The Effect of Specific Vs Non-Specific Diagnoses of Learning Disabilities on Parental Coping and Family Functioning

A portfolio of study, practice and research

by
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Submitted in fulfilment of the requirement for the Doctor of Psychology (PsychD) in Clinical Psychology as part of the conversion programme.

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• The Relationship Between Family Functioning and the Psychological Adaptation of Siblings of Children with Chronic Liver Disease (MSc research)
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OVERALL AIMS AND OBJECTIVES:

Aim
To attain greater professional competence in order to enhance the contribution of Clinical Psychology to healthcare

Objective
To produce a portfolio of study, practice and research that will demonstrate increased competence in each of these areas.

Process
A personal study plan tailored by audit to professional needs and demands

1. Academic Dossier
1.1 Aims
To enhance academic competence in two specialist areas of Clinical Psychology so as to develop the services offered by the department or profession.

1.2 Objectives
To complete two academic reviews, one for each of two specialist areas within the clinical field of children with learning disabilities.

1.3 Rationale
To increase areas of knowledge within the field of child psychology, and specifically, children with learning disabilities. This increased level of specialist knowledge will increase the quality of the service being offered by the Psychology Department.

1.4 Plan
To focus on two key academic areas, and carry out a literature review within each, of 4,500 words. The following two areas will be addressed:
• Selective Mutism, differential diagnosis and how this relates to its treatment,
• the psychological aspects of Turner’s syndrome in children and adolescents,

2. Clinical Dossier
2.1 Aims
To increase personal professional competence, to develop the services offered by the department and by the profession.
To increase my clinical repertoire in order to qualify for Chartership by the British Psychological Society.
2.2 Objectives
To present a dossier on clinical activity that will make evident increased personal clinical competence thus satisfying both BPS and personal requirements.

2.3 Rationale
To report on clinical duties carried out as an employee of Greenwich Healthcare, and Lambeth Healthcare, in order to demonstrate areas of increased clinical competence within the field of children with learning disabilities and general work in the field of children and families.

2.4 Plan
To present a clinical case report based on the history including a brief literature review on the relevant clinical area, problem of referral, formulation, treatment plan and outcome of a child with learning disabilities referred to Greenwich Clinical Psychology Department.
To present a detailed log summarising all clinical duties undertaken for two years following qualification as a Clinical Psychologist. This will include information on teaching attended and undertaken, multidisciplinary work and all clinical cases - joint, group, individual and family work. The two pieces of written work will amount to at least 7,000 words.

3. Research Dossier

3.1 Aims
To increase research competence so as to develop the services offered by the profession and to increase knowledge available to the department and the profession. To increase the profile of the department within the service area specific to children with learning disabilities and within the general area of published research.

3.2 Objectives
To develop a research dossier, part of which will be the original MSc dissertation, which will present a contribution to knowledge in the field of children with learning disabilities and their families.

3.3 Rationale
To investigate relationships between issues which arise within the everyday clinical setting of children with learning disabilities and their families. This will help to develop Clinical Psychology services in relation to the specific topics investigated.

3.4 Plan
To present MSc research entitled “The relationship between family functioning and the psychological adaptation of siblings of children with chronic liver disease.”
Personal Study Plan

To develop, carry out and present a piece of research within the merged Greenwich and Bexley health districts which scrutinises issues regarding diagnostic needs for children with learning disabilities and their families. This research will investigate issues relating to family functioning, parental coping, and diagnosis. These issue will be explored by the use of standardised and specially developed non-standardised questionnaires and interviews with relevant parties. The two pieces of research together will amount to 40,000 words of written material.

5. Portfolio Outline

1. To carry out and present two literature reviews which will further academic knowledge and improve quality of service for children with learning disabilities.

2. To present a clinical case report and log of clinical activity in order to demonstrate enhanced clinical competence and to attend further teaching and training events in order to increase and update knowledge.

3. To present MSc research and to develop and present a new piece of research which will address pertinent issues regarding children with learning disabilities. This will increase the knowledge and status of the Psychology Department and enhance the quality of the service provided.
ACADEMIC DOSSIER

- Selective Mutism and It's Treatment In Children with Learning Disabilities: A Review
- Psychological Aspects of Turner's Syndrome in Children and Adolescents: A Review

Louise Connor
Definition
The essential feature of selective mutism (formerly known as elective mutism) is defined in DSM IV (1994) as ‘the persistent failure to speak in specific social situations .... where speaking is expected, despite speaking in other situations’. The condition interferes with educational or occupational achievement, lasts for more than a month, and should not be associated with a lack of knowledge of the language or a communication disorder. These children may communicate by use of gestures, expressions, by directing people towards what they want or short monosyllabic utterances. However, as the disorder is under voluntary control it may be difficult to establish in children with a speech disorder.

Tramer (1934) first coined the phrase ‘elective mutism’ to describe children who were silent with everyone except a small group of intimate relatives or peers, although the condition was initially described by Kussmaul in 1877 as ‘aphasic volutaria’. The disorder usually takes the form of children speaking at home with close family members, but being silent at school and in other social settings. However the converse has also been found where children speak at school but not at home (Wilkins, 1985). Those children who refuse to speak in all situations, or will only speak when asked a question, are not considered to be selectively mute (Blake & Moss, 1967; Williamson et al., 1977), as there should be demonstrable failure to speak in some social situations but not in others. Nor is the diagnosis made if the mutism is secondary to conditions such as a pervasive developmental disorder, hearing loss or schizophrenia (Rutter, 1977).

Prevalence
Selective mutism is quite a rare condition. Fundudis et al. (1979) conducted a large epidemiological study in which they found a prevalence rate of 0.8 per 1000 children. Brown & Lloyd (1975) found a prevalence rate of 0.3 to 0.6 per 1000. The ratio of
selectively mute girls to boys ranges between 2.4:1 (Wright, 1968) to 1.2:1 (Kolvin & Fundudis, 1981). In contrast, other speech and language disorders are more common in boys than girls (Baker & Cantwell, 1991). Kolvin & Fundudis suggest that this unusual gender ratio reflects the emotional component of selective mutism, as emotional disorders in children are more common in girls than boys.

Onset normally occurs between the ages of 3 and 8 years (Kolvin & Fundudis, 1981), although onset after 12 years has been reported in some cases (Kaplan & Escoll, 1973). The onset of mutism tends to coincide with entering a new school environment.

**Other forms of mutism**

Selective mutism is a motivational disorder in that there is no significant abnormality of language comprehension or production, and should be distinguished from other forms of mutism. For example ‘transient mutism’, which is not uncommon in children first starting a new school. Brown & Lloyd (1975) reported 7.2 per 1000 children not speaking in the first eight weeks of school, this figure had fallen to 0.3 to 0.6 per 1000 after twelve months. This form of mutism reflects normal separation anxiety, as the anxiety diminishes with familiarity, so the child begins to speak (Cantwell & Baker, 1985).

Another form is ‘traumatic mutism’, this can be distinguished from selective mutism by it’s sudden onset which occurs as a result of psychological or physical shock. In this condition, sufferers are generally mute across all situations. This in turn differs from ‘speech phobic mutism’ which is least common, this is characterised by a fear of hearing one’s own voice (Halpern et al., 1971). However, means for determining this condition are not clearly defined.

Paniagua & Saeed (1988) make the distinction between ‘selective’ and ‘progressive’ mutism. Progressive mutism is described as the child progressively withdrawing from talking to anyone over time, rather than only speaking in specific situations. Paniagua & Saeed proposed that this distinction has implications for treatment, as selectively
mute children will need to extend their verbal interactions to include an increasing number of people, while progressively mute children will first have to develop the ability to speak to selected people, i.e. parents, then extend this speech into more situations. However the researchers do not attempt to explain the differences in psychological and developmental processes between the two forms of mutism, but instead describe the two forms and propose staged treatment strategies for each. This model, therefore, has some descriptive use for classification, but limited clinical use in the absence of a formulation. This distinction between 'progressive' and 'selective' mutism has not been reported by other researchers, and so it's validity as a theory is yet to be established.

Other terms used for selective mutism include 'voluntary mutism' (Herbert 1959), 'reluctant speech' (Morin et al., 1982) described by Labbe & Williamson as a milder form of selective mutism (1984), 'situation specific mutism', 'functional mutism', 'symbiotic mutism' (Hayden, 1980), and 'speech avoidance' (Kratochwill, 1981). This lack of consensus in terminology reflects the different theories of aetiology and function which are proposed by the different researchers, and highlights the differences in inclusion criteria of subjects.

**Associated features**

A number of features have been found to be associated with selective mutism, concurrently or pre-morbidly. One of the first reports was from Spieler (1944) who identified a neurotic personality as being an outstanding feature of selectively mute children. In their large epidemiological study, Kolvin & Fundudis (1981) collected clinically based data on 24 selectively mute children, matched speech retarded children and a control group. They were able to describe a number of anxiety related characteristics which they felt were linked to the condition. Excessive shyness and withdrawal were characteristic in 80% of their sample from a very early age. One quarter were described as 'sensitive' children who would cry easily and become easily distressed. One third of the children were more withdrawn in relation to their peers than to adults, while roughly half of the children demonstrated sulky behaviour, mostly with strangers, and aggressive behaviour, mainly at home. Oppositional behaviour, identified by aggression and sulky moods, and poor malleability, defined by a stubborn
Review: Selective Mutism

attitude, both at home and school were seen in most of the children, unfortunately comparison figures were not given so few conclusions can be drawn regarding the specificity of these characteristics to selective mutism.

However, in an epidemiological study by Wright (1968), only 50% of children with selective mutism demonstrate oppositional behaviour as a prominent feature. This was most evident when the child was under considerable stress. Wright (1994) claims that oppositional and controlling behaviours are not mutually exclusive from the apparently anxiety related and withdrawn behaviours exhibited by these children.

Kolvin & Fundudis also found behavioural problems in 71% of the children. 29% had excessive motor activity, 2 children were obsessional and 1 had fainting attacks, while one child developed exhibitionism in their adolescent years. Fear of social embarrassment, social isolation and withdrawal, clinging, compulsive traits, negativism, temper tantrums, severe impairment in social and school functioning, teasing or scapegoating by peers are also described as associated features in DSM IV.

Black & Uhde (1992) propose that 'elective mutism...may be no more than a developmental variant of social phobia'. They suggest that the diagnosis of social phobia is not dissimilar to that of selective mutism as it includes fear and avoidance of speaking in public or to strangers, and generally has a childhood onset. They point out that remaining quiet and withdrawn are common signs of apprehension of danger. Significantly high levels of anxiety were also reported by Wright et al. (1985), Crumley (1993) and Leszczyk (1993). Interestingly ICD-9 includes selective mutism as a subcategory of sensitivity, shyness and social withdrawal disorder.

Unfortunately many of the descriptive studies carried out do not mention the use of control groups (e.g. Wright, 1994), this could lead to assumptions being made while any causative link is unproven. While Kolvin & Fundudis (1981) describe using speech retarded and matched controls, the data from these two groups are not presented for many of the variables, and these findings are discussed in isolation from the control groups.
**Family characteristics**

Much of the literature in this field reports an abnormally strong tie between the mother and the selectively mute child, with the mother often being described as anxious, dominating and overprotective (Browne et al., 1963; Hayden, 1980; Parker et al., 1960; Wilkins, 1985; Wright, 1968). Krohn et al. (1992) found a 50% rate of mother-child overenmeshment as recorded by the initial treating therapist, although no standardised form of assessment was made. Overprotection and spoiling by the mother was described significantly more often in selectively mute children than in those with emotional disorders. These findings provide evidence of anxiety and related disorders in mothers of selectively mute children.

Hayden (1980) reported that mothers appeared jealous of their child’s interaction with others, and commented on the general lack of family communication. Kolvin & Fundudis (1981) found that 20% of parents of selective mute children, compared with 8% of normal controls, has received specialist psychiatric help at a clinic. This difference did not reach statistical significance.

In one third of the Kolvin & Fundudis sample parents were either aggressive or shy. 42% of families had at least one parent with personality problems, overall, 58% of families had some kind of personality disorder, psychiatric disorder or serious marital problems although the method for collecting these data was not described. Wright (1968) reported a higher rate of 75% of disturbed families, and these general effects have been reported in a number of other studies (Hayden, 1980; Parker et al., 1960; Wergerland, 1979; Wright, 1968).

Wilkins (1985) carried out a study comparing selectively mute children to those with emotional disorders. He found that while over half of families in both groups had a history of marital disharmony, all the families of children with selectively mute children were two parent families. This was only the case in half of the families with emotionally disordered children. Meyers, in an earlier study, proposed that mutism serves to maintain the family homeostasis of marital discord (Meyers, 1984). However, it has been noted that it is impossible to predict cause and effect between
contentious issue of drawing conclusions regarding causality from correlational evidence, and the need for full information regarding methodology and analysis of data such that any interpretations made are within the context of the study.

These findings provide evidence that there may be an association between childhood selective mutism and a parental history of anxiety related personality characteristics, psychiatric illness and family discord. However none of this evidence provides information on the nature of the relationship between these factors, or of any direction of causality.

**Developmental aspects**

Kolvin & Fundudis found some developmental abnormalities in their sample of children with selective mutism. Selective mute children spoke significantly later than children with language disorders, 42% were enuretic and 17% encopretic compared with 25% and 7% of children with other speech disorders and 17% and 2% of normal controls. 79% of the group had abnormal EEGs as was also described in Wilkins’ sample. Wilkins also reported that 33% of his sample had some kind of problem with speech. Kolvin & Fundudis found delayed speech milestones and difficulties in articulation occurring frequently in selective mutes. A high incidence of mouth trauma or trauma experiences in mother child relationships at the time of speech acquisition has also been suggested (Browne et al., 1963; Parker et al., 1960).

**IQ**

Kolvin & Fundudis found that mean non-verbal IQ of selectively mute children was 85, significantly lower than that of normal controls (101) and other speech retarded children (95). Half the sample scored within the 85-99 range of overall intelligence, one fifth were in the 70-84 range with another fifth below 69 i.e. within the range of learning disabilities. This finding of low non-verbal IQ replicated those of Wright (1968). Kolvin & Fundudis also found a significant difference between mean non-verbal IQs of girls (89) and boys (79).
Learning disabilities

Many classification systems differentiate selective mutism from language problems seen in developmentally disordered or learning disabled children, thus excluding them from any research. It is the case, in fact, that many classification systems require that the child’s verbal abilities are normal (e.g. ICD 10). However those studies which have included children in the IQ range of borderline or above, have found a wide range of intellectual potential (Hayden, 1980) as well as the developmental difficulties previously described. There is also a problem in that many of the assessment procedures carried out on selectively mute children have a verbal element. Klin & Volkmar (1992) point out the need for assessments of either non-verbal cognitive skills, or measures of receptive language to circumvent this complicated issue. However so far, only a few studies in the selective mutism literature have reported the presence of cognitive deficits (e.g. Klin & Volkmar, 1992; Kupietz & Schwartz, 1982; Reed, 1963).

It may be the case that children with learning disabilities are excluded from research on selective mutism as they are considered a different sample. However Klin & Volkmar suggest that including these children may lead to a greater understanding of the disorder. They point out that it is also important to consider this group for four clinical reasons: (1) The psychoeducational needs of these children may differ from other children with selective mutism, (2) the presence of learning disabilities may lead to inappropriate exclusion from research projects possibly resulting in associated mental retardation not being properly appreciated, (3) the frustration of parents and teachers may be exacerbated by unrealistic expectations based on the assumption that the child’s problem is solely motivational, (4) overemphasis on the motivational aspects of the disorder may minimise broader prognostic issues associated with low IQ.

Klin & Volkmar (1992) recommend that full assessment should identify the proportion of motivational and cognitive ability components, and lead to a tailor-made intervention package which makes realistic demands on the child. This assessment should identify cognitive deficits as well as parental and social influences on the child, unfortunately there has been no work in this area of influences on motivation and
cognition as yet. Klin & Volkmar describe two cases where parents felt that their children were underachieving according to their potential although, on assessment, it became evident that this was not the case. This situation resulted in continual demands on the children which in turn led to heightened anxiety and chronic depression. Klin & Volkmar stress the possible comorbidity of selective mutism and mental retardation and highlight the importance of cognitive assessment. These results also provide further evidence for the proposal than selective mutism may be an anxiety related disorder.

Matson et al. (1992) posit that developmentally delayed children may experience the problem of selective mutism in greater numbers as they have greater difficulty in generalising learned skills to new situations, as is the case in autistic children. Matson et al. identified a number of flaws in studies of developmentally disabled children; lack of controlled research designs, lack of systematic variation of treatments components, poor measures of change, no observer agreement, no generalisation measures, use of verbal measures to identify retardation and lack of reporting on adaptive behaviour scales.

Matson et al. used modelling and contingency management to treat two developmentally delayed children with the target of getting the children to label objects and name familiar people. For one of the children peer modelling was used, for the other, the therapist modelled the desired behaviours. Edible reinforcers were used with both children, and significant improvement in language use was reported. Matson et al. concluded that speech patterns seen in the developmentally delayed population are not fundamentally different from those seen in selective mutists. However this treatment appeared to focus on developing language rather than intervening at the level of the underlying function of the behaviour. Another problem with this study is that one of the children used was autistic, the other attended an autistic school thus suggesting autism. Both children had developed speech and lost this skill, rather than displaying situation specific language as is required for the diagnosis of selective mutism. This loss of language skills is a common profile of overall language development in young autistic children and so may have a very different basis to selective mutism. One must also consider that Autism is a social communication
disorder, and autists lack the social motivation to communicate. The selective mutism may therefore be seen as secondary to the social interaction problems.

In summary it would appear that researching selective mutism in children with learning disabilities may shed light on the underlying psychological processes of selective mutism, and that an assessment of cognitive skills, however problematic, should be an essential element in the evaluation and establishment of intervention priorities for individuals exhibiting this disorder. However, any social communication disorders should be considered separately as the underlying psychological processes of disorder may be very different from those with normal social communication abilities in the absence of speech.

**Prognosis**

Following unspecified but allegedly intensive treatment, Kolvin & Fundudis' follow-up study found that only 59% of the children in their study had improved in their mutism, and subsequently behavioural problems. From this study it was proposed that if the child does not improve by the age of 10 years, then they are less likely to recover from this more chronic form of selective mutism. This proposition was based on the finding that 46% of the sample recovered before the age of 10 years, whereas only 13% of the remainder of the sample recovered after 10 years. Interestingly more than half of those children who failed to improve, had parents with significant personality problems.

**An anxiety based disorder?**

There would appear to be a common theme running through all of the findings in the literature which suggests a link between selective mutism and anxiety. However the nature of this relationship has not yet been established. The majority of children will speak at home, in a familiar situation, but not in less familiar or more demanding situations. Kolvin & Fundudis (1981) argue that there is a strong emotional component to the disorder, as there is in anxiety. This proposal is supported by the suggestion that transient mutism diminishes as anxiety reduces (Cantwell & Baker, 1985) and that many of the associated features are also described as anxiety symptoms (DSM IV 1994). Additionally, many mothers of selectively mute children are described as being overprotective, exhibiting anxiety related problems themselves. In turn, this parenting
style has been documented as resulting in submissiveness, dependency and poor creativity (Schaefer, 1959) as well as poor development of social skills (Baumrind, 1971). These assertions put forward a strong case for selective mutism being a symptom of social anxiety, as proposed by Black & Uhde (1992).

There is also a high incidence of minor developmental difficulties associated which should be considered. These difficulties may also lead to problems around speech and language production which in turn may lead to anxiety about speaking, and avoidance. The high incidence of mouth trauma and psychic trauma described by Browne et al. (1963), and Parker et al. (1960) around the time of speech acquisition would be understood in behavioural terms as being negatively associated with speech, and would therefore lead to avoidance. These propositions therefore have implications for intervention.

An intervention package that would take account of these issues would therefore focus on the anxiety related characteristics using cognitive and behavioural methods to eliminate anxiety. Social skills training should also be employed as these skills may be delayed as a result of the condition and the associated parenting style. Finally, any developmental deficits need to be dealt with in an appropriate manner such that they do not continue to hinder speech development or lead to anxiety regarding speaking.

Treatment
Unfortunately the majority of treatment studies reported in the literature have been single case reports, few of which have used stringent single case methodology (Labbe & Williamson, 1984). Diagnostic criteria also varies widely between studies, which limits any generalisations which can be made from their findings. Krohn et al. (1992) report one of the largest treatment studies with 20 selectively mute children, resulting in a successful outcome of 85%. This technique combined empathic dynamic interventions, firm behavioural expectations, family involvement, and close liaison with the school.

Behaviour modification is often reported as being the most effective form of treatment for the condition (e.g. Cunningham et al., 1983; Labbe & Williamson, 1984; Nolan &
Pence, 1970), while psychodynamic treatments have reported little success (e.g. Pustrom & Speers, 1964). Lachenmeyer & Gibbs (1985) used behavioural techniques to 'increase self attributions of competence and to foster internalisation', rewards were used as an incentive and as feedback in their successful treatment for a selectively mute child. Albert-Stewart (1986) used positive reinforcement as a successful treatment procedure and found a significant relationship between administration of positive reinforcement and the production of audible, intelligible speech. Afnan & Carr (1989) describe the successful use of a multidisciplinary approach using both individual and family therapy in the treatment of a child.

Labbe & Williamson (1984) reviewed behavioural treatment literature identifying specific treatment strategies used successfully with specific forms of mutism. From this review they developed a model in which the outcome of behavioural assessment defined the most suitable specific treatment strategy. For example if, in assessment, the child is found to speak to most persons in only one test environment, intervention should involve stimulus fading of environmental stimuli, then contingency management in all environments, followed by reinforcer fading and finally maintenance of speech via natural reinforcers.

Labbe & Williamson's model of specific treatment strategies could also be applied to children with dual diagnosis of learning disabilities and selective mutism (1984) as treatment is based on individual assessment. Behavioural treatment is widely used in the field of learning disabilities (e.g. Clements & Zarkowska, 1988) and so would be appropriately applied to selective mutism in the same way as it is to other behavioural disorders.
Elson et al. (1965) concluded that counselling, suggestion, exhortation and insight psychotherapy were ineffective treatment techniques for selective mutism while Rosenberg & Lindblad advocate family therapy as being most effective (Rosenberg & Lindblad, 1978) and would seem appropriate in the light of the family problems often identified (e.g. Wilkins, 1985). Meyers (1984) argued that the root of selective mutism lies in dysfunctional family relationships and reports a successful treatment case using family therapy. Hoffman & Laub (1986) used paradoxical intervention in polarised cotherapy in combination with behavioural techniques. Black & Uhde (1992) reported dramatic improvements with pharmacological treatment which was administered on the premise that selective mutism is a variant of social phobia.

There have been a huge variety of treatment techniques described, all with varying degrees of success, therefore leaving it very difficult to generalise any specific techniques which are more, or less, effective. However behaviour therapy is the commonest approach and therefore boasts a higher number of successful treatment cases. It is noticeable across many studies that the theme of the child’s need for control has surfaced as an important consideration (Barlow et al., 1986; Black & Uhde, 1992; Hoffman & Laub, 1986; Lachenmeyer & Gibbs, 1985; Rosenberg & Lindblad, 1978). This highlights the need for future treatment plans to carefully assess the child’s need for control, and build this into the therapeutic approach, as has been proposed by Lachenmeyer & Gibbs (1985).

Conclusion
Problems within the field of selective mutism relate to issue of definition, underlying psychological process and treatment. There is a lack of agreement amongst researchers regarding which symptoms constitute selective mutism, and which characteristics may, or may not, be associated. Many of the symptoms overlap with other conditions, e.g. social anxiety, traumatic stress reaction, phobic conditions, to name a few.

There are many methodological problems with research in this area, for example low sample sizes are used presumably resulting from the condition’s rarity. Researchers often have to go back through clinical notes to obtain epidemiological information thus
threatening validity and presenting the problem of missing data. There is no agreed approach to studying selective mutism such that similar aspects and characteristics are measured using similar methods in order to build a large enough data bank to establish statistically significant evidence of any hypotheses. This point is illustrated in that one of the largest studies in selective mutism carried out by Kolvin & Fundudis (1981). This study’s sample size of 24 children was collected from a number of different clinics over 5-6 years, presumably spanning a wide range of ages.

However the research does illustrate that selective mutism is a rare disorder with many complicated associated factors. The presence of early developmental problems and specifically speech problems, an association with low IQ and learning problems would suggest early failure in the face of demands. A parental history often of anxiety related disorders as well as evidence of poor family functioning contribute to the formulation that selective mutism is an anxiety based disorder. Additionally, by the nature of their diagnostic labels other forms of mutism are considered to be anxiety related, i.e. ‘traumatic mutism’ related to post traumatic stress disorder, ‘speech phobic mutism’ resulting in heightened levels of anxiety and ‘transient mutism’ which disappears on increasing familiarity with the situation. The very nature of the disorder only being problematic in situations outside the familiar setting of the home and parents, where greater demands are made on the child further provide evidence that selective mutism is a behavioural response to heightened levels of social anxiety.

Another consideration in the formulation of this disorder is the issue of the selectively mute child requiring control over their environment. Bandura’s self efficacy model in which the individual is reinforced by the success of their actions, would explain the initial onset of the mutism in relation to early developmental problems and treatment successes reported using behavioural therapy (Bandura, 1977). This highlights the need for the child to perceive a sense of control over their environment in order to increase in their confidence and ability to act within it.

Treatment literature has been problematic due to the rarity of the disorder preventing large experimental designs, although it would appear that much of the successful treatment work has involved a behavioural approach or one which at least involves a
behavioural component. Overall it is important to bear in mind that there may be real differences in terms of aetiology or development of selective mutism. Different researchers may arrive at the same end point form a variety of directions. It may therefore be unrealistic to develop a single therapy for the condition and the therapist must maintain an open mind regarding multiple causation.

Finally clinicians should be aware of the possible comorbidity of selective mutism and learning disabilities, as recommended by Klin & Volkmar. Therefore cognitive assessment although problematic, is essential, and if necessary, adaptive behaviour scales should be used to estimate level of functioning. Having assessed the child one could then apply an appropriate intervention strategy imposing demands well within the capabilities of the child.
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Review: Selective Mutism


Psychological Aspects of Turner's Syndrome in Children and Adolescents: A Review

Definition

The syndrome of sexual infantilism was first described by Turner in 1938. Turner's syndrome (or Ullrich-Turner syndrome) is the total or partial absence of one of two X chromosomes in some or all cells in the body. There are a number of X chromosome abnormalities which could occur resulting in different karyotypes of the disorder. Turner's syndrome is estimated to occur in 1 in 2000-2500 live female births (Nielsen & Wohlert, 1991; Nielsen & Sillesen, 1975; Evans, 1977), although only 1% of foetuses reach and survive birth (Hook & Warburton, 1983) and it has been estimated that as many as 10% of spontaneous miscarriages carry the 45,X karyotype (Hall, 1990).

The principle features are short stature, as Turner’s syndrome girls are generally 20cm shorter than peers, and gonadal dysgenesis which inhibits spontaneous puberty onset and fertility (Turner, 1938). Although more recently it has been reported that 10-20% of girls with Turner’s Syndrome will have spontaneous pubertal development (Lippe et al., 1993). A number of associated physical abnormalities may also be present, for example webbed neck, minor heart defects, high palate, kidney malformations, impaired hearing, digital defects, low hair line and hypertension. These physical features may not necessarily be detectable, resulting in many girls or women only being diagnosed as having Turner’s Syndrome after being diagnosed as infertile in their early adolescence.

Late diagnosis of the condition, however, may do these individuals and their families a great disservice as there are many social, personality, cognitive and behavioural characteristics associated with the disorder which will affect their social, family and educational lives. It is therefore essential that a behavioural phenotype of this condition be clearly identified such that unrealistic demands are not placed on the individual, and intervention strategies may be developed to assist in the appropriate development of more problematic areas.
Psychosocial and personality characteristics

Gender Identity

Gender identity and gender role have consistently been reported to be feminine and heterosexual fantasies are common (Hampson et al., 1955; McCauley, 1990; Money & Mittenthal, 1970; Nielsen et al., 1977). Turner’s Syndrome girls show patterns of conventional stereotyped female behaviour with a low incidence of tomboyism (Ehrhardt et al., 1970).

Personality characteristics

Money & Mittenthal (1970) described a predominance of inertia of emotional arousal, unassertiveness and ready acceptance of misfortune. High tolerance to adversity, passivity & over compliance have also been reported (Sabbath et al., 1961; Money & Mittenthal, 1970). Baekgaard et al., (1978) looked at the performance of 31 of the Turner’s syndrome women on the Maudsley Personality Inventory in contrast to that of 16 sisters, 9 control women and an additional control group. The Turner’s syndrome women scored significantly lower than control groups on a neuroticism scale indicating that these individuals are not easily aroused and have a high tolerance for stress. This low arousal is therefore seen as a pervasive personality characteristic based on anomolous formation of early central nervous system development.

However later studies have not shown such consistent results, in Rovet & Ireland’s study (1994) decreased emotional arousal in adolescents was not typically observed and McCauley et al. (1986), reported that mothers do not see their children as shy and retiring, but in fact as having more ‘acting out’ behaviours. This discrepancy in findings may result from a sampling bias, as many of the earlier studies use subjects referred for educational or behavioural evaluation. Those studies recruiting from endocrine clinics may also be biased as parents of children with behavioural problems may be more willing to participate (Rovet & Ireland, 1994). A further problem with this concept is the interpretation placed on low emotional arousal. Parents and teachers may interpret this as poor motivation and as oppositional behaviour, or it may be interpreted in a positive light as being a mature reaction to conflict. Many of the parent interviews used in studies consider the interpretation rather than the processes underlying any problems.
Review: Turner's Syndrome

Behavioural problems

Turner's Syndrome babies have been found to exhibit feeding problems from early childhood (Chen et al., 1981). These may be associated with structural abnormalities, oral-motor dysfunction and possible pharyngeal and gastro-oesophageal disorder. These babies weigh significantly less than controls at six months (Mathisen et al., 1992).

Hyperactivity and attention deficit have been noted to occur with increased frequency in girls with Turner's Syndrome (Bender et al., 1986; Hier et al., 1980; Robinson et al., 1986), as have problems reflecting impulsivity, poor attention and poor concentration (McCauley et al., 1986). This may result in problems both at home and the classroom environment where the child may be expected to sit and attend for long periods of time.

Immaturity has also been identified by a number of researchers (Rovet & Ireland, 1994), as has poorer functioning, compared with short stature control, on measures of social competence, behavioural problems, social problems and nervous behaviour (McCauley, 1986). These social problems may in turn result in poor self concept and behavioural difficulties as the girls repeatedly experience negative social interactions and rejection. Swillen et al. (1993) failed to find evidence of a high risk in Turner's Syndrome girls for behavioural problems, although reported hyperactivity in children between the ages of 4-6 years. Unfortunately the researchers did not specify behavioural problems investigated, nor which measures were used. These findings cannot, therefore, be compared with other studies reporting high levels of behavioural problems.

Contrary to Sonis et al. (1983), Rovet & Ireland did not find that these behavioural difficulties decreased with age. They did, however, find significant differences between karyotypes on behavioural problem scores suggesting an association between behavioural problems and 'Turner' genes. This is further supported by the finding that girls with Turner's syndrome have abnormalities in frontal lobe functioning which are known to mediate behaviour problems (McGlone, 1985).
Psychosocial deficits

Psychosocial deficits involve immaturity, unassertiveness, problems with social relations (Money & Mittenthal, 1970; Sonis et al., 1983; Nielsen et al., 1977), poor peer relationships and being disliked by other children (McCauley et al., 1986). McCauley et al., (1987) reported that girls with Turner’s syndrome were rated by themselves and others as less socially adept, with a high level of behavioural distress and poor social functioning, they were also found to be less accurate at reading facial affect than short stature girls. McCauley et al. reasoned that the interpretation of facial cues, and their accurate perception, is a prerequisite to establishing effective interpersonal relationships, therefore any deficit in this skill will result in interpersonal problems. This inability to read facial cues has been attributed to poor non-verbal abilities common in girls with Turner’s syndrome (McCauley et al., 1987).

Psychopathology

A number of single case reports have documented serious psychopathology including anorexia nervosa, depression and schizophrenia in women with Turner’s syndrome (e.g. Raft et al., 1976), although an inconsistent pattern of psychiatric symptoms has been found. Bender et al. (1986) propose that the unusual appearance of women with Turner’s syndrome may place them at risk for developing anorexia nervosa, reflecting extreme concerns about body image. Most studies on psychopathology and social functioning have found that women and girls with Turner’s Syndrome reported less mental disorder and psychiatric symptoms compared to women with constitutional short stature (Downey et al., 1989; Garron & van der Stoep, 1969; Money & Mittenthal, 1970) although they may be more prone to mild depression (McCauley, 1990). A number of studies have reported poor self image in children with Turner’s syndrome (e.g. McCauley et al., 1987), although there are no reports of childhood psychopathology.

Karyotypes and personality characteristics

Disagreement between findings on specific characteristics related to Turner’s syndrome may not simply be an artefact of methodological problems, but may result from genuine differences between karyotypes of the syndrome. So far in this field, the
issue of karyotype linked to specific personality characteristics is contentious. In their behavioural and cytogenic study Pásaro Mendez et al. (1993) found that females with a child with the non-mosaic form of Turner’s syndrome exhibit a social and extroverted personality and were emotionally stable. In contrast, the mosaic group had poorer peer relations, had more reserved and introverted personalities and were less emotionally stable, of all groups they believed themselves to be the least attractive. Children in both groups had a quiet and accepting manner possibly reflecting the high tolerance to adversity previously described (Money & Mittenthal, 1970). This characteristic is also reflected in the low incidence of psychopathology in patients with Turner’s Syndrome.

In contrast Rovet & Ireland (1994) found that children with chromosomal rearrangements were socially least competent, children with deletions had the most behavioural problems while children with mosaicism or a non-mosaic karyotype were the least affected in both domains. This discrepancy may be explained by small sample size in the Pásaro Mendez et al. study (33 children) as compared with the Rovet and Ireland study (130 children), and a use of different measures to evaluate behavioural characteristics. This suggest that there may be certain personality characteristics associated with specific karyotypes, although further research with larger sample sizes is required to identify these patterns. Identification of psychological characteristics related to specific karyotypes will expand the spectrum of the clinical phenotype, and result in greater clarification of appropriate intervention strategies.

Changes with age

Swillen et al. (1993) found that younger girls are hyperactive, but this improves with age and in puberty even some degree of hypoactivity has been noted. Recent studies describing problems with immaturity, concentration, and increased activity levels in younger Turner’s Syndrome girls, report that these behaviour patterns change with age as anxiety, social withdrawal and increased immaturity become more of a central issue (Rovet & Ireland, 1994). Not all studies report anxiety as a central characteristic although there is a common theme of increasing immaturity in psychosocial development throughout adolescence, such that as social functioning decreases over
time, the Turner's Syndrome adolescent seeks out their peers less (Steinhausen & Smith, 1986; McCauley, 1991; Nielsen et al., 1977).

Family functioning
Stace & Danks (1981a) found a surprisingly high incidence of mental and behavioural disturbance among family members, the pubertal period being an especially stressful time. Those Turner's Syndrome girls demonstrating greatest behavioural, social and psychological impairment are often described as having a dysfunctional family background, or having parents who were unable to cope with the diagnosis (McCauley, 1991). Bender et al. (1987) revealed that children with sex chromosome abnormalities were more at risk from dysfunctional family influences which may in turn result in impaired cognition, school and psychosocial development. However there is little information on the nature of this association and the direction of influences.

Size
Short stature in children and adolescents with Turner's Syndrome may have an enormous impact on their sense of self worth, psychological development and may explain some of the social and behavioural characteristic described. The child with small stature has to cope with an identity that is determined primarily by her size. Self concept has often been reported as being poor amongst girls with Turner's Syndrome (e.g. Skuse, 1987). and the greater the number of physical anomalies, the poorer the self image (McCauley et al., 1986). Short stature may result in parents and peers responding to the girl with Turner's Syndrome as younger than her actual age, which in turn may result in the immaturity reported by a number of researchers (Skuse, 1987).
Supporting this view is the finding that height was correlated with social competence and social impairment (Rovet & Ireland, 1994). Short statured girls may be viewed as helpless, fragile as well as immature and childish by family, teachers and friends (Meyer-Bahlburg, 1985; Skuse, 1987). Underwood (1991) summarised research findings concluding that there were many negative effects associated with being short including being perceived as less competent, being seen less positively by peers and themselves, teasing, being treated as younger than their age and overprotection both at home and school.

However many studies have used short stature comparison groups, and found significantly greater problems among the Turner’s syndrome group in terms of poor peers relationships, more behavioural problems, having fewer friends, needing more help with completing tasks and more difficulties understanding social cues (McCauley et al., 1986; Downey et al., 1989). These conflicting findings suggest that problems experienced by girls and women with Turner’s syndrome result from a combination of both underlying processes due to the syndrome and psychological issues related to their short stature. Attempts to attribute effects to one or other of these processes may not be realistic.

