the same constructs. This finding would be predicted by Kelly's personal construct theory which allows for both individuality and commonality in construing (even for researchers!). However, further investigation of the categorisation system would be expected to produce interesting findings.

(4) Had time permitted, the use of the "construct elaboration" process would have added further depth to the meaning of the constructs generated by the children.

Salmon (1979) suggests using requests such as *"Tell me a bit more about that"*, and *"How would you know if a thing was .... ?"*. The purpose of these questions is to get at the meaning behind each construct e.g. *"What does it mean when someone knows how you're feeling ?"*, *"How do you know when someone is telling the truth/is being friendly ?"*. Attempts could also be made to explore the reasons behind the children's choice of ratings e.g. *"How come you like being with X more than you like being with Y ?"*.

(5) Finally, it might have been helpful to have ratings of the nature of the sibling relationship and/or the perceived adjustment of the nonautistic child made by external sources such as parents and teachers. These would not override the child's own perceptions of the sibling relationship (which was the writer's main area of interest).

However, this extra information could be employed in the process of triangulation - adding a further source of information to test whether the same story is being told.

XIV. Conclusion

The wealth of data generated by the 45 children taking part in this study has been difficult to impart without an inevitable loss of detail. Whilst belonging to one of the three 'sibling groups' for the purpose of the present study, these children are first and foremost individuals - each with a unique and personal story to tell. However, given the convergent findings from the different data sources used within this study and the consistency between these findings and those of other similar studies, some tentative conclusions can be made.

Using the process of triangulation, the two research hypotheses concerning the outlier status of the autistic child and the nature of the discriminatory constructs were supported. It should be reassuring to professionals to note that the criteria they use to diagnose autism (i.e. impaired social communication and interaction) are the same characteristics which the siblings of these children use to discriminate their autistic brother or sister.

However, the findings of this study also highlight a number of other possible areas of concern for these children which professionals may be less aware of. These include: a lack of understanding concerning autism and how to explain their sibling's disability to their friends; the problems faced in coping with negative reactions from other people; worries about the psychological well-being of parents and other members of the family; a desire for more support and attention from parents; and how to cope with the mixed feelings they have towards their autistic sibling. Some suggestions for clinical practice have been made, but further research is needed in this area.

Overall, the results indicate that the experience of being a sibling to an autistic child is neither unequivocally positive or negative. Most children were able to describe both 'the good things' and 'the difficult things' about having an autistic brother or sister. It also became apparent that these children are likely to face different concerns at different ages which strengthens the case for conducting longitudinal research.

There was no indication that the children's social and emotional development had suffered noticeably as a consequence of having an autistic sibling. The children described experiencing problems interacting with their autistic brother or sister and many expressed frustration and sadness at not having 'a normal sibling relationship'. However, these children displayed resilience in their attempts to build a relationship with the autistic child, and it was clear that most children expressed fondness towards their sibling. These conclusions should nevertheless be viewed with some caution due to the variability within the Sib A group in the ratings given to the autistic child. Possible sources of bias relating to the characteristics of the sample have also been noted.

The children taking part in this study demonstrated a remarkable degree of openness when discussing their relationship with their autistic sibling. It was suggested that this candour may have been partly due to the methodology chosen to explore these experiences. The repertory grid technique provided a structured tool grounded in a comprehensive psychological theory, and attempts were made to remain close to the language used by the children themselves.

Several authors advocate caution in the use of repertory grids (e.g. Beail, 1985). Some studies have been criticised for using grids in a rather mechanical fashion with little theoretical rationale guiding their administration and interpretation. Leitner (1988a) argues that the "personal" constructs elicited under these conditions are more or less ignored in favour of countless scores, and the researcher begins to construe subjects as objects rather than as partners in research.

The aim in the present study has been to encourage the democratisation of the process of research. The subjectivity of *both* the researcher and the researched was embraced (Banister et al, 1994). As Kelly remarked on one occasion:

> "while most psychological experiments have the subject guessing what the experimenter is after, PCP prefers to have the experimenter guessing what the subject is thinking" (cited in, Jahoda, 1988, p.4)

By displaying a genuine interest in hearing what these children had to say about their own experiences, some valuable insight was gained into the personal and shared constructs of this group of children - supporting Kelly's contention that the way to find out what is wrong with someone is to:

> "ask them, they may tell you".

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APPENDICES

APPENDIX A: INFORMATION SHEETS

I. Parent.

Dear Parent,

I am currently undertaking my post-graduate training in Clinical Psychology at the University of Leeds. Part of my training involves conducting some research into an area of psychology.

Throughout my training, I have become increasingly interested in the area of autism. From discussions with families who have an autistic child, I have become more aware that autism affects not only the individual child, but can also have far-reaching effects on other family members.

The focus of my research project, will be to begin to explore the impact having an autistic brother or sister may have on the ***siblings***. Little research has been done in this area, and so I believe that asking the siblings to describe 'in their own words' their relationship with their autistic brother or sister, will provide valuable information to professionals working with this client group.

I am looking for volunteers to take part in this study. In particular, I wish to conduct interviews with siblings (aged between 8 and 19 years old) who have an autistic brother or sister (of any age). During the interview, the sibling would be asked to describe the kind of relationship he/she has with his/her autistic brother or sister, and also how this relationship is similar to and/or different from the types of relationship they have with other children e.g. other siblings and/or similar aged peers.

The interview is likely to last approximately 30-40 minutes, but the interview may finish at any point should the sibling wish to. The interviews will be conducted in a sensitive manner, and no pressure will be put on the child to respond to any question. the child's responses to the interview questions will be kept confidential, and personal details will only be known to myself.

I am aware that it may be upsetting for some children to talk so openly about their relationship with their autistic brother or sister. Should they feel upset during the interview, it will be made clear to them that they can stop at any point. I would be able to talk to them about any worries they may have, or I could arrange for them to be seen by another psychologist or family worker if they would prefer it. In cases where the upset is not immediately apparent, and occurs in the days, weeks or months following the interview, I can be contacted at the addresses below:

II. Child.

My name is Justine, and I am a psychologist working in Wakefield. You might have met a psychologist before, but if not, I'll tell you a bit about what we do. Psychologists work with people of all ages - children, grown-ups, and old people. They can work with people on their own, but sometimes they work with families and groups. A psychologist helps people with their feelings and behaviour. We don't give medicine like doctors, instead we try to help people by talking to them and listening very carefully to what they have to say.

Some psychologists have talked to families who have a child with autism. A lot of the time it is the mum or dad who have been asked what it feels like to have an autistic son or daughter. I think it is also important to ask the brothers and sisters how it feels for them too !

I am looking for some children to help me learn what it feels like to have a brother or sister with autism. This isn't because I'm being nosy. I think it is important for psychologists to understand what it is like for the brothers and sisters of someone who has autism.

I would like to ask each brother and sister about some of the ways they would describe their relationship with their autistic brother or sister. I would also like to know whether they see this relationship as being the same or different from the kinds of relationship they have with other children, for example, other brother or sisters (if they have any), and other children of their age.

If you would like to take part, the questions I have would last about 30 or 40 minutes. You don't have to answer any question if you don't want to, and you can ask me to finish at any time. If you don't understand a question you can ask me to try to make it clearer. If you feel upset or tired at any time, please let me know, and we can stop. If you still feel upset after the questions are finished, then you can talk to me about your worries, or I can arrange for another psychologist or family worker to talk to you if you would prefer it.

Your answers to the questions will be kept private. When I talk to other people, I will not use your name, so no-one will know exactly what you said. If you want to tell other people about your answers you can, but I will not say anything.

APPENDIX B: GRAN OUTPUT

GRAN is a program for analysing repertory grids. It carries out cluster analyses of elements and constructs and produces a rearranged version of the grid with similar elements and similar constructs close together. It can analyse dichotomous, ranked or rating grids up to size 45 x 45.

The Output:

1. THE ORIGINAL GRID AS INPUT.

2. MATRIX OF DISTANCES BETWEEN ELEMENTS.
   This compares the elements in pairs using Euclidean distances, normalised to the range 0-1. The distances printed out are multiplied by 100 for convenience, so a distance of 0.07 is printed as 7. Small values indicate that the two elements are viewed similarly across the constructs.

3. MINIMUM SPANNING TREE FOR ELEMENT DISTANCES.
   This is a stage on the way to the cluster analysis. It is not necessary to know about these in order to interpret the results of the analysis, but they may be interesting to anyone with a knowledge of graph theory.

4. SINGLE LINK CLUSTERS AT EACH LEVEL.
   This shows the clusters obtained at each level of the cluster analysis. The analysis uses a Single-Link Hierarchical Cluster Analysis. The first number on each line is the level (from the Element Distance Matrix) at which a new cluster is formed. The remaining numbers are the element labels, with a star showing the end of any clusters. For example, the line:
   4 1 3 5 8 6 * 2 * 4 7 9 * 10 * 11 *
   shows that at distance 4, there are two element clusters, consisting of elements 1,3,5,8,6 and 4,7,9, with elements 2, 10 and 11 not belonging to any cluster.