**Neurocognitive profile**

In earlier studies, impairment of intellect and learning in Turner’s Syndrome was mislabelled as mental retardation (Grumbach et al., 1955). However, in the process of psychohormonal testing, Money & Alexander (1966) coined the phrase *Space-form blindness* to describe an assembly of related cognitive deficits, thus indicating that Turner’s Syndrome is an exception to the rule that chromosomal abnormalities cause general retardation (Pásaro Mendez et al., 1993). Garron (1977) concluded that earlier interpretations of increased mental deficiency in patients with Turner’s Syndrome were the product of the failure to recognise the verbal-performance discrepancy, such that non-verbal difficulties were interpreted as resulting from global learning disabilities. However, Bender et al. (1994) pointed out that the impact of the V-P discrepancy on IQ would only constitute 6 points, and would therefore not reduce the score below the normal range. The consensus of opinion amongst researchers at
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learning which has been identified as characteristic in girls with Turner’s Syndrome (Money 1993).

This deficit does not affect verbal intelligence but may severely affect non-verbal intelligence. The disparity between verbal and performance IQ may be as much as 30 points on the Weschler scale (Money 1993). Landowski et al. (1985) argued that there is no particular subtest pattern although this has been a contentious area. The range of specific subtests of spatial processing skills found to be deficient in girls with Turner’s Syndrome include: Picture Completion (Garron, 1977; Silbert et al., 1977), Picture Arrangement (Waber, 1979), Block Design (Downey et al., 1991, Garron, 1977), Object Assembly (Downey et al., 1991; Garron, 1977; Waber, 1979) and Coding/Digit Symbol (Downey et al., 1991; Garron, 1977). Unfortunately, all subtests have been identified in one study or another invalidating any claims to a more specific subtest profile.

Lower scores have also been demonstrated on Digit Span and Arithmetic verbal subtests, suggesting a problem with distractibility and/or short term memory (Downey et al., 1991; McCauley et al., 1987) although others would argue that poor arithmetic skills are a result of problems with spatial abilities (Nielsen, 1989). Equally, tasks of spatial rotation (Rovet & Netley, 1982), visuospatial memory and visual motor integration (Silbert et al., 1977) as well as difficulties with conceptual, attentional and retrieval processes have been highlighted as problematic. Pennington et al. (1985) also found evidence of long-term memory and visuospatial deficits.

This cognitive profile may present as early as 4 years of age (Pennington & Smith, 1983) and has been found to persist into adulthood (Downey et al., 1991). A wide variation in cognitive abilities among individuals with Turner’s Syndrome are described, ranging from pronounced deficits to none. Rourke et al. (1989) labelled this profile as characteristic of a non-verbal learning disability syndrome, stressing that the children’s assets are their abilities to deal with auditory information and perception as well as reception, storage and associations of verbal information. This cognitive
profile has serious implications for the child’s education as Turner’s Syndrome girls have been found to be at increased risk of significant underachievement (Rovet, 1993).

Karyotypes and cognitive profile
Some researchers claim that there is no evidence that Turner’s Syndrome patients with differing karyotypes of Turner’s Syndrome have different patterns of intelligence (Aran et al., 1991; Stace & Danks, 1981b; Swillen et al., 1993) although others have reported that cognitive deficiencies have been found to be less marked in children with mosaicism (Salbenblatt et al., 1989; Temple & Carney, 1993). Temple & Carney (1993) suggest that children with ‘pure’ Turner’s Syndrome represent a pattern of performance at the female end of the spectrum in terms of behavioural sex-differences on spatial tasks. However this was less well defined for the mixed children. Rovet (1993) found no effect of karyotype on IQ. There is an overall methodological problem of small sample sizes within each group, making any conclusions tenuous. However, in relation to developing an understanding of the disorder, cognitive deficits should be identified on an individual basis such that specific strengths and weaknesses are the focus any intervention plans rather than making assumptions about abilities based on karyotype.

Theories regarding aetiology of the Turner’s Syndrome profile
Psychosocial mechanisms
A number of hypotheses have been proposed in order to attempt to explain this specific profile of personality, social and cognitive characteristics seen in girls with Turner’s Syndrome. Skuse (1987) suggests that the learning problems associated with Turner’s Syndrome may be as a result of emotional immaturity possibly fostered by inappropriate parent handling and infantilization, subsequently leading to frustration and poor attention in the classroom. This immaturity may be as a result of parental guilt leading to overprotectiveness and excessive control, a claim supported by reports of girls with Turner’s syndrome coming from a dysfunctional family background (McCauley, 1991)

However studies using short stature controls demonstrate that differences in Turner’s Syndrome patients cannot be explained by short stature alone (McCauley et al., 1986,
Downey et al., 1989), and may be related to other psychosocial, genetic, endocrine or CNS effects of the syndrome (Baekgaard et al., 1978; Pásaro Mendez et al., 1993; Sonis et al., 1983). McCauley et al. (1986) proposed that the psychological effects of delayed sexual maturation and of physical anomalies, and the neurocognitive effect of abnormal brain development and maturation, combine, resulting in the problems seen in girls with Turner’s Syndrome.

Neurological mechanisms

Structural and functional abnormalities in brain formation have been identified which are purported to be developmental in origin (Brun & Skold, 1968; Money, 1973). A number of neurological explanations for differences between girls with Turner’s syndrome and controls have been proposed. Many investigators implicate right hemispheric dysfunction (Gordon & Galatzer, 1980; Reske-Nielsen et al., 1982; Silbert et al., 1977) while others suggest more general, non-lateralized impairment (McGlone, 1985; Pennington et al., 1985; Waber, 1979). Although abnormalities in frontal lobe functioning have also been observed and offered as explanations for some of the behavioural problems associated with the syndrome (McGlone, 1985; Waber, 1979).

Money (1993) claims that the Turner’s Syndrome cognitive profile must be an error of brain differentiation associated with parietal lobe dysfunction. McCauley et al. (1987) proposed that decreased social competence and affective discrimination are not simply secondary to poor perceptual problem solving or attentional /memory skills, they proposed that spatial ability and affective discrimination skills are independent of each other but related to a common underlying mechanism that is right hemisphere related.

Bender et al (1994) argue that attempts to define a neurocognitive profile of Turner’s Syndrome are based on two misconceptions. Firstly there is not necessarily a specific profile related to the genetic disorder which is matched to a highly localised area of the brain. They argue that genetic homogeneity does not necessarily result in phenotypic homogeneity. Secondly, right hemisphere based cognitive impairment in Turner’s Syndrome subjects does not necessarily reflect a process comparable to patients with known right hemisphere damage. Evidence following an autopsy on a woman with Turner’s syndrome supports this suggestion (Brun & Skold, 1968). The conflicting
evidence demonstrates that the neurological mechanisms underlying the disorder and their effects on psychological functioning are still not fully understood and require further investigation.

**Biological mechanisms**

Possible causes of these neurological abnormalities have been discussed by Pennington et al. (1982) who suggested that reduced hormone exposure in girls with Turner’s Syndrome leads to a failure in right hemisphere development. Geshwind & Galaburda (1985) propose that sex hormones have a specific effect on the growth and development of regions subserving specific cognitive skills. A number of researchers have found a certain degree of maturation in performance on visuo-spatial tasks in Turner’s Syndrome patients as they get older, and proposed that this maturation process could be under hormonal control (Nielsen & Nyborg, 1981; Perheentupa et al., 1974; Waber, 1979). This is further supported by Nielsen & Nyborg’s findings that oestrogen therapy had a positive influence on problem solving thinking with a group of Turner’s Syndrome girls.

Barlow (1973), Polani (1977) and Netley (1977) developed the hypothesis that as a result of characteristics associated with the absence of an X chromosome, the brains of girls with Turner’s syndrome develop faster than normal, and as a result, critical periods of hemispheric development are disrupted. Rovet and Netley (1982) go on to propose that this may account for atypical lateralization and poor performance on spatial thinking tasks.

Both theories suggest that hormonal imbalance has an impact on neurodevelopment with the possible result that the right hemisphere is less specialised for spatial thinking and shares with the left hemisphere more responsibility for language processing than found in normal girls.
Methodological Issues

There are a number of methodological flaws with the research on Turner’s Syndrome. Firstly, McCauley et al. (1987) excluded 20% of females with Turner’s Syndrome from their study due to severe retardation or having verbal IQ’s of 79 or below. However, Swillen et al. (1993) also identified a 5% rate of mental retardation in girls with ‘classical’ Turner’s Syndrome while there was a 30% rate of mental retardation in the group with a rare karyotype. This suggests a higher rate of learning disabilities in girls with Turner’s Syndrome than in the general population and reflects a general finding that IQ in Turner’s Syndrome groups tends to fall within the lower ranges (Bekker & van Gemund, 1968; Lamy et al., 1965; Money & Granoff, 1965). Therefore the exclusion of girls with borderline IQ or below, from any research study, will impose a bias on the results.

McCauley (1990) emphasised that the presence of physical anomalies associated with the syndrome can significantly impact on the psychological and possibly neurocognitive development. These factors, however, were not controlled for in the studies. Rovet (1990) noted an inadequacy of controls, and proband samples, for age, verbal IQ, socio-economic status, race, ethnicity, growth retardation or family membership. These differences in controls may be responsible for the wide variations in result and their conclusions.

McCauley (1990) and Bender et al. (1994) identified a variation in selection criteria across studies making comparison between them almost impossible. Many of the Turner’s syndrome samples were obtained from endocrinology clinics and medical centres, where the more extreme cases with the most prominent problems only will be identified. Multivariate approaches would therefore be required to tease out causal issues although large sample sizes would be required in order to reach any useful conclusions. Rovet (1990) proposed that the variety of conclusions, sometimes conflicting, may reflect variations in control groups as well as in proband samples.
Conclusions

Turner’s Syndrome is an abnormality of one of two X chromosomes which result in a wide range of physical, psychosocial and neurocognitional problems. Many researchers have attempted to identify a homogenous phenotype of the syndrome with varying degrees of success. The phenotypic characteristics present a profile of a girl with Turner’s syndrome displaying passivity and high levels of tolerance, a variety of behavioural problems from a very young age including hyperactivity, nervous behaviour, immaturity and poor social skills. Self esteem is reported as being low in these girls where a number of factors including short stature lack of pubertal development and poor social skills will contribute to this. Families of children with Turner’s syndrome tend to exhibit poor levels of family functioning. These girls also tend to exhibit a cognitive profile of specific deficits in areas of non-verbal functioning. Researchers have attempted to identify characteristics specific to karyotypes, and a number of theories have been developed in an attempt to explain this Turner’s Syndrome profile with an emphasis on abnormal hemisphere development and lateralization. Unfortunately a number of methodological problems with many of the studies have distorted the picture, making conclusions tenuous.

The relevance of attempting to establish a specific phenotype has been questioned as “genetic influences are multifactorial, and individuals with the same chromosomal lesion may have quite different phenotypes” (Bender et al., 1994). However, in terms of positive psychological outcome, a clear and accurate formulation is required regarding problems which may arise during childhood and adolescence, on which to base appropriate intervention strategies. An essential element to the intervention strategy would be to reattribute problems to specific deficits, and teach skills where appropriate. Rather than allowing parents to feel frustrated and angry because they incorrectly interpret a problem behaviour as being motivational. Families need detailed information available to them in order to maximise their control over any problems, and that they can seek help when they deem necessary.
It is also vital that the school have a clear picture of cognitive strengths and weaknesses such that an education plan can be developed to utilise good verbal skills, develop non-verbal skills as far as is possible, and to avoid the child being penalised for poor performance on non-verbal tasks. Careful consideration should also be paid to developing social skills in a structured, supervised environment such that the child can learn to make peer relationships rather than being overwhelmed in an unstructured situation and being unable to cope with the social demands.

The identification, over the past 30 years, of the behavioural phenotype of Turner’s syndrome is an invaluable source of information for families and professionals. However, there are many contentious issues regarding associated characteristic and their underlying mechanisms. In order to develop appropriate intervention strategies at an early age for these children, a clearer profile is required such that a greater understanding of the condition may be fostered amongst non-specialist health and educational professionals.
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CLINICAL DOSSIER

- Clinical Case Report
- Logbook

Louise Connor
Introduction

The following is a case report on a young teenager referred to the Clinical Psychology Service for Children with Learning Disabilities, with behavioural problems. Very little information was passed on along with the referral and it transpired that many of the problems were exacerbated by the lack of information available to the various people involved. Therefore the first few sessions were spent on seeking information, revealing a more complex case than the family or school were initially aware of.

Referral

A. was initially referred to Psychology in April 1994 by the Educational Social Worker for increasingly aggressive behaviour, lying, stealing, swearing and bullying. She attends C. school for children with moderate learning disabilities and was described as having an unusual chromosomal complement which doctors had advised could not give rise to her behavioural difficulties. A. was first seen with her parents in November 1994 on a home visit.

Background History

In 1991 A. and Mrs S. had seen a psychologist on two occasions, having been referred for behavioural difficulties. Family Therapy and behavioural advice had been offered. Unfortunately no clear formulation had been made as there had been many failed attendance’s, and the family were finally discharged.
Mr & Mrs S. had been married prior to A.'s birth but Mr S. left the marriage and divorced Mrs S. not knowing that she was pregnant. A. was then brought up solely by her mother. At the age of 7 years A. was labelled as being “slow”, and since then has attended special schools. Mrs S. described her behaviour as always having been difficult to manage, and that she would have been able to attend mainstream schools if she would have been well behaved.

When A. was 12 years old, Mr S. came back to join the family having married twice in that time. During one of these marriages Mr S. had lived with his wife and her 13 year old daughter who attended mainstream school and was an independent, able girl. Mr & Mrs S. reunited as a result of Mr S. being contacted for a blood sample regarding A.’s diagnosis, thus implying a causal link between Mr S. and his daughter’s condition. Mr S. then divorced his third wife, and remarried Mrs S. At this time, A. was diagnosed as having Turner’s Syndrome associated with 10% Down’s Syndrome. Mr & Mrs S. were told that this would result in a failure to develop secondary sex characteristics, and A. was prescribed Hormone Replacement Therapy in order to reverse this effect. A referral had also been made by the local Paediatrician for an Autism assessment at Guy’s hospital, although no appointment had yet been sent.

At the time when Mr S. came back to the family Mrs. S. was very unwell with angina, highly stressed and finding it very difficult to cope with A., therefore Mr S. immediately took over the role of head of the household and tried to impose limits on A.’s behaviour. After 1 year of returning Mr S. left A. and her mother, claiming to be on the verge of a nervous breakdown due to A.’s difficult behaviour. However he returned to the family soon afterwards, a few months prior to the family being seen for psychological intervention.

**Psychological aspects of Turner’s Syndrome**

Turner’s syndrome is a total or partial absence of one of two X chromosomes (Turner, 1938) and therefore only affects girls. This results in a lack of spontaneous pubertal development and short stature, it may be associated with a number of physical abnormalities i.e. webbed neck, hearing impairment. Associated psychological aspects
Clinical Case Report

include emotional inertia (Money & Mittenthal, 1970), hyperactivity and attention deficit disorder (Bender et al., 1986), immaturity, poor social competence (Rovet & Ireland, 1993) inability to read facial cues and behaviour problems (McCauley et al., 1986). There is also a specific cognitive profile associated with Turner’s syndrome whereby non-verbal intelligence is significantly poorer than verbal, by as much as 30 points (Money, 1993).

Assessment
Initial investigatory interviews were carried out with the referrer, Mr and Mrs S., and A.’s class teacher on separate occasions. The following problems were described by Mr & Mrs S.:

• she could not be trusted to go out on her own as she had poor awareness of road safety,
• she had stolen goods from shops in the past,
• she did not have friends in the area, so never visited other’s houses or had friends visiting. This resulted in her having to remain in the flat all the time that she was not at school.
• she would do things which annoyed her parents and refuse to stop on request.
• she was incontinent at night on about 3 occasions a week. This presented enormous problems as Mr and Mrs S. did not own a washing machine.
• Neither Mr or Mrs S. were employed and finances were a problem.

Problems in the home were managed by Mr S., while Mrs S. would withdraw and not become involved. Mr S. would sometimes hit A., but her inappropriate responses, e.g. laughing rather than crying, would result in an increase in his level of anger. Mr S. openly admitted feeling that on these occasions he lost control and was frightened by what he might do to A. Mr & Mrs S. felt that A. was totally responsible for all her actions, and could control her actions if she so wished, although they had very little evidence of her doing so.
A. was also often difficult at school, she was described as having poor peer relationships, and would often play up in class for apparently no reason. A.'s teacher stated that these problems resulted from A. receiving mixed messages at home, with few boundaries being enforced. Mr and Mrs S. felt that the only reason that A. was at a school for children with moderate learning disabilities was because of her behavioural problems and they had been told by teachers that she was inappropriately placed in the school. Classroom observation was also carried out in order to define these problems in clearer terms. During observation A. appeared to have reasonable social skills, but was inappropriately intimate with both peers and staff which would result in rejection.

Interestingly, it was difficult for anyone to describe in concrete terms exactly what was difficult, and prioritise problems. Mr and Mrs S. had written a list of problems for our initial interview which included items such as picking her nose, biting her toe nails and laughing when she was told off. The problems described did not initially seem to justify the level of distress and anger expressed and it was difficult to draw out the major issues. The principal problems appeared to fall within the categories of: disinhibition, lack of awareness or response to subtle social cues, immaturity, and inappropriate emotional responding.
Clinical Case Report

Formulation

FATHER
High expectations - previous experiences of 13 year old step daughter
- lack of knowledge re: diagnosis
Hopelessness - lack of control over the situation
Lack of warmth - own childhood experiences

= angry, rejecting & demanding, blaming

A.
Damaged relationship
Different approaches to parenting
Father's recent appearance in the family

Syndrome related problems i.e. poor social skills, inappropriate emotional responding. Constant failure
Lack of self confidence

= reduces chances of developing skills. No reward for appropriate behaviour. Adult contact rewarding negative behaviours.

MOTHER
High expectations - lack of knowledge re: diagnosis
- unresolved grief re: A.'s learning disabilities
Ambivalent/cold - own childhood experiences
- repeated failures at controlling A.

Hopelessness

= rejecting, passive

SCHOOL
High expectations - unaware of disability and syndrome

= Blame parents for lack of control
Clinical Case Report

The general lack of knowledge regarding A.'s syndrome and the associated behavioural implications will have led to a misinterpretation of her behaviours and responses. This blaming of problems on A. had been reinforced by the doctors stating that her condition would not be associated with her behavioural difficulties. As a result, demands had been made on A. over many years which appeared to be unrealistic.

Intervention and Outcome

1. A referral was made to the child protection team regarding the risk that Mr S. had identified of him hurting A. It was put to Mr & Mrs S. that this may help them to gain extra resources and support, and to ensure A.'s safety. Both were receptive to this plan, and Mr S. stated that it was even a relief as he was concerned that he might harm A.

The Child Protection Team advised that they would not place A. on the child protection register as there was no evidence of abuse nor a specific incident which had occurred to date. They did however refer A. to the Children with Disabilities Team who allocated a social worker to the family. This resulted in A. attending a social club out of school time under supervision of an allocated worker, thus assisting her to develop her social skills. Mr and Mrs S. were also assisted in applying for social security allowances to which they were entitled. This included obtaining funding for a washing machine.

2. A referral was made to the special investigations clinic regarding A.'s incontinence. It was felt that the clinic, rather than psychology, should carry out this work to stress the possibility that this behaviour may not be intentional, and so that psychology could focus on other aspects of work.

The special investigations clinic recommended the use of a star chart system for night time continence, they provided the family with a waterproof mattress covering, and a bell and pad such that A. could control her bladder at night. On our last meeting Mr & Mrs S. reported that the bell and pad had not been effective and was no longer used.
A. was still wetting as often as usual and was developing rashes as a result of not washing herself or her bed on a regular basis. This had become the major issue between A. and her parents as they felt she was doing it simply because she didn’t care. This belief was supported by A. keeping dry when she slept at her grandparents home. Intervention from the team was ongoing.

3. A Star chart reward system was used to help A. gain control over the consequences of her actions and to ensure that she was able to obtain rewards both at home and school. It was important that her parents and her teacher could see when there were successes, thus shifting their focus from the problems, and to dispel their sense of hopelessness. Specific behaviours were defined so that A. knew what was expected, and others knew when to reward her. This included categories such as watching T.V. quietly with mum or dad for 30 mins, helping to prepare the evening meal (which she enjoyed), keeping her room tidy, etc. There were 10 defined categories for which A. could gain a star for each day, 5 at school and 5 at home. Therefore, over the week there were a possible 25 stars obtainable at home, and 25 at school:

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</tr>
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<td>8.5.95 - 14.5.95</td>
<td>23</td>
<td>programme stopped</td>
</tr>
<tr>
<td>15.5.95 - 21.5.95</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>22.5.95 - 28.5.95</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>29.5.95 - 4.6.95</td>
<td>34/35</td>
<td></td>
</tr>
<tr>
<td>5.6.95 - 10.6.95</td>
<td>22</td>
<td></td>
</tr>
<tr>
<td>11.6.95 - 17.6.95</td>
<td>27/27</td>
<td></td>
</tr>
<tr>
<td>18.6.95 - 24.6.95</td>
<td>26/27</td>
<td></td>
</tr>
</tbody>
</table>
This data collected from A.'s star charts indicated that she responded well to a structured reward system. This also ensured that rewards were available to her, which was less often the case prior to the initiation of the reward system, and that Mr & Mrs S. recognised her achievements and good behaviour. A. enjoyed having the chart and would discuss it often with her parents, demonstrating motivation to be rewarded. By the last session Mr & Mrs S. reported that A.'s behaviour was now OK, and they felt they could cope. However, they would continue to use the star charts. Improvements were also reported in school, who then stopped using the charts.

4. Individual sessions were carried out with A. to work on anger management and developing her social skills. This work was based on a stress inoculation training approach and social skills training. This approach was taken in order for A. to have more control over her environment, as well as having a positive one to one interaction at which she could experience successes, such that her sense of self esteem and confidence would increase. A. was seen for 11, 1/2 hour sessions at school on a weekly basis. This work was based on identifying situations which had been difficult or for which she had got into trouble. A mood diary was used to increase her awareness of her moods their triggers and her responses. A. was to complete this on a daily basis for homework, and the situations were then used in sessions to discuss triggers and consequences. (See Appendix 1 for mood diary). Alternative responses were explored, and their consequences examined in relation to her goals for each situation using a problem solving chart. (See Appendix 2 for problem solving chart).

Initially A. found these sessions difficult and would often distract herself from the work. However as she became more familiar with the format of the sessions she attended well to them, and would voluntarily bring situations to work on which had been difficult for her during the week. A. reported using the strategies learned in sessions on difficult situations which had arisen at school and her tutor reported that her responses were becoming more appropriate as she was taking more responsibility for her own actions.
5. Sessions with Mr and Mrs S. were carried out to monitor and support the star chart programme, to explore and develop more realistic expectations of A. and to explore their own parenting experiences. Mr & Mr S. were seen on 8 occasions.

- The star chart was monitored on a regular basis and any problems were addressed. Mr & Mrs S. would often report on the number failures, rather than stars obtained. However this focus slowly changed, and they were able to look at A.’s achievements in a more positive light. Towards the end of the intervention, A. was being given more responsibility at home, which she enjoyed, and a more rewarding relationship with A. was enjoyed.

- Mr & Mrs S. demonstrated very different parenting patterns, Mr S. was quite aggressive and blaming while Mrs S. was ambivalent and would leave any rule making and disciplining up to her husband. Both Mr & Mrs S.’s parental backgrounds were explored in order to understand their own patterns of parenting, and Mr S. felt that he was able to move forward to thinking about a more adaptive way of parenting rather than repeating some of the more painful patterns from his own childhood. Mrs S. described her parental experiences as being very similar to her parenting style, but was less eager to move forward from this. She would always remain very quiet in sessions, allowing Mr S. to dominate, and when addressed directly would make token responses but defer responsibility to Mr S. This situation was addressed, but neither of us felt that this pattern had changed by the last session.

A.’s needs were also discussed, and Mr & Mrs S.’s expectations of her capabilities explored. A profile of possible psychological characteristics of a child with Turner Syndrome was drawn up and discussed in terms of A.’s present behaviours and her future needs. The focus of this work was to shift attributions of blame from A. and to concentrate on ways of meeting her needs. Mr & Mrs S.’s initial reaction to this information was that of amazement and relief as they were able to identify so many of the Turner Syndrome characteristics in A. As a result they were more accepting of some of her more subtle behavioural difficulties, which were more likely to be as a result of her syndrome, and were less angry regarding her inappropriate emotional responding. They were also able to appreciate that as a result of these characteristics, A. would not be able to attend a mainstream school and may not develop as a fully
independent adult. While they felt sad on this realisation, it also relieved the pressure on the whole family to push her towards unachievable goals.

6. A Meeting was held with teachers and parents to develop a set of guidelines regarding rewards and sanctions to be applied at home and school ensuring a consistent approach. These outlined A.'s basic needs with regards to her intellectual profile of strengths and weaknesses and problems as a result of her syndrome. The guidelines also highlighted tasks and lessons which would be difficult for her and with which she would require extra support, as she would be more likely to exhibit task avoidant behaviours. Rewards included the use of stars and smiling faces on a chart for carrying out desired activities such as sitting attending to a specific task when asked as well as asking for help in an appropriate manner. Sanctions involved excluding A. from the group or room if she did not comply with the task after 2 requests, these were to be discussed with A. before each lesson so that she had the opportunity of making a choice and was able to take more responsibility for her actions. Unfortunately some teachers did not appear to fully appreciate A.'s needs regarding her Turner Syndrome profile of personality characteristics, and so the guidelines were not always used consistently at school. However some staff felt it was useful to have these available in times of difficulties.

7. Psychometric assessment was carried out in order to investigate A.'s neuropsychological profile in relation to her diagnosis of Turner's Syndrome, and to provide evidence of her cognitive deficits and abilities to school and Mr and Mrs S. The WISC-III was used:

<table>
<thead>
<tr>
<th>Verbal Subtests</th>
<th>Scaled Scores</th>
<th>Performance Subtests</th>
<th>Scaled Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>4</td>
<td>Picture Completion</td>
<td>1</td>
</tr>
<tr>
<td>Similarities</td>
<td>1</td>
<td>Coding</td>
<td>6</td>
</tr>
<tr>
<td>Arithmetic</td>
<td>3</td>
<td>Picture Arrangement</td>
<td>1</td>
</tr>
<tr>
<td>Vocabulary</td>
<td>2</td>
<td>Block Design</td>
<td>1</td>
</tr>
<tr>
<td>Comprehension (Digit Span)</td>
<td>(7)</td>
<td>(Symbol Search)</td>
<td>(2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>(Mazes)</td>
<td>(3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>13</strong></td>
<td></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>
Clinical Case Report

Verbal IQ 58 Range 54-66
Performance IQ 54 Range 50-66
Full Scale IQ 52 Range 48-60

There was a difference of 4 points in the direction expected in girls with Turner Syndrome, i.e. superior verbal to performance scores. However this difference is not significant. Elevated scores on digit span and coding subtests demonstrated good concentration and immediate memory. Overall A.'s full scale IQ is within the moderate learning disabilities range. This evidence further supported Mr & Mrs S.'s developing realisation that A. would not be able to cope in a mainstream school environment.

Process

At the time when I first interviewed the parents there was a lot of anger directed towards A. which had clearly been building up over the last few years, resulting in little or no positive interaction between A. and her parents, and occasional violence towards A. This was exacerbated by A.'s incontinence. Although A. had always been incontinent at night, Mr and Mrs S. felt that she was able to control it, but chose not to, as she was fully continent during the day, and at night when staying with grandparents.

At the beginning of intervention Mrs S. felt confident that success could be achieved, and had a realistic view of the time scale i.e. around 6 months, Mr S. was less optimistic about success. However both parents committed themselves fully to the plan, tackling problems as they arose without giving up. Despite Mrs, S. having the most realistic and optimistic outlook, a certain amount of hopelessness remained with her, and less change in attitude was made than in Mr S. Her withdrawn manner made it difficult to form a strong relationship. We discussed the possibility of her being depressed, although she felt that she did not want to seek help for this. Mr S., however, changed noticeably in his approach to the issues being discussed, he found some of our sessions difficult and was able to comment on this. On the whole by the end of the intervention, he was able to think more analytically about A.'s behaviour.
Summary
A. is a 13 year old girl diagnosed with Turner Syndrome and 10% Downs Syndrome, who attends an MLD school and lives at home with her parents. She was referred for aggressive behaviour which was becoming increasingly violent. The situation had become so difficult at home that there was anger and blame directed towards A. and very little positive interaction between her and her parents, or in her school relationships. Problems were confounded by difficult parenting issues which resulted in violence towards A., A.’s night time incontinence and a general lack of understanding of A.’s Syndrome and her specific needs. On formulation, A.’s problems were as a result of lack of awareness of subtle social cues, immaturity, and inappropriate emotional responding. These were maintained by poor social skills, an inability to read social cues and respond appropriately due to her Turner Syndrome, and a lack of positive reinforcement for any appropriate responding.

Intervention involved a number of external referrals regarding father’s violence and A.’s incontinence, developing behavioural guidelines and reward systems to take place at both school and home, individual work on social skills and anger management with A., and sessions with A.’s parents. A.’s difficult and aggressive behaviours reduced within a few weeks of the reward system being established in school, and after a couple of months at home. Her social responding became more appropriate, and Mr & Mrs S.’s expectations of her achievements and abilities became more realistic. A social worker was allocated to the family who offered practical help in a number of ways. Unfortunately A.’s night time incontinence was not resolved, and this became a focus of Mr S.’s blame and anger. Incontinence clinic appointments were, however, ongoing.

Louise Connor
Clinical Psychologist
References


DATE:
MORNING
Excited  Happy  O.K.  Worried  Sad  Angry
Why?

AFTERNOON
Excited  Happy  O.K.  Worried  Sad  Angry
Why?

EVENING
Excited  Happy  O.K.  Worried  Sad  Angry
Why?
<table>
<thead>
<tr>
<th>The situation as it was</th>
<th>What is your Goal in this situation?</th>
<th>What did you do?</th>
<th>What was the result?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

How did it make you feel?

What Happened?
## Problem solving the situation

<table>
<thead>
<tr>
<th>List all the alternative things you could have done.</th>
<th>What would have happened for each of these?</th>
<th>Which is closest to your goal?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
CLINICAL LOG BOOK

October 1994 - October 1996

POST 1

Supervisor: Barley Oliver
Placement Address: Psychology Department
Philipot Path
off Passey Place
Eltham
SE9 5DL

Speciality: Children with Learning Disabilities
Dates of Post: 17/10/94 - 1/9/95
Number of Days: 5
Base: Psychology Department and services within Greenwich Healthcare Trust

Client Group: Children between the ages of 0-19 years with learning disabilities.

Amount of time: 4 clinical days per week
1/2 day study time
1/2 day departmental time

Sessional allocation: 1 session at Greenwood Assessment Nursery
1 session at Griffin Manor School for Autistic Children (5-19 yrs)
1 Session at Eastcombe Ave. Respite home
5 sessions working with the range of children from the waiting list.

Supervision: 2 hours per week
| Type & Range of Problems: | Developmental  
|                         | Behavioural  
|                         | Emotional  
|                         | Family Problems  
|                         | Sexual Abuse  
| Range of Assessment Experience: | Psychometric  
|                             | Behavioural  
|                             | Living Skills  
|                             | Communication Skills  
|                             | Portage  
| Range of Treatment Experience: | Families  
|                                 | Behavioural  
|                                 | Consultation to other  
|                                 | professionals  
|                                 | Counselling  
|                                 | Experience of Family Therapy  
| Monitoring of work: | Monitoring and evaluation of clinical work through  
|                        | supervision, feedback from other professionals and  
|                        | carers, and regular follow up.  
|                        | Presentation of clinical cases to colleges at a  
|                        | departmental forum  
| Multidisciplinary Work: | Liaison with carers, educational, social services  
|                        | and health care professionals with regards to  
|                        | overall service provision and individual clients.  
| Research: | Service related research as part fulfilment of  
|           | Surrey conversion course.  

2
POST 2

Supervisor: Orlee Udwin
Placement Address: Mary Sheridan Centre for Child Health
                       405 Kennington Road
                       London
                       SE11 4QW
Speciality: Children and Families/ Children with Autism
Dates of Post: 11/9/95 - Present
Number of Days: 5
Base: Mary Sheridan Centre for Child Health
Client Group: Children between the ages of 0-18 years and their families
Amount of time: 4 clinical days per week
1/2 day research
1/2 day continuing professional development

Sessional allocation: Special Needs
1/2 session at Shelly SLD School
1/2 session at Windmill SLD School
3 sessions working with children from the waiting list
1 session monthly multidisciplinary Learning Assessment Clinic.
1/2 session with Multidisciplinary Assessment Team

Autism
1/2 session at Larkhall Autistic Unit
1/2 session at Gillian Fraser Language Unit
2 sessions as member of multidisciplinary team carrying out diagnostic assessments
1 session working with children from the Autism waiting list
Supervision: 2 hours every second week
   Peer supervision at monthly case presentations held
   within the Child Psychology Department

Type & Range of Problems: Developmental
   Behavioural
   Emotional
   Family Problems
   Abuse

Range of Assessment Experience: Psychometric
   Behavioural
   Living Skills
   Communication Skills
   Diagnostic

Range of Treatment Experience: Families (systemic, parent training)
   Cognitive/Behavioural
   Consultation to other professionals
   Counselling
   Group work

Monitoring of work: Monitoring and evaluation of clinical work through
   supervision, feedback from other professionals and carers, and regular follow up.
   Case presentations to colleagues on a regular basis

Multidisciplinary Work: Liaison with carers, educational, social services
   and health care professionals with regards to overall service provision and individual clients.
   Member of Lambeth Social, Communication Disorders and Autism Team
Member of under 5's Multidisciplinary Assessment Team.
Member of Learning Assessment Team.
Multidisciplinary meetings at the four schools.

Research:
Completion of service related research as part fulfilment of Surrey University conversion course.
### POST 1

#### Summary Of Patients/Clients Seen

<table>
<thead>
<tr>
<th></th>
<th>No. of in-patients</th>
<th>No. of out-patients</th>
<th>Age Range</th>
<th>M/F ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct involvement with</td>
<td>0</td>
<td>4</td>
<td>5 - 16</td>
<td>3:1</td>
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<tr>
<td>individuals/ families for</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>assessment only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct involvement with</td>
<td>0</td>
<td>21</td>
<td>3 - 16</td>
<td>14:7</td>
</tr>
<tr>
<td>individuals/ families for</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>assessment and intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work with families</td>
<td>0</td>
<td>5</td>
<td>5 - 11</td>
<td>1:4</td>
</tr>
<tr>
<td>Work with groups</td>
<td>0</td>
<td>0</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Work with direct care staff</td>
<td>0</td>
<td>2</td>
<td>5 - 8</td>
<td>2:0</td>
</tr>
</tbody>
</table>

### POST 2

#### Summary Of Patients/Clients Seen

<table>
<thead>
<tr>
<th></th>
<th>No. of in-patients</th>
<th>No. of out-patients</th>
<th>Age Range</th>
<th>M/F ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct involvement with</td>
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<td>48</td>
<td>3 - 14</td>
<td>39:9</td>
</tr>
<tr>
<td>individuals/ families for</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>assessment only</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct involvement with</td>
<td>0</td>
<td>33</td>
<td>3 - 12</td>
<td>26:7</td>
</tr>
<tr>
<td>individuals/ families for</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>assessment and intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work with families</td>
<td>0</td>
<td>0</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Work with groups</td>
<td>0</td>
<td>7</td>
<td>Not Known (parents)</td>
<td>2:5</td>
</tr>
<tr>
<td>Work with direct care staff</td>
<td>0</td>
<td>19</td>
<td>5 - 18</td>
<td>10:9</td>
</tr>
</tbody>
</table>
## POST 1
### Joint & Independent Work

**Individuals/Families.** I = Individual, J = Joint.

<table>
<thead>
<tr>
<th>I/J</th>
<th>Sex</th>
<th>Age</th>
<th>Referred for</th>
<th>Initial assessment methods</th>
<th>Brief description of intervention (e.g. model, methods)</th>
<th>Total Hours</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>J M</td>
<td>13</td>
<td>Severe learning disabilities. Reintegration into the borough with past history of severe challenging behaviour</td>
<td>No formal assessment. Reports on behaviour from carers/teachers. Functional analysis recording forms used for incidents of challenging behaviour.</td>
<td>Teaching day for all staff involved on use of specific behavioural methods, monitoring of behaviours and co-ordination of roles. Meeting with other staff to develop programmes. Chair of weekly feedback meetings between relevant professionals and client’s family.</td>
<td>30</td>
<td>No re-emergence of previous difficult behaviours, clear channels of communication between all professionals developed.</td>
<td></td>
</tr>
<tr>
<td>I F</td>
<td>12</td>
<td>Moderate learning disabilities. Temper tantrums with the potential of causing harm to herself or others.</td>
<td>Observations at home and school, interview with parents, teachers and client.</td>
<td>Behavioural reward system in the form of a star chart for both school and home. Feedback to teachers and parents on psychological aspects of client’s genetic abnormality. Weekly individual sessions with client based on stress inoculation training and anger management approach. Biweekly sessions with parents to explore their expectations of client. Referral to child protection team as father expressed concern that he would hurt client.</td>
<td>18</td>
<td>Increase in good behaviours from 40% to 100% in 10 weeks at home, 50% to 100% in 2 weeks at school. Reduction in parental expectations. Appreciation of child’s needs</td>
<td></td>
</tr>
<tr>
<td>I M</td>
<td>10</td>
<td>Moderate learning disabilities. Sudden appearance of challenging behaviours on visits from his biological father. History of physical abuse from father.</td>
<td>Interview with parents and teachers, observation of client at home and in class. Interview with client.</td>
<td>No problems evident as no contact with father since the summer. Planning with parents actions for if there was further contact. Supporting mother and stepfather regarding their fears for the future if the biological father became involved.</td>
<td>4</td>
<td>Father refused further contact through the courts. Problems did not re-emerge. Case discharged.</td>
<td></td>
</tr>
<tr>
<td>I/J</td>
<td>Sex</td>
<td>Age</td>
<td>Referred for</td>
<td>Initial assessment methods</td>
<td>Brief description of intervention (e.g. model, methods)</td>
<td>Total Hours</td>
<td>Evaluation/Outcome</td>
</tr>
<tr>
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<td>------------------------------------------------------------------------------</td>
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<td>----------------------------------------------------------------------------------------------------------------</td>
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<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>15</td>
<td>Moderate learning disabilities. Extreme mood swings, violent outbursts with physical threats of violence to her sister. Past history of rape.</td>
<td>Interview with mother, teacher, respite care staff and client. ABC data collected by mother.</td>
<td>Individual sessions with client to engender personal responsibility using stress inoculation training. Sessions with mother to explore expectations and future plans.</td>
<td>14</td>
<td>No change in behaviour, inability to use problem solving model. Referred on to Social Services following request from mother and client's consent.</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>8</td>
<td>Severe learning disabilities with autistic features. Challenging behaviours of soiling, smearing and eating faeces &amp; ripping paper in a destructive manner.</td>
<td>Interview with mother, teachers, respite care staff &amp; ABC data recorded in all 3 settings. observations in school and respite care setting.</td>
<td>Sessions with mother discussing and supporting behavioural strategies being carried out. referral of mother to Clinical Psychologist for adults in order to fulfil her own personal needs. Organisation of planning meeting between all professional agencies involved in order to discuss client’s long term needs. Discussion with teacher on use of behavioural strategies in order to prevent the difficult behaviours and develop more adaptive behaviours.</td>
<td>6</td>
<td>Client’s behaviour improved moderately over time. Referral made to special education needs panel for boarding placement, funding was agreed.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>7</td>
<td>Mild learning disabilities. Violence towards other children both at home and school.</td>
<td>Interview with mother and subsequent observation of client.</td>
<td>Mother felt that initial problems of referral no longer exist, therefore no further intervention offered.</td>
<td>1</td>
<td>Discharged with no follow up.</td>
</tr>
<tr>
<td>1/J</td>
<td>Sex</td>
<td>Age</td>
<td>Referred for</td>
<td>Initial assessment methods</td>
<td>Brief description of intervention (e.g. model, methods)</td>
<td>Total Hours</td>
<td>Evaluation/Outcome</td>
</tr>
<tr>
<td>-----</td>
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<td>-----------------------------------------------------</td>
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<td>-------------------</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>10</td>
<td>Severe learning disabilities. Challenging behaviours including persistent screaming, refusal to walk to shops, tantrums.</td>
<td>Interview with parents, respite staff and teacher. Vineland Adaptive Behaviour Scale. Video of behaviour in different settings.</td>
<td>Behavioural model used in order to develop boundaries at home and respite centre. Guidelines developed in order to ensure continuity across settings. Sessions with parents around acceptance of needs based on grief model (Worden)</td>
<td>12</td>
<td>Almost complete reduction in screaming. Satisfaction amongst respite staff regarding client's management. Greater willingness on parents part to realise needs and attempt more behavioural strategies.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>3</td>
<td>Fragile X with severe learning disabilities. Constant distressed crying in the classroom. Early signs of headbanging.</td>
<td>Interview with parents and teacher. Observations at home and school. Discussion with paediatrician.</td>
<td>Advised teacher of creating a more secure environment in the class, i.e. 'home corner'. Discussed behavioural theory of development of self-injurious behaviours with parents. Advised parents of developing communication strategies with client using objects of reference.</td>
<td>7</td>
<td>Reduction of distressed behaviour in the class to minimal levels, leading to an increase in school attendance hours. Use of objects in order for client to express needs and a reduction in injurious behaviours.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>4</td>
<td>Down's syndrome with moderate learning disabilities. Unmanageable behaviour at home not exhibited in school.</td>
<td>Interview with parents and teacher. Observation at home and school. ABC data collected at home.</td>
<td>Sessions with parents explaining behavioural theory, gave them a handout enforcing these ideas. Developed the use of behavioural techniques with the parents in order to extend the use of specific skills from school to home and to extinguish maladaptive behaviours.</td>
<td>12</td>
<td>Marked reduction in most of the more extreme behavioural problems. Support system established for parents. Greater parental understanding of needs and more realistic expectations.</td>
</tr>
</tbody>
</table>
## Individuals/Families - Post 1 (cont.)

<table>
<thead>
<tr>
<th>I/J</th>
<th>Sex</th>
<th>Age</th>
<th>Referred for</th>
<th>Initial assessment methods</th>
<th>Brief description of intervention (e.g. model, methods)</th>
<th>Total Hours</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>J</td>
<td>M</td>
<td>5</td>
<td>Moderate-severe learning disability. Uncontrollable behaviour at home and to a lesser extent at school.</td>
<td>Assessment carried out by previous psychologist.</td>
<td>Intervention plan developed by previous psychologist using behavioural star chart reward system. Sessions with mother in order to assist problem solving regarding client and support her in carrying out behavioural work.</td>
<td>15</td>
<td>Mother failed to adhere to programmes developed possibly as a result of overwhelming guilt regarding her son’s condition.</td>
</tr>
<tr>
<td>I</td>
<td>F</td>
<td>5</td>
<td>Mild learning disabilities, tantrums and other difficult behaviours.</td>
<td>Interview with mother.</td>
<td>No intervention as problem was no longer occurring. Case remained open for 6 months if mother wished to do any work regarding client’s behaviour.</td>
<td>1</td>
<td>Discharged after 6 months as no further contact.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>4</td>
<td>Severe learning disabilities. Temper tantrums and uncontrollable behaviours at school and to a lesser extent at home.</td>
<td>Interview with teachers and parents. Structured observation at home and school. ABC data collected at home and school.</td>
<td>Advised teachers and parents of client’s specific developmental needs. Discussed communication needs with speech therapist. Worked with teachers on developing an appropriate time structure for him in class.</td>
<td>12</td>
<td>Improvement in classroom behaviour, development of more play skills.</td>
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<tr>
<td>I/J</td>
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<tr>
<td>I</td>
<td>M</td>
<td>7</td>
<td>Severe learning disabilities. Problematic behaviour at home not experienced at school, e.g. refusing to heed mothers wishes, refusing to enter certain shops, temper tantrums if thwarted.</td>
<td>Interview with mother. Structured observation at home. Interview with school teacher and observation of shopping trip with school.</td>
<td>Desensitisation used regarding entering shops. Development of photobook to enhance expressive communication and develop sequencing. Work with mum on impact and meaning of her son’s disability.</td>
<td>10</td>
<td>Increased flexibility in the home environment. Increase in tolerance of certain shops.</td>
</tr>
<tr>
<td>I</td>
<td>F</td>
<td>7</td>
<td>Severe learning disabilities. Violent behaviour causing harm to others.</td>
<td>Interview with mother and school staff, observation at both home and school. Functional analysis data recorded at school.</td>
<td>Set of guidelines developed for home and school regarding decreasing demands, increase availability of appropriate games and toys and management of difficult behaviours.</td>
<td>12</td>
<td>Decrease in difficult behaviours at school and home. Later increase in difficult behaviours at school on changes of teacher and class regime. Increase in self initiated play.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>5</td>
<td>Severe learning disabilities, autistic traits and behavioural problems.</td>
<td>Brief interview with mother.</td>
<td>Advice to mother on behavioural management techniques in a consultative manner. Handouts given.</td>
<td>2</td>
<td>No further contact</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>3</td>
<td>Severe learning disabilities, moderate behavioural problems.</td>
<td>Brief interview with mother and observation.</td>
<td>Advice to mother on one specific problem area based on behavioural techniques.</td>
<td>2</td>
<td>No further contact</td>
</tr>
<tr>
<td>I/J</td>
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<td>1</td>
<td>F</td>
<td>9</td>
<td>Tantrums and immature behaviour.</td>
<td>Semi-structured interview with mother. Semi-structured interview with teacher. WISC-III&lt;sup&gt;10&lt;/sup&gt;, WORD.</td>
<td>Star chart reward system for behaviour at home. Feedback to family and school on performance on psychometric testing. Helping agencies think through how to best meet her previously unrecognized severe learning disabilities. Individual sessions at school using social skills training.</td>
<td>14</td>
<td>Little change in behaviour. Parents and school beginning to appreciate her more severe needs, and consider her future.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>14</td>
<td>Increasingly violent behaviour at school. Diagnosed with Autism</td>
<td>Observations at home and school. Semi-structured interview with mother. Semi-structured interview with school staff.</td>
<td>Videeing child at school with different members of staff. Feedback to staff in order to develop a consistent approach. Wrote reports supporting mothers request for her son to be found a boarding school.</td>
<td>14</td>
<td>School staff feeling more competent at managing difficult behaviours. Boarding place found for child.</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>6</td>
<td>Diagnosed with Down’s Syndrome. Unmanageable behaviour at home.</td>
<td>Observations at home and school. Semi-structure interview with Mother.</td>
<td>Strict behavioural programme developed for specific daily routines using a timer to delineate clear boundaries.</td>
<td>8</td>
<td>Difficult behaviours ceased immediately for those routines covered by the programme. General boundaries at home became clearer and good behaviours over all increased (to a lesser extent).</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>16</td>
<td>Severe physical and mental handicap. Extreme episodes of clothes ripping and hand biting.</td>
<td>Semi-structured interview with mother.</td>
<td>No intervention carried out as behaviour no longer existed following the removal of a particular stressor</td>
<td>1</td>
<td>Discharged, no follow up.</td>
</tr>
<tr>
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<td>1</td>
<td>M</td>
<td>15</td>
<td>Moderate/severe learning disabilities. Autism. Disruptive behaviour at school, refusing to enter the classroom, wandering and posting.</td>
<td>Observation at school. Interview with school staff. Brief telephone conversation with father who felt that there was no problem at home.</td>
<td>Meetings with school staff on their feelings regarding the boy, with the aim of diffusing anger directed towards him. Structured recording of behaviour carried out by staff in order to redirect the focus of their demands on child.</td>
<td>15</td>
<td>A little observable reduction in anger felt towards the child by the staff. Increased attendance in class and activities in certain tasks.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>4</td>
<td>Moderate learning disabilities. Uncontrollable behaviour at home and nursery.</td>
<td>Observation at home and nursery. Semi-structured interview with nursery staff. Semi structured interview with mother.</td>
<td>Recommendation made to Educational Psychologist to place in assessment nursery. Development of behavioural programme based at home using strict boundaries, sanctions and rewards for both client and brother.</td>
<td>6</td>
<td>No further contact</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>4</td>
<td>Violent and uncontrollable behaviours at home and school. Moderate/severe learning disabilities.</td>
<td>Observation at home and school. Interview with school staff and mother.</td>
<td>Report written based on assessment and formulation recommending appropriate actions for school, respite centre and home. Accompanied mother to Toy Library to ensure use of appropriate level toys. Limited number of home based play sessions.</td>
<td>5</td>
<td>No further contact</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>6</td>
<td>Severe learning disabilities. Extremely disruptive and violent behaviour at school.</td>
<td>Observation at home and school. Interview with mother and with school staff.</td>
<td>More a school based than home based problem. Discussion of the case with educational psychologist. Limited number of sessions with mother on possible strategies should problems arise.</td>
<td>3</td>
<td>Referral made by school to educational psychology. Discharged, no follow up.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>5</td>
<td>Severe learning disabilities and Autism.</td>
<td>Observation at school, interview with school staff.</td>
<td>Advise to staff on how to refer to appropriate authority of residence. Helping school staff to develop short term behaviour management strategies.</td>
<td>2</td>
<td>Discharged, no follow up.</td>
</tr>
</tbody>
</table>
POST 2
Joint & Independent Work
Individuals/Families. I = Individual, J = Joint.

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<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>7</td>
<td>MLD. Aggressive and destructive behaviours at home. Some behavioural problems at the language unit</td>
<td>Interview with mother, paediatrician and staff at language unit. Observation at home and unit. WISC-III as part of full Autism diagnostic assessment.</td>
<td>Advised mother on developing structure and routine at home. Developed a communication book with photos of activities for child to have a comprehensible, predictable structure and offer the ability to make choices. Work with unit staff on retribution of problems within Autism framework, and developing structure.</td>
<td>22</td>
<td>Marked improvement of destructive behaviour over time and improvement in relationships with siblings.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>4</td>
<td>Separation anxiety from mother, controlling behaviour, poor use of English or mother tongue despite good language ability.</td>
<td>Assessment interview with parents. Discussion with nursery teacher.</td>
<td>Behavioural work using a desensitisation approach and use of rewards for carrying out tasks individually and for appropriate use of language.</td>
<td>12</td>
<td>Developed confidence in being in separation from mother and increasing use of language, both English and mother tongue. Mother increased confidence in parenting.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>5</td>
<td>SL/D. Unpredictable behaviours, toileting problems.</td>
<td>Interview with mother regarding behaviours. Autism Diagnostic Interview.</td>
<td>Reward programme for toileting and other behavioural problems. Rettribution of behavioural difficulties in relation to Autism. Developed a structure at home for play.</td>
<td>32</td>
<td>Fully continent. Continuation of a number of problems at home and school.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8</td>
<td>MLD. Behavioural problems at home and at language unit.</td>
<td>Interview with mother and staff at unit. Autism Diagnostic Interview. WISC-III</td>
<td>Behavioural programme at home for both child and younger sibling, consultation to staff at unit.</td>
<td>13</td>
<td>Great reduction in problems and aggression at home. Settled well into new school.</td>
</tr>
</tbody>
</table>
### Individuals/Families - Post 2 (cont.)

1 = Individual, J = Joint

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<thead>
<tr>
<th>I/J</th>
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<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>11</td>
<td>Poor peer relationships, victim of bullying, school refusal for 6 months.</td>
<td>Interview with child and mother.</td>
<td>Anger management and social skills work with the child. Work with mother on parenting issues.</td>
<td>6</td>
<td>Work incomplete due to non-attendance.</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>9</td>
<td>Defiant behaviour at home and school.</td>
<td>Interview with family.</td>
<td>Social skills training with child, Work with parents on parenting issues and boundaries.</td>
<td>15</td>
<td>Great reduction in arguments at home, parents increased their confidence in abilities to manage the child.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8</td>
<td>MLD and diagnosed with Autism. Behavioural problems, mother also had MLD</td>
<td>Interview with mother.</td>
<td>Work with mother to develop routine, boundaries and rewards at home. Consultation to school staff on increasing child’s self-esteem and ability to work with others.</td>
<td>4</td>
<td>Mother terminated work, stating she did not need help, some improvement in behaviour at school.</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>5</td>
<td>Diagnosed with Autism. Rigid behaviours and extreme levels of distress.</td>
<td>Interview with family.</td>
<td>Work with parents on using a program of graded exposure. Consultation to school.</td>
<td>11</td>
<td>Increased flexibility in ability to tolerate change although some resistance by parents to increase flexibility in routines at home. Marked improvement at school.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>5</td>
<td>SLD oppositional behaviour at home.</td>
<td>Interview with parents, Merrill-Palmer, Vineland Adaptive Behaviour Scale, Autism Diagnostic Interview.</td>
<td>Advice on use of structure and clear communication. Discussed realistic expectations.</td>
<td>16</td>
<td>Improvement of behavioural problems alongside development of communication abilities.</td>
</tr>
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<tr>
<td>I</td>
<td>M</td>
<td>6</td>
<td>Diagnosed with Autism and M.I.D, aggression and oppositional behaviour.</td>
<td>Interview with parents and school teacher. Observation at school and clinic</td>
<td>Discussed possible intervention strategies including use of rewards to reinforce desired behaviours. Advice to school.</td>
<td>2</td>
<td>Parents did not attend further appointments stating that his behaviour had deteriorated since initial interview.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>5</td>
<td>Poor social and communication skills. Oppositional behaviour at home.</td>
<td>Interview with family, class teacher and speech and language therapist. Observation at school and home. Merrill-Palmer and Play observation as part of diagnostic assessment.</td>
<td>Developed routines at home and a communication book to increase his awareness of the routine, and his ability to make choices about using his own time. Multidisciplinary meetings to ensure consistency across settings.</td>
<td>18</td>
<td>Improvement of behavioural problems although social and communication skills did not develop well. Referral made for Autism assessment - no diagnosis made.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>3</td>
<td>Language disordered. Extreme violent behaviour with severe temper tantrums.</td>
<td>Interview with Mother. Observation at home and playgroup.</td>
<td>Work on parenting issues with mother. Behavioural advice regarding clear boundaries, identifying desired behaviours and use of rewards.</td>
<td>9</td>
<td>Some improvement, inconsistent attendance, mother unable to benefit from parenting work.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>7</td>
<td>Non-compliance and obsessionality both at home and school. Poor peer relationships.</td>
<td>Interview with mother, child, teacher and SENCO. WISC-III.</td>
<td>Formulated problems with mother as Asperger's syndrome, and reallocated many behaviours within this framework. Discussed use of obsessions as rewards for desired behaviours. Consultation to school staff.</td>
<td>13</td>
<td>Little change at home as structured program used inconsistently. Continued concern at school regarding management.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>12</td>
<td>Extreme anger and oppositional behaviour of child and younger brother of 7 years.</td>
<td>Interview with family. WISC-III &amp; WORD with younger brother.</td>
<td>Family work on systemic issues. Identified specific learning difficulties in younger brother, feedback and advice to school. Behavioural work when father failed to attend appointments.</td>
<td>7</td>
<td>Father refused to attend more than 2 family appointments thus terminating family work. Some reduction in family arguments. Great improvement at school in younger brother.</td>
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<tr>
<td>I</td>
<td>M</td>
<td>6</td>
<td>Language disordered. Phobic behaviour to unusual stimuli. Temper outbursts.</td>
<td>Interview with mother and school staff. Observation at home.</td>
<td>Referral to team for Autism assessment. Use of structure for time at home and reward system for desired behaviours. Contacted Housing Department for more appropriate accommodation.</td>
<td>13</td>
<td>Slight improvement of temper outbursts at home although continues to have extreme reactions to some stimuli.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>10</td>
<td>Severe aggressive behaviours at school, and to a lesser extent at home. Bedwetting.</td>
<td>Interview with family and teacher. Observation at school. WISC-III &amp; WORD.</td>
<td>Developed a reward system at home for all three children. Use of bell and pad for bedwetting. Identified specific learning difficulties, advised school of appropriate management strategies.</td>
<td>11</td>
<td>Complete improvement at home. Increasing problems at school who rejected further psychology input.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>5</td>
<td>Poor social communication skills.</td>
<td>Merrill-Palmer and play observation as part of Social, Communication skills and Autism assessment.</td>
<td>Diagnosed as Autistic. Advice to mother and to nursery staff regarding appropriate management. Advice regarding services. Offered parents group.</td>
<td>5</td>
<td>Ongoing support from the team. Declined offer of group work.</td>
</tr>
<tr>
<td>J</td>
<td>F</td>
<td>10</td>
<td>Family distress in response to child's progressive disabling condition.</td>
<td>Interview with mother and children.</td>
<td>Family work on adjustment to worries and realistic expectations. Behavioural work on boundary setting.</td>
<td>4</td>
<td>Mother declined more work as the sessions were very stressful, although reported feeling that important issues had been addressed.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>3</td>
<td>Poor social communication skills.</td>
<td>Merrill-Palmer and play observation as part of diagnostic assessment.</td>
<td>Diagnosed as Autistic. Advice to parents regarding appropriate management and services.</td>
<td>4</td>
<td>Family moved out of the area.</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>9</td>
<td>On child protection register. Extreme violence and aggression at school.</td>
<td>Interview with mother and child. Discussion with class teacher and social worker.</td>
<td>Work with mother and child to explore issues of appropriate management and reward for desired behaviours. Discussed management strategies with school teacher.</td>
<td>5</td>
<td>Mother attended 2 sessions, but did not continue attending despite having agreed a contract of work.</td>
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<td>1</td>
<td>F</td>
<td>5</td>
<td>SLD. Extreme behavioural problems and aggression. Mother no longer takes child out.</td>
<td>Interview with whole family, functional analysis of behaviour.</td>
<td>Behavioural work to develop skills and reduce undesirable behaviours. Exploration with parents of expectations.</td>
<td>8</td>
<td>Increase in parents confidence of their own control and parenting skills. Mother able to take child on bus.</td>
</tr>
<tr>
<td>1</td>
<td>M</td>
<td>8</td>
<td>Diagnosed as Autistic. Mother has mild learning disabilities. Management advice.</td>
<td>Interview with mother, teacher and paediatrician separately. observation at school, clinic and home.</td>
<td>Work with mother on understanding what the diagnosis means and introducing behavioural methods. Advice to teacher on management in class.</td>
<td>4</td>
<td>Mother refused further contact was not able to carry through suggestions discussed. Improvement in aggression at school.</td>
</tr>
<tr>
<td>1</td>
<td>F</td>
<td>9</td>
<td>Self-esteem problems relating to dyspraxia.</td>
<td>Interview with child and mother.</td>
<td>Child reported having few concerns and did not want individual work. Mother had many fears for child’s future and problems with management. Cognitive work with mother and parenting work.</td>
<td>5</td>
<td>Dropped out - no further contact.</td>
</tr>
<tr>
<td>J</td>
<td>F</td>
<td>5</td>
<td>Query social, communication disorder.</td>
<td>Merrill-Palmer and play observation as part of Autism assessment.</td>
<td>Diagnosis of Atypical Autism made. Feedback to local services. offered parents place for next set of Parent’s groups.</td>
<td>5</td>
<td>Contact ongoing with mother and relevant services.</td>
</tr>
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<td>I</td>
<td>M</td>
<td>5</td>
<td>Moderate learning disabilities. Toileting problems.</td>
<td>Interview with mother and referrer.</td>
<td>Behavioural work focused on rewarding specific toileting problems.</td>
<td>6</td>
<td>Used toilet when needed, or would say ‘toilet’. No accidents or use of nappy.</td>
</tr>
<tr>
<td>I</td>
<td>F</td>
<td>12</td>
<td>Somatic symptoms in daughter. One of two younger brothers has behavioural problems. Both parents deaf.</td>
<td>Interview with family and with social worker. (Used sign interpreter). Interview with psychiatric services involved in the past. Interview with school teachers.</td>
<td>Systemic based family work focusing on goals and attributions of problems. (Somatic symptoms no longer a problem, but management of children was an issue).</td>
<td>4</td>
<td>Reduction in scapegoating within the family. Mother imposed firmer boundaries on the children whilst allowing negotiation of treats. Family decided not to attend further sessions which had been difficult for them.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>4</td>
<td>Query social communication disorder.</td>
<td>Merrill-Palmer, Vineland adaptive behaviour scale and play observation as part of Autism assessment.</td>
<td>Diagnosed as Autistic with Severe Learning Disabilities. Feedback to parents and relevant services. Parents offered a place in the next set of Parent’s groups.</td>
<td>5</td>
<td>Contact ongoing with family and relevant services.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>5</td>
<td>Diagnosed with Autism. Toileting problems.</td>
<td>Interview with mother. Functional analysis. Observation at home.</td>
<td>Behavioural programme using graded change and appropriate rewards.</td>
<td>4</td>
<td>Contact ongoing. Supervising Psychology Assistant taking the case on.</td>
</tr>
<tr>
<td>Referral for</td>
<td>Initial assessment methods</td>
<td>Brief description of intervention (e.g. model, methods)</td>
<td>Total Hours</td>
<td>Evaluation/Outcome</td>
<td></td>
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</tr>
<tr>
<td>J3</td>
<td>M 6</td>
<td>Behavioural work on developing management strategies. Cognitive work with mother on confidence regarding her parenting abilities.</td>
<td>4</td>
<td>Complete improvement in problems using basic reward system. Mother increased confidence in parenting abilities.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>J M 7</td>
<td>Behavioural work with family on management of rigid and distressed behaviours. Interview with family.</td>
<td>3</td>
<td>Work ongoing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>J M 10</td>
<td>Diagnosed as Autistic. Did follow-up work with mother to ensure appropriate educational placement. Benefits and services involved. Provided feedback to school to ensure needs are met.</td>
<td>7</td>
<td>Mother and school more confident about management and handling.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**POST 1**

**Family Therapy**

N.B. All work documented under previous section involves an element of family work.

This section documents families seen as a member of a family therapy team.

<table>
<thead>
<tr>
<th>I/J</th>
<th>Sex</th>
<th>Age</th>
<th>Referred for</th>
<th>Initial assessment methods</th>
<th>Brief description of intervention (e.g. model, methods)</th>
<th>Total Hours</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>J</td>
<td>F</td>
<td>6 (4)</td>
<td>Emotional distress/behavioural problems. Father suddenly started exhibiting violent behaviour 1½ yrs previously.</td>
<td>Previously assessed through structured interview by team</td>
<td>Systemic family therapy exploring changes and family coping.</td>
<td>2</td>
<td>Continued to be seen by the team.</td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>10 (13)</td>
<td>Behavioural problems (emotional needs of mother affecting responses to daughter).</td>
<td>Previously assessed through structured interview by team</td>
<td>Systemic family therapy exploring positive aspects of mother daughter relationship.</td>
<td>2</td>
<td>Discharged (having been seen over a 2 year period by the team).</td>
</tr>
<tr>
<td>J</td>
<td>F</td>
<td>5 (7)</td>
<td>Emotional distress triggered by death of maternal grandfather. Past history of sexual abuse.</td>
<td>Previously assessed through structured interview by team</td>
<td>Systemic family therapy exploring relationships developed with parents and by the child with other friends.</td>
<td>2</td>
<td>Continued to be seen by the team.</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>11 (36)</td>
<td>Obesity. Behavioural problems at home.</td>
<td>Previously assessed through structured interview by team</td>
<td>Systemic family therapy exploring individual roles in the home and attempting to engender a positive attitude towards identified patients good points.</td>
<td>2</td>
<td>Continued to be seen by the team.</td>
</tr>
<tr>
<td>J</td>
<td>F</td>
<td>8 (9)</td>
<td>Emotional distress and behavioural problems. Past history of abuse.</td>
<td>Previously assessed through structured interview by team</td>
<td>Systemic family therapy consolidating work done by family and giving positive feedback regarding progress made. No further exploration of family issues.</td>
<td>1</td>
<td>Discharged</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>34 (36)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td>36 (34)</td>
<td></td>
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</tr>
</tbody>
</table>

19
### POST 2
**Family Therapy**
None

### POST 1
**Indirect Work With Client (through staff)**

<table>
<thead>
<tr>
<th>#</th>
<th>Profession &amp; numbers of staff</th>
<th>Identified client/s (ages and sex)</th>
<th>Nature of assessments</th>
<th>Brief description of Intervention</th>
<th>Formulation</th>
<th>Total contact time with staff (hrs)</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3 teaching staff in special needs school.</td>
<td>8yrs Male</td>
<td>Interview with staff. Observations in classroom, ABC data collected by teachers.</td>
<td>Consultation to staff based on behavioural theory regarding rewards, sanctions and demands made on the client.</td>
<td>Client hit out and masturbates in order to avoid demands made upon him. This behaviour is maintained by staff reaction which is to remove him from the demand situation.</td>
<td>8</td>
<td>Marked reduction in difficult behaviours from up to 20 incidents of masturbation in 1 week, to 2 incidents in 1 week. Reduction in hitting and pinching but to a lesser extent.</td>
</tr>
<tr>
<td>2</td>
<td>3 teaching staff in specialist school for children with autism.</td>
<td>5yrs Male</td>
<td>Interview with staff. Observations in classroom, ABC data collected by teachers.</td>
<td>Development of behavioural guidelines in order to encourage client to sign ‘please’ using makaton through rewards when he wants something and to then show the member of staff what he wants. Also to extinguish his use of violent behaviours in order to fulfil his needs.</td>
<td>Child experience distress at any change in his environment, hits out, bits and scratches in order to express this. Also used these behaviours at other times in order to express needs, e.g. cold, hungry, wanting a specific activity.</td>
<td>7</td>
<td>Reduction of those specific challenging behaviours however temper tantrums still occur on occasions possibly due to distress for reasons unknown.</td>
</tr>
</tbody>
</table>
### POST 2

#### Indirect Work With Client (through staff)

<table>
<thead>
<tr>
<th>I/J</th>
<th>Profession &amp; numbers of staff</th>
<th>Identified client/s (ages and sex)</th>
<th>Nature of assessments</th>
<th>Brief description of Intervention</th>
<th>Formulation</th>
<th>Total contact time with staff (hrs)</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3 teaching staff in school for children with severe learning disabilities.</td>
<td>8yrs Male</td>
<td>Classroom observations, ABC data collected by staff. Discussion with staff.</td>
<td>Advised referral to child psychiatry. Advised short periods of individual work using reinforcers to increase communication and create opportunity for positive contact.</td>
<td>Possible onset of depression 3 months previously resulting in withdrawal and increase in aggression on demands being made.</td>
<td>6</td>
<td>Increase in interaction and reduction in disruptive behaviours. Referral to psychiatry not made.</td>
</tr>
<tr>
<td>1</td>
<td>1 class teacher in school for children with severe learning disabilities.</td>
<td>15yrs Male</td>
<td>Discussion with teacher.</td>
<td>Advised individual sessions with tangible reinforcers to increase eye contact. Sought out information regarding progressive condition for teacher.</td>
<td>Progressive neurological disease resulting in loss of skills. Staff uncertain of what to expect so made minimal demands on him.</td>
<td>3</td>
<td>Increased understanding in condition. Increase in compliance and eye contact with staff.</td>
</tr>
<tr>
<td>1</td>
<td>3 teaching staff in school for children with severe learning disabilities.</td>
<td>6yrs Female</td>
<td>Discussion with teaching staff. Observation in class.</td>
<td>Developed a set of guidelines involving realistic demands and reinforcement.</td>
<td>Autistic girl avoiding interaction and increasing repetitive stimulation on task demands.</td>
<td>4</td>
<td>Increase in group participation and decrease in repetitive behaviours.</td>
</tr>
<tr>
<td>1</td>
<td>3 teaching staff in school for children with severe learning disabilities.</td>
<td>6yrs Male</td>
<td>Discussion with teaching staff. Observation in class.</td>
<td>Developed a set of guidelines for increasing stimulation in class and reducing undesirable behaviours.</td>
<td>Wheelchair bound child, if with reduced ability to participate or interact, when unattended threw chairs for which he gained attention.</td>
<td>5</td>
<td>Increase in ability to participate in class, slight decrease in undesirable behaviours.</td>
</tr>
<tr>
<td>I/J</td>
<td>Profession &amp; numbers of staff</td>
<td>Identified client/s (ages and sex)</td>
<td>Nature of assessments</td>
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</tr>
<tr>
<td>1</td>
<td>1 teacher in specialist unit for children with Autism.</td>
<td>9yrs Male</td>
<td>Interview with staff. Observation in class.</td>
<td>Development of guidelines for withdrawing 1.1 staff member and developing appropriate communication with staff.</td>
<td>Uses aggressive and disruptive behaviour as a means of reducing demands.</td>
<td>7</td>
<td>Successful reduction of 1.1 input with no increase in aggression</td>
</tr>
<tr>
<td>1</td>
<td>2 class teachers in specialist unit for children with Autism.</td>
<td>7yrs Male</td>
<td>Interview with staff. Observation in class.</td>
<td>Development of clear structure of time in classroom, building in rewards for adherence to timetable.</td>
<td>Distress at small changes as a result of Autism.</td>
<td>4</td>
<td>Successful use of timetable leading to reduction in distressed behaviour</td>
</tr>
<tr>
<td>1</td>
<td>1 class teacher in specialist unit for children with Autism.</td>
<td>8yrs Male</td>
<td>Interview with staff. Observation in class.</td>
<td>Developed programme to reduce aggression towards other pupils and reward positive social contact. Inclusion of family in programme</td>
<td>Distress at being unable to get his own way leading to an aggressive reaction reinforced by other pupils giving in and staff attention.</td>
<td>10</td>
<td>Slight reduction in aggression when staff present although continued problems in unstructured settings.</td>
</tr>
<tr>
<td>1</td>
<td>3 class staff in SLD school</td>
<td>12yrs Male</td>
<td>Interview with staff. Observation in class using ABC schedule</td>
<td>Developed guidelines for choice and appropriate activities within the class.</td>
<td>Autistic child carrying out specific rituals in the class when not engaged in other activities.</td>
<td>6</td>
<td>Slight reduction in rituals and increased use of 'activities box'.</td>
</tr>
<tr>
<td>1</td>
<td>2 staff in class, SLD school</td>
<td>13yrs Male</td>
<td>Interview with staff. Observation in class.</td>
<td>Developed aims with staff member, although 1.1 staff member failed to attend meetings.</td>
<td>Autistic child, aggressive when any demands made or his space intruded. Unable to cope with social demands in school.</td>
<td>2</td>
<td>Child expelled from school as a result of a violent attack.</td>
</tr>
<tr>
<td>I/J</td>
<td>Profession &amp; numbers of staff</td>
<td>Identified client/s (ages and sex)</td>
<td>Nature of assessments</td>
<td>Brief description of Intervention</td>
<td>Formulation</td>
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</tr>
<tr>
<td>1</td>
<td>1 staff teacher in SLD school</td>
<td>8yrs Male</td>
<td>Interview with staff, observation in class</td>
<td>Advice to staff on appropriate management of potentially difficult behaviours.</td>
<td>No specific problems but staff concern as brother is extremely violent.</td>
<td>2</td>
<td>No problems emerged.</td>
</tr>
<tr>
<td>1</td>
<td>1 staff teacher in SLD school</td>
<td>8yrs Female</td>
<td>Interview with staff, observation in class</td>
<td>Advice to staff on adapting present behavioural programme.</td>
<td>Use of inappropriate behaviours to obtain staff input, although responds well to responsibility and rewards.</td>
<td>3</td>
<td>Reward systems working to increase appropriate behaviours.</td>
</tr>
<tr>
<td>1</td>
<td>3 staff in SLD school</td>
<td>5yrs Male</td>
<td>Interview with staff, observation in class.</td>
<td>Correspondence with outside agency on management. feedback to staff.</td>
<td>Autistic child with self injurious behaviour resulting from ill health and lack of communication.</td>
<td>4</td>
<td>Complete reduction in self injury on change of medication.</td>
</tr>
<tr>
<td>1</td>
<td>1 teacher in language unit</td>
<td>7yrs Male</td>
<td>Interview with teacher</td>
<td>Work with teacher on formulation of problems and management strategies.</td>
<td>Inappropriate means of communicating needs and withdrawal when unable to do so.</td>
<td>2</td>
<td>Increased confidence in teacher. Some reduction in withdrawal.</td>
</tr>
<tr>
<td>1</td>
<td>1 teacher in language unit</td>
<td>8yrs Male</td>
<td>Interview with teacher and paediatrician. Observation in class.</td>
<td>Advice to staff on appropriate management following diagnosis of Autism.</td>
<td>Inability to understand subtle social cues</td>
<td>2</td>
<td>Teacher felt more confident and used more consistent strategies in class. reported mild improvement.</td>
</tr>
</tbody>
</table>
**POST 1**

**Teaching**

<table>
<thead>
<tr>
<th>Profession &amp; Numbers</th>
<th>Hours Involved</th>
<th>Objectives</th>
<th>Brief Description of Content</th>
<th>Brief Description of teaching method and format</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Prep.</td>
<td>Sess.</td>
<td></td>
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</tr>
<tr>
<td>Cure Staff, Teaching Staff, Social Services Staff, Members of Relevant Family. (N=12)</td>
<td>4</td>
<td>5</td>
<td>To co-ordinate work regarding one client returning to the borough. To teach monitoring techniques and programme development.</td>
<td>Discussion around previous teaching regarding this client. Definition of roles. Identifying appropriate programmes and monitoring systems. Structuring future plans.</td>
<td>Whole day structured into 6 segments using didactic teaching, large group discussion and small group workshops. Use of overheads and flip chart. Clarity of roles, programmes and long &amp; short term plans. (No structured evaluation carried out).</td>
</tr>
<tr>
<td>Senior House Officers. (N=4)</td>
<td>3</td>
<td>1</td>
<td>To run a seminar informing SHO's on psychological issues regarding elective mutism.</td>
<td>Information on diagnosis, aetiology, assessment, treatment and associated psychological aspects of selective mutism.</td>
<td>I recommended a paper to one of the SHO's prior to the talk. This paper was then presented by the SHO to colleagues and I chaired a general discussion and fielded questions. Handouts were given. Immediate feedback that the session had been interesting and informative. (No structured evaluation carried out).</td>
</tr>
<tr>
<td>General Practitioners and Health Visitors. (N=70)</td>
<td>6</td>
<td>2</td>
<td>One of 4 speakers to present different perspectives to consider at infant health surveillance check-ups. My perspective was emotional and behavioural development of infants at ages of 4 major check-ups.</td>
<td>Literature on developmental ages of receptive and expressive emotional development. Environmental, biological, social and emotional influences on behaviour.</td>
<td>Lecture format using overheads and handouts summarising information. Positive written feedback from organiser. (No structured evaluation carried out).</td>
</tr>
<tr>
<td>Profession &amp; Numbers</td>
<td>Hours Involved Prep. Sess.</td>
<td>Objectives</td>
<td>Brief Description of Content</td>
<td>Brief Description of Teaching method and format</td>
<td>Evaluation/Outcome</td>
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<tr>
<td>Care Staff (N=6 estimated)</td>
<td>3</td>
<td>Cancelled</td>
<td>To inform care staff of aspects of, and influences on, communicating with people with learning disabilities. To inform of differing methods of communicating with people with learning disabilities.</td>
<td>Information regarding how people without learning disabilities communicate. The communication needs of people with learning disabilities and how to meet these. How to overcome obstacles to conventional methods of communication.</td>
<td>Teaching session was cancelled with 1 days notice.</td>
</tr>
<tr>
<td>Educational Psychologist, Headteacher, Deputy headteacher and teaching staff.</td>
<td>1 2</td>
<td>To clarify my overall job remit. To inform of my link with the school. Clarify the difference between myself and the educational psychologist. To build relationship with teachers.</td>
<td>Breakdown of clinical training and job description. Details of referral system and considerations in assessment &amp; intervention models.</td>
<td>Presentation and discussion in staff meeting using flip charts, encouraging informal discussion and questions.</td>
<td>Positive feedback from all staff. A more positive approach in school towards using clinical psychology more appropriately.</td>
</tr>
<tr>
<td>Child Clinical Psychologists (N=4)</td>
<td>3 2</td>
<td>Present a case for discussion in clinical forum format.</td>
<td>Research background reviewed for specific syndrome. Full case presented in form of referral, history, assessment, formulation, intervention and outcome.</td>
<td>Discussion format with summary handouts prepared for both literature review and case study.</td>
<td>Informal positive feedback from all staff.</td>
</tr>
</tbody>
</table>
## Teaching Post 1 (cont.)