5. SINGLE LINK TREE
   This shows the full cluster analysis in dendogram or tree form. It contains the same information as given in 4, apart from the numerical level. This is the most convenient way of representing the analysis.

6. CONSTRUCT CORRELATION MATRIX.
   This is a matrix of Pearson product-moment correlations between all pairs of constructs, with values multiplied by 100 for convenience.

7. CONSTRUCT DISTANCE MATRIX.
   This converts the correlations into distances by subtracting the absolute value of the correlation from 1. again multiplied by 100 for convenience.

8. MINIMUM SPANNING TREE FOR CONSTRUCT DISTANCES.
   The construct distances are now analysed using a single link hierarchical cluster analysis and this is a step on the way to the full cluster analysis.

9. SINGLE LINK CLUSTERS AT EACH LEVEL.
   The clusters of constructs given level by level.

10. SINGLE LINK TREE.
    The cluster analysis of constructs in dendogram form.

11. REARRANGED GRID.
    The grid is now rearranged in accordance with the output of the two cluster analyses, with similar elements and similar constructs brought together. Constructs labelled R have been reversed to make the structure of the grid more obvious. Missing entries are printed with an X. It is usually helpful to superimpose the two cluster analysis trees on this rearranged grid.

Adapted from: Leach (1990) - GRAN: IBM-PC compatible version.

APPENDIX C: INTER-RATER RELIABILITY

(Kappa analysis)

<u>**Agreement Matrix:**</u> **Sib A Group** Random sample of 50 construct pairs

Rows = First Rater Columns = Second Rater

Kappa = .809

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	T
1	3																		3
2																			0
3			2																2
4				1															1
5					1														1
6						2													2
7			1				2							1					4
8													2						2
9									1	1									2
10										1									1
11											1								1
12												2							2
13													15						15
14			1						1				1	7					10
15															3				3
16																1			1
17																			0
18																			0
T	3	0	4	1	1	2	2	0	2	2	1	2	18	8	3	1	0	0	50

Agreement Matrix: **Sib DS Group** Random sample of 50 construct pairs

Rows = First Rater Columns = Second Rater

Kappa = .724

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	T
1	1																		1
2																			0
3																			0
4				1															1
5					2														2
6			1			6													7
7			1				2							1					4
8								1											1
9							2		4				1						7
10										3									3
11																			0
12												2							2
13												2	9	1					12
14						1	1						1	6					9
15															1				1
16																			0
17																			0
18																			0
T	1	0	2	1	2	7	5	1	4	3	0	4	11	8	1	0	0	0	50

Agreement Matrix: **Sib ND Group** Random sample of 50 construct pairs

Rows = First Rater Columns = Second Rater

Kappa = .791

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	T
1	5						1												6
2																			0
3																			0
4			1	3															4
5				2	2				1										5
6						1													1
7							2							1					3
8																			0
9									5										5
10										4									4
11																			0
12												1							1
13						1	1		1				14						17
14														3					3
15																			0
16																1			1
17																			0
18																			0
T	5	0	1	5	2	2	4	0	7	4	0	1	14	4	0	1	0	0	50

APPENDIX D: PARENT QUESTIONNAIRE

Name .... **Date ....**

(A) Family Details

Parents:

	Occupation	Age
Mother		
Father		

Children:
(Please indicate with a * which child/children has/have received a diagnosis of autism)

	Male / Female	Age
1.		
2.		
3.		
4.		
5.		

Other:
Are there any other people who live in your house on a continual or regular basis e.g. grandparents, uncles/aunts, friends, foster children etc. ?

Yes / No

If yes, please give the following details:

Relationship	Male / Female	Age

Information about your autistic child

(B) Diagnosis:

1) What age was your child when you first suspected that something was wrong with his / her development ? ....

2) What early signs concerned you most ? ....
....
....

3) What age was your child when they received a diagnosis of autism ? ....

4) Who actually made this diagnosis e.g. G.P, Psychiatrist, Psychologist, Multi-Disciplinary Team ? ....

(C) Problem Behaviours: Does your child with autism display any of the following behaviours ? Please indicate how ***severe*** you consider the behaviour to be using the following scale:

0 = My child does not exhibit this form of behaviour.
1 = My child exhibits a mild form of this behaviour.
2 = My child exhibits a moderate form of this behaviour.
3 = My child exhibits a severe form of this behaviour.