<table>
<thead>
<tr>
<th>Profession &amp; Numbers</th>
<th>Hours Involved</th>
<th>Objectives</th>
<th>Brief Description of Content</th>
<th>Brief Description of teaching method and format</th>
<th>Evaluation/Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Child Psychologists and Trainees (N=5)</td>
<td>1</td>
<td>To present WISC-III&lt;sup&gt;UK&lt;/sup&gt; to psychologists familiar with the WISC-R</td>
<td>Discussed content and criteria for WISC-III&lt;sup&gt;UK&lt;/sup&gt;, outlining administration, failure and reversal rules for each subtest. Presented compatibility with WORD.</td>
<td>Informal presentation in staff meeting using WISC-III&lt;sup&gt;UK&lt;/sup&gt; materials and WISC-R materials for comparison.</td>
<td>Considered informative for all involved.</td>
</tr>
<tr>
<td>Profession &amp; Numbers</td>
<td>Hours Involved</td>
<td>Objectives</td>
<td>Brief Description of Content</td>
<td>Brief Description of teaching method and format</td>
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</tr>
<tr>
<td>School Nurses (N=6)</td>
<td>3 Preps 3 Sess.</td>
<td>To increase awareness of specific psychological issues in school children</td>
<td>Theoretical information on self esteem issues and different intervention approaches.</td>
<td>Presented theory using flip chart and OHP projector. Invited participant to describe examples so we could fit these into the theory.</td>
<td>Positive verbal feedback from nurses.</td>
</tr>
<tr>
<td>Clinical Psychologists, Trainees and Assistant Psychologists (N=4)</td>
<td>4 Preps 3 Sess.</td>
<td>To impart information about the Autism Diagnostic Interview</td>
<td>Summarised the different areas of investigation, theoretical background and practical issues.</td>
<td>Viewed the ADI being administered on video, and discussion of the interview format.</td>
<td>Positive verbal feedback.</td>
</tr>
<tr>
<td>Teachers and Classroom Assistants (N=6)</td>
<td>1 Prep 3 Sess.</td>
<td>For staff team to develop a school behavioural policy.</td>
<td>Discussed aims of having policy, identified areas needing to be included, and drew up specific guidelines.</td>
<td>Presented issues to consider on flip chart. Collated ideas and drew up list of guidelines.</td>
<td>Positive verbal feedback</td>
</tr>
<tr>
<td>Teachers and Classroom Assistants (N=8)</td>
<td>1 Prep 2 Sess.</td>
<td>For staff team to develop a school behavioural policy.</td>
<td>Discussed aims of having policy, identified areas needing to be included, and drew up specific guidelines.</td>
<td>Presented issues to consider on flip chart. Collated ideas and drew up list of guidelines.</td>
<td>Staff went on to complete writing of policy.</td>
</tr>
<tr>
<td>Teachers and Classroom Assistants (N=16)</td>
<td>1 Prep 2 Sess.</td>
<td>For staff team to develop a school behavioural policy.</td>
<td>Discussed aims of having policy, identified areas needing to be included, and drew up specific guidelines.</td>
<td>Presented issues to consider on flip chart. Collated ideas and drew up list of guidelines.</td>
<td>Staff went on to complete writing of policy.</td>
</tr>
<tr>
<td>Teaching Post 2 (cont.)</td>
<td>Hours Involved Prep. Sess.</td>
<td>Objectives</td>
<td>Brief Description of Content</td>
<td>Brief Description of teaching method and format</td>
<td>Evaluation/Outcome</td>
</tr>
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</tr>
<tr>
<td>Teachers and Classroom Assistants (N=16)</td>
<td>2 2</td>
<td>To describe the role of the Clinical Psychologist in the SLD school setting.</td>
<td>Presentation of functional analysis, behaviour management strategies.</td>
<td>Presented ABC method of functional analysis on flip chart. Asked staff to present a child, applied problems within the ABC framework and developed functional hypotheses.</td>
<td>Positive feedback from staff; improved working relationships with staff; increased behavioural assessment within the school.</td>
</tr>
<tr>
<td>Teachers and Classroom Assistants (N=21)</td>
<td>2 1½</td>
<td>Increase knowledge in Autism and appropriate management</td>
<td>Presented model of Autism.</td>
<td>Presented model of Autism.</td>
<td>Positive verbal feedback from staff and head.</td>
</tr>
<tr>
<td>Junior Doctors (N=16)</td>
<td>2 1</td>
<td>Inform Junior Doctors on the role of the Clinical Psychologist in Child Health.</td>
<td>Presented background in training, problems referred, models of intervention and settings worked in.</td>
<td>Presentation using O/HI projector. Also presented clinical case to brainstorm possible influencing factors and models of intervention.</td>
<td>Positive verbal feedback.</td>
</tr>
<tr>
<td>Teachers and Classroom Assistants (N=6)</td>
<td>1 1½</td>
<td>Increase knowledge in Autism</td>
<td>Presented model of Autism.</td>
<td>Presented Autistic ‘triad’ using flip chart including possible manifestations. Discussion on applying this model to specific children at the unit.</td>
<td>Positive verbal feedback.</td>
</tr>
</tbody>
</table>
# POST 1

## Courses and Training events.

<table>
<thead>
<tr>
<th>Date</th>
<th>Title</th>
<th>Brief description of topic</th>
<th>Location</th>
<th>Outcome (value of)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.11.94 - 11.11.94</td>
<td>Training day regarding client.</td>
<td>Specific behavioural theories and techniques as applied to children with extremely challenging behaviours.</td>
<td>Organised by Greenwich Social Services, held at Woolwich YMCA.</td>
<td>All staff &amp; family involved with this client gained a collaborative approach to the client's future programmes and management.</td>
</tr>
<tr>
<td>2.12.95</td>
<td>Autism, and It’s Link To Fragile X.</td>
<td>Lecture on phenotypes and genotypes of autism and associated Fragile X.</td>
<td>Institute of Psychiatry.</td>
<td>Greater academic understanding of the classification of autism and Fragile X.</td>
</tr>
<tr>
<td>16.12.95</td>
<td>Working With Other Professionals. CPT day for newly qualified psychologists.</td>
<td>Exploring professional relationships and problems that arise from these.</td>
<td>Salomon’s Centre, South East Thames Regional Training Centre.</td>
<td>Valuable to bring ideas back to my own work place.</td>
</tr>
<tr>
<td>9.6.95</td>
<td>Medico-Legal aspects of care.</td>
<td>Mental capability to give consent to treatment and evidence in court.</td>
<td>University of Surrey</td>
<td>Of relevance within the field of learning disabilities.</td>
</tr>
<tr>
<td>5.7.95</td>
<td>Statistics</td>
<td>Using different statistical analyses in psychological research.</td>
<td>University of Surrey</td>
<td>Relevant to research being carried out in clinical setting.</td>
</tr>
<tr>
<td>28.7.95</td>
<td>Reflections after qualification</td>
<td>Issues regarding clinical work post qualification.</td>
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<td>Personally relevant to my clinical role.</td>
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Courses and Training events.

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<td>22.9.95</td>
<td>Behavioural Phenotypes</td>
<td>Aetiological, descriptive and prognostic information regarding children with a variety of disorders.</td>
<td>Salomon’s Training Centre, Tunbridge Wells</td>
<td>Increased knowledge regarding conditions relevant to clinical cases.</td>
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<tr>
<td>13.10.95</td>
<td>A Clinician’s Involvement in the Statementing Process.</td>
<td>Information on the 5 stages of the statementing procedure and legal requirements.</td>
<td>Mary Sheridan Centre for Child Health, Lambeth</td>
<td>Clearer knowledge on the statementing procedure.</td>
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<tr>
<td>23.10.95 - 27.10.95</td>
<td>Autism Diagnostic Interview training course.</td>
<td>Detailed training on the development and administration of the ADI</td>
<td>Maudsley Hospital Children’s Department, Camberwell</td>
<td>Qualified to administer and interpret the ADI</td>
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<tr>
<td>22.11.95</td>
<td>Cognitive Behaviour Therapy with Children and Adolescents.</td>
<td>Theory, intervention and practical issues for using cognitive behaviour therapy.</td>
<td>Salomon’s Training Centre, Tunbridge Wells</td>
<td>Increased awareness of practical and theoretical issues in using this technique.</td>
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<td>6.12.95</td>
<td>Intervention Work with Young Abusers</td>
<td>Development and evaluation of an intervention group</td>
<td>Department of Child and Family Psychiatry, Lambeth</td>
<td>Increased awareness of issues relating to more general clinical work.</td>
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<td>8.12.95</td>
<td>The Long Term Consequences of Childhood Language Disorder</td>
<td>Evaluation of treatment outcome and prognostic information</td>
<td>Mary Sheridan Centre for Child Health, Lambeth</td>
<td>Increased knowledge in the area of outcome regarding language disorders relating to clinical work.</td>
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<td>15.12.95</td>
<td>Working with Adolescents.</td>
<td>Workshop and discussions on pertinent issues in adolescence and issues to consider during intervention</td>
<td>Kingston Hospital, Surrey</td>
<td>Increased awareness of issues arising in therapy and problems during adolescence directly related to clinical work.</td>
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<td>Transition from Child to Adult Learning Disabilities Services</td>
<td>Therapeutic service needs for late teenagers.</td>
<td>Mary Sheridan Centre for Child Health, Lambeth</td>
<td>Developed better links with adult services to ensure smooth transition across services.</td>
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<tr>
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<td>Attention Deficit Disorder</td>
<td>Diagnostic issues and intervention strategies</td>
<td>Mary Sheridan Centre for Child Health,</td>
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<td>Training on the use of the Baileys Developmental Assessment Scales</td>
<td>Specific training on use of Bayleys instrument.</td>
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<td>Ethical Issues around Intellectual Capability to Give Evidence In Court</td>
<td>Discussion on ethics of proclaiming an individual capable or not of giving evidence.</td>
<td>Surrey University</td>
<td>Trained in use of instrument applicable to clinical assessments.</td>
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<td>4.3.96</td>
<td>Children in Control, Children Out of Control - Shifting the Balance.</td>
<td>Theory and intervention issues on behaviour management.</td>
<td>Solomon’s Training Centre, Tunbridge</td>
<td>Corroborated and developed clinical skills.</td>
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<td>Effective Parenting</td>
<td>Parenting theories and development of intervention groups and techniques.</td>
<td>Northampton Hospital.</td>
<td>Increased knowledge on parenting issues related to clinical intervention.</td>
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<td>17.4.96</td>
<td>Developments in the Assessment and Management of Autism</td>
<td>Recent theoretical perspectives and intervention developments</td>
<td>Floral Hall, Southport</td>
<td>Increased knowledge in the area specifically related to clinical practice.</td>
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<td>Systemic Family Therapy in Britain Today.</td>
<td>Workshop on different perspectives on family therapy techniques.</td>
<td>Solomon’s Training Centre, Tunbridge</td>
<td>Broadened theoretical knowledge on family therapy.</td>
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<td>15.5.96</td>
<td>Child Protection in a Multicultural Society</td>
<td>Multicultural issues on child care and abuse.</td>
<td>St Thomas’ Hospital, London</td>
<td>Increased awareness of multicultural issues as related to clinical caseload.</td>
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<td>Legal rulings according to the children’s act and court procedures.</td>
<td>South Western Hospital, Lambeth, London</td>
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<td>Ticehurst House Hospital, Surrey.</td>
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<td>Appearing as an Expert Witness.</td>
<td>Legal protocol and practical advise on fulfilling court requirements as an expert witness.</td>
<td>Solomon’s Training Centre, Tunbridge Wells.</td>
<td>Increased knowledge of courtroom procedure and requirements.</td>
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<td>28.10.96</td>
<td>Attention Deficit and Hyperactivity Disorder.</td>
<td>Report from BPS working party, classification and recent research relating to underlying psychological mechanisms.</td>
<td>Regents College, London.</td>
<td>Increase in theoretical understanding relating to clinical intervention.</td>
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POST 1
Groups
None

POST 2
Groups
Group for parents of newly diagnosed Autistic children
No. of sessions: 10 + 2 follow-up
Length of sessions: 1½ hours
No. of attendants: 7
Run by: Louise Connor - Clinical Psychologist
Sue Harris - Assistant Psychologist
Aims:
- To have an opportunity to share experiences
- To specifically discuss experiences of having a child newly diagnosed with Autism
- To discuss exactly what Autism means in relation to each child
- To develop strategies to enhance the child's skills and manage difficult behaviours

POST 1 & 2
Research Activity
Title: The Effect of Specific vs. Non-specific Diagnoses of Learning Disabilities on Parental Coping and Family Functioning
Purpose and objective: The aim of the study was to explore the effects of young children having a specific diagnosis vs. non-specific diagnosis associated with their learning disabilities, on family functioning. Secondly to consider the effect that having a learning disabled child has on well established vs. newly established families in terms of family functioning. Other areas considered will be support received by the family, employment status and separation occurring between parents. This was based on a within group design.
Measures:
Three measures were used to structure the parent interview.
1. Family Experience Questionnaire, a non standardised questionnaire developed solely for the purposes of this study.
2. Family Adaptability and Cohesion Scale (FACES) II Scale (Olsen et al 1994).
3. Ways of Coping Questionnaire (Folkman & Lazarus 1988)

Time:
1/2 day per week.

SUMMARY
Since completing clinical training in 1994 my experience has involved working with children and their families. Specifically I have developed skills in working with children with a variety of special needs, and engaging professionals and families involved with their care. In a clinical capacity I have been a member of a family therapy team, have given sessional time to schools and units for children with a variety of special needs, have been involved in a range of multidisciplinary work including developing a diagnostic and intervention service for children with Autism, I have also carried out teaching for a range of professionals, have attended a number of courses as part of my continuing professional development and as part of the University of Surrey Conversion Course have completed a piece of research and literature reviews of direct clinical relevance.

While a range of experience has been gained in working with children and families, no in-patient work or group work with children has been carried out.
Future Professional Development Plans

Skills developed from the past 2 years experience will be used to refine general clinical skills in working with children and families, and specifically to continue to develop the new local service for diagnosis and intervention work with children with Autism.

My longer term aims are to increase my skills in working therapeutically with families and to develop skills in systemic family work by carrying out family therapy training. These skills could then be used to further develop community based Clinical Psychology services for children and their families.
RESEARCH DOSSIER

- The Relationship Between Family Functioning and the Psychological Adaptation of Siblings of Children with Chronic Liver Disease (MSc research)
- The Effect of Specific Vs Non-Specific Diagnoses of Learning Disabilities on Parental Coping and Family Functioning

Louise Connor
The Relationship Between Family Functioning and the Psychological Adaptation of Siblings of Children with Chronic Liver Disease

By

Louise Connor

Dissertation submitted in partial fulfilment of the requirements for the MSc in Clinical Psychology
Institute of Psychiatry
University of London
August 1994
Sibling Research: Acknowledgements

ACKNOWLEDGEMENTS

I would like to thank the following people who helped me to orchestrate this work. Irene Sclare for supervising the project, Jeanette Singer, Pediatric Nurse Specialist for Liver Disease, for helping me identify and contact families of children with liver disease. Sandra Rothwell, Pediatric admissions officer, for helping me to contact children under the E.N.T. surgeon. Joan, Susan and Anna, secretaries at the Belgrave Department for their time, help and friendliness. Professor Mowat and Dr Thomas for permission to see their patients. Professor Everitt for statistical advice. Ursula Prezlik for her advice on the use of Kidcope. Finally my heartfelt thanks go out to Tim Cousin who tirelessly supported me throughout.
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1 ABSTRACT

Liver disease is a chronic, potentially life-threatening disease having illness and treatment consequences, with psychological implications, which may result in lifestyle changes. Any adversity for a child can effect all family members, specifically healthy siblings. There have been contradictory reports of poor adjustment in healthy siblings (Spinetta & Deasy-Spinetta 1981) as well as coping problems (Varri & Wallander 1988). In order to be able to understand adjustment and coping in healthy siblings, family functioning styles need to be examined, specifically cohesion and expressiveness (Daniels et al 1987). The aim of this study was to consider adjustment and coping in children with liver disease, and in their healthy siblings, within the context of family functioning. Results indicate that healthy siblings in high functioning families used coping strategies more effectively than healthy siblings in low functioning families. This difference was not found for adjustment. Healthy siblings in high functioning families were also better adjusted than the child with liver disease although this difference was not found in poor functioning families. Both ill child and sibling in high functioning families demonstrated a trend towards better adjustment, and a different quality of coping strategies, than children in low functioning families. No differences were found between children from control families. In conclusion, adjustment may not be the most relevant measure of difference in well being of healthy children in the face of their sibling's chronic disease. However coping strategies developed in the face of this adversity, and the influence of the family functioning style on the development of these strategies, must
Sibling Research: Abstract

be considered in order to develop clinical skills which may nurture coping in chronically ill children and their siblings.
2 INTRODUCTION

2.1 Pediatric Liver Disease

Liver disease may be present at birth or developed at any time after birth through to adulthood. Severity may vary greatly, the consequences including:- side effects from medications, numerous trips to hospital, drips, blood samples, itching, diarrhoea, bleeding from varices, tiredness and risk of complications. Treatments range from none being available, to a change in diet, to multiple hospitalizations and liver transplant, which only has an 80% success rate.

There is a trend for children with earlier onset disease and/or longer duration of end-stage liver disease to have a higher risk of developmental morbidity (Sexton & Rubenow 1992), although there is no standardised information on the present morbidity rate for paediatric liver disease. The problems experienced by these children are variable in occurrence, severity and impact on their development. This often means that children are unable to maintain their previous activities or keep up with peers. Above all, the children and their families must live with the knowledge that the condition is potentially life threatening.

Some children with liver disease are immediately identifiable by their appearance as they may have a reduced rate of growth, jaundiced skin or a distended stomach, often
Sibling Research: Introduction

resulting in teasing at school. Little is understood by the public about the disease and blame is often laid upon the children themselves and their families.

These children also have many other adjustments to make, such as maintaining a special diet or medication regimen and/or abstaining from high impact sports. Families may have to travel large distances to attend specialist hospitals which will mean time away from work and school. Despite often high levels of medical input children and families can experience a high degree of uncertainty with regards to the new medications being used and for the future in general. Children will also be isolated in that they are unlikely to meet a peer with similar health problems other than at the hospital. Thus these children will almost certainly have to alter their lifestyle resulting in family, social and psychological implications for adjustment depending on the symptoms and effects of the disease.

2.2 Sibling Adjustment to Chronic Illness

Siblings socialize with and educate one another, mediate parental attention and control and provide a peer like context for intense emotional experience and power negotiation (Lobato, Faust and Spirito 1988). Changes in the health of a child will therefore have an effect on their siblings, these changes being influenced by characteristics of the children, the family and the disease itself.
Sibling Research: Introduction

There have been a variety of categorizations used for organizing the many research findings regarding siblings' adjustment to childhood chronic illness. The most useful for these purposes is presented by Brett (1988), who defined three perspectives from which sibling responses are studied: 1. crisis/stress, 2. coping, 3. family systems. This structure will be used to summarize the relevant topics and related research.

2.2.1 The Crisis/Stress Perspective

- Maladjustment in siblings

Most of the earlier research into childhood chronic illness has taken the crisis/stress perspective which implies that illness results in psychopathology of individual family members and seeks to identify dimensions of maladjustment.

Behavioural and psychological difficulties have been found in siblings. Raised levels of such difficulties are used as indicators of maladjustment in siblings of children with chronic disease. These include: bad behaviour, poor school performance, withdrawal, psychosomatic symptoms, sleep problems, enuresis, appetite problems, headaches, stomach aches and preoccupation with their own health. Problems are also reported to be internalized and exhibited as depression and other psychological disturbance. In a qualitative study, Tritt and Esses (1988) reported that siblings felt they had more chores and responsibilities as a result of the illness and this was often accompanied by resentment. They also felt worry and a sense of exclusion and loss.
Sibling Research: Introduction

There is no established prevalence rate of sibling problems, although Binger (1973) studied siblings of children who had died from leukaemia, and found that in half of the families studied, a sibling showed evidence of some kind of difficulty during the illness. Furthermore there is general agreement of chronic illness increasing siblings’ subjective distress (Drotar & Crawford 1985).

If this statistic is accurate then it is clear that sibling responses must be considered in more depth during the process of caring for the ill child. This is supported by more detailed reports of disturbance in siblings by Cairns et al. (1979). In this study of children of school ages, siblings showed more distress than the patients in terms of perceived isolation, fear of expression of negative feelings within the family, perception of the parents being over attentive to the patient, and fear of failure.

Spinetta and Deasy-Spinetta (1981) similarly reported that siblings suffer as much as, and sometimes more than the patients with regard to the meeting of their needs within the family. Siblings were less well adjusted and in greater need of support then any other family members. In a 4-6 year old group, siblings showed less adaptive coping, lower self concept and were more sensitive to the patient than vice versa. These children also saw their parents as more distant. Siblings scored poorly even when families as a whole were coping relatively well. This effect has also been found in siblings’ academic performance (Miller et al 1982) and self esteem (Carr-Gregg et al 1985).
Sibling Research: Introduction

- Explanations for poor sibling adjustment

Burton (1975) found that healthy children rarely ask questions of their parents as they feel the need to protect their parents from additional stress. This pattern of diminished communication spreads to other aspects of family life producing what Turk (1964) described as a gradual 'web of silence'.

Chesler, Allswede and Barbarin (1991) reported that many siblings didn't discuss issues with their parents for fear of upsetting them, although denial may increase stress and feelings of isolation. Furthermore parents may try to protect siblings by shielding them from knowledge of the disease (Kazak & Meadows 1988). This inability to discuss issues may also be coupled with changes in family activity, roles and relationships as a result of the illness. In turn these changes affect the healthy sibling. The extent of adjustment problems has been found to be inversely related to the degree of sibling conflict (Hanson et al 1992). Boer (1990) stated that differential treatment of the children by the parents was related to more conflict and more negative behaviour between the siblings.

In contrast, Taylor (1979) reported that siblings, experiencing a range of chronic illnesses, who had been given frequent and complete information about the child's illness and were included in their care, consistently made statements indicating that it had been a positive and maturing experience.
Sibling Research: Introduction

Taylor's findings introduce an adjustment perspective of chronic childhood disease, and identifies factors promoting adjustment. Brett (1985) defines this perspective as 'that orientation which emphasizes positive family and individual adaptation, to the point of either equilibrium or further growth, in the presence of the chronically ill child'.

- Good Adjustment in Siblings

Many of the studies reporting equivocal findings to the 'maladjustment' studies were more methodologically sound. These studies took account of influencing factors such as family functioning, severity and threats of illness, visibility of illness, demands on the sibling and support systems available. More attention was also paid to the source of information on adjustment. Teacher, parent or health professional's reports alone were not accepted and more child self report methods were used. This more detailed methodology resulted in findings being less unanimous. For example, Breslau & Marshall (1985) found no differences in adjustment between chronically ill and control siblings, in families of children with physical disabilities.

Within the research in this area children have been found to have adapted well to their sibling’s chronic illness, demonstrating increased levels of maturity, altruism and tolerance (Cleveland & Miller 1977), and increased levels of social competence (Ferrari 1984). In fact, a group of 6-10 year old siblings demonstrated a non-defensive attitude, closeness to parents, happiness with themselves and the use of an open communication style.
Sibling Research: Introduction

While there may be a huge burden on the sibling, this may serve as a means whereby children can both act out their sense of caring for the ill sibling and feel needed within the family. This is supported by the finding that siblings developed better coping strategies under increased levels of stress, in a study across many chronic illnesses (Lavigne & Ryan 1979). The experience may enhance understanding of others and lead to the development of empathy and consideration (Parmelee 1986, Horowitz & Kazak 1990). Tritt & Esses (1988) found that siblings reported intellectual growth and maturity and conclude that the pathology model of chronic illness is not useful from a clinical perspective.

In their review of the literature, Lobato et al (1988) stated that well controlled studies have failed to uncover one to one correspondence between the disease and adverse psychological outcome of the sibling. They therefore postulate that the impact of the disease on the sibling can be seen as a stress factor mediated by other individual and family resources. Supporting this proposal, Eiser (1993) postulated that adjustment of the child and healthy siblings may be determined by family attitudes and behaviours, or at least sibling perceptions of these.

2.2.2 The Coping Perspective

The importance of coping strategies have been emphasized because the method of coping with stress may be even more important to psychosocial functioning than frequency or severity of the episodes of stress themselves. It may be that siblings who are well adjusted are those who have more effective coping strategies.
Sibling Research: Introduction

- Definitions

Within the framework of childhood disease, coping can be defined as the way children adapt to the disease and its treatment (Van Dongen-Melman and Sanders-Woudstra 1986). However childhood coping has been considered within the theoretical framework of adult coping which has then been adapted according to research findings in children. Lazarus & Folkman (1984) define coping, with reference to adults, as the process activated when threat is perceived, intervening between threat and the perceived outcome, and is aimed at regulating emotional distress and eliminating the threat.

There have been a number of studies attempting to identify patterns of coping in children, Spirito et al (1988) developed 'Kidcope' a coping checklist for use with children which was adapted from the 'Ways of Coping' questionnaire for adults. This presents children with 10 coping strategies which they may or may not have used in self defined stressful situations. Spirito et al. found that children who reported being distressed by problems used more emotion focused strategies than children who were not distressed. 10, 11 & 13 year old boys were more likely to blame others than girls of the same ages. In contrast to older children, 9-11 year olds tended to use cognitive restructuring, problem solving, emotional regulation and wishful thinking. This result and others (Curry & Russ 1985, and Wertleib et al 1987) suggest that children of around 9-11 years use a variety of coping strategies more often than younger or older children. Unfortunately there was no measure of adjustment or adaptation against which these coping strategies could be validated.
Sibling Research: Introduction

A number of coping models and taxonomies have been developed (Pless & Pinkerton 1975, Walker 1988, Band & Weiss 1988, Varni & Wallander 1988), the most commonly used distinction being that between emotion focused and problem focused coping strategies, within which an almost inexhaustible list of strategies are proposed.

- Developmental patterns

Eiser (1993) states that a child's adjustment towards a disease depends on their cognitive, social and emotional changes within the framework of normal development. The child's concerns become more social as they grow up. This suggests that their ability to cope with problems changes developmentally.

a) Changes with Age

Developmentally, emotion focused coping and wishful thinking are used more by older children who are exhibiting anxiety or sadness. Chronically ill adolescents use self blame and wishful thinking less often than young chronically ill children (Spirito et al). Brown, O'Keeffe, Sanders and Baker (1986) studied coping strategies in children between the ages of 8-18 years, finding that the number of children reporting any kind of coping strategy increased with age. The most frequent strategy reported was positive self talk (an emotion focused strategy).

In light of these, and similar findings Compas, Worsham and Ey (1992) proposed the theory that problem focused coping develops first, this is modelled by parents and is
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more easily observed by children. Emotion focused coping develops later as it is less easily observed by children. Children may slowly become aware that their emotions can be brought under control.

b) Influences on effective coping

Band (1990) studied coping in diabetic children, finding that they used primary coping (emotion focused), secondary coping (problem solving) or relinquished control. Those children who used primary coping were better adjusted. Children with sickle cell anaemia with a greater number of strategies were more physically active and required less frequent health care. Those who used more emotion focused strategies were less active, more distressed and more frequent users of health care (Gil et al 1992). This supports Compas et al's view that despite the later development of emotion focused coping, one should not assume that it is superior to problem focused coping.

Health issues play a role in the use of specific strategies from quite an early age. Children with chronic disease who were referred for emotional help were more likely to use distraction, social withdrawal and wishful thinking. Children with chronic disease and adjustment problems exhibit different coping strategies from those without adjustment problems (Spirito et al 1988).
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c) Knowledge of the Illness

The understanding of the illness will vary with age and this will undoubtedly influence the child's coping style. For example very young children tend to use 'magical' thinking and so may see an illness as witchcraft, whereas an older child will have a deeper understanding of their bodies and the processes of illness (Band & Weisz 1988).

Bradford and Tomlinson (1990) claimed that the knowledge that children have of their illness and the way in which that knowledge was acquired is associated with psychological adjustment. Those children who were informed of their diagnosis of cancer within 1 year, or by the age of 6 were better adjusted than uninformed children. This effect is also found with healthy siblings (Pettle-Michael & Lansdown 1986).

In summary there would appear to be a trend that younger children employ problem solving coping strategies while older children use more emotion focused strategies. There have been many attempts at finding the 'best' coping strategies in relation to psychological outcome (Uzark et al 1992, Van Dongen-Melman and Saunders-Woudstra 1986). However it may be the case that there is no 'most successful strategy', but rather that individuals must employ strategies which take account of their age, the type of stress, situational context and the characteristics of the situation (Rutter 1981).
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2.2.3 The Family Systems Perspective

Brett’s third perspective from which to view sibling responses is the family systems perspective. This is of vital importance as the family provides the framework for major adjustments made by the child (Clapp 1976). Within the family systems perspective issues are considered in terms of the family being an entity greater than the sum of its members. Family research into chronic childhood illness, specifically, has focused on the change in roles in response to the illness and the restructuring of interaction patterns.

Within the family systems literature there exist different viewpoints. The pathology view implies that poor family functioning results in children’s adjustment problems as demonstrated in Walker’s proposition (Walker 1988). Walker states that the mother may find it difficult to adjust to the growing independence of the child and relinquish her protective caretaking role. The relationships between the members of a family system are interdependent. The coalition that develops between the caretaker-parent and ill child will organize the entire family into roles relative to this central relationship.

In a study on Cystic Fibrosis 22% of the variance in height and weight changes were explained by family stress, family resources and parental coping. Family functioning also explained a proportion of the variance in pulmonary functioning changes and 3 month height and weight changes (Patterson et al. 1990) It is also proposed that the
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negative impact of a chronic illness on family life may render a child vulnerable to further stress in the near future (Stewart et al 1992).

An adjustment rather than pathology perspective within family systems work addresses the interaction between family stress, family resources, parental coping and the factors which promote coping. Aspects of family functioning were the focus of work carried out by Kerns & Curley (1985). They examined the relationships between variables involved in chronic childhood illness. They state that: 'Children with chronic illness should have more favourable outcomes in families where the parents are functioning better, experience fewer stressful events and have more adaptive resources available'. This is supported by the results of a study in which family functioning, maternal social support and chronic illness were significantly related to the psychological adjustment of the child (Hamlett et al 1992).

The family also plays a key role in influencing the course of childhood chronic illness. Family interaction and functioning can directly influence adaptation via behavioural and attitudinal approaches, and can affect compliance to medical regimen of paediatric patients (Hauser et al 1985).

Where there is chronic illness in the family it is essential for families to have as many resources available to them as possible. Behavioural problems in children have been found to be associated with greater family stress and a decrease in family resources. Uzark et al (1992) found that families who are under stress and those from a lower
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social economic status (SES) have fewer resources. Uzark suggested that resources of significance include minimal marital strain, family esteem and communication.

Quality of communication between family members has often been cited as a vital resource. For example Spinetta and Maloney (1978) carried out a study into childhood leukaemia from which they were able to conclude that the level of communication about the illness, as expressed by the mother, is related to the coping strategies used by the child.

2.3 The Role of Communication and Cohesion

The relationship between ineffective family communication styles and an inability to cope has often been demonstrated in families experiencing chronic illness (Allan et al 1974, Binger et al 1969, Cain et al 1964). Furthermore Townes & Wold (1977) found that adjustment as measured on a symptom checklist is positively related to the level of communication between parents and the siblings. Open and honest communication results in a more favourable environment in which all family members can function (Klein & Simmons 1979). This is further substantiated by findings that the quality of the marital relationship affects sibling adaptation by influencing family communication and cohesion (Drotar & Crawford 1985).
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Chesler Allswede & Barbarin (1991) claim that when parental concern for the ill child seems to be out of proportion to the explanations communicated to the healthy siblings, the siblings' anxieties about favouritism and rejection may escalate. The study also revealed that 20 out of 21 healthy siblings interviewed believed that the family had grown closer together in some ways since their brother or sister had become ill, although this sometimes brought ignored or hidden conflicts to the surface.

Daniels, Moos, Billings & Miller (1987) carried out a study into childhood rheumatic disease comparing effects on healthy siblings and controls using the Family Environment Scale to measure family functioning. They found that lack of family cohesion and expressiveness was related to sibling adjustment problems. High family cohesion and expressiveness and the lack of family conflict were related to fewer childhood problems among both healthy siblings and the controls.

In the Daniels et al study better sibling functioning and lower burden of the illness on the family was related to fewer physical problems among patients and siblings. Longer disease duration and severity were related to greater adjustment problems. The conclusion drawn was that the optimal environment for psychological functioning was good parental functioning with low family stress and a supportive and expressive family milieu which would help children to manage their problems.
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2.3.1 The Effect of Family Coping Styles on the Healthy Sibling

There are a number of myths which surround the issue of coping within the family which can lead to the assumption that there is a 'right' and a 'wrong' way of coping. Coping is neither linear nor constant as many families experience ups and downs (Spinetta et al 1981).

However there have been specific patterns of family coping which have been found to be associated with better adaptation of family members. McCubbin and Patterson (1981) proposed three positive coping patterns:

1. maintaining family integration, cooperation and holding an optimistic view of the situation.
2. maintaining social support, self esteem and psychological stability
3. understanding the medical situation through communication with other parents and staff.

Sanger, Copeland and Davidson (1991) found that children with the most difficulties came from families in which parents reported using fewer coping strategies. However children who were better adjusted came from families in which parents tried to maintain organization, cooperation and remain optimistic about the disease. In support of McCubbin & Patterson their conclusion was that hopeful parents promote positive coping strategies. Unfortunately this ignores the fact that different coping strategies will be required depending on the demands of the disease.
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It would therefore appear from the existing literature that chronic childhood illness creates a strain on the family, which in turn can have repercussions on the functioning of the individual family members. However if the family has many resources available, are cohesive and have open patterns of communication, then the negative impact of the illness on all family members is likely to be minimized. The impact of these family variables on the adjustment of the sibling will depend on a number of other factors which must be considered.

2.4 Other Protective Factors

Weiner (1987) identified other influencing factors on adjustment, namely sibling age and maturity, ability to integrate the meaning of the illness, relationship with the patient, place and adjustment within the family, honesty of communication, how the sibling is involved in the family adaptation to the crisis, and ordinal position (Lavigne & Ryan 1979).

Garmezy (1985) described three sets of variables which operate as protective factors for all children under stress: a) personality features such as self esteem, b) family cohesion and absence of discord, c) availability of external support systems that encourage and support the child's coping efforts.
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An important consideration when studying the healthy sibling’s adjustment to chronic illness is the severity of the disease. Tew and Lawrence (1973) reported that siblings of slightly handicapped children were the most disturbed, siblings of severely handicapped children were not quite as disturbed and siblings of moderately handicapped children were the least disturbed. Lavigne and Ryan claimed that siblings experienced higher rates of psychological disturbance if the child had visible handicaps, although Klein and Simmons (1979) propose that perceived severity of disease is more important than actual severity.

2.5 Methodological Issues

There are a number of weaknesses in the methodological designs in many of these studies which should be noted. Previous research has often relied on the mother’s report of sibling adaptation, which may reflect a bias in the mothers anxieties about the sick child or misconceptions associated with the disease related to her depression (Lancaster et al 1989). Studies of siblings are often based on observation or parent report rather than self report (McKeever 1983), and mothers have a more negative perspective than siblings themselves (Lobato et al 1988).

To complicate matters further, 25% of siblings of children with epilepsy were rated as disturbed by their teachers but not by their parents (Hoare and Kerley 1991). Teachers therefore may be more aware of, or more willing to admit to, problems of
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these children compared with healthy children. Healthy siblings are often used as controls, but this is an inaccurate control as siblings of disabled children show self destructive tendencies, conflict with their parents and regressive anxiety which was not present in control subjects (Klein & Simmons 1979).

2.6 Conclusion

Liver disease is a chronic illness which may involve changes in lifestyle and is therefore implicated in having a psychological effect on all family members, specifically the patient's healthy sibling. There has been relatively little research into the adjustment of healthy siblings in the face of chronic childhood illness. Much of the research carried out has focused on maladjustment as opposed to adjustment in the face of stressors. More recently, however, the focus has been on the coping strategies used by the siblings and the influence of family functioning on the sibling (Drotar & Crawford 1985). Communication and cohesion have been identified as specific factors which maximise children's opportunities to develop their own adaptive coping strategies.
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2.7 Aim of the Study

The main aim of the study was to consider differences in adjustment and coping between healthy and chronically ill siblings, and to relate this to family functioning. This explores and extends the finding of Spinetta & Deasy Spinetta (1981) by addressing differences in high and low family functioning, and specifically focusing on these effects in relation to pediatric liver disease. Quality of coping strategies was scrutinized and adjustment considered from three different perspectives: parent's, teachers' and children's self report.

2.8 Hypotheses

1- Healthy siblings of children with liver disease in families demonstrating high levels of expression and cohesion will be better adjusted and more effectively use coping strategies than healthy siblings in families demonstrating low levels of cohesion and expressiveness.

2- Healthy siblings in families exhibiting high levels of expressiveness and cohesion will also be better adjusted and more effectively use coping strategies than the child with liver disease. In contrast, in families exhibiting poor cohesion and expressiveness healthy siblings will be less well adjusted than their sibling with chronic liver disease and less effectively use coping strategies.
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3- In the chronic liver disease group, children from more expressive and cohesive families will show a different, more effective pattern of coping strategies than those in less expressive and cohesive families.

4- Both sibling and patient in the control family will exhibit equivalent levels of adjustment and coping outcome which will correspond to family functioning rather than to health status, i.e., in those families with high cohesion and expressiveness the siblings will be equally well adjusted, but in families exhibiting poor cohesion and expressiveness, both siblings will be less well adjusted.
3 DESIGN

3.1 Participants

Nineteen families participated in the study. 13 of these were children with chronic liver disease and their families, 6 were children who had recently undergone an ear, nose or throat surgical procedure. Participants consisted of one or both parents, the ill child and their healthy sibling. The sibling closest in age to the ill child was used in the case of three or more children in the family.

3.1.1 Families of children with liver disease

Families in the liver group were those attending King’s College Out-Patients department for paediatric liver disease. Both children were within the age range of 7 - 18 years. The child with liver disease was diagnosed at least one year prior to the research procedure, and there were no plans for liver transplantation. Their siblings did not have any chronic illness themselves. The 1 year time lag since diagnosis was chosen to assess long term patterns of coping and adjustment and to avoid the early crisis period (Rolland 1987).

Of the 22 families of children with liver disease contacted, 14 families agreed to participate, although one of these families was used as a pilot for the measures and was therefore not used in analysis. 8 families refused or did not reply to a number
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of attempts to contact them. Of the group used for analysis two siblings refused to take part although the rest of the family data are used.

3.1.2 Families of children having ear, nose or throat operations

In order to test hypothesis 4, families of children who had undergone curative surgery for a non life threatening condition, were used. This control helps to test the hypothesis that any difference between the patient and the healthy sibling is due to the chronic illness. According to Olsen et al’s (1989) model of family response to illness, the family will not have undergone major role changes if illness has been temporary.

These families were used as a comparison group in order to ascertain how children and their siblings cope with a non-chronic, non life-threatening illness, having undergone a curative minor surgical procedure. The ill child from this group was attending King’s College Hospital for surgery under the ear, nose & throat specialist. The age criterion for this group matched that of liver families. Families carried out the research procedure within a month following surgery. Neither of the children were suffering from any chronic illness. The aim was also to control for age and social economic status.

Of the 40 control families contacted 12 families did not reply to being contacted twice. 14 families refused for unknown reasons. 7 families did not have
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appropriately aged siblings for the study. 1 family had children of the appropriate age but both were suffering from chronic illnesses. 6 families agreed to participate.

3.2 Measures

3.2.1 Family Environment Scale (FES)

In order to measure family functioning characteristics the FES was used. This measure, developed by Moos & Moos (1974), comprises of 10 subscales which measure social environmental characteristics of families. Three forms have been developed for Real (R), Ideal (I) and Expectations (E) of the family environment. The Real form only was used in this study, this measures people’s perceptions of their nuclear family environment. The measure consists of 90 statements. Form R instructions require the respondent to state true of false for each statement in relation to their family.

Three underlying domains are evaluated: Relationship, as measured by cohesion, expressiveness and conflict subscales, Personal Growth, as measured by independence, achievement orientation, intellectual-cultural orientation, active-recreation orientation and moral religious emphasis, and thirdly, Systems Maintenance as measured by organization and control. The test-retest reliability for the Real form ranges from .68 for the independence subscale, to .86 for the cohesion subscale (see Appendix 1).
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3.2.2 Kidcope

This measure was used in order to measure the coping construct. Kidcope, developed by Spirito et al (1988), assesses 10 common cognitive and behavioral coping strategies utilized by children and adolescents. Each child is asked to describe 3 situations which worry them; firstly regarding their chronic/acute illness, secondly a general medical situation and thirdly a general situation. Healthy siblings are asked about the last two of these situations. Levels of anger, sadness and anxiety are assessed for each situation.

Ten coping strategies are then assessed in terms of the frequency of use and the perceived efficacy according to the child’s report for each situation. Age appropriate versions for younger (7-12 years) and older (13-18 years) children have been developed, the younger having fewer options for frequency and perceived efficacy of coping strategy. A Visual Analogue scale was used for the younger form of the measure which shows coloured squares shaded with increasing intensity for the options of perceived efficacy, and for frequency of the three emotions angry, sad and nervous (Prezlik 1993) (see Appendix 2).

The 10 coping strategies are: distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support, resignation. Test-retest reliability coefficients are available for all ten coping strategies although reliability decreases somewhat between one and two week retrial (Spirito et al 1991). In any case a test-retest format may not be the
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most appropriate indicator of soundness of this checklist as it is designed to measure process rather than a stable personality trait. (See Appendix 3 for example).

3.2.3 Two Adjustment Scales

In order to measure adjustment two scales were used:

Speilberger State-Trait Anxiety Questionnaire for Children

This self report measure, developed by Speilberger et al (1973), assesses two distinct anxiety concepts. Anxiety 'state' measures how the child feels at a particular moment in time, and 'trait' measures how the child generally feels. For each form the child is asked to rate a set of 20 statements of anxiety on a three point scale. The test-retest reliability for this measure is .68 for the trait form, and .39 for the state form. Each child was read the instructions for each form and then offered the opportunity to complete it themselves or for the administrator to go through each statement with them. (See appendix 4).

Rutter Behavioral Rating Scale, Forms A & B.

This is a behavioral rating scale developed by Rutter (1965) which consists of two forms. Form A is completed by parents and assesses health problems and habits in 31 statements. (See Appendix 5). Form B is completed by the child's teachers and
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consists of 26 statements concerning the child's behaviour. (See Appendix 6) From this measure subscores can be obtained of emotional and conduct disorder as well as a hyperactivity score. Test-retest reliability over a three month period is .74 for Form A (mothers) and .89 for Form B.

3.3 Procedure

An initial contact letter was sent to identified families explaining the nature of the research. Any family who did not respond to the letter within 3 weeks was contacted by phone where possible. Those who refused or who were not contactable by phone were not contacted again.

Only those families living within a 50 mile radius of King's College Hospital were approached. Those families who responded positively to the request of participation were interviewed and tested at King's College Hospital or at their home. Only those liver families in which the patient was known to be both within the necessary age range, and who had a healthy sibling within the age range, were contacted.

Control families were approached if the patient was within the age range of the study. Those families with a healthy sibling within the required age range were seen at their
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homes at least 1 week after the child’s operation. These families were offered a £10 fee as an incentive, this was necessary as participation rate was very poor.

If both parents were present, the mother was asked to complete the FES, the father to complete a general information sheet about their family members and parents’ occupations, as well as a Rutter A form for each of the children involved in the study. Each of the children were seen individually in a room away from other family members. The child was presented with the KIDCOPE scale and the instructions read out, the item discussed and the form completed by the researcher following the child’s response to each item. The child was then presented with the instructions for the Spielberger Anxiety Questionnaire and given the option to complete this themselves. Finally the family were asked to consent to each of the children’s teachers to be contacted. Subject to permission, the teachers were then asked to complete and return the Rutter B form.
4 RESULTS

4.1 Descriptive Data

4.1.1 Age and Economic Status

Mean ages for children, and mean social economic status in liver and control families

<table>
<thead>
<tr>
<th>Age of</th>
<th>Mean</th>
<th>SD</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>ill child</td>
<td>12.7</td>
<td>3.2</td>
<td>8.5</td>
<td>1</td>
</tr>
<tr>
<td>sibling</td>
<td>13</td>
<td>2.6</td>
<td>11.1</td>
<td>3.6</td>
</tr>
<tr>
<td>Family SES</td>
<td>2.6</td>
<td>1.1</td>
<td>3.83</td>
<td>2.04</td>
</tr>
</tbody>
</table>

Table 1

Table 1 shows means and standard deviations of ill and healthy children’s ages as well as family social economic status. There is a noticeable difference in mean age and social economic status between the two groups.

4.1.2 Transformations made to Raw Data

Kidcope scores for younger and older versions were transformed to share a common denominator, such that they have equal ranges, for the purposes of comparison. The
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10 coping strategies for each scenario were totalled in order to obtain a total coping score for a particular child describing a particular scenario. Therefore higher total coping scores denoted use of more strategies and/or more effective use of strategies. This measure will be referred to as a child 'more effectively' coping.

The FES subscales of Cohesion and Expressiveness were correlated (r.6416, p=.003) and therefore merged, and the norms for these groups (as developed by Moos & Moos 1974) averaged and applied as a dividing line. Any families scoring above this figure were defined as a high functioning group, any families falling below this figure were defined as a low functioning group.

4.1.3 Normality of Data

Of the 14 main variables used for comparison, 6 were normally distributed in the liver group, including family functioning. However only 4 variables were normally distributed in the control group. Parametric tests were used for liver data on account of their robust nature. However non-parametric tests were used for control data because of the high number of skewed distributions and the small sample size.

4.1.4 Recruitment

There was a large refusal rate in families with liver disease (8 out of 22), although those who did participate in the research were very eager, this willingness may have
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come about as a result of the chronicity of the disease and a need to be involved in all attempts to actively help developing treatments for the illness.

Control families were even more difficult to recruit (refusal rate of 34 out of 40). This may have been due to a perception of the surgical procedure as non-threatening to the child or family, and therefore parents were not interested in dwelling on the issue. On contacting families by phone a number of parents reported that the research was not relevant to them, and therefore declined to participate. One parent of the control group consented to participating in the hope that her youngest son’s behavioral problems could be dealt with.

Given the locality and the need for a financial incentive, the control group overall appeared to be a non representative sample of the population, which may influence the results. All families were financially deprived and many lived on large housing estates and therefore possibly in socially challenging circumstances.

4.2 Liver Group: Coping, Adjustment and Family Functioning

The first hypothesis stated that healthy siblings of children with liver disease in families demonstrating high levels of expression and cohesion will be better adjusted and more effectively use coping strategies than healthy siblings in families demonstrating low levels of cohesion and expressiveness. This predicted that healthy
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siblings of children with liver disease, from high functioning families will score lower on the Speilberger and Rutter scales and higher on the Kidcope scale than healthy siblings in low functioning families.

4.2.1 Coping in High and Low Functioning Families

A t-test for independent samples was carried out on total coping scores for the two sibling scenarios comparing between high and low functioning families. Siblings of children with liver disease in high family functioning groups used more coping strategies more effectively than siblings of children with liver disease in low functioning families (t = 2.82, p = .01 1-tailed). See Figure 1. This significant effect was present for the general medical scenario only.

Boxplot of coping scores for healthy siblings in high and low functioning families

![Boxplot of coping scores for healthy siblings in high and low functioning families](image)
Sibling Research: Results

4.2.2 Adjustment in High and Low Functioning Families

There was no significant difference between high and low functioning families on the four adjustment scores for healthy siblings or children with liver disease.

4.2.3 Possible Influences

Other areas of possible influence were explored in order to explain differences between high and low functioning families. A t-test for independent samples was performed on number of years since diagnosis of liver disease, social economic status and number of medications taken daily (as a measure of severity of illness) for high and low functioning families. There was no significant difference on any of these variables between high and low family functioning. Ethnic origin was not studied as only two of the families interviewed were from a background other that white British. Interestingly both siblings who refused to participate were members of low functioning families.

4.3 Inter-Sibling Relationships

Hypothesis 2 stated that healthy siblings in families exhibiting high levels of expressiveness and cohesion will be better adjusted and more effectively use coping strategies than the child with liver disease. In contrast, in families exhibiting poor cohesion and expressiveness healthy siblings will be less well adjusted than their sibling with chronic liver disease and less effectively use coping strategies. This
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predicted that healthy siblings in high functioning families will have lower Rutter and Speilberger scores and higher Kidcope scores than the patient with liver disease. In low functioning families, healthy siblings will have higher Rutter and Speilberger scores and lower Kidcope scores than the patient.

4.3.1 High Functioning Families

On a paired t-test the liver patient Rutter A score was significantly different from the sibling Rutter A score in high functioning families $t=2.03$ $p=.041$ (1-tailed). The direction of this difference is revealed by the means in Table 2. Patients are less well adjusted than their healthy siblings on the Rutter A measure. However this difference was not present in this group for efficacy of coping strategies.
Sibling Research: Results

Means and standard deviations for liver patients and healthy siblings in high and low functioning families, on adjustment and coping measures.

<table>
<thead>
<tr>
<th>Liver Group</th>
<th>Children with Liver Disease</th>
<th>Healthy Sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High FF N=8</td>
<td>Low FF N=5</td>
</tr>
<tr>
<td>Speilberger Mean</td>
<td>29.50</td>
<td>31.40</td>
</tr>
<tr>
<td>C-1 SD</td>
<td>5.63</td>
<td>3.36</td>
</tr>
<tr>
<td>Speilberger Mean</td>
<td>33.50</td>
<td>37.80</td>
</tr>
<tr>
<td>C-2 SD</td>
<td>5.78</td>
<td>4.38</td>
</tr>
<tr>
<td>Rutter A Mean</td>
<td>7.25</td>
<td>16.60</td>
</tr>
<tr>
<td>SD</td>
<td>4.95</td>
<td>11.33</td>
</tr>
<tr>
<td>Rutter B Mean</td>
<td>1.17</td>
<td>4.20</td>
</tr>
<tr>
<td>SD</td>
<td>1.17</td>
<td>2.95</td>
</tr>
<tr>
<td>Coping- Liver Disease Mean</td>
<td>78.63</td>
<td>80.60</td>
</tr>
<tr>
<td>SD</td>
<td>30.32</td>
<td>26.33</td>
</tr>
<tr>
<td>Coping- Medical Mean</td>
<td>80.25</td>
<td>70.40</td>
</tr>
<tr>
<td>SD</td>
<td>17.33</td>
<td>16.02</td>
</tr>
<tr>
<td>Coping- General Mean</td>
<td>83.88</td>
<td>79.40</td>
</tr>
<tr>
<td>SD</td>
<td>29.79</td>
<td>21.08</td>
</tr>
</tbody>
</table>

Table 2

A Pearson’s correlation was carried out to examine relationships between family functioning, adjustment and coping in children with liver disease and their siblings. There was a correlation between liver patient Rutter A and sibling Rutter A scores for high functioning families in the liver group $r = .8738$, $p = .005$ (see Figure 2).
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*Scattergram of patient and healthy sibling Rutter A scores in high functioning families*

![Scattergram](image)

On consideration of table 2, neither liver patients', or healthy siblings' scores reach the maladjustment cut off point of 12 (Rutter 1965).

4.3.2 Low Functioning Families

A paired samples t-test was carried out between children with liver disease and healthy siblings on both adjustment and coping scores for those children in low functioning families. There were no significant differences on adjustment or coping scores between children with liver disease and their healthy siblings in those families exhibiting poor cohesion and expression. However mean score for liver patients in this group is well above the Rutter A maladjustment cut off point of 12, and their
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healthy sibling scores above both children in high functioning families, on Rutter A and both Speilberger scores.

4.3.3 Magnitude of Difference Between Ill and Healthy Children

A separate variable was computed which denoted liver patient’s score minus their sibling’s score for each adjustment measure and the two matched coping measures. A t-test for paired samples was performed on this variable between high and low functioning families. There were no significant differences for any of these variables between high and low family functioning.

4.4 Specific Patterns of Coping

The third hypothesis stated that in the chronic liver disease group, children from more expressive and cohesive families will show a different, more effective pattern of coping strategies than those in less expressive and cohesive families. This predicted that children from high functioning families will score higher on Kidcope strategies than children from low functioning families.

4.4.1 Liver Group

Means of coping scores were considered for each strategy. The means for each coping strategy were considered in high and low functioning families of children with liver disease. Tables 3 & 4 show the coping strategies with the highest and lowest
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mean scores according to family functioning, for each of the Kidcope scenarios presented to the children.

_Coping strategies considered most effective by children from high and low functioning families_

<table>
<thead>
<tr>
<th>Scenario</th>
<th>High Functioning Families</th>
<th>Low Functioning Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient, Liver</td>
<td>Distraction</td>
<td>Distraction</td>
</tr>
<tr>
<td>Patient, Medical</td>
<td>Social Support</td>
<td>Distraction</td>
</tr>
<tr>
<td>Patient, General</td>
<td>Problem Solving</td>
<td>Distraction</td>
</tr>
<tr>
<td>Sibling, Medical</td>
<td>Emotional Regulation</td>
<td>Social Withdrawal</td>
</tr>
<tr>
<td>Sibling, General</td>
<td>Problem Solving</td>
<td>Distraction</td>
</tr>
</tbody>
</table>

_Table 3_

_Coping strategies considered least effective by children from high and low functioning families_

<table>
<thead>
<tr>
<th>Scenario</th>
<th>High Functioning Families</th>
<th>Low Functioning Families</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient, Liver</td>
<td>Blaming Others</td>
<td>Blaming Others</td>
</tr>
<tr>
<td>Patient, Medical</td>
<td>Blaming Others, Social</td>
<td>Self Criticism, Blaming Others</td>
</tr>
<tr>
<td>Patient, General</td>
<td>Self Criticism</td>
<td>Self Criticism</td>
</tr>
<tr>
<td>Sibling, Medical</td>
<td>Blaming Others</td>
<td>Blaming Others, Problem Solving, Emotional Regulation</td>
</tr>
<tr>
<td>Sibling, General</td>
<td>Social Withdrawal, Resignation</td>
<td>Cognitive Restructuring</td>
</tr>
</tbody>
</table>

_Table 4_
Sibling Research: Results

The total means for the five scenarios were considered for high and low family functioning. An independent t-test was used in order to detect any difference on mean efficacy score for each coping strategy used in each scenario, between high and low family functioning. There was a significant difference in healthy siblings in high and low functioning families for Emotional Regulation (t=2.56, p=.031, 2 tailed). The means for these two groups are displayed in table 5.

<table>
<thead>
<tr>
<th>Emotional Regulation</th>
<th>High FF</th>
<th>Low FF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>58.37</td>
<td>32.66</td>
</tr>
<tr>
<td>SD</td>
<td>16.25</td>
<td>8.1</td>
</tr>
</tbody>
</table>

Table 5

There were no other significant differences between high and low family functioning for individual coping strategies in the liver group.

4.4.2 Control Group

There were no significant differences between high and low functioning families for any of the coping strategies in the control group. However there was a near significant difference on a Mann-Whitney U between the two groups for self criticism (U=.0, p=.057). The mean ranks were 1.5 for high functioning families and 4.5 for low functioning families.
4.5 Adjustment, Coping and Family Functioning in Control Families

The forth hypothesis states that both sibling and patient in the control family will exhibit equivalent levels of adjustment and coping outcome which will correspond to family functioning rather than to health status, ie in those families with high cohesion and expressiveness the siblings will be equally well adjusted, but in families exhibiting poor cohesion and expressiveness, both siblings will be less well adjusted. This predicted that both children in low functioning control families will score high on Rutter and Speilberger measures and low on the Kidcope scale, while children in high functioning control families will score low on Rutter and Speilberger measures and high on the Kidcope measure.

A Mann-Whitney U was carried out on control data. There was no significant difference between ill and healthy siblings in control families on coping or adjustment scores. Nor was there a significant difference in coping or adjustment scores of the patient and their healthy sibling according to family functioning. Similarly there was no significant correlation between adjustment scores and family functioning for siblings in the control group.
Sibling Research: Results

4.6 Additional Findings: Family Environment Scale

Within the Family Environment Scale for the liver group both cohesion and expressiveness (used in this study to denote overall family functioning) were highly correlated with intellectual-cultural orientation (cohesion, $r = .6859$, $p = .01$, expressiveness $r = .8538$, $p < .01$), whereas in the Moos & Moos study the correlations between intellectual-cultural orientation and the two relationship measures were low (cohesion $r = .38$, expressiveness $r = .35$).
5 DISCUSSION

5.1 Hypothesis 1 - Siblings, Coping and Adjustment in High and Low Functioning Families

5.1.1 High Family Functioning

In support of the first hypothesis, healthy siblings of children with liver disease, in families demonstrating high levels of family functioning, used coping strategies more effectively than healthy siblings in families demonstrating low family functioning. However contrary to this hypothesis, healthy siblings in high functioning families were not significantly better adjusted than those in low functioning families, although there is a trend in that direction on Rutter A scores.

The possibility of this difference being due to the period of time since diagnosis, social economic status or severity of the disease as defined by number of medications taken daily, has been ruled out. In support of Pettle-Michael & Lansdown (1986) one can conclude, from these results, that healthy siblings are influenced by childhood chronic illness, but how they may be affected will depend on the functioning of the family, in terms of cohesion and expressiveness. Good family functioning may nurture healthy siblings' development of adaptive coping strategies to adverse conditions.
Sibling Research: Discussion

5.1.2 Low Family Functioning

There is no statistical support for the suggestion that low levels of communication and cohesion in the family, result in maladjustment in healthy siblings. However, mean behavioral adjustment score of the healthy sibling in this group show a trend towards higher means across the group (indicating poorer adjustment) than either of the children in high functioning families. On a behavioral scale rated by mothers, the child with liver disease in low functioning families scores well above the cut off point suggesting maladjustment (see Table 2). This partially supports the finding by Daniels et al (1987) that a non-cohesive family environment was related to multiple problems in children suffering from chronic juvenile rheumatic disease.

5.1.3 Healthy Siblings and Coping

A matter of interest in these findings is that healthy siblings in high functioning families demonstrated significantly more effective use of coping strategies than healthy siblings in low functioning families only on the medical scenario. There was no difference between the two groups for a general problem situation as defined by problems at school, with friends or at home. Siblings of children with liver disease may have developed effective coping strategies for dealing with medical problems as a direct result of their brother or sister having a chronic illness who has to cope with medical situations on a regular basis. However, the child's condition will not necessarily provide insight into dealing with general issues outside of the illness, so coping strategies in these situations may not be so affected.
5.1.4 Healthy Siblings and Adjustment

The fact that healthy siblings in the high functioning group demonstrated significantly more effective use of coping strategies than those in low functioning families, but with no difference in adjustment scores, does not support this hypothesis. One could speculate that coping can be seen as a more sensitive measure of adjustment such that an effect was seen, but the behavioral and self report adjustment scores used would only detect an extreme psychiatric level of distress and maladjustment.

5.1.5 Difference between High and Low Family Functioning and Sibling Differences

The difference between high and low functioning families was also considered in terms of the magnitude of difference between sibling and patient adjustment and coping scores. The absence of a difference between high and low functioning groups may be a result of the trend seen in table 2. In poor functioning families, both sibling and patient scores are numerically higher on maladjustment measures and lower on coping scores than those in the high functioning families. This finding also validates the family functioning variable used.

5.1.6 Sibling Non-Participation

Interestingly, the two siblings who refused to take part in the study both came from low functioning families. One could speculate that this may be due to a reduced level of communication in these families and poor compliance of the children to carry out
Sibling Research: Discussion

their parents wishes. Alternatively the parents may have perceived, and communicated to the healthy child, a negative view of the research.

5.2 Hypothesis 2 - Between Ill and Healthy Siblings

In support of the second hypothesis, healthy siblings in high functioning families are found to be significantly better adjusted than the child with liver disease, substantiating the findings of Spinetta & Deasy Spinetta (1981). However these siblings do not demonstrate more effective use of coping strategies. One could speculate here that if the sibling has learnt adaptive coping strategies through the ill child’s condition and through family supportiveness, as has the ill child, then the sibling will fare better by these strategies as she/he arguably has less to cope with than the ill child.

The hypothesis that in families exhibiting poor cohesion and expressiveness, the healthy siblings will be less well adjusted than their sibling with chronic liver disease, and less effectively use coping strategies, can be rejected and the null hypothesis supported. In fact, in considering the means of ill and healthy siblings from low functioning families, there would appear to be a trend in the opposite direction (See Table 2).
Sibling Research: Discussion

This therefore contradicts the suggestion that siblings suffer more maladjustment in families demonstrating low levels of expressiveness and cohesion and fails to replicate the findings of those researchers who propose that healthy siblings in these families become isolated, demonstrate an inability to cope and develop adjustment problems (Binger et al 1969, Daniels et al 1987).

5.3 Hypothesis 3 - Coping Strategies and Family Functioning

5.3.1 Most Effective Strategies

Table 3 lists most effective coping strategies for both high and low functioning families. One can see a clear distinction in that children in high functioning families found more active coping strategies useful, eg. problem solving, social support, whereas children in low functioning families found more passive and avoidant coping strategies useful eg. distraction and social withdrawal. These more passive and avoidant strategies are arguably less useful (Carver et al 1989). This replicates Spirito et al’s finding that children referred for help used distraction, social withdrawal and wishful thinking (Spirito et al 1988).

The only situation in which the children from the high functioning families found a passive strategy useful (distraction in this instance) was in medical situations relating to their liver disease. These children clearly have more active coping strategies available to them as demonstrated in the other two scenarios, but it may be the case
Sibling Research: Discussion

that the situation regarding their liver disease is less controllable and highly stressful. It may therefore be more adaptive to be passive and accept the situation, than to make futile attempts to gain control. This supports a proposal by Averill et al (1977) who state that if vigilance (an active form coping) has a chance of paying off, it is useful, but in uncontrollable situations, it only arouses anxiety.

Manning et al (1988) discussed active coping in adult stress behaviour, labelled 'transformational coping', which is defined as a dual process of cognition and action. They provided experimental evidence which supports the view that although transformational coping may have a protective factor in low to moderate levels of stress, it's protection does not extend to highest stress levels.

5.3.2 Least Effective Strategies

In considering least effective strategies, there is not such a clear cut distinction between the types of strategy considered least effective by children in high and low functioning families (table 4). However there are a couple of interesting points. Overall, blaming others and self is often cited as the least effective by both groups. However, in the high functioning families, only passive or avoidant strategies were scored as not useful, whereas siblings in the low functioning families scored active strategies, such as problem solving, low on efficacy.

Most interestingly of all, healthy siblings in poor functioning families score low on efficacy for emotional regulation in the medical scenario, whereas healthy siblings in
Sibling Research: Discussion

High functioning families score highest for efficacy on this strategy. In fact this was the only coping strategy which scored significantly differently between high and low functioning families.

5.3.3 Patterns of Coping

One can therefore state that in support of Hypothesis 3 there is a specific pattern of coping strategies used. The trend is for children from high functioning families to use a more active or problem solving type of coping strategy than those from low functioning families. This trend is further supported by the significant difference between healthy siblings in high and low family functioning with regard to emotional regulation.

In both conducting and analysing the Kidcope measure it became evident that the child’s interpretation of each coping strategy was very different. There were a number of occasions when the younger children would ask what was meant, specifically, by the items identifying cognitive reconstruction and resignation. There was also a wide variation between children in situations described for each scenario. The two medical scenarios were fairly clear cut and the children would express fairly similar worries eg. injections, pain at the dentists. However the interpretations of general scenarios would range from an argument with a brother over clothing, to an excessive workload at school. This huge variance in the specification of general situations gave an interesting widespread picture of an individual’s coping strategies.
but prevented the possibility of deriving an overall coping score, as this would have rendered the detailed information gained from each scenario meaningless.

5.4 Hypothesis 4 - Control Families

Hypothesis 4 proposes two effects. The first, that both healthy siblings and patients in the control family will have the same adjustment and coping outcome, was supported. However the second proposal was not supported. Adjustment and coping in both siblings in control families did not correspond to family functioning, such that children in poor functioning families were not less well adjusted. This second finding is surprising, although this, and the findings regarding hypothesis 2, are evidence for the argument that maladjustment in children may not be the most useful measure of well-being or adaptation, and that good adjustment and maladjustment are two extreme ends of a continuum which may not be as sensitive or as useful a measurement as coping.

One can also postulate that the difference found in coping between children with liver disease and their healthy siblings in high functioning families was only due to the effect of the chronic illness, since in the control group there was no difference between siblings for adjustment or coping across high and low functioning families.
5.5 Additional Findings - FES

One finding of interest was that cohesion and expressiveness scores (the two scores from the relationship domain) were both highly correlated with intellectual-cultural orientation (from the personal growth domain) for the liver group.

The cohesion subscale is defined by Moos & Moos (1974) as the degree of commitment, help and support, family members provide for one another'. The expressiveness subscale is defined as 'the extent to which family members are encouraged to act openly and to express their feelings directly'. Therefore the family functioning variable in this study was concerned specifically with levels of support and communication within the family. The correlation between these two variables and intellectual-cultural orientation is not supported by the weak correlations found by Moos & Moos. However this cannot be considered a spurious finding as the strong correlations were present for both subscales.

Intellectual-cultural orientation is defined, by Moos & Moos, as 'the degree of interest in political, social, intellectual and cultural activities'. One could speculate that a family with common interests would generally be more communicative and feel more strongly supported by members of the family with whom they are more intellectually active.
5.6 Conclusions

Clearly the distinction in family functioning is useful in order to predict children’s ability to cope with, and adapt to, chronic illness. In this study high family functioning predicted a specific pattern of more effective coping in healthy siblings, which was superior in quantity and quality to coping skills in healthy siblings in low functioning families.

High family functioning also predicted healthy sibling adjustment which was significantly better than that of their sibling with chronic liver disease, an effect which was not present in low functioning families. Both siblings in high functioning families showed a general trend towards better adjustment than siblings in low functioning families, although there was no significant difference between the two family groups.

These results support Lavigne & Ryan’s findings (1979) that healthy siblings developed better coping strategies when under stress and supports their suggestion that family functioning is crucial in promoting this. Tritt & Esses’s conclusion (1988), that the pathology model of chronic illness is not useful, is substantiated by this study. The evidence supports the use of a coping rather than a maladjustment perspective from which to view siblings’ adaptation to chronic illness. Thus the relevant issues arising from this study are with regards to styles of coping.
Sibling Research: Discussion

The results indicate that coping cannot necessarily be linked with adjustment and suggests that this possibly crude comparison may not be very useful. It would appear to be more useful to consider subjective distress, rather than behavioural adjustment, and measures of good coping within the family as a unit, rather than focusing on an individual in a family where chronic illness is present.
Sibling Research: Discussion

5.7 Future Research

It is evident that further research is required, using bigger samples and better matched comparison groups according to age, IQ and stage of illness. This research should focus specifically on identifying styles of coping and specific strategies which are adaptive for patients with chronic illness, their siblings and families. To aid this there is a need for a more stringent measure of both subjective and objective efficacy of coping strategies.

Research should scrutinize, in more detail, family functioning profiles which nurture adaptive coping styles in different situations. Links should be sought between patterns of family functioning and patterns of coping in both patients with chronic illness and their healthy siblings.

It is necessary to identify from the children's self report, coping needs in different situations, rather than to make assumptions, or to attempt to apply findings from the adult research. Issues such as individual needs for control, which have been addressed in the adult literature, should be carried out specifically for children with chronic illness and their healthy siblings.
5.8 Clinical Implications

It is essential to learn directly from children which is the best coping strategy for specific situations, in the way that distraction was found to be the best overall strategy for medical situations specific to the patient’s liver disease in this study. This information can then be used clinically in a number of ways. Doctors and health care staff can help the child to use the best strategy for a situation, for example help to distract the child from a medical procedure, offer the child more information, allow the child some control over the procedure or treatment etc.

Ultimately with knowledge from this, and further research, clinicians would utilize their skills to encourage and develop cohesion and expressiveness in families. One would also be in a position to teach specific coping strategies in order for all the children in the family unit to optimize their adaptation to the adverse effects of chronic illness.
REFERENCES


Sibling Research: References


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APPENDICES

TABLE OF APPENDICES

1. Family Environment Scale

2. Colour Kidcope Chart for Younger Children

3. Kidcope, Younger Chronic Illness Version

4. Speilberger Anxiety Questionnaire

5. Rutter, Form A

6. Rutter, Form B
69. Each person’s duties are clearly defined in our family.
70. We can do whatever we want to in our family.
71. We really get along well with each other.
72. We are usually careful about what we say to each other.
73. Family members often try to one-up or out-do each other.
74. It’s hard to be by yourself without hurting someone’s feelings in our household.
75. “Work before play” is the rule in our family.
76. Watching T.V. is more important than reading in our family.
77. Family members go out a lot.
78. The Bible is a very important book in our home.
79. Money is not handled very carefully in our family.
80. Our household.
81. There is plenty of time and attention for everyone in our family.
82. There are a lot of spontaneous discussions in our family.
83. In our family, we believe you don’t ever get anywhere by raising your voice.
84. We are not really encouraged to speak up for ourselves in our family.
85. Family members are often compared with others as to how well they are doing at work or school.
86. Family members really like music, art and literature.
87. Our main form of entertainment is watching T.V. or listening to the radio.
88. Family members believe that if you sin you will be punished.
89. Dishes are usually done immediately after eating.
90. You can’t get away with much in our family.

Instructions

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheet. If you think the statement is True or mostly True of your family, make an X in the box labeled T (true). If you think the statement is False or mostly False of your family, make an X in the box labeled F (false).

You may feel that some of the statements are true for some family members and false for others. Mark T if the statement is true for most members. Mark F if the statement is false for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

Remember, we would like to know what your family seems like to you. So do not try to figure out how other members see your family, but do give us your general impression of your family for each statement.

Rudolf H. Moos

Consulting Psychologists Press, Inc.
3803 E. Bayshore Road, Palo Alto, CA 94303
Copyright © 1974 by Consulting Psychologists Press, Inc., Palo Alto, CA 94303. All rights reserved. This test, or parts thereof, may not be reproduced in any form without permission of the publisher. Printed in the U.S.A.
Family members sometimes hit each other.
52. Family members usually get upset if someone makes a mistake.
53. Family members sometimes hit
63. Money and paying bills is a big issue in our family.
64. Family members often feel like they've been shortchanged or taken advantage of.
65. Family members often feel like they've been shortchanged or taken advantage of.
66. Family members often feel like they've been shortchanged or taken advantage of.
67. Family members often feel like they've been shortchanged or taken advantage of.
68. Family members often feel like they've been shortchanged or taken advantage of.
69. Family members often feel like they've been shortchanged or taken advantage of.
70. Family members often feel like they've been shortchanged or taken advantage of.
71. Family members often feel like they've been shortchanged or taken advantage of.
72. Family members often feel like they've been shortchanged or taken advantage of.
73. Family members often feel like they've been shortchanged or taken advantage of.
74. Family members often feel like they've been shortchanged or taken advantage of.
75. Family members often feel like they've been shortchanged or taken advantage of.
76. Family members often feel like they've been shortchanged or taken advantage of.
77. Family members often feel like they've been shortchanged or taken advantage of.
78. Family members often feel like they've been shortchanged or taken advantage of.
79. Family members often feel like they've been shortchanged or taken advantage of.
80. Family members often feel like they've been shortchanged or taken advantage of.
81. Family members often feel like they've been shortchanged or taken advantage of.
82. Family members often feel like they've been shortchanged or taken advantage of.
83. Family members often feel like they've been shortchanged or taken advantage of.
84. Family members often feel like they've been shortchanged or taken advantage of.
85. Family members often feel like they've been shortchanged or taken advantage of.
86. Family members often feel like they've been shortchanged or taken advantage of.
87. Family members often feel like they've been shortchanged or taken advantage of.
88. Family members often feel like they've been shortchanged or taken advantage of.
89. Family members often feel like they've been shortchanged or taken advantage of.
90. Family members often feel like they've been shortchanged or taken advantage of.
91. Family members often feel like they've been shortchanged or taken advantage of.
92. Family members often feel like they've been shortchanged or taken advantage of.
93. Family members often feel like they've been shortchanged or taken advantage of.
94. Family members often feel like they've been shortchanged or taken advantage of.
95. Family members often feel like they've been shortchanged or taken advantage of.
96. Family members often feel like they've been shortchanged or taken advantage of.
97. Family members often feel like they've been shortchanged or taken advantage of.
98. Family members often feel like they've been shortchanged or taken advantage of.
99. Family members often feel like they've been shortchanged or taken advantage of.
100. Family members often feel like they've been shortchanged or taken advantage of.
APPENDIX 2

Did it make you NERVOUS?