1) An absence of desire to communicate with others [ ]

2) Is aloof & indifferent to others [ ]

3) Shows no sign of symbolic or pretend play [ ]

4) Has a restricted repertoire of activities & interests [ ]

5) Has "odd" motor responses e.g. hand flapping, spinning, tiptoe walking, facial grimaces etc. [ ]

6) Displays repetitive / ritualistic behaviour [ ]

7) Lacks an understanding of social rules [ ]

8) Is confused & frightened by unexpected events [ ]

9) Shows aggression towards other people [ ]

10) Shows aggression towards objects [ ]

11) Screaming [ ]

12) Displays Self-Injurious behaviour [ ]

13) Displays inappropriate laughing & giggling [ ]

14) Is not cuddly [ ]

15) Shows little or no eye contact [ ]

16) Displays extremes in activity level i.e. is overactive / restless or is inactive / lethargic [ ]

17) Shows emotional immaturity & inappropriate emotional responses [ ]

18) Displays high levels of anxiety [ ]

19) Lacks motivation [ ]

20) Demands constant supervision [ ]

Analysis

Information about the autistic child:

(B) Diagnosis

(1) Age of the child when the parents first had suspicions that something was wrong:

Concerns about their child's development were experienced by parents at different stages. Approximately one third became concerned when the child was between the ages of 12-18mths. A similar percentage were first aware that something was wrong when the child was 2-3 years of age. The remainder had not become overly concerned until the child was 5-6 years old.

(2) Early signs causing most concern:

A wide range of behaviours were described by the parents; including:

- Odd speech. No language. Making funny sounds e.g. humming. Many parents initially thought their child was deaf.
- Asocial behaviour. Not responding to people. No smiling. Screaming when picked up. Screaming for no apparent reason.
- Problems feeding / toileting / sleeping / walking. Developmental milestones not reached.
- Younger sibling(s) 'overtaking' the autistic child developmentally.
- Odd behaviours e.g. rocking; picking skin; phobias; anxiety about loud noises.

(3) Age when child was diagnosed autistic:

More than half the children had received a diagnosis by the time they were 4 years old. Two children had not been diagnosed until they reached 5 years, and a further two were 7 years old when they had received a diagnosis. The children who had not been diagnosed until mid-childhood were the same children whose parents had not become overly concerned about their development until the child was 5-6 years old.

(4) Who made the diagnosis:

Ten children had received their diagnosis from a Multi-Disciplinary Team (MDT). Four children had been diagnosed by a psychiatrist, and only one had been diagnosed by a psychologist.

(C) Problem Behaviours

Fig. 9. shows a stem-and-leaf display of the total problem behaviour severity score for the target child in each sibling group. The minimum score possible = 0 and the maximum = 60.

Fig. 9.: Stem-and-leaf display of the total problem behaviour severity score for the target child in the Sib A, Sib DS and Sib ND groups.

Stem width = 10.0
Each leaf = 1 case

	Sib A	Sib DS	Sib ND
6			
5			
4	0 1 1 2 4		
3	1 4 4 4 4		
2	3 4 4 9		
1	8	0 3 3 4 4 7 7 9	
.		5 5 6 7 7 7 9	0 0 0 0 0 0 0 0 0 0 2 3 5 6 8

Comments: The scores on the problem behaviour checklist are noticeably greater for the target sibling in the Sib A group. This finding is not particularly surprising considering the nature of the items chosen (i.e. from: The Childhood Autism Rating ; Schopler et al, 1988). There is, however, evidence of some problem behaviours amongst the target siblings in the two control groups. A correlational analysis was undertaken to assess the relationship between the total problem behaviour severity scores for each target child and the 'identification' and 'outlier' ratings made by their siblings in the GRAN analysis.

'Identification' with the target sibling

The Spearman's Correlation Coefficient for the degree of association between the severity of problem behaviours exhibited by the target sibling and level of 'identification' between the self-target sibling elements was: rho (N = 45) = .73, p<.001.

This finding suggests, that the more severe the problem behaviours exhibited by the target sibling, the less identification there is with the child.

'Outlier' status of the target sibling

The Spearman's Correlation Coefficient for the degree of association between the severity of problem behaviours exhibited by the target sibling and the outlier status of the target sibling was: rho $(N = 45) = .62$, $p<.001$.

The more severe the problem behaviours exhibited by the target sibling the greater the likelihood is that they will be perceived as an 'outlier'; sharing few characteristics with the other children (elements) in the grid.

Summary: Whilst these findings are limited by the small number of children sampled, and the use if a checklist of problem behaviours which has not been standardised on an autistic population, the strength of the measures of association shown above suggest that the level of problem behaviours exhibited by an autistic child has an impact on how he/she is construed in relation to other children. Further research examining the relationship between this variable and the level of adjustment of the nonautistic child would be of value.