Not at all  A little  Somewhat  A lot  Very Much

Did it make you SAD?

Not at all  A little  Somewhat  A lot  Very Much

Did it make you CROSS?

Not at all  A little  Somewhat  A lot  Very Much
How much did it help?

Not at all  A little  A lot
APPENDIX 3

Kidcope Younger Version
Chronic Illness

Name Date
Age Sex

Patient/Sibling (delete as applicable)

Instructions
I am trying to find out how children deal with problems related to their illness. Think about something that has to do with your liver disease that has bothered you in the past month. Please describe the situation below:

Did that time (related to the above described problem) make you feel NERVOUS?
Not at all A little Somewhat Pretty much Very much

Did that time make you feel SAD or UNHAPPY?
Not at all A little Somewhat Pretty much Very much

Did that time make you feel CROSS or ANGRY?
Not at all A little Somewhat Pretty much Very much

Now please turn over the sheet and circle whether you used any of the following ways to deal with this problem.
### APPENDIX 3 Cont.

<table>
<thead>
<tr>
<th>DID YOU:</th>
<th>Did you...?</th>
<th>How much did it help</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>1) Try to forget it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Do something like watch telly or play a game to forget it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Stay on your own?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4) Keep quiet about the problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Try to see the good side of things?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) Blame yourself for causing the problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7) Blame someone else for causing the problem?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8) Try to sort out the problem by thinking of answers?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9) Try to sort it out by doing something or talking to someone about it?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10) Shout, scream or get angry?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11) Try to calm yourself down?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12) Wish the problem had never happened?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13) Wish you could make things different?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14) Try to feel better by spending time with others like family, grown-ups or friends?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15) Do nothing because the problem couldn’t be solved?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement carefully and decide how you feel right now. Then put an X in the box in front of the word or phrase which best describes how you feel. There are no right or wrong answers. Do not spend too much time on any one statement. Remember, find the word or phrase which best describes how you feel right now, at this very moment.

1. I feel . . . . . .  □ very calm □ calm □ not calm
2. I feel . . . . . .  □ very upset □ upset □ not upset
3. I feel . . . . . .  □ very pleasant □ pleasant □ not pleasant
4. I feel . . . . . .  □ very nervous □ nervous □ not nervous
5. I feel . . . . . .  □ very jittery □ jittery □ not jittery
6. I feel . . . . . .  □ very rested □ rested □ not rested
7. I feel . . . . . .  □ very scared □ scared □ not scared
8. I feel . . . . . .  □ very relaxed □ relaxed □ not relaxed
9. I feel . . . . . .  □ very worried □ worried □ not worried
10. I feel . . . . . . □ very satisfied □ satisfied □ not satisfied
11. I feel . . . . . . □ very frightened □ frightened □ not frightened
12. I feel . . . . . . □ very happy □ happy □ not happy
13. I feel . . . . . . □ very sure □ sure □ not sure
14. I feel . . . . . . □ very good □ good □ not good
15. I feel . . . . . . □ very troubled □ troubled □ not troubled
16. I feel . . . . . . □ very bothered □ bothered □ not bothered
17. I feel . . . . . . □ very nice □ nice □ not nice
18. I feel . . . . . . □ very terrified □ terrified □ not terrified
19. I feel . . . . . . □ very mixed-up □ mixed-up □ not mixed-up
20. I feel . . . . . . □ very cheerful □ cheerful □ not cheerful
HOW-I-FEEL QUESTIONNAIRE
STAIC FORM C-2

NAME ____________________________________________ AGE ________ DATE ____________

DIRECTIONS: A number of statements which boys and girls use to describe themselves are given below. Read each statement and decide if it is hardly-ever, or sometimes, or often true for you. Then for each statement, put an X in the box in front of the word that seems to describe you best. There are no right or wrong answers. Do not spend too much time on any one statement. Remember, choose the word which seems to describe how you usually feel.

1. I worry about making mistakes . . . □ hardly-ever □ sometimes □ often
2. I feel like crying ...................................... □ hardly-ever □ sometimes □ often
3. I feel unhappy.......................................... □ hardly-ever □ sometimes □ often
4. I have trouble making up my mind . . □ hardly-ever □ sometimes □ often
5. It is difficult for me to face my problems . □ hardly-ever □ sometimes □ often
6. I worry too much . . . . . □ hardly-ever □ sometimes □ often
7. I get upset at home .................................. □ hardly-ever □ sometimes □ often
8. I am shy . . . . . . . . . . . . . . . □ hardly-ever □ sometimes □ often
9. I feel troubled . . . . . . . . . □ hardly-ever □ sometimes □ often
10. Unimportant thoughts run through my mind and bother me . □ hardly-ever □ sometimes □ often
11. I worry about school . . . . . . . . □ hardly-ever □ sometimes □ often
12. I have trouble deciding what to do . □ hardly-ever □ sometimes □ often
13. I notice my heart beats fast . . . . □ hardly-ever □ sometimes □ often
14. I am secretly afraid . . . . . . . . □ hardly-ever □ sometimes □ often
15. I worry about my parents . . . . . □ hardly-ever □ sometimes □ often
16. My hands get sweaty . . . . . . □ hardly-ever □ sometimes □ often
17. I worry about things that may happen .. □ hardly-ever □ sometimes □ often
18. It is hard for me to fall asleep at night . □ hardly-ever □ sometimes □ often
19. I get a funny feeling in my stomach . □ hardly-ever □ sometimes □ often
20. I worry about what others think of me . □ hardly-ever □ sometimes □ often

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**SCALE A (2)**

TO BE COMPLETED BY PARENTS

<table>
<thead>
<tr>
<th>Name of Child</th>
<th>Boy/Girl</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dress</th>
<th>School</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**HOW TO FILL IN THIS FORM**

The questionnaire asks about various kinds of behaviour that many children show at some time. Please give the answers according to the way your child has been during the PAST 12 MONTHS.

**ALTHER PROBLEMS**

Below is a list of minor health problems which most children have at some time. Please tell us how often each of these happens with your child by putting a cross in the correct box.

<table>
<thead>
<tr>
<th>Health Problem</th>
<th>Never</th>
<th>Occasionally, but not as often as once per week</th>
<th>At least once per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complains of headaches</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Has stomach-ache or vomiting</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Asthma or attacks of wheezing</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Wets the bed or pants</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Soils or loses control of bowels</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Has temper tantrums (that is, complete loss of temper with shouting, angry movements, etc.)</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Had tears on arrival at school or refused to go into the building</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Truants from school</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>
**HABITS.** Please place a cross in the box by the correct answer.

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>II. Is there any difficulty with speech other than stammering or stuttering?</td>
<td>□ No. □ Yes—mild. □ Yes—severe.</td>
</tr>
<tr>
<td>If &quot;Yes&quot;, please describe the difficulty:</td>
<td></td>
</tr>
<tr>
<td>If &quot;Yes&quot; (occasionally or frequently), does it involve</td>
<td></td>
</tr>
<tr>
<td>□ minor pilfering of pens, sweets, toys, small sums of money, etc.</td>
<td></td>
</tr>
<tr>
<td>□ stealing of big things</td>
<td></td>
</tr>
<tr>
<td>□ both minor pilfering and stealing of big things</td>
<td></td>
</tr>
<tr>
<td>is stealing done</td>
<td>is stealing done</td>
</tr>
<tr>
<td>□ in the home</td>
<td>□ on own</td>
</tr>
<tr>
<td>□ elsewhere</td>
<td>□ with other children or adults</td>
</tr>
<tr>
<td>□ both in the home and elsewhere</td>
<td>□ sometimes on own, sometimes with others</td>
</tr>
<tr>
<td>If &quot;Yes&quot;, is it</td>
<td></td>
</tr>
<tr>
<td>□ faddiness</td>
<td></td>
</tr>
<tr>
<td>□ not eating enough</td>
<td></td>
</tr>
<tr>
<td>□ eating too much</td>
<td></td>
</tr>
<tr>
<td>□ other, please describe:</td>
<td></td>
</tr>
<tr>
<td>If &quot;Yes&quot;, is it difficulty in</td>
<td></td>
</tr>
<tr>
<td>□ getting off to sleep</td>
<td></td>
</tr>
<tr>
<td>□ waking during the night</td>
<td></td>
</tr>
<tr>
<td>□ waking early in the morning</td>
<td></td>
</tr>
<tr>
<td>□ other, please describe:</td>
<td></td>
</tr>
</tbody>
</table>
Below are a series of descriptions of behaviour often shown by children. After each statement are three columns—“Doesn't Apply”, “Applies Somewhat”, and “Certainly Applies”. If your child definitely shows the behaviour described by a statement, place a cross in the box under “Certainly Applies”. If he or she shows the behaviour described by a statement but to a lesser degree or less often, place a cross under “Applies Somewhat”. If, as far as you are aware, he does not show the behaviour, place a cross under “Doesn’t Apply”.

Please put one cross against each statement.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Doesn’t Apply</th>
<th>Applies Somewhat</th>
<th>Certainly Applies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very restless, has difficulty staying seated for long</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Squirmy, fidgety child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often destroys own or others’ property</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently fights or is extremely quarrelsome with other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not much liked by other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often worried, worries about many things</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tends to be on own—rather solitary</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irritable, is quick to ‘fly off the handle’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often appears miserable, unhappy, tearful or distressed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has twitches, mannerisms or tics of the face or body</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently sucks thumb or finger</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequently bites nails or fingers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is often disobedient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cannot settle to anything for more than a few moments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tends to be fearful or afraid of new things or new situations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fussy or over-particular child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often tells lies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bullies other children</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there any other problems?

Signature: Mr./Mrs.

Thank you very much for your help.
**SCALE B(2)**

**TO BE COMPLETED BY TEACHERS**

**Name of Child:** ______________________  **Boy/Girl**  
**Address of Child:** ______________________ 
**Date of Birth:** ______________________

Below are a series of descriptions of behaviour often shown by children. After each statement are three columns:— “Doesn’t Apply”, “Applies Somewhat” and “Certainly Applies”. If the child definitely shows the behaviour described by the statement place a cross in the box under Column 2 “Certainly Applies”. If the child shows the behaviour described by the statement but to a lesser degree or less often place a cross in the box under Column 1 “Applies Somewhat”. If, as far as you are aware, the child does not show the behaviour, place a cross in the box under Column 0 “Doesn’t Apply”.

Please complete on basis of child’s behaviour IN THE PAST 12 MONTHS.

Put ONE cross against EACH statement. Thank you.

<table>
<thead>
<tr>
<th>STATEMENT</th>
<th>0 Doesn’t Apply</th>
<th>1 Applies Somewhat</th>
<th>2 Certainly Applies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Very restless, has difficulty staying seated for long</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>2. Truants from school</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>3. Squirmy, fidgety child</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>4. Often destroys or damages own or others’ property</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>5. Frequently fights or is extremely quarrelsome with other children</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>6. Not much liked by other children</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>7. Often worried, worries about many things</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>8. Tends to be on own—rather solitary</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>9. Irritable. Touchy. Is quick to ‘fly off the handle’</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>10. Often appears miserable, unhappy, tearful or distressed</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>11. Has twitches, mannerisms, or tics of the face or body</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>12. Frequently sucks thumb or finger</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>13. Frequently bites nails or fingers</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Statement</td>
<td>0 Doesn't Apply</td>
<td>1 Applies Somewhat</td>
<td>2 Certainly Applies</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>--------------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>14. Tends to be absent from school for trivial reasons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Is often disobedient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Cannot settle to anything for more than a few moments</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Tends to be fearful or afraid of new things or new situations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Fussy or over-particular child</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Often tells lies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Has stolen things on one or more occasions in the past 12 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Unresponsive, inert or apathetic</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Often complains of aches or pains</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Has had tears on arrival at school or has refused to come into the building in the past 12 months</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Has a stutter or stammer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Resentful or aggressive when corrected</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Bullies other children</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Is there anything else unusual about this child's behaviour?—or are there any other comments you would like to make?

Signature: Mr./Mrs./Miss

Date:

THANK YOU VERY MUCH FOR YOUR HELP
The Effect of Specific Vs Non-Specific Diagnoses of Learning Disabilities on Parental Coping and Family Functioning

Louise Connor

Word Count: 18,632

December 1996
ACKNOWLEDGEMENTS

I would like to thank Patricia Howlin for her invaluable supervision and support. I would also like to thank Mags Towers at Greenwood Assessment Nursery, for her time, support and access to the children and families attending the Nursery. The Greenwich Portage Service and staff at the Early Intervention Centre. Oxleas Psychology Department for funding the PsychD. Orlee Udwin for giving me space and time to carry out the work, Paul Devonshire, Lorraine Nanke, and finally, Tim Cousin for reading through the work and being infinitely patient.
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</tr>
<tr>
<td>2</td>
<td>Mothers' Use of Coping Strategies Across Both Diagnostic Groups</td>
</tr>
</tbody>
</table>
1. ABSTRACT

Research over the past two decades has clearly documented the profound psychological impact of the learning disabled child on parents, and the resulting stress (e.g. Shapiro, 1983). There is evidence that parents develop strengths and resources in the form of coping strategies and adaptive family functioning in order to adjust to the stressors presented by their child's condition (Holahan & Moos, 1990). Early identification of the child's condition has also been reported to reduce the family's experience of stress (Bristol, 1987), as does having a specific diagnosis rather than the vague description of "learning disabilities" (Quine & Pahl, 1986).

The aim of this study was to explore the effects of having a specific diagnosis of learning disabilities, (e.g. Downs Syndrome), vs. a non-specific learning disability, (e.g. severe learning disabilities), on dimensions of family functioning and parents' use of coping strategies. The age at which the child was diagnosed, the number of professionals involved with the child and past experience of childrearing were also considered. Two additional measures were designed for this study to elicit information about the child's diagnosis and related variables.

Two major themes emerged from the findings of the study. Firstly, having had prior childrearing experience tended to be associated with positive outcome relating to the use of the Positive Reappraisal coping strategy, when coupled with having a child with a specific diagnosis, this situation providing the most information for families which can then be used adaptively. Secondly, use of a less adaptive coping strategy and rating a family functioning scale as low, may reflect mothers' guilt regarding their child's problems for which they have no alternative explanation in the absence of a diagnosis. Mothers of children with a specific diagnosis, on the other hand, may be able to attribute the problems externally as a result of the information they obtain regarding the aetiology, phenotype and prognosis of their child's condition.

These findings highlight the need for a specific diagnosis for a child with learning disabilities in order to provide information on aetiology, phenotype and prognosis, thus
promoting healthy parental outcome in terms of both individual coping and family functioning.
2. INTRODUCTION

With a few exceptions, (Bristol, 1984; Bristol, 1987; Crnic et al., 1983; Gallagher et al., 1981; for example) most research on families of learning disabled children has considered the negative effects of the children's disabilities. Problems with adaptation and family crisis (Bristol, 1984), depression (Burden, 1980) and institutionalisation (DeMyer & Goldberg, 1983) have been documented. Some studies have highlighted the fact that parents of these children report more stress than parents of children with other kinds of handicap (e.g. Holroyd & McArthur, 1976). However, there is also evidence to show that many families adapt successfully to the presence and care of a learning disabled child, and are able to function well despite the increased demands (Bristol, 1984; Burden, 1980; amongst others). It is therefore important to be able to determine the most adaptive styles of family functioning, coping patterns and their predictors, in families attempting to deal with the constant stress that is presented when caring for a learning disabled child.

2.1 Stress

Lazarus (1966) defines stress as 'The psychological state which derives from people's appraisals of their adaptation to the demands which are made of them'. Hill (1958), in specific relation to families, defines stress as 'a crisis provoking event or situation for which the family has little or no preparation'. Caring for a child with a disability is a stressor affecting well-being of the parents which in turn affects the outcome of the child (Shapiro, 1983). Parents of children with learning disabilities have been shown to experience more stress than parents of children with a physical handicap (Holroyd, 1982). The initial diagnosis of their child as having learning disabilities has also been documented as having a profound impact on the parents, leading to extreme experiences of stress (Doernberg, 1982; Moses, 1983; Wooley et al., 1989).

The diagnosis of learning disabilities in children has been described as a crisis producing grief, followed by stages of shock and disbelief, denial, anger, adaptation
and adjustment, similar to phases identified in the bereavement literature (e.g. Emde & Brown, 1978). Reference has also been made to chronic sorrow (Olshansky, 1962). This refers to the issues of loss and disappointment on an ongoing and unresolved basis where there is no actual death. Quine & Pahl (1987) reported that most parents' reactions to diagnosis were overwhelming shock, feelings of being stunned, confused or numb. Other studies have reported loss of self esteem, anxiety, guilt, mourning, hostility, rejection, frustration, helplessness, shame and disorganisation of personality (Matheny & Vernick, 1969).

Parents' sense of competence appears to be severely challenged by the presence of their child's chronic condition; they also experience increased isolation, decreased social mobility and fatigue (Marcus, 1977). Bristol (1979), in considering stressors in parents of autistic children, found that the child's difficult personality characteristics, degree of dependency and extent of physical incapacitation significantly contributed to levels of stress. Similarly, Konstantareas (1991), considered groups of children with learning disabilities, finding that symptomatic children, i.e. those with overt physical abnormalities, were more stressful to their parents than non-symptomatic children. Internal attribution of cause of the child's handicapping condition is also related to greater levels of stress (Lavelle & Keogh, 1980). A review of the literature on stresses of caregiving and developmental disabilities suggests that high levels of stress in parents of autistic children may be related to emotional strain, marital disharmony, difficult developmental transitions, a lack of social and instrumental support and types of coping strategies adopted (see McCallion & Toseland, 1993).

There appears to be a qualitative difference between stressors affecting mothers and those affecting fathers (Krauss, 1993). Much of the literature reports that mothers generally experience higher levels of stress than fathers (e.g. Tavormina et al., 1981). However the effect on fathers cannot be said to be negligible as fathers of learning disabled children seem to derive less pleasure and satisfaction from their child than do fathers of non-learning disabled children (Cummings, 1970). It would appear that overall both parents find the experience of the learning disabled child stressful, but not necessarily equally so.
Much of the literature (e.g. Bristol, 1987) has conceptualised families’ adaptation to the stress of having a learning disabled child by using the ABCX model (Hill, 1949), and its extension, the Double ABCX model (McCubbin & Patterson, 1981). The ABCX model proposes that the characteristics of the stressor event (A), the family’s internal crisis-meeting resources (B), and the family’s definition of the stressor (C) contribute to the prevention or the precipitation of a family crisis (X). The double ABCX model includes additional stressors that make adaptation more difficult, the social and psychological resources, coping strategies, the meaning the family assigns to the event, and the range of positive and negative outcomes possible. Bristol (1987) used this model in order to predict outcome, measuring: Severity of handicap (A), pile up of other stresses (aA), family cohesion (B), social support (bB), externalisation of blame (C), the definition of the handicap as a family crisis (cC), and the patterns of coping (BC). The model was found to be an effective way of conceptualising the process of adaptation in families of autistic or communication disordered children.

In the past many studies have focused on the negative effect of the learning disabled child on parents and negative traits in the parents themselves. Thus, parents have been described as formal, rigid, perfectionistic or obsessive (Eisenberg & Kanner, 1956; Kanner, 1949), overprotective or overstimulating (Anthony, 1958), emotionally impoverished, disturbed in their thinking process (Alanen et al., 1964), unhappy, depressed, hostile and rejecting (Donnelly, 1970), inadequate in communicative capacity, anxious and infantilizing (Goldfarb et al., 1966). While it is widely acknowledged that the experience of having a child diagnosed with a mentally or physically handicapping condition is stressful, more recent studies have highlighted that this need not necessarily result in maladaptive outcomes. Exposure to stress may broaden a person’s perspective on life, promoting new coping skills and leading to positive psychological growth (Holahan & Moos, 1990). Quine & Pahl (1991) reported that mothers of children with learning disabilities, who had positive adjustment to and acceptance of their child, had lower stress scores. Tavormina et al., (1981) conclude from their study of handicapped children that parents exhibit a family functioning profile mid-way between normal families and those of psychiatric clinic
samples, and furthermore, propose that this is the cost of coping with the associated stressors.

2.2 Adaptive vs. Maladaptive Outcomes

Many studies focus on adaptation of parents to the stress of having a handicapped child. Despite much research into coping resources and strategies, family functioning and environmental factors, few studies provide a clear definition of adaptation or maladaptation. Early research in this area focused on maladaptive responses of parents and families, and defined these as negative affect characterised by anxiety, depressive mood and other mental health problems. Also documented are problems with impulse control accompanied by aggressive feelings (Miller & Keirn, 1978). Therefore, negative personality and emotional characteristics are considered to be maladaptive responses. Marital relationships have also been highlighted as suffering in response to the stress of parenting a handicapped child (e.g. Locke & Wallace, 1959). Psychosocial problems have been cited (Watson & Midlarsky, 1979), as well as difficulties in the mother-child relationships (Vietze et al., 1978).

More recent research has considered the family’s capacity for successful adjustment, growth and healthy outcomes (Darling, 1988). There appears to be a consensus of opinion that resilience to the stressor is considered to be a result of positive adaptation (Holahan & Moos, 1990; McCubbin, 1979). Bristol (1987) defines successful adaptation in terms of personal, conjoint and child-focused aspects. However personal adaptation is measured in this study by a depression scale, implying that the absence of depressive symptoms, rather than positive affect, indicates successful adaptation.

Maladaptive parental responses have been documented in greater detail than adaptive responses although there are contradicting views on the direction of causality. Early studies document familial psychopathology as having an impact on the disturbed child (e.g. Kanner, 1949). Parents have been described as being unhappy, depressed, hostile rejecting (Donnelly, 1970) and being inadequate in communicative capacity (Goldfarb et al., 1966). Although more recently, research has focused on the effect of the
learning disabled child on the family (e.g. Margalit & Ankonina, 1991), this change in approach, and poor universal definition of an adaptive outcome make it very difficult to tease apart cause and effect factors.

2.3 Coping

Coping has been defined as 'all responses made by the individual who encounters a potentially harmful outcome, including overt behaviours, cognitions, physiological responses and emotional reactions' (Cohen & Lazarus, 1979). Lazarus (1981) later went on to define coping as 'efforts, both action-oriented and intrapsychic, to manage environmental and internal demands, and conflicts among them, which tax or exceed a person's resources'.

Coping efforts can be directed toward the threat itself, or toward efforts to regulate the emotional distress caused by the threat. The former style is labelled active, instrumental, or problem-solving, and is defined as 'the process of taking active steps to try to remove or circumvent the stressor or to ameliorate it's effects' (Carver et al., 1989). Carver et al (1989) propose a number of dimensions within this framework for conceptualising coping. Within active coping, they distinguish between: planning (i.e. thinking about how to cope with a stressor), suppression of competing activities (i.e. putting other projects aside) restraint coping (i.e. waiting until an appropriate opportunity to act presents itself) and seeking social support for instrumental reasons (i.e. seeking advice, assistance or information).

The latter style of coping, first described by Lazarus (1974), is labelled passive, palliative or emotion focused. Within passive or emotion-focused coping Carver et al (1989) distinguish between: seeking social support for emotional reasons (getting moral support, sympathy or understanding), focusing on and venting of emotions (focusing on whatever distress one is experiencing and venting those feelings), behavioural disengagement (reducing one's efforts to deal with the stressor, or giving up the attempt to attain goals with which the stressor is interfering) and, mental disengagement (distraction from thinking about the behavioural dimension or goal with
which the stressor is interfering). The nature and type of coping strategy used will be defined by coping resources available to the individual (Lazarus, 1974).

Folkman et al. (1979) outline five categories of coping resource including utilitarian resources e.g. socio-economic status, money, available services; health, energy or morale, e.g. depression, pre-existing physical and psychiatric illness; social networks, close personal relationships; general and specific beliefs, e.g. self-efficacy, mastery, self-esteem; and problem solving skills, e.g. intellectual skills, cognitive flexibility, complexity and analytic ability which enable people to formulate alternative courses of action.

**2.3.1 Adaptive Coping**

Many studies have considered the coping needs of parents of children with learning disabilities. However, it would appear that there is no single common language for the coping strategies described, nor one coping measure that is commonly used. Much of the evidence is poorly defined or anecdotal in nature, making it difficult to replicate, and of limited clinical use. Denhoff & Holden (1971), in a study of pre-school children with cerebral palsy, conclude that good parental coping consists of 1. acceptance, 2. developmental understanding, 3. warm and secure family relationships, 4. encouragement of self help, 5. initiative and stamina in the area of therapy and rehabilitation, and 6. professional trust. It is, however, important to acknowledge that coping is both a person-, and situation-specific phenomenon (Cohen & Lazarus, 1971). Some themes have emerged from the literature regarding adaptive coping strategies used by parents of children with learning disabilities. These include:

*Prior experience*

Murphy (1974) and McCubbin (1979), amongst others, suggest that prior experience may be vital in reducing stress and enhancing family stability, implying that greater coping resources are available to those who have developed expertise in dealing with similar situations.
Social Support

Utilisation of support systems, for both emotional and practical support, is often implicated in adaptive coping (Edelstein & Styrdom, 1981; Strand, 1979). Support from other families in similar positions is also a vital element (Valman, 1981), although it has been argued that perception of social support is more important than social support per se (Bristol, 1987; Prieto-Bayard, 1993; Valle & Bensussen, 1986).

Active coping

Much of the literature discusses the use of active coping strategies, although the definitions vary across studies. Bristol (1987) noted that active coping strategies made a significant contribution to the prediction of quality of parenting. Unfortunately no formal definition was offered, although active coping strategies are now generally understood to mean actions taken in order to change the situation in some way. McCubbin (1979) suggested that active coping strategies play a role that goes beyond the passive receipt of support, this claim being supported by Bristol (1987). In studies of childhood disability, active coping has generally been found to be adaptive and to hold a strong stress-resilience function in predicting positive affect, as did, to a lesser extent, familial resources (Margalit, 1990; Margalit & Ankonina, 1991). The individual may develop resilience through effective confrontation with the stressful experience, developing effective problem solving techniques, and through adaptive emotional behavioural coping (Kirkham et al., 1986). Holahan & Moos (1985) found that among individuals under a high level of stress, those who adapted to stressors without experiencing physical or emotional distress were less likely to rely on avoidant coping responses.

Active coping is dependent on attribution and perceived controllability of the situation. Individuals who see their situation as amenable to change engage in more active coping, compared with subjects who view their situation as uncontrollable and unchangeable, and who consequently engage in higher levels of acceptance, but also denial and disengagement from activity (Carver et al., 1989)
Lack of self blame
Mothers who did not blame themselves or other family members for the child’s handicap reported happier marriages, and were rated as exhibiting higher levels of family adaptation (Bristol, 1987; Lavelle & Keogh, 1980).

Financial resources
The importance of adequate financial resources as a stress buffer has been noted by a number of researchers (e.g. Strand, 1979). This highlights the strong impact of utilitarian coping resources (Quine & Pahl, 1991)

Familial strengths
Daniels and Berg (1967) state that good parental coping consists of love and acceptance, communication within the family, limit setting for the disabled child and flexibility in managing daily crisis. Good familial communication has been identified as necessary for positive coping in a number of studies (Edelstein & Styrdom, 1981; Strand, 1979). Adaptive behaviours of families are a vital consideration in this field.

Many parents in Leff & Walizer’s study (1992) reported using hope as an adaptive coping strategy, which provided ‘courage, energy and faith in oneself’.

Congruent Parental Coping Styles
Parents’ coping efforts were found to be more effective if their respective strategies were either parallel or complimentary (Schilling et al., 1985). Congruencies between fathers and mothers regarding family variables may serve as an indication of cohesiveness and shared perceptions among the parents, therefore higher interparent discrepancies would highlight the impact on the family of raising a disabled child (Moos & Moos, 1981).

However, congruence in parental coping styles may be a rare phenomenon. Rogner & Wessels (1994) reported that mothers showed more emotional stress, more self-criticism, searched more for social support and experienced more “ups and downs” in the process of adaptation to the diagnosis of their child as having learning disabilities,
than did fathers. Generally mothers cope more by expressing their feelings than fathers.

2.3.2 Maladaptive Coping

Severe and unchanging denial of the reality of the condition tends to impede successful adaptation. In a representative community sample of over 400 individuals, Holahan & Moos (1987), found that stressful life events and a reliance on avoidant coping were identified as risk factors indicating a vulnerability to psychological or physical morbidity. Margalit & Ankonina, (1991) identified an increased use of avoidant coping as the central factor predicting negative affect in parents of disabled children, pinpointing the crucial maladaptive role played by those parents' attempts to deny or avoid their stressful difficulties. Carver et al. (1989) describe poor coping outcomes in people using the strategy of behavioural disengagement and mental disengagement, including distraction. Avoidant coping is also often found to lead to psychological distress (e.g. Margalit, 1990).

Carver et al (1989) describe a number of maladaptive strategies that are emotion focused:

Seeking social support for emotional reasons

While social support can foster a return to problem focused coping in an adaptive way, this can also be used as an outlet for the ventilation of one's own feelings, which is not always very adaptive (Berman & Turk, 1981; Billings & Moos, 1984; Constanza et al., 1988; Tolor & Felon, 1987).

Focusing on and venting emotions

This emotion focused strategy described by Carver et al. (1989), can be maladaptive. Focusing on negative emotions, particularly for long periods of time, can impede adjustment (Felton et al., 1984) and may exacerbate the distress (Scheier & Carver, 1977).
Family Rigidity
Extreme rigidity on the part of the family system has been identified as a further sign of poor coping (Cohen & Lazarus, 1979).

2.3.3 Appropriate Coping
It is not always possible to predict whether or not a specific strategy will be adaptive. For example, the use of distraction may be a highly adaptive response (Klinger, 1975), even though this response often impedes adaptive coping (Billings & Moos, 1984). In order to conceptualise this discrepancy there have been a number of models of coping which are based on the balance between blame (attribution of problems) and control (attributions for solutions) e.g. Seligman & Weiss (1980), and Haan (1977). Shapiro conceptualises coping strategies as an attempt to maintain a sense of control over the situation (Shapiro, 1983). However it is important to take account of the actual degree of control that is possible.

Pot-Mees (1989) concluded that an active coping approach, by parents of terminally ill children, was not adaptive, arguing that this was a result of the little actual control which could be gained over the situation. In this situation denial was found to be adaptive, as predicted by Lazarus (1982). Chodoff et al. (1964), stated that there was an intermediate range of defensive strength which allows for optimum coping, while extreme deviations at either end of the scale (i.e. total denial or no denial at all), have adverse effects. However, it should be noted that both studies focused on terminally ill children, i.e. children in a totally uncontrollable situation. This highlights the need to consider the controllability of the situation, before predicting potential adaptive and maladaptive coping strategies.

2.3.4 Summary
It would appear from the available literature that coping is both individual and situation specific, and depends on perception of, and actual, controllability of a situation. However, parental coping in the face of bringing up a child with learning disabilities, appears to benefit from active, problem solving approaches, perceived social support,
adequate financial resources and a congruent and cohesive family coping approach, whereas family rigidity, denial and distancing would appear to be maladaptive.

2.4 The Interrelationship between Coping and Family Functioning

Good coping has been associated with good communication and assistance between parents. In fact, the family environment constitutes one of the primary social resources mediating stress and can have an enormous impact on adaptation in stressful situations (Folkman et al., 1979; Holahan & Moos, 1990). Coping, family functioning and adaptation are used interchangeably to describe predictors of positive outcome (see Shapiro, 1983). These three aspects of the process of dealing with stressors are clearly interrelated, and it is therefore almost impossible to tease apart the effects that each has upon the other. The process is a developing and reciprocal one, which cannot be considered in a linear ‘cause and effect’ manner. An effectively coping family has been defined as one that is able to obtain a new adaptive equilibrium around a particular stressor (Shapiro, 1983). However it is unclear as to whether family coping is an aggregate of individual strategies, or the family unit functioning as a whole. As the double ABCX model makes clear, adaptation to stress is not merely an individual process, but one on which the family system has much influence.

2.5 Family Functioning

2.5.1 Models

Successful adaptation to any type of stressor is a process that changes over time. Adaptation to a child with learning disabilities must be considered within the family system, a network of interpersonal relationships characterised by a continuous interchange between members and by reciprocal causal effects (Miller & Miller, 1980).
Hill & Hansen (1962) formulate four propositions with regard to family coping:

1. Adaptive behaviour is more likely in families that are intact and well integrated than in families that are not.
2. Adaptive behaviour is more likely in families in which channels of communication are open.
3. Adaptive behaviour is more likely in families in which authority and status structures are flexible.
4. Adaptive behaviour is more likely in families that have successfully met past disasters.

These propositions suggest that coping behaviour is an integral part of the family's total repertoire of adaptive behaviours, although this relationship is not necessarily unidirectional.

Severity of the child's handicap, pile up of other stressors, perceived adequacy of informal social support and self blame, add significantly to the prediction of marital adjustment. Bristol (1987) reported that elements of the stressor, family resources and family definition of the stressful event significantly predicted family adaptation. However the same study also found that greater family cohesion was associated with less healthy, rather than more healthy, ratings of adaptation. This finding is consistent with the notion of the circumplex model in which excessive cohesion becomes enmeshment and interferes with healthy family adaptation.

The circumplex model has been used to conceptualise the process of adaptation to a range of family crisis situations, including children with chronic illness (e.g. Horowitz & Kazak, 1990) and learning disabilities (Michaels & Lewandowski, 1990). This model considers the family system using three basic dimensions, cohesion, adaptability and communication (Olsen et al., 1979). Communication is seen as a facilitating dimension between adaptability and cohesion. Each dimension ranges across balanced, midrange and extreme levels of family functioning.

*Adaptability* is identified across four levels: 'rigid', 'structured', 'flexible' and 'chaotic'; cohesion is also identified across four levels: 'disengaged', 'separated', 'connected'
and ‘chaotic’. Overall sixteen types of marital and family systems are identified by combining the cohesion and adaptability dimensions. This is a three dimensional model on which too little or too much cohesion or adaptability is seen as dysfunctional to the family system.

Olsen (1970) proposed that good adjustment to illness is found in families where there is a) a good separation between generations, b) a satisfying of each other’s emotional and psychological needs, c) flexibility within roles, d) toleration for individuation and e) communication which is direct and consistent, and tends to confirm the self esteem of the other.

2.5.2 Negative Effects of the Learning Disabled Child on the Family

Studies of families with a disabled child demonstrated less supportive family relationships and fewer opportunities to pursue personal growth activities (Margalit & Heiman, 1984; Margalit et al., 1988; Margalit & Raviv, 1983). There is little evidence to suggest that perceived family solidarity, marital happiness or close family ties protect the family against the disruptive impact of a member’s illness on family relations. Indeed those with disparate family ties often reported being drawn together by illness (Haggerty, 1968), whilst other evidence suggests that dealing with a handicapped child can destroy family life (Green, 1981).

Margalit et al. (1992) report that parents with disabled children experienced a lower sense of coherence and an increased use of avoidant coping. Within their family climate, less emphasis on family relations and fewer opportunities for personal growth were reported. These findings may be considered to represent parents’ reduced confidence in the controllability and comprehensibility of their world. Communication within the family can also become a problem when family members may be at different stages of the grief process (Gruppo, 1978).
2.5.3 Positive Effects of the Learning Disabled Child on the Family

While there is evidence to show that the presence of a learning disabled child can have a negative effect on marital relations, even resulting in divorce (Kazak & Marvin, 1984), this is not a necessary outcome. Some studies found that the divorce rate in parents of children with chronic illness was lower than in the general population, (Lansky et al., 1978, McAndrew, 1976). It has also been suggested that the more severely handicapped the child, the less adverse an effect on the marriage than a more normal and less obviously handicapped child (Bristol, 1987).

2.5.4 Family Predictors of Positive Adjustment

While being vulnerable to the negative effects of stress, the family system can also serve to buffer, and successfully adapt to the stress. Research on family climate has shown that families characterised by supportive relationships and a greater emphasis on personal growth, show increased levels of adjustment and present fewer complaints of emotional distress. When families are stressed by the diagnosis of a handicapped child, the need for effective communication becomes even more important (Gottman et al., 1976).

However, the continued projection of angry feelings onto other family members, with no efforts at resolution or movement, is considered dysfunctional, as is extreme rigidity on the part of the family system (Shapiro, 1983). It is therefore vital to consider the reciprocal influences between the child with a learning disability, family functioning and parental coping.

2.6 Early Identification

An issue which is addressed in much of the literature is the necessity of early identification of the child's disability in order to reduce the amount of stress experienced by the family (Bristol, 1987; Cunningham & Sloper 1977; Pueschel & Murphy, 1976; Quine & Pahl, 1986). This research supports the need for early identification of the handicap, and early education in order to prevent parental
Diagnosis Research: Introduction

misconceptions from interfering with successful family coping, and adaptation, to the handicapped child.

While it is generally agreed that early identification, assessment and intervention is associated with more positive outcome (Esterly & Griffin, 1987; Gemma, 1988; National Joint Committee on learning Disabilities, 1986) problems have also been defined. These include definitional issues, the dangers of labelling resulting in low expectation sets, and failure to use services appropriately (Haring et al., 1992). Pollack (1985) also described the pitfall of parents who, by clinging to the label, escape facing the child's real needs. However the majority of research has overwhelmingly stressed the positive effects of early identification.

2.6.1 Specific vs. Non-Specific Diagnosis

With a few exceptions most of the research has focused on specific diagnostic groups, for example children with Down's Syndrome (Cunningham et al., 1984), and Autism (Bristol, 1987). Studies considering satisfaction with diagnosis report greater satisfaction in parents of children with a specific diagnosis, such as Down's Syndrome, and a higher proportion of dissatisfaction in parents of children with a diagnosis of non-specific handicap (Smith & Philips, 1978; Quine & Pahl, 1986). Parents find 'coming to terms with' a learning disability of uncertain origin much more difficult than those who have an aetiological explanation (Hunter, 1980; Sleigh, 1981). There is a great deal of literature regarding parental satisfaction with the diagnostic process suggesting that an increase in satisfaction reduces the burden of stress on the parents. This literature states that parents are relieved at their child's condition being named, the cause located and, some prognostic estimate offered (Wooley et al., 1989). Honesty and full information are seen as vital elements (Leff & Walizer, 1992; Quine & Pahl, 1986; Quine & Rutter, 1994), while the absence of knowledge and understanding regarding their child's condition, can lead to despair and doubt (Leff & Walizer, 1992).
Age at diagnosis has also been reported as differing between children with specific and non-specific diagnoses. Children with a non-specific diagnosis of mental handicap tend to be diagnosed at a later age than those with a specific diagnosis (Quine & Pahl, 1986). Palfrey et al (1987) identified the age of diagnosis of a variety of conditions, reporting that children diagnosed with 'mental retardation', 'learning disability', and 'other developmental' problems were often not diagnosed until the age of 8 years. This delay in diagnosis leads to stress and dissatisfaction. Additionally, more than two decades of data seem to confirm the efficacy of early intervention (Meisels, 1985). It is therefore essential that any condition is diagnosed at the earliest possible age.

Arguably, if parents are satisfied with the diagnostic process, they will be able to move on to a more adaptive method of coping with the diagnosis and its implications for the care of the child (Quine & Pahl, 1986). Unfortunately there is no literature comparing family adjustment and coping between groups of children with specific and non-specific diagnoses of learning disabilities. The implication, from the literature on early identification, is that, as a result of the lack of aetiological and prognostic information, as well as delay in any kind of diagnosis, dissatisfaction and resulting stress would be more common in parents of children with a non-specific diagnosis.

2.7 Aims

The aim of this study was to examine the relationship between diagnosis, parental coping and family functioning. Research has suggested that parents of children diagnosed with learning disabilities, with no associated label, experienced greater degrees of dissatisfaction, have greater difficulties in coming to terms with the child’s disability and are often diagnosed later. These factors result in parental stress, which has negative implications for family functioning and parental coping. Furthermore, during my clinical work in this area, many parents stated their dissatisfaction with their child’s lack of specific diagnosis, and described their painful search for a professional who could give them more information about their child’s condition. Research in this area was therefore considered to be of considerable clinical importance.
This study compares parental coping, and family functioning in two groups of learning disabled children: those with specific diagnoses e.g. Down's syndrome, and those with non-specific diagnoses e.g. severe learning disabilities. The study aims to identify coping profiles and patterns of family functioning in parents, and highlight the overall implications of labelling a child's learning disability on parental adaptation. Four main hypotheses were investigated.

2.8 Hypotheses

1. Parents of children with specific diagnoses would report a greater use of active coping strategies, and fewer passive or avoidant strategies. Thus, on the Ways of Coping Questionnaire, scores on Escape Avoidance and Distancing would be lower than the scores of parents of children with non-specific diagnoses (Margalit & Ankonina, 1991).

2. There would be greater agreement between mothers and fathers of children with specific diagnoses on ratings of coping strategies and family functioning, than between mothers and fathers of children with non-specific diagnoses. Thus discrepancies between parents on the Ways of Coping Questionnaire and measures of Cohesion, Adaptability and Type on the FACES (II) would be lower than the discrepancies between parents with a specific diagnosis.

3. Parents of children with specific diagnoses would demonstrate higher levels of family functioning, than parents of children with a non-specific diagnosis. Thus scores on Cohesion, Adaptability and Type scales as measured by the FACES (II), would be higher than in parents of children with non-specific diagnoses.

4. Parents from families in which there are siblings older than the child with a learning disability, would demonstrate greater levels of Cohesion and Adaptability, as well as demonstrating a greater use of adaptive coping strategies, as a result of their previous childrearing experience, albeit with a non-handicapped child.
In addition, based on related research findings, further questions were examined:

- Whether children with specific diagnoses were diagnosed at a younger age than children with non-specific diagnoses.
- Whether teacher ratings of severity of behaviour were related to parents' ratings.
- Whether diagnostic status had an effect on the number of health professionals involved with the child's care.
3. METHOD

3.1 Participants

Families of children with learning disabilities under the age of five years, were contacted within the Greenwich Healthcare Trust area. Families were identified through three different sources: the Early Intervention Centre - 15 families, the Portage Service - 8 families, and the Assessment Nursery - 35 families. A total of 58 families were contacted.

21 Families of children attending the Assessment Nursery agreed to participate, but only 3 families of children receiving the Portage service, and 2 families of children attending the Early Intervention Centre. There were 2 refusals and 30 families failed to reply. Because of the very low overall response rates, and differences in the three services from which families were approached, the 5 families with children attending the Early Intervention Centre and using the Portage service were not included. Analysis is therefore based on data from the 21 families contacted through the Assessment Nursery.

Children in the specific diagnostic group had been given a firm diagnosis labelling their condition, whereas children in the non-specific diagnostic group had been identified as having learning disabilities, but did not have a specific diagnosis or label.

3.2 Measures

3.2.1 FACES II

The Family Version of the Family Adaptability and Cohesion Evaluation Scale (II), (FACES II), was used to measure family Adaptability and Cohesion (Olsen et al., 1982). The measure is based on the circumplex model described by Olsen et al. (1979). FACES II is a 30 item scale containing 16 Cohesion items, and 14
Adaptability items. The respondent is asked to read each statement, and decide how frequently, on a scale that ranges from 1 (almost never) to 5 (almost always), the described behaviour occurs in his/her family.

The measure gives a number of scores; individual Adaptability and Cohesion scores, Family Adaptability and Cohesion scores which are a computation based on the two scores, individual Type based on an amalgamation of individual Adaptability and Cohesion scores and, Family Type based on an amalgamation of Family Adaptability and Cohesion scores.

This measure has an alpha reliability, of .87 for the Cohesion scale, .78 for the Adaptability scale, and .90 for the Total scale. Although there is a later version available, FACES III has lower reliability coefficients.

FACES II identifies four levels of Cohesion: disengaged, separated, connected and very connected; four levels of Adaptability, rigid, structured, flexible and very flexible; and four levels of Family Type: extreme, mid-range, moderately balanced, and balanced. This measure is scored in a linear way, where categories of ‘chaotic’ and ‘enmeshed’, as described in the circumplex model, are not measured.

Cohesion assesses the degree to which family members are separated from or connected to their family. It is defined as the emotional bonding that family members have towards one another. Within the circumplex model, specific concepts used to diagnose and measure the Cohesion dimension are: emotional bonding, boundaries, coalition, time, space, friends, decision-making, interests and recreation.

Adaptability, or change, has to do with the extent to which the family system is flexible and able to change. It is defined as the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress. Specific concepts used to diagnose and measure Adaptability are: family power (assertiveness, control, discipline), negotiation style, role relationships and relationship rules. Family Type is an amalgamation of Cohesion
and *Adaptability* scores, and describes the individual’s, and family’s, overall position on the circumplex model.

(See Appendix 1 for questionnaire).

### 3.2.2 *Ways of Coping Questionnaire*

The Ways of Coping Questionnaire is a 50 item measure that can be completed by the interviewer or the respondent (Folkman & Lazarus, 1988). Despite the problems in defining adaptive and maladaptive coping responses, this measure has been used as a research instrument for many years, from which there are useful data based these strategies. The items comprise of eight scales:

<table>
<thead>
<tr>
<th>Scale</th>
<th>Description</th>
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<tbody>
<tr>
<td>Confrontative Coping</td>
<td>Describes aggressive efforts to alter the situation and suggests some degree of hostility and risk taking.</td>
</tr>
<tr>
<td>Distancing</td>
<td>Describes cognitive efforts to detach oneself and to minimise the significance of the situation.</td>
</tr>
<tr>
<td>Self-Controlling</td>
<td>Describes efforts to regulate one’s feelings and actions.</td>
</tr>
<tr>
<td>Seeking Social Support</td>
<td>Describes efforts to seek informational support tangible support and emotional support.</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>Acknowledges one’s own role in the problem with a concomitant theme of trying to put things right.</td>
</tr>
<tr>
<td>Escape-Avoidance</td>
<td>Describes wishful thinking and behavioural efforts to escape or avoid the problem. Items on this scale contrast with those on the Distancing scale, which suggest detachment.</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>Describes deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem.</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>Describes efforts to create positive meaning by focusing on personal growth. It also has a religious dimension</td>
</tr>
</tbody>
</table>
Respondents are asked to describe a stressful encounter, in the case of this study parents were asked a number of specific questions regarding the time when they received their child’s diagnosis, or consultations when they were first told of their child’s condition. They are then asked to rate 50 statements on a 4-point Likert scale, ranging from 0 (does not apply) to 3 (used a great deal), indicating the frequency with which each strategy was used at that time.

The alpha reliability of the eight scales ranges between .61 for Distancing, to .79 for Positive Reappraisal.
(See Appendix 2 for questionnaire)

3.2.3 Family Experiences Questionnaire

This was a questionnaire specifically designed for this study to elicit information from three broad categories: diagnostic information (demographic information about the child and their diagnosis, the parents’ experience of the diagnostic procedure and rating of severity of behaviour), family information (information about parents, number and ages of siblings and socio-economic information), and information regarding support received (both real and perceived practical and emotional support). Most of the data collected in this questionnaire are factual, although a lot of qualitative data were also gathered. No reliability or validity studies were carried out on this measure.
(See Appendix 3 for questionnaire)

3.2.4 Teacher’s Severity Ratings

The head teacher of the Assessment Nursery was asked to rate each child included in the study on three aspects of their functioning: level of learning disability, level of communication and severity of behaviour. Ratings were based on a comparison with the other children in the Nursery and were made on a 5 point Likert scale, ranging from 1 (less severe than others) to 5 (a lot more severe than others).
(See Appendix 4 for ratings scale).
3.3 Procedure

Families were contacted by letter explaining the aims of the research and the procedure, requesting that they return the reply slip in the stamped addressed envelope provided (See Appendix 5). If no reply was received within 3 weeks, the letter was sent again either by post or through the home-school book for those children attending the Nursery.

Those families who agreed to participate were then offered an appointment either at the Psychology Department, the school or Nursery attended by their child, or their home. The aim and procedure of the study was explained again, and a consent form completed by one of the parents. The Family Experiences Questionnaire was then used as a structure for an interview, and was completed by the interviewer. The Ways of Coping Questionnaire and FACES II were completed either by the interviewer, reading out each statement, or by the parent themselves depending on their preference. GPs were contacted informing them of the family's participation in the study.

For many of the interviews fathers were not present and so the Ways of Coping Questionnaire and FACES II were left with the mother, along with a stamped addressed envelope, for the father to complete. If these questionnaires were not returned within two weeks, the fathers were requested, in writing, to return them. If they had not been returned by two weeks after that, the fathers were contacted by phone and requested to return the completed questionnaires. A total of 4 fathers did not return their completed forms. A further 3 children came from single parent families, all mothers.
4. RESULTS

4.1 Statistics

The Mann-Whitney $U$ test was used to investigate differences between groups, the Wilcoxon was used to investigate differences within groups, and correlations were used to investigate relationships between variables. Non-parametric statistics were used as the data were at an ordinal level, sample sizes were small, and the data were unlikely to be normally distributed.

4.2 Social Economic Status

The socio-economic status of the sample was studied in order to ascertain how representative the sample was of the local population. Socio-economic status was based on the occupation of fathers, as the principal wage earner of the household. None of the mothers interviewed were employed, and those that had been, had given up their jobs to care for their child with learning disabilities. These data were collected using the Family Experiences questionnaire. Local population figures were collected from census data.

Table 4.1

<table>
<thead>
<tr>
<th></th>
<th>Professional</th>
<th>Managerial &amp; technical</th>
<th>Skilled. non-manual</th>
<th>Skilled. manual</th>
<th>Partly skilled</th>
<th>Unskilled</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Participants</td>
<td>5.8</td>
<td>29.6</td>
<td>18.3</td>
<td>24.8</td>
<td>14.7</td>
<td>6.8</td>
</tr>
<tr>
<td>N = 21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greenwich Residents</td>
<td>33.3</td>
<td>9.5</td>
<td>19</td>
<td>9.5</td>
<td>23.8</td>
<td>4.7</td>
</tr>
<tr>
<td>N = 4,533</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>


As can be seen in Table 4.1 the overall profile of the participants does not reflect that of the local population. In particular there were far fewer families of professional status, and far more managerial and technical, and skilled manual workers in the sample than in the local population. These differences may be a result of the small sample size, or the possibility that professional families may chose to use private facilities rather than local education authority facilities.

4.3 Characteristics of Specific vs. Non-Specific Diagnostic Groups

From the final sample of 21 families, 9 children had a specific diagnosis, while 12 had a non-specific diagnosis. Of those children with specific diagnoses 3 had Cerebral Palsy, 2 had Downs Syndrome, 2 had Autism, 1 had Fragile X and 1 had a chromosomal abnormality. A number of variables were compared between specific and non-specific diagnostic groups in order to identify any differences or similarities of note. Age when parents noticed that something was wrong, age at diagnosis and number of professionals involved with the child have been identified as differentiating characteristics between specific and non-specific diagnostic groups in the literature (Quine & Pahl, 1986).

<table>
<thead>
<tr>
<th></th>
<th>Specific Diagnosis (N=9)</th>
<th>Non-Specific Diagnosis (N=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>No. of professionals currently involved</td>
<td>4.33</td>
<td>1.58</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>2y1m</td>
<td>1.85</td>
</tr>
<tr>
<td>Age when noticed something was wrong</td>
<td>0y9m</td>
<td>1.15</td>
</tr>
</tbody>
</table>
Table 4.2 reveals that the number of professionals currently involved with the child were compared between the two diagnostic groups. Professional involvement refers to a specialised health or education authority employee whose role it is to attend to a child’s identified special need. There was no significant difference between groups in number of professionals involved.

Children given a specific diagnosis were diagnosed 5 months later, on average, than children with non-specific learning disabilities. However there was no significant difference in age at diagnosis between these two groups.

From Table 4.2 it is apparent that the age when families noticed that there was something wrong with their child’s development was similar between groups, although the specific diagnostic groups exhibited a greater range and variation in age. No significant differences were found on this variable between the two groups.

4.4 Diagnostic Groups and Coping Measures

4.4.1 Differences Between Diagnostic Groups

Coping strategies based on the Ways of Coping Questionnaire, were examined for each parent, and mothers and fathers in specific and non-specific diagnostic groups were compared for each coping strategy used. There was a significant difference between mothers of children with and without specific diagnoses for Positive Reappraisal ($z=-1.97$, $p=.025$, 1-tailed), indicating that mothers of children with a specific diagnosis used this strategy significantly more than mothers of children with a non-specific diagnosis. There were no other significant differences between groups for other coping strategies.

4.4.2 Differences Within Families

The Wilcoxon test for related samples was used to look at differences between mothers and fathers in specific and non-specific diagnostic groups for coping measures.
Diagnosis Research: Results

Mothers scored significantly higher than fathers on *Accepting Responsibility* in the non-specific diagnostic group ($z=-2.1129$, $p=.017$ 1-tailed). There were no other significant differences between fathers and mothers.

### 4.4.3 Discrepancies Between Parents: Differences Between Diagnostic Groups

Size of discrepancy between parents for each coping strategy was calculated, and these discrepancies compared between diagnostic groups. There were no differences between groups on these discrepancies.

### 4.4.4 Relationships Between Parents Ratings

A correlation was carried out in order to examine relationships between mothers’ and fathers’ ratings on uses of coping strategies. There were no significant correlations between parents in the specific diagnostic group. However there was a correlation between mother’s and father’s ratings for the strategy of *Accepting Responsibility*, in the non-specific diagnostic group ($r=0.790$, $p=0.01$, 1-tailed).
Figure 1
Fathers’ Use of Coping Strategies
Across Both Diagnostic Groups

Figure 2
Mothers’ Use of Coping Strategies
Across Both Diagnostic Groups
Diagnosis Research: Results

The 4 graphs on mothers’ and fathers’ coping in Figure 1 and Figure 2 are based on means of each group for each coping strategy. Although most differences were not statistically significant, an interesting profile on some coping strategies did seem to emerge.

4.4.5 Coping Profiles

Self Controlling i.e. regulating one’s own feelings and actions
All parents used this strategy to a large extent. This was the most commonly used strategy by fathers in both groups, and was a close second as a strategy for mothers. Mothers scored slightly higher than fathers in both groups, and parents in the specific diagnostic groups scored higher than parents in the non-specific diagnostic groups.

Seeking Social Support i.e. efforts to seek informational, tangible and emotional support
This was the highest scoring strategy for mothers of children with a non-specific diagnosis. Although this strategy was frequently used by mothers of children with a specific diagnosis, with whom it was still only the third most popular coping strategy. Fathers in both groups used this strategy moderately and to very similar extents.

Escape Avoidance i.e. wishful thinking or behavioural efforts to escape or avoid the problem.
This strategy was used to almost exactly the same extent by parents in both groups, but was more prominent in fathers than in mothers.

Distancing i.e. cognitive efforts to detach oneself and minimise the significance of the situation
Overall, fathers used distancing more than mothers. Parents in the specific diagnostic group used this strategy more than parents in the non-specific diagnostic group, this difference being more marked in fathers than in mothers.
Planful Problem Solving  
i.e. problem focused efforts to alter the situation using an analytic approach to problem solving

Fathers in both groups used this strategy to a similar extent, i.e. little, and notably less than mothers. Mothers in the non-specific diagnostic group used the strategy more than mothers in the specific diagnostic group.

Positive Reappraisal  
i.e. creating positive meaning by focusing on personal growth

This strategy was used more by fathers in the specific diagnostic group than in the non-specific diagnostic group, and more by mothers than fathers in the corresponding groups. The difference between fathers and mothers was more marked in the specific diagnostic group, this being the most popular strategy used by mothers. As previously mentioned there was significant difference between mothers in the two groups on this strategy.

Confrontative Coping  
i.e. aggressive efforts to alter the situation and suggests some degree of hostility and risk taking.

Fathers in both groups used this strategy to a similar moderate degree and less than mothers in both groups. Mothers in both groups used this strategy to a similar degree. This was one of the least used strategies across all four groups.

Accepting Responsibility  
i.e. acknowledging one’s own role in the problem with a concomitant theme of trying to put things right.

Fathers in the two groups hardly differed on the use of this strategy, and it was almost the least used. There was, however, a marked difference between mothers in each group for this strategy. Mothers of children with no specific diagnosis used it significantly more than fathers in both groups (as previously mentioned), and a great deal more than mothers of children with a specific diagnosis, who used this strategy least of all, and to a minimal extent.

(See Appendix 6 for table of means and standard deviations for parent’s coping strategies in both groups)
4.5 Diagnostic Groups and Family Functioning Measures

Mothers and fathers were compared within and between diagnostic groups on individual and family Cohesion and Adaptability. Cohesion refers to the degree to which family members are separated from or connected to their family, whereas Adaptability refers to the extent to which family members are flexible and able to change. Parent Type is determined by merging Adaptability and Cohesion scores and describes a certain point on the circumplex model at which the family member is functioning. Family Cohesion, Adaptability and Type are determined by merging both parents’ ratings on each of these scales.

Parents in both diagnostic groups fell within the ‘structured’ range on the Family Adaptability scale, within the ‘separated’ range on the Family Cohesion scale, and ‘mid-range’ on Family Type.

Table 4.3

<table>
<thead>
<tr>
<th></th>
<th>Specific Diagnosis</th>
<th>Non-Specific Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Family Adaptability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father’s Adaptability</td>
<td>3.83</td>
<td>1.72</td>
</tr>
<tr>
<td>Mother’s Adaptability</td>
<td>4.56</td>
<td>2.07</td>
</tr>
<tr>
<td>Family Cohesion</td>
<td>3.67</td>
<td>1.63</td>
</tr>
<tr>
<td>Father’s Cohesion</td>
<td>3.50</td>
<td>1.64</td>
</tr>
<tr>
<td>Mother’s Cohesion</td>
<td>4.78</td>
<td>1.99</td>
</tr>
<tr>
<td>Family Type</td>
<td>3.88</td>
<td>1.62</td>
</tr>
<tr>
<td>Father’s Type</td>
<td>3.67</td>
<td>1.60</td>
</tr>
<tr>
<td>Mother’s Type</td>
<td>4.67</td>
<td>1.85</td>
</tr>
</tbody>
</table>
Table 4.3 identifies firstly that fewer fathers participated than mothers, across both groups. *Family Cohesion* is highest in the non-specific diagnostic group, whereas *Family Adaptability* is highest in the specific diagnostic group. There is a large difference between the two groups in fathers' *Adaptability* scores. There is also a marked difference between mothers' and fathers' *Cohesion* scores in the specific diagnostic group. The non-specific diagnostic group exhibit the highest *Family Type* score.

### 4.5.1 Differences Between Diagnostic Groups

There were no significant differences between diagnostic groups for *Family Adaptability* or *Family Cohesion*. Nor were there differences between the two groups for mother *Type*, father *Type* or *Family Type*. This suggests that there is no difference in the effect on family functioning of specific and non-specific diagnosis of a child with learning disabilities.

### 4.5.2 Differences Within Families

A Wilcoxon test for related samples was used to look for differences between mothers and fathers in the specific and non-specific diagnostic groups. There were no significant differences for *Adaptability*, *Cohesion* or *Type*, between parents in either diagnostic group. Thus diagnostic status did not have any effect on the magnitude of difference between mothers and fathers on family functioning measures.

### 4.5.3 Discrepancies Between Parents Scores

Discrepancies between fathers and mothers in both diagnostic groups were calculated on *Adaptability* and *Cohesion* measures. This gave a measure of parental similarities or differences for each of the family functioning dimensions. The size of these discrepancies was then compared between the two diagnostic groups. There was a significant difference between the two diagnostic groups on discrepancies between parents on family *Type* \((z=-2.41, p=.008, 1\text{-tailed})\). There was also a significant difference between diagnostic groups on discrepancies on *Adaptability* \((z=-2.62,\)
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p=.004, 1-tailed). For both of these findings the discrepancies were greater between parents of children with a non-specific diagnosis indicating that parents’ perceptions of their families differed more on these two scales, in families of children with a non-specific diagnosis. In other words a non-specific diagnosis of learning disabilities was associated with less cohesive parental responses on the Adaptability scale, and therefore larger discrepancies in Family Type, than families of children with a specific diagnosis.

4.5.4 Relationships Between Parents Scores

A correlation was carried out on these data in order to examine relationships between parents’ scoring on all aspects of family functioning. There was a significant correlation between mothers’ and fathers’ Types for the group with a specific diagnosis (r=.8709, p<.05, 1-tailed), but not between parents’ Types in the non-specific diagnostic group. However there was no difference between the two diagnostic groups on either mother Type or father Type. Parent Type scores were significantly similar between parents of children with a specific diagnosis, but not between those of children with a non-specific diagnosis.

There were no differences on any other family functioning measures between specific and non-specific diagnostic groups.

4.6 Diagnostic Groups and Prior Childrearing Experience

The presence of older siblings was studied as this was considered to have a possible effect on family functioning measures and parental coping with the disabled child. Past literature has shown that prior experience of dealing with a problem reduces the negative effect. While none of the families had prior experience of bringing up a child with learning disabilities, the presence of an older child was considered to be indicative of previous childrearing experience and so some of the general coping skills required would already be established. The presence of children in the family older than the proband, was identified using the Family Experiences Questionnaire.
Table 4.4

Numbers of Siblings in Specific and Non-Specific Diagnostic Groups

<table>
<thead>
<tr>
<th></th>
<th>Specific Diagnosis (N= 9)</th>
<th>Non-Specific Diagnosis (N= 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>No. of older siblings</td>
<td>0.89</td>
<td>1.05</td>
</tr>
<tr>
<td>No. of younger siblings</td>
<td>0.56</td>
<td>0.73</td>
</tr>
</tbody>
</table>

Table 4.4 indicates similarities between the two groups on number of older and younger siblings in the household. There were more older siblings than younger siblings in both groups.

4.6.1 Prior Childrearing Experience and Coping

In the non-specific diagnostic group, fathers from families in which the learning disabled child had older siblings, reported a greater use of Distancing \((z=-2.3233, p=.010, 1\text{-tailed})\) and Self Controlling \((z=-2.0329, p=.021, 1\text{-tailed})\) strategies than fathers in families with no older siblings. In the specific diagnostic group, mothers in families with older siblings reported a greater use of Escape Avoidance \((z=-2.4598, p=.006, 1\text{-tailed})\) and Positive Reappraisal \((z=-1.9678, p=.025 1\text{-tailed})\), than mothers in families without older children. There were no other differences between parents in families of learning disabled children with and without older siblings. Statistical analysis could not be carried out for fathers in the specific diagnostic group as there were only 4 cases with older siblings and 2 cases with no older siblings.

4.6.2 Prior Childrearing Experience and Family Functioning

There was a significant difference on family level of Cohesion, between families with children older than the identified child with learning disabilities, and families where the identified child was the first. Those families with children older than the proband exhibited higher levels of family Cohesion \((z=-1.9729, p= 0.024, 1\text{-tailed})\). This finding covers both families of children with a specific diagnosis and those with a non-specific diagnosis. There was also a significant difference between families with and
without older children in the non-specific diagnostic group on *Cohesion* \( z = -1.976, p = 0.024, \) 1-tailed) such that families with older children exhibited higher levels of *Cohesion*. This analysis was not carried out for the specific diagnostic group as there were only 2 cases of families with no older siblings, and 4 with older siblings, in this group, compared with 5 and 6 respectively in the non-specific diagnostic group.

### 4.7 Diagnostic Groups and Parent and Teacher Ratings

Behaviour ratings were taken in order to exclude this as a potentially confounding variable. The child's difficulty in behaviour, level of communication and level of learning disability needed to be constant across both diagnostic groups so that they could be regarded as influencing parental coping and family functioning equally.

**Table 4.5**

*Parent and Teacher Ratings of Behaviour, Communication and Learning Disability.*

<table>
<thead>
<tr>
<th></th>
<th>Specific Diagnosis (N= 9)</th>
<th>Non-Specific Diagnosis (N= 12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Parent - severity of behaviour</td>
<td>2.67</td>
<td>1.41</td>
</tr>
<tr>
<td>Teacher - severity of behaviour</td>
<td>3.11</td>
<td>1.69</td>
</tr>
<tr>
<td>Teacher - level of communication</td>
<td>2.22</td>
<td>1.48</td>
</tr>
<tr>
<td>Teacher - level of learning disability</td>
<td>2.56</td>
<td>1.67</td>
</tr>
</tbody>
</table>

Table 4.5 indicates a close similarity between means for specific and non-specific diagnostic groups. There were no significant differences between the two groups on parent or teacher ratings. For both groups, teachers rated the child's behaviour as more severe than did parents although this difference was not statistically significant.
4.7.1 Differences Between Ratings and Groups

Differences between diagnostic groups on ratings were assessed to determine whether or not behaviour, communication and level of learning disability were constant across both groups. A Wilcoxon test for related samples was carried out on teacher and parents ratings of severity of behaviour. There were no significant differences between the non-specific and specific diagnostic groups on parents ratings of severity of behaviour or teacher ratings of a) severity of behaviour, b) communication and language ability, and c) level of learning disability. Nor were there significant differences between parents and teachers, on ratings of severity of behaviour.

4.7.2 Relationships Between Parent and Teacher Ratings

Relationships were considered in order to establish whether or not parents' and teachers' perceptions of the child's behaviour were associated, and whether or not behaviour, communication and level of learning disability were perceived by the teacher as related concepts for each child. Correlations were carried out in order to examine relationships between teacher and parents ratings of severity of the child's behaviour, the three teacher ratings of severity of behaviour, level of language and communication, and level of learning disabilities. Teacher's ratings of behaviour, language and severity of learning disability are highly interrelated, but none are related to parent behaviour ratings (see table 4.5).
Table 4.6

Correlations Between Parent and Teacher Ratings

<table>
<thead>
<tr>
<th>Parents rating of severity of behaviour (PSB)</th>
<th>Teachers rating of severity of behaviour (TSB)</th>
<th>Teachers rating of level of communication (TLC)</th>
<th>Teachers rating of level of learning disabilities (TLD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSB</td>
<td>-</td>
<td>r=.338</td>
<td>r=.341</td>
</tr>
<tr>
<td>TSB</td>
<td>-</td>
<td>r=.178</td>
<td>r=.774**</td>
</tr>
<tr>
<td>TLC</td>
<td>r=.522*</td>
<td>r=.614**</td>
<td></td>
</tr>
</tbody>
</table>

2-tailed significance

*<.05
**<.005

Table 4.6 demonstrates that teacher’s ratings of level of learning disabilities were highly correlated with their ratings of severity of behaviour, and level of language and communication (p<.005, 2-tailed), Teacher ratings of severity of behaviour were also correlated with their ratings of level of language and communication to a lesser extent (p<.05, 2-tailed). There were no relationships between parents’ ratings of severity of behaviour and any of the teacher ratings.

4.8 Parents Views of the Diagnostic Procedure and Support

There was therefore some indication from quantitative data that parents of children with a specific diagnosis exhibited better adaptation in some areas of coping and family functioning. A number of other themes emerged from the interviews. The topics which were most pertinent to parents were those concerning the diagnostic process and service provision.
4.8.1 Parents’ Views on Diagnostic Process, Family and Professional Support

Table 4.7
Parents’ Views on Diagnostic Process, Family and Professional Support

<table>
<thead>
<tr>
<th></th>
<th>Specific Diagnosis (N=9)</th>
<th>Non-Specific Diagnosis (N=12)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents expressing dissatisfaction with the</td>
<td>Yes: 8</td>
<td>Yes: 9</td>
</tr>
<tr>
<td>diagnostic process (N/A=4)*</td>
<td>No: -</td>
<td>No: -</td>
</tr>
<tr>
<td>Would you rather have a diagnosis than not</td>
<td>Yes: 9</td>
<td>Yes: 10</td>
</tr>
<tr>
<td></td>
<td>No: 0</td>
<td>No: 2</td>
</tr>
<tr>
<td>Receive enough support from extended family</td>
<td>Yes: 5</td>
<td>Yes: 7</td>
</tr>
<tr>
<td></td>
<td>No: 4</td>
<td>No: 5</td>
</tr>
<tr>
<td>Receive enough professional support</td>
<td>Yes: 6</td>
<td>Yes: 10</td>
</tr>
<tr>
<td></td>
<td>No: 3</td>
<td>No: 2</td>
</tr>
</tbody>
</table>

Satisfaction with diagnostic procedure was not discussed directly, although when discussing the diagnosis, parents described what they had been told, and the way this information had been given to them. It was clearly evident from most responses whether parents were satisfied or not, and many parents expressed strong feelings about this issue. However 4 parents did not give their views on the procedure (3 parents in the non-specific diagnostic group and 1 in the specific diagnostic group).

Table 4.7 indicates that the majority of parents in both groups expressed dissatisfaction with some part of the diagnostic process. All those families of children with a specific diagnosis felt that having the diagnosis was a positive experience, while there was not

* This rating was made on the basis of parents’ overall responses to questioning about the diagnostic process. They were not directly asked about satisfaction.
total agreement of opinion in the non-specific group. Parents' families were viewed as being equally supportive between the two groups, but parents in the specific diagnostic group were generally less satisfied with the professional support received than parents of children with a non-specific diagnosis. There was, however, no difference between the two groups in number of professionals involved.

4.8.2 Reasons Why Parents Wanted a Specific Diagnosis

93% of all parents claimed that they wanted a diagnosis, for various different reasons. Some parents only had one reason, whereas others had several. The reasons for wanting a diagnosis fell into five categories:

Table 4.8

Reasons Why Parents Wanted a Diagnosis

<table>
<thead>
<tr>
<th>Theme</th>
<th>No. of times mentioned</th>
</tr>
</thead>
<tbody>
<tr>
<td>In order to be able to understand the condition and problems</td>
<td>5</td>
</tr>
<tr>
<td>To explain the child’s condition to others</td>
<td>3</td>
</tr>
<tr>
<td>In order to know what the future holds</td>
<td>1</td>
</tr>
<tr>
<td>In order to know how to best meet the child’s needs</td>
<td>1</td>
</tr>
<tr>
<td>In order to get appropriate services</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>0</td>
</tr>
</tbody>
</table>

Table 4.8 indicates that the main reason cited was wanting to know more about their child’s condition, along with aetiological and prognostic information. The second most frequent reason was to be able to explain to friends, family and observing strangers that there was a reason for whatever problems their child might be exhibiting. Those parents whose children had a non-specific diagnosis mentioned the need to know what the future holds more than parents of children with a specific diagnosis. Some parents felt that a diagnosis would be useful to know how to best
meet their child’s needs, and it was deemed useful to obtain appropriate services by a couple of parents with children with a specific diagnosis.

4.8.3 Reasons Why Parents Did Not Want a Specific Diagnosis

Two parents did not want a specific diagnosis, although one parent who did want a diagnosis also had concerns. It is important to note that the two parents who did not want a diagnosis had already been through extensive medical and diagnostic procedures which had been inconclusive. One parent of a child with a non-specific diagnosis gave the reason of not wanting to subject the child to more tests. Two others were concerned about the effects of labelling their child. No parents with a specific diagnosis felt that they would prefer to not have the diagnosis.

Although other qualitative data were collected, e.g. regarding parents’ knowledge of their child’s condition, these data could not be summarised into themes, and are therefore not explored further.
5. DISCUSSION

5.1 Aims

The aim of this study was to consider the relationship between parental adaptation and having a child with a diagnosable condition, compared with a non-specific diagnosis, and parental adaptation. Parents in the two groups were compared on measures of family functioning and coping strategies in order to identify any association between the child’s specific or non-specific diagnosis with these variables, and to identify coping profiles and patterns of family functioning.

5.2 Hypotheses

On the basis of previous research within this area, the assumption was made that parents of children with a specific diagnosis would report the use of more effective coping strategies as a result of having more information on cause, behavioural phenotype and prognosis, offered by the diagnosis. The four hypotheses for the study were as follows:

1. Parents of children with specific diagnoses would report a greater use of active coping strategies, and fewer passive or avoidant strategies.

2. There would be greater agreement between mothers and fathers of children with specific diagnoses on ratings of coping strategies and family functioning, than between mothers and fathers of children with non-specific diagnoses.

3. Parents of children with specific diagnoses would demonstrate higher levels of family functioning, than parents of children with a non-specific diagnosis.
4. Parents from families in which there were siblings older than the child with a learning disability, would demonstrate greater levels of *Cohesion* and *Adaptability*, as well as demonstrating a greater use of adaptive coping strategies, as a result of their previous childrearing experience, albeit with a non-handicapped child.

In addition, based on related research findings, further questions were examined:

- Whether children with specific diagnoses were diagnosed at a younger age than children with non-specific diagnoses.
- Whether teacher ratings of severity of behaviour were related to parents’ ratings.
- Whether diagnostic status had an effect on the number of health professionals involved with the child’s care.

### 5.3 Coping Strategies

The coping strategies that parents reported using at the time of their child’s diagnosis, were rated on 8 different categories. Significant differences between the two groups were found for only two coping strategies, *Positive Reappraisal* (efforts to create positive meaning by focusing on personal growth) and *Accepting Responsibility* (acknowledging one’s own role in the problem with a concomitant theme of trying to put things right).

There were no significant findings for any of the other coping strategies.

#### 5.3.1 Do Parents of Children with a Specific Diagnosis use More Adaptive Coping Strategies?

Mothers of children with a specific diagnosis used the strategy of *Positive Reappraisal* more than mothers of children with a non-specific diagnosis. Parents may be more likely to use this strategy when they have a definite diagnosis, as a result of having something identifiable towards which they can take positive action. Interestingly there was a consensus among parents of children with a specific diagnosis that having the diagnosis was a positive experience. This consensus of opinion may reflect the greater use of *Positive Reappraisal* by mothers in this group, who were the information
providers for the structured interview. There was not, however, such a consensus of opinion among parents in the non-specific diagnostic group.

Lazarus et al., (1980) suggested that the impact of the learning disabled child on the family is related to family members’ cognitive reappraisal of the stress. Carver et al. (1989) also studied the use of this adaptive coping strategy, describing it as ‘positive reinterpretation and growth’. This is a form of coping aimed at managing distress emotions rather than at dealing with the stressor per se., although construing a transaction in positive terms should intrinsically lead the person to continue (or resume) active, problem-focused coping actions. For this reason it is described as an adaptive strategy. As Quine & Pahl (1986), pointed out, parents of children with a specific diagnosis have more information about their child’s condition than parents of children with a non-specific diagnosis, they therefore have more resources with which to reappraise the situation.

This is further supported by the qualitative findings in this study regarding reasons that parents wanted a diagnosis for their child. The most commonly reported reason was to be able to understand the child’s condition and associated problems. Although this issue was not explored further, presumably parents would use this information to cope with the problems on an emotional level, and to provide for their child’s needs on a practical level.

There were no other significant differences in the use of coping strategies between the two groups. The prediction that parents of children with a specific diagnosis would report significantly less use of Escape Avoidance and Distancing coping strategies than parents of children with a non-specific diagnosis was not borne out. Escape Avoidance and Distancing are purported to be less adaptive strategies (Bristol, 1987; Margaret & Ankonina, 1991), and were expected to reflect the increased stress levels in parents of children with a non-specific diagnosis.
5.3.2 Is There Greater Agreement Between Parents of Children with a Specific Diagnosis?

The prediction that there would be fewer discrepancies between mothers and fathers of children with specific diagnoses on ratings of coping strategies, than between mothers and fathers of children with non-specific diagnoses, was not supported. There were no significant differences between the two groups in the size of discrepancies between parents on coping measures.

There was, however, a significant difference between parents' scoring on the strategy of Accepting Responsibility in the non-specific diagnostic group, with mothers scoring higher than fathers. There was also a significant correlation between parents in this group, for this strategy. These findings indicate that mothers with high ratings had partners with high ratings, although mothers' rating were higher that their partners' ratings overall. There were no such findings between parents in the specific diagnostic group.

Accepting Responsibility may be categorised as a subsection of the overall strategy of 'acceptance' described by Carver et al. (1989). Acceptance is described as an adaptive strategy which is a functional coping response, in that the person who accepts the reality of the stressful situation is engaged in an attempt to deal with the situation. However, this strategy is only adaptive when the individual has some control over their situation (Shapiro, 1983). Parents in this study have little or no control over their situation, in which case this strategy could be maladaptive (Pot-Mees, 1989).

These findings may also reflect the fact that mothers are frequently blamed for their child's behavioural problems, so mothers have to take responsibility for more of the situation than they actually have control over. This could also explain the significantly lower ratings which fathers gave in response to these items, a difference found in previous studies (e.g. Rogner & Wessels, 1994). Internalisation of blame is described by Bristol in the double ABCX Model as an additional stressor predicting outcome (Bristol, 1987). Mothers in the specific diagnostic group, however, had an explanation
for their child's difficulties to which they could apply an external attribution, so were less likely to take responsibility for more than they had control over.

There were no other significant differences between or within groups. One possible explanation for the limited number of predicted differences between the two groups on coping strategies could be that parents in the two diagnostic groups may have developed similar coping strategies despite differing experiences of stress. According to Holahan & Moos (1990), exposure to stress may result in maladaptive outcomes and negative affect, but may also broaden a person's perspective on life, promoting new coping skills and leading to more positive psychological growth. This suggests that parents of children with a non-specific diagnosis may well experience more stress, but as a result of this stress, develop new coping skills which then match those of parents of children with a specific diagnosis.

5.4 Family Functioning

On the FACES (II), parents rated statements on family functioning, which produced three separate measures: Cohesion (the emotional bonding that family members have towards one another), Adaptability (the ability of a marital or family system to change in response to stress) and Family Type (an amalgamation of Cohesion and Adaptability scores identifying the individual’s, and family’s, overall position on the circumplex model, Olsen et al., 1979).

5.4.1 Do Parents of Children with a Specific Diagnosis Report Higher Levels of Family Functioning?

Parents of children with a specific diagnosis and of those with a non-specific diagnosis, exhibited no difference in levels of Cohesion, Adaptability and overall Type on a family functioning measure. Therefore the prediction that parents of children with specific diagnoses would demonstrate higher levels of family functioning, than parents of children with a non-specific diagnosis was not supported.
5.4.2 Is There Greater Agreement Between Parents of Children with a Specific Diagnosis?

On calculating discrepancies between parents on family functioning ratings, it was found that these discrepancies were significantly larger on *Family Type* and *Adaptability*, in the non-specific than in the specific diagnostic group, with fathers scoring higher on *Adaptability* than mothers. Fathers in the non-specific group had an inflated perception of the family’s adaptability to mothers. As previously shown, mothers in this group had significantly higher ratings for the coping strategy of *Accepting Responsibility*, possibly reflecting a greater sense of burden. This acceptance of responsibility would also account for these mothers having a reduced perception of their family’s adaptability.

Furthermore, a significant correlation was found between mothers’ and fathers’ family functioning *Types* in the specific diagnostic group, indicating that mothers who had higher merged ratings on *Cohesion* and *Adaptability*, had partners who had higher merged ratings. This relationship was not present in the non-specific diagnostic group. Thus the prediction that there would be greater agreement between parents on measures of *Adaptability* and *Type* in families of children with a specific diagnosis was supported. However this prediction was not borne out for the *Cohesion* measure.

Families of children with a specific diagnosis, therefore, were more cohesive in their responses, and perceptions, of their family’s *Adaptability* and on the *Family Type* measure, although, somewhat paradoxically, this ‘cohesion’ in perceptions of their family functioning was not identified by the *Cohesion* dimension of the measure. This suggests that parents may have cohesive *perceptions* of their family’s method of functioning, without actually having a cohesive *approach* to dealing with daily family issues.
5.5 Prior Childrearing Experience

Those families with a sibling older than the proband child were identified. However the older sibling did not have learning disabilities themselves, so the childrearing practices and experiences will be somewhat different from those needed to deal with the issues presented by the child with learning disabilities.

5.5.1 Does Prior Childrearing Experience Result in More Adaptive Levels of Coping?

Mothers in families with a child older than the proband child with a specific diagnosis, used the strategies of Escape Avoidance (wishful thinking and behavioural efforts to escape or avoid the problem) and Positive Reappraisal (efforts to create positive meaning by focusing on personal growth) more than mothers in families without older children in this group.

Thus, it may be that mothers in families where there is a child older than their child with a specific diagnosis will have more knowledge, both about their own abilities as a parent, and their child’s special needs, and so may be more confident regarding their attributions of control over their situation. As a result, they have the information with which to reappraise the situation in a positive light as well as knowing their limitations and applying an avoidant strategy. Full information has been identified as a vital element for positive adaptation (Leff & Walizer, 1992). Mothers who do not have a child older than the proband have no such information, and so will be less likely to apply these strategies. Although Escape Avoidance is considered to be a less adaptive strategy (Billings & Moos, 1984), there is some literature proposing that avoidant coping strategies and denial may in fact be adaptive, in that they minimise distress, thereby facilitating coping (Breznitz, 1983; Cohen & Lazarus, 1973; Wilson, 1981). This applies especially in situations of no control (Lazarus, 1982).

Fathers in the non-specific diagnostic group used the Distancing (cognitive efforts to detach oneself and to minimise the significance of the situation) and Self Controlling
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(efforts to regulate one's feelings and actions) coping strategies more if the child had an older sibling child, than in families where there was no older sibling.

These emotion focused, avoidant coping strategies are described as being less adaptive, as they prevent active coping with the stressor (Aldwin & Revenson, 1987; Cronkite & Moos, 1984; Mathews et al., 1983; Wills, 1986). However, as previously stated, these strategies may also facilitate coping by minimising distress. The prediction that parents of children with specific diagnoses would report a greater use of active coping strategies, and fewer passive or avoidant strategies is therefore supported in different ways for fathers and mothers. This finding may reflect the differing effect of stress on fathers and mothers described by Krauss (1993), although this highlights the complexity of the coping process, and the problems with attempting to distinguish between adaptive and maladaptive strategies.

5.5.2 Does Prior Childrearing Experience Result in More Adaptive Levels of Family Functioning?

The hypothesis that families with children older than the identified child with learning disabilities would exhibit higher levels of Cohesion and Adaptability than families with no previous child rearing experience, can be accepted in relation to Cohesion, but not Adaptability. This goes some way towards supporting the suggestion that families with past experience of bringing up young children exhibit healthier adaptation in the face of bringing up a child with learning disabilities. These families exhibit less 'disengagement' and more 'connectedness' as described by the circumplex model, than families without prior childrearing experience. This also supports findings from past research stating that prior experience may be vital in reducing stress and enhancing family stability, implying that greater coping resources are available to those who have developed expertise in dealing with similar situations (McCubbin, 1979; Murphy, 1974).

Although parents in families with previous childrearing experience and a child with a specific diagnosis exhibit higher levels of Cohesion than parents in families with
previous childrearing experience and a child with a non-specific diagnosis, this
difference was not found when examining differences between specific and non-specific
groups overall, excluding the factor of previous childrearing experience. This suggests
that the presence of an older sibling in conjunction with having a specific diagnosis
may be a crucial factor in predicting family cohesion in the face of having a young child
with learning disabilities.

5.6 Other Findings

A number of other issues related to having specific vs. non-specific diagnoses were
also considered in this study.

5.6.1 Age at Diagnosis

Children in this study with a specific diagnosis were diagnosed on average 5 months
later than those with a non-specific diagnosis although this difference was not
significant. The findings do not support other findings described in the literature
stating that children with a non-specific diagnosis are diagnosed at a later age than
those with a specific diagnosis (Palfrey et al., 1987; Quine & Pahl, 1986). This
discrepancy in findings may be explained by a possible difference in parents’
interpretation of the question about age of diagnosis in this study. Parents of children
with a non-specific diagnosis generally reported the time when they first learned of
their child’s learning disability, whereas parents of children with a specific diagnosis
often gave the age when they received that diagnosis, rather than the age when they
were first made aware that their child had a disability. Parents’ awareness of, and a
professional’s first suggestion of the disability, often come a long time before the
actual diagnosis, as was reported both by parents in this study, and parents interviewed
in Leff & Walizer’s study (Leff & Walizer, 1992). Ideally, both the point at which
parents were made aware of their child’s condition, and time of receiving a specific
diagnosis, if any, would be separately identified in the interview.
5.6.2 Diagnostic Groups and Parent and Teacher Ratings

There were no significant differences between parents in specific and non-specific diagnostic groups on ratings of severity of their child’s behaviour. Nor were there differences between the two groups on teacher ratings of severity of behaviour, level of communication and level of learning disability. This demonstrates that the two groups were similar on these two ratings and that these variables did not differentially effect the results. However, as found in previous studies, there was also a lack of significant relationship between parent and teacher ratings on severity of behaviour, with the teacher generally rating the behaviour as more severe than parents. Achenbach et al. (1987) concluded from their study that the mean correlation between parent and teacher measures of psychopathology was only .30, which matches very closely to the finding in the present study of .33.

The lack of relationship between parent and teacher ratings of severity of behaviour can be explained by their different basis for comparison, despite using the same scale, parents would have had a different basis for comparison of the difficulty of their child’s behaviour, than the teacher. Parents were asked to rate the severity of the behaviour overall, without a comparative example being provided. The teacher, on the other hand, simply completed a written questionnaire in which the child was compared with others on the unit.

Other influencing factors include possible differences across settings (Achenbach et al., 1987). The level of knowledge of appropriate behaviour for the child’s developmental level may have been different between parent and teacher and so their expectations of the child may have differed. Individual characteristics of the informant may also explain the differences between parent and teacher ratings (Jensen et al., 1988) e.g. their knowledge and understanding of learning disabilities, and of the specific condition of that child as well as their perceived ability to cope with the difficulties being assessed. Stress levels in parents have also been found to increase parents ratings of behavioural severity of their child, thereby increasing the difference between parent and teacher ratings (Szatmari et al., 1994), although in the present study teacher ratings of behavioural problems are higher than parents'.
The two settings, home and Nursery, would provide very different facilities and means of managing any difficult behaviours, which may make a difference to perception of severity. The Nursery environment is generally more structured than home with specially trained staff and support therapists, whereas parents generally have fewer practical resources to manage their children, and have other demands to manage alongside those made by the disabled child. On the other hand, parents may have more emotional resources, in terms of feelings of love for the child and tolerance of difficult behaviours, than teaching staff. Finally there may well be true differences in the children's behaviour across the two settings. Again, this may result from a difference in expectations, structure and expertise between home and school.

5.6.3 Number of Professionals Involved

The findings suggest that diagnostic status has no effect on number of professionals working with the child in relation to their specific needs. This contradicts Quine & Pahl's finding that diagnostic status has a bearing on the number of support agencies and health professionals involved with the child (Quine & Pahl, 1987).

This finding might be explained by local models of service provision. The Assessment Nursery, attended by all children, has a number of health and education professionals linked to it, such that on attendance the child automatically receives many of these services. Therefore, although some children had received a few more services e.g. Portage, prior to attending the Nursery, the overall service provision once they reached the Nursery was consistent for all children. Hopefully, this demonstrates that the individual needs of the children are being met regardless of diagnostic status.

5.7 Parents' Views

Although detailed qualitative analysis was not carried out on interview data, many of the themes that emerged cast light on some of the pertinent issues for parents.
5.7.1 *Parents’ Experiences and Views Regarding the Diagnosis*

High levels of dissatisfaction with the diagnostic procedure were expressed by parents in both groups although experiences varied in nature greatly. For example one parent described her distress at overhearing the consultant describing her daughter as having Cerebral Palsy to a medical student. Another parent learned of her child’s undiagnosed condition by being told ‘you do realise he’ll be mentally and physically handicapped’. While dissatisfaction with the diagnosis of childhood learning disabilities has been extensively reported (e.g. Quine & Pahl, 1986), it is not necessarily inevitable, providing care is taken over giving parents the message (Cunningham et al., 1984).

Not surprisingly, there was an overwhelming preference in both groups for having a specific rather than a non-specific diagnosis, thus supporting past findings (e.g. Bristol, 1987; Quine & Pahl, 1986). There were five themes as to why parents preferred a specific diagnosis for their child, and the frequency with which each theme was mentioned did not vary greatly between the two groups. As mentioned, the reasons given for preferring a specific diagnosis were not explored in greater depth with parents, however they seem to serve both emotional and practical purposes. The three most commonly mentioned themes appear to serve an emotionally supportive function. These were (in order of frequency mentioned):

1. **In order to be able to understand the condition and problems.** Many of those parents without a diagnosis for their child reported feeling very uncertain and confused about the aetiology and prognosis of their child’s condition, and those with a diagnosis often mentioned this aspect as an important requirement. This issue has also been reported by parents in previous studies (e.g. Leff & Walizer, 1992).

2. **To explain the child’s condition to others.** In fact two mothers of undiagnosed children said that they did not particularly want a diagnosis for themselves, but instead to explain to others. A number of mothers said that it would help their own families to accept the extent of their problems if their child had a specific diagnosis.

3. **In order to know what the future holds.** The fact that this theme was mentioned more frequently by parents of children with a non-specific diagnosis, than by parents with a specific diagnosis, may reflect the confusion felt by these parents and again highlights the value of having a specific diagnosis.
The other two reasons identified for having a specific diagnosis were both of a practical nature. These were:

- In order to know how to best meet the child’s needs.
- In order to get appropriate services.

These findings indicate that a specific diagnosis may serve multiple purposes for parents’ coping, having both an emotional and a practical value. This supports the suggestion that appropriate information regarding the child’s problems, needs and abilities increases the likelihood of positive parental adaptation to the many stresses presented by having a child with learning disabilities.

5.7.2 Parents’ Suggestions For a Better Service

Despite 71% of parents feeling that they did receive adequate support from health professionals, there were a number of complaints and suggestions made concerning the service provision:-

COMPLAINTS

- Felt as though concerns were not taken seriously initially,
- No confidence in GP,
- Earlier diagnosis would have ensured earlier provision of appropriate services,
- Parents shouldn’t have to fight for services that their child is entitled to,

SUGGESTIONS

- More input and therapy is required in the child’s early years,
- A ‘key worker’ should help the family obtain services and information,
- Ongoing therapeutic support for the child is required rather than a short burst on diagnosis,
- Telephone support, or a support group for parents of undiagnosed children should be available,
- Special play areas for children with special needs should be provided, more provision made for school holidays and more respite care,
- More contact between parents and therapist\school, so parents can continue therapeutic work at home.
In summary, most parents were in agreement about wanting a diagnosis for their child, and felt that this would bring benefits in terms of emotional and practical support. However in considering parents' complaints and recommendations, families had individual requirements. Evidently a 'blanket' provision would not be considered to be useful, but the suggestion of a keyworker type system to co-ordinate services throughout the child's early years was one expressed in a number of different ways by many parents, and could help ensure a more coherent provision of services. Importantly many parents expressed the need for more opportunity to obtain information and the chance to discuss this in the setting of some kind of support system, thus highlighting parents need for control over the amount of information they receive.

5.8 Methodological Issues

Although the study raises some interesting findings, many differences were not significant and hypotheses based on previous findings in this area were not supported. It is important to recognise that there were a number of problems with the measures used and with the methodology of this study. These issues should be taken into account when considering the overall implications of the findings.

5.8.1 Problems with Measuring Coping Strategies

The concept of adaptive or active vs. maladaptive and passive coping strategies may in itself be problematic. Folkman & Lazarus point out that some of the strategies can be at the same time active or problem focused and passive or emotion focused (1988). It may therefore be misleading to categorise active strategies as adaptive, and passive strategies as maladaptive. The controllability of the situation must also considered. Many researchers have stated that a strategy can only be considered to be adaptive if the situation lends itself to the use of that strategy, as highlighted by Carver et al. (1989), Lazarus (1982), Pot-Mees (1989) amongst others. Despite the recognition by researchers of the importance of the issue of perception of control on coping behaviour, it is not a variable tapped in the Ways of Coping Questionnaire. Similarly
the perceived usefulness of each strategy has been identified as an important variable (Spirito et al., 1991) but is not tapped by the questionnaire used.

Coping has been described as a dynamic process that shifts in nature from stage to stage of a stressful transaction, rather than being a static individual trait (Folkman et al., 1986). A number of researchers postulate that some coping strategies are useful at some stages of the stressful transaction, but may be maladaptive at other stages (Levine et al., 1987; Mullen & Suls, 1982; Suls & Fletcher, 1985). In this study families will have been at different stages in terms of mourning, adaptation and coping with their child's learning disability. This will have affected their memory of how they coped at the time of diagnosis, depending on their present perception of the stress and their resulting emotional state. While it would be impossible to control for every individual and process effect, it would be valuable to carry out a longitudinal study assessing coping and family functioning variables from the time of diagnosis. With these data one might be able to identify changes over time on these aspects of adaptation, as well as any variation in differences, if any, between the two diagnostic groups.

Another problem with measuring coping concerns the number of assumptions made regarding the function of each strategy used. For example, the consensus is that Avoidance is used as a passive strategy which in no way deals with the problem situation. However, Carver et al. describe the scenario where, for example, an individual may turn to religion for a number of reasons; emotional support, a vehicle for positive reinterpretation and growth, or as a tactic of active coping with the stressor (Carver et al., 1989). Therefore the function of the strategy will define whether or not it is adaptive, rather than the strategy per se. While Folkman & Lazarus (1988) acknowledge that a strategy may have more than one purpose, again this is not addressed in the Ways of Coping Questionnaire.
5.8.2 Problems with Retrospective Reporting

Parents are required to report on their thoughts and feelings around the time of their child's diagnosis on the Ways of Coping Questionnaire, and to a lesser extent on FACES II. Because the time since diagnosis varied between 6 months and 5 years, the experience is likely to be more memorable for those parents whose children received a more recent diagnosis.

A further complicating factor is that present state of mind or mood will strongly affect the accuracy of parents memories of the time of diagnosis. It has been well documented in the literature on state-dependent memory recall that if the respondent is in the same state of mind at the point of learning and recall, then the material will be recalled 30% more accurately than if state of mind differs between these two times (Schare et al., 1984). However, according to Olshansky's theory of chronic sorrow (1962), parents will have moved on from the initial state of shock on first receiving the diagnosis, and will be experiencing different states of mind at the time of the research interview. Their present state of mind will also depend on the efficacy of the coping strategies used.

There is only marginal support for reliability of retrospective reporting. Finkel & McGue (1993) investigated the reliability of retrospective reporting of childrearing practices, and found little reliability in retrospective accounts. These findings were based on a 25 year follow-up study, which is a considerably longer delay between event and recall, than the period covered in the present study (6 months to 5 years). However Monroe (1982), found a decrement in reports of life events assessed retrospectively for the shorter period of 1 or 2 years. These findings demonstrate the poor reliability of information provided on a retrospective basis and highlight the need for assessment at the time of the event. This brings into question the results of previous research in coping strategies, which are based on retrospective reports. However, this decrement in the reliability of reports over time may also go some way to explain the lack of expected differences between groups in this study.
5.8.3 FACES II and Single Parent Families

The use and interpretation of the Family Functioning Questionnaire was also somewhat problematic. A number of the families were single parent families, and although the family version, rather than the couple version, of the questionnaire was used, a number of questions were difficult for these mothers to answer. For example Question 2, ‘in our family it is easy for everyone to express his/her opinion’, was not relevant for a single mother with a young child who had no language. For these more ambiguous questions, the mothers were instructed to rate the item in relation to how she felt she ran the household.

5.8.4 The Need for a Pre-Diagnosis Measure of Family Functioning

A significant difference between diagnostic groups might have been detected if all families exhibited poor overall family functioning prior to their child’s diagnosis. Parents in the non-specific diagnostic group may have been significantly more vulnerable to the stress of their situation than parents in the specific diagnostic group as a result of their family vulnerability. Families with good family functioning prior to their child’s diagnosis, on the other hand, might not have exhibited significant differences, as parents in the non-specific diagnostic group may be protected from their heightened levels of stress as a result of the family’s resilient nature. This argument is supported by the literature stating that although having a non-specific diagnosis for a child’s learning disability is more stressful than having a specific diagnosis (Quine & Pahl, 1986) good family communication, integration and flexibility, could lead to good family adaptation to stress (Hill & Hansen, 1962), and act in a stress resistant way (Olsen, 1970).

5.8.5 Absence of Stress Measurement

Levels of stress experienced by parents were not measured in this study as there is a plethora of evidence stating that a non-specific diagnosis of learning disabilities is more stressful for parents than a specific diagnosis (e.g. Smith & Philips, 1978; Hunter, 1980; Sleigh, 1981; Quine & Pahl, 1986). However in order to tease apart the results of this study, some of which contradict coping and family functioning literature, a
measure of stress experienced on the initial diagnosis might not only have identified differences in stress levels between the two groups, but also the reciprocal effects on levels of family functioning and coping strategies used. Alternatively a measure of concurrent levels of stress might have given a more accurate picture of the results of the child’s disability on coping strategies used and levels of family functioning.

5.8.6 Measuring Point of Diagnosis

The literature on receiving a childhood diagnosis of learning disabilities, states that parents have vivid memories of receiving a diagnosis of Down’s syndrome for their child (Cunningham et al., 1984). However, the nature of this study was to consider children without a specific diagnosis, and as a result, the point of diagnosis was often quite difficult for parents to identify. While some families had had a diagnostic consultation, others learned of their child’s disability by a vague comment from their health visitor, a query by their GP, or other such ill defined means. Many of the parents in the present study who were unable to recall the child’s age at diagnosis clearly, never received an identifiable diagnostic consultation, but the diagnosis was a slow process involving many procedures and professional consultations. These tended to be families of children with a non-specific diagnosis. Future research should aim to identify the point when parents first become aware of a problem with their child’s development, as well as the point, if any, when their child was formally diagnosed.

For example, one parent describes how they knew there was problem with their child’s development but were initially not told anything by their doctor. They were then told their son was autistic, with no explanation of what this meant, but at a later stage were told by a paediatrician that he had severe learning disabilities with autistic tendencies. Another family describe how their son was initially diagnosed with infantile spasms, with no known cause. At a further consultation with a specialist they were told ‘you do realise he’ll be mentally and physically handicapped’. All chromosome results were negative and the family were told that at the age of 2 years a full assessment of their son’s level of functioning could be carried out. In both these cases the diagnosis
changed somewhat over time, so the realisation of the children’s needs in both families was a gradual process, and both are still unclear about their child’s future.

5.8.7 Social Economic Status

The population of the study does not reflect that of the local population of Greenwich. The study population consisted of a far lower percentage of professional workers as well as fewer partly skilled workers, a far higher percentage of managerial and technical workers, and skilled manual workers, and similar percentages of skilled non-manual workers and unskilled workers. This figure is unlikely to have been biased by the effect that the learning disabled child had on parent’s employment status, as the ratings were based on the major wage earner’s job in each family. However, the effect of the presence of the child on both parents’ employment status was not specifically considered in this study. A number of mothers reported having stopped work in order to look after their disabled child, but this could not explain the observed differences. Instead these differences may well be a result of small sample sizes.

5.8.8 Participation Rate

Only 44.8% of families contacted agreed to participate in the study, despite being contacted directly by post, and then at a later date through the Nursery. This again may have influenced the results and it is very possible that the sample size was simply not large enough in order to identify genuine differences. However the issue addressed in the study was a sensitive one for many families, and required the participation of parents of very young children who may have been struggling with their child’s recent diagnosis, specific or otherwise.

In order to counteract this problem, it would be important to make attempts to engage the family at an early stage in the process through a professional with whom they are familiar e.g. the health visitor, or even recruiting health visitors to carry out the interview with families. Accepting that this may be a difficult time for families and participation rates are likely to be low, a larger sample would need to be contacted initially.
6. CONCLUSIONS

In this study the parents of children in two diagnostic groups were compared on measures of family functioning and coping. An assessment was also carried out on the effects of prior childrearing experience on parental adaptation. A number of further issues were explored, including the effects of diagnostic status on the child’s age at diagnosis, similarity between parent and teacher ratings of behaviour, and the effect of diagnostic status on number of health professionals involved with the care of the child.

Based on past research, the expected findings were that parents of children with a specific diagnosis would report the use of more adaptive coping strategies and more adaptive levels of Cohesion (i.e. the emotional bonding that family members have towards one another), and Adaptability (i.e. the ability of the family system to change its power structure, role relationships and relationship rules), than parents with children with a non-specific learning disability. Past research would also predict that families with prior childrearing experience might exhibit more positive adaptation to their situation, and that children with a specific diagnosis would be diagnosed at an earlier age and have more professional involvement.

Results obtained in this study presented a complex picture and should be considered with a number of methodological problems in mind. Small sample sizes and low participation rates jeopardise the generalisability of the results. There are also a number of conceptual problems that undermine the measurement of coping strategies. Additionally, single mothers had difficulties completing the family functioning questionnaire as a number of the items were not relevant to their situation. In common with other studies of this kind, findings were based on retrospective reports, although there is considerable evidence showing that the reliability of this method is often poor. The point of diagnosis was problematic for many parents to identify as they were often not given a diagnostic consultation. Finally, the absence of a measurement of stress means that any conclusions are based on the assumption that parents of children with a non-specific diagnosis would experience higher levels of stress than parents of children with a specific diagnosis, as has been suggested in past research (e.g. Bristol, 1987).
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Overall the results suggest two main themes relating to positive adaptation: Firstly a specific diagnosis may help to provide information and knowledge to parents, which could then be used to help mothers to cope in a more adaptive way. For example, if parents have more information about their child’s condition, they may be better able to understand any problems that arise and perhaps develop more effective strategies to deal with these.

Secondly, the presence of a sibling older than the proband is associated with more positive adaptation in some areas of family functioning and coping only when the proband has had a specific diagnosis of learning disabilities. It may be that the combination of more information about the child’s condition and previous experience of child rearing affects adaptation more than one or the other separately.

Further research relating to positive adaptation in families should focus on defining the constituent features of 1) the child having a specific diagnosis and 2) the child having an older sibling. Additionally, further exploration is required into which aspects of those features combine to be associated with positive adaptation, and why the combination of having a specific diagnosis and having an older sibling affects mothers and fathers differently. This might enable therapeutic work with families exhibiting poor adaptation or with no specific diagnosis to focus more effectively on developing these essential features.

The cumulative evidence leads to the conclusion that all efforts should be made to provide a specific diagnosis for each child as early as possible. However, in those cases where a specific diagnosis cannot be made, it is important to identify the variables related to having a non-specific diagnosis that lead to poor adaptation. Results from the present study relating to poor adaptation suggest two main areas of focus.

Firstly, mothers of children with a non-specific diagnosis appear to accept more responsibility for their child’s condition. If no physical or genetic explanation is
Diagnosis Research: Conclusions

available for their child’s condition mothers may experience a greater sense of guilt about their role in causation either during the birth, pregnancy, or even prior to this time. However, if a cause is identified, it may be possible to ameliorate this guilt to a certain extent. Again this highlights the need to make as much information as possible available to families.

Secondly, it appears that having a non-specific diagnosis is associated with greater discrepancies between parents on a family functioning measure. Discrepancies within the family may have a continuing impact on the development of effective strategies. Factors associated with these discrepancies should be identified in the hope that intervention will reduce the disparity and allow the family to develop more positive relationships.

The main implications of these findings are that having a specific diagnosis for the child’s learning disability is an important factor in the prediction of positive parental adaptation but that a number of other factors are also involved. One of those identified in this study was the presence of an older sibling, which provides greater childrearing experience. Parents participating in the study also proposed a number of suggestions for service, which may be vital to their adaptation, such as a keyworker to co-ordinate services using an individual, need-dictated approach.

In order to clarify findings from this study, the following issues would need to be addressed in future research:

- Perceptions of stress experienced, both at the time of diagnosis, and concurrent, should be identified in order to establish any direct links between stress, family functioning and coping.
- Larger samples are required, on which to base both quantitative and qualitative analysis, such that the rich information given by parents about, amongst other issues, parents experiences of the diagnostic procedure could be evaluated.
- An alternative measure of coping should be considered, for example the lesser cited COPE (Carver et al., 1989), which examines strategies in more distinct categories.
Diagnosis Research: Conclusions

- Measures of coping and family functioning should be gathered as close as possible to the time of diagnosis, in order to avoid the problems inherent in retrospective reporting and with state dependent recall.

Future studies should focus on aspects of the diagnosis, the diagnostic procedure, services provided for both children and parents, interfamily factors, environmental factors, support and personality variables in order to identify predictors related to better parental adjustment. With the issues teased apart, services might be better able to provide for families with a child with learning disabilities in order to promote more positive adjustment among all family members.
7. REFERENCES


Diagnosis Research: References


Diagnosis Research: References


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8.

APPENDICES

Appendix 1  Family Adaptability and Cohesion Evaluation Scale - II
Appendix 2  Ways of Coping Questionnaire
Appendix 3  Family Experiences Questionnaire
Appendix 4  Teacher Rating Scales
Appendix 5  Information Sheet for Parents
Appendix 6  Table of Means and Standard Deviations for Coping Strategies of Mothers and Fathers in Both Diagnostic Groups
Name:
Mother or Father:

**FACES II: Family Version**
David H. Olsen, Joyce Portner & Richard Bell

Please number each of the following statements according to how often they apply.

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Almost Never</td>
<td>Once in a while</td>
<td>Sometimes</td>
<td>Frequently</td>
<td>Almost Always</td>
</tr>
</tbody>
</table>

1. Family members are supportive of each other during difficult times.
2. In our family it is easy for everyone to express his/her opinion.
3. It is easier to discuss problems with people outside the family than with other family members.
4. Each family member has input regarding major family decisions.
5. Our family gathers together in the same room.
6. Children have a say in their discipline.
7. Our family does things together.
8. Family members discuss problems and feel good about solutions.
9. In our family everyone goes his/her own way.
10. We shift household responsibilities from person to person.
11. Family members know each other's close friends.
12. It is hard to know the rules in our family.
13. Family members consult other family members on personal decisions.
14. Family members say what they want.
15. We have difficulty thinking of things to do as a family.
16. In solving problems the children's suggestions are followed.
17. Family members feel very close to each other.
18. Discipline is fair in our family.
19. Family members feel closer to people outside the family than to other family
members.

20. Our family tries new ways of dealing with problems.
21. Family members go along with what the family decides to do.
22. In our family, everyone shares responsibilities.
23. Family members like to spend their free time with each other.
24. It is difficult to get a rule changed in our family.
25. Family members avoid each other at home.
26. When problems arise, we compromise.
27. We approve of each other's friends.
28. Family members are afraid to say what's on their minds.
29. Family members pair up rather than do things as a total family.
30. Family members share interests and hobbies with each other.
Appendix 2

Name:
Mother or Father:

Ways of Coping Questionnaire
Sarah Folkman & Richard S. Lazarus.

I would like you to think about the time when your child was first diagnosed as having a learning disability.

Please briefly describe the situation.

What was the most stressful thing about the situation?

How did it make you feel?

How long ago was this?
Please number the following statements according to how often you used each coping strategy.

<table>
<thead>
<tr>
<th>Does Not Apply</th>
<th>Used Somewhat</th>
<th>Used Quite a Bit</th>
<th>Used a Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Just concentrated on what I had to do next - the next step.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I did something which I didn't think would work, but at least I was doing something.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Tried to get the person responsible to change his or her mind.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Talked to someone to find out more about the situation.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Criticised or lectured myself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Tried not to burn my bridges, but leave things open somewhat.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Hoped a miracle would happen.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Went along with fate, sometimes I just have bad luck.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Went on as if nothing had happened.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I tried to keep my feelings to myself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Looked for a silver lining, so to speak; tried to look on the bright side of things.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Slept more than usual.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I expressed anger to the person(s) who caused the problem.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Accepted sympathy and understanding from someone.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. I was inspired to do something creative.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Tried to forget the whole thing.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. I got professional help.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Changed or grew as a person in a good way.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. I apologised or did something to make up.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. I made a plan of action and followed it.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. I let my feelings out somehow.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Realised I brought the problem on myself.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I came out of the experience better than I went in.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Talked to someone who could do something concrete about the problem.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Tried to make myself feel better by eating, drinking, smoking, taking drugs or...</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
medication etc.

26. Took a big chance or did something very risky.
27. I tried not to act too hastily or follow my first hunch.
28. Found new faith.
29. Rediscovered what is important in life.
30. Changed something so things would turn out alright.
31. Avoided being with people in general.
32. Didn't let it get to me, refused to think about it too much.
33. I asked a relative or friend I respected for advice.
34. Kept others from knowing how bad things were.
35. Made light of the situation, refused to let it get too serious.
36. Talked to someone about how I was feeling.
37. Stood my ground and fought for what I wanted.
38. Took it out on other people.
39. Drew on my past experiences; I was in a similar position before.
40. I knew what had to be done, so I doubled my efforts to make things work.
41. Refused to believe that it had happened.
42. I made a promise to myself that things would be different next time.
43. Came up with a couple of different solutions to the problem.
44. I tried to keep my feelings from interfering with other things too much.
45. I changed something about myself.
46. Wished that the situation would go away or somehow be over with.
47. Had fantasies or wishes about how things might turn out.
48. I prayed.
49. I went over in my mind what I would say or do.
50. I thought about how a person I would admire would handle the situation and used that as a model.
Appendix 3

Diagnosis Research: Appendices

Name of Child:
Name of Parent:
GP Name:
Address:

Family Experiences Questionnaire

DIAGNOSIS
1. Which service does your child with special needs attend/receive?
   Early Intervention Centre □
   Greenwood Nursery □
   Portage Service □

2. Does your child have a specific diagnosis?
   Yes/No (if no please go to question 6)

3. What is your child's diagnosis?

4. What do you understand by this diagnosis?

5. At what age was your child diagnosed?

6. Please tell me a bit about what you were told about your child's learning disability.
7. What have you been told about your child’s future regarding their learning disability?

8. Did you know anything about this condition before the birth of your child?
   Yes/No
   If yes - what?

9. Would you prefer to have a specific diagnosis for your child or would you prefer not to know?
   Why?

10. At what age did you notice that there was something wrong with your child’s development?

11. How do you see the future of your child?

12. How difficult do you feel your child’s behaviour is?

<table>
<thead>
<tr>
<th>Extremely</th>
<th>Quite</th>
<th>a little</th>
<th>hardly</th>
<th>not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>
FAMILY INFORMATION

13. Please could you list the age and sex of all the children in your family (from the oldest to the youngest, putting a * next to the age of the child with learning disability).

<table>
<thead>
<tr>
<th>Age</th>
<th>Sex (M/F)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

14. How long were you and your partner together before having children?

15. Do both parents live at home with the child/children?
   Yes/No
   If not at what was your son/daughter with learning disability when you separated?

16. If either parent is employed could you please state their job.

Mother ____________________________________________

Father ____________________________________________

17. Please state your ethnic origin:
SUPPORT

18. Please list other family members who help with the care of your child/children.

__________________________________________

__________________________________________

__________________________________________

19. Do you feel that your extended family are supportive?
   Yes/No

20. Does your child receive respite care?
   Yes/No
   If So:
   Where ________________________________
   How often __________________________
   For how long _______________________

21. Do you feel you receive enough respite care?
   Yes/No

22. What professional support do you, or have you, received for your child with learning disability? (please tick)
   Educational Psychologist □
   Clinical Psychologist □
   Speech and Language Therapist □
   Consultant Paediatrician □
   Occupational Therapist □
   Community Nurse □
   Mencap Support Worker □
   Social Worker □
   Care Manager □
   Portage Worker □
Diagnosis Research: Appendices

Music Therapist □
Teacher □
Other (please specify) __________________________

23. Do you feel that the professional support you receive for your child is adequate?
   Yes/No
   If No, what kind of extra support would be useful to you?

Thank you for your help
## Teacher Rating Scales

1. What is this child’s behaviour like in relation to the other children at the nursery?

<table>
<thead>
<tr>
<th>A lot less difficult</th>
<th>A little less difficult</th>
<th>About average difficult</th>
<th>A little more difficult</th>
<th>A lot more difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. What is this child’s level of language and communication like in relation to the other children at the nursery?

<table>
<thead>
<tr>
<th>A lot less language</th>
<th>A little less language</th>
<th>About average language</th>
<th>A little more language</th>
<th>A lot more language</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

3. What is this child’s degree of learning disability in relation to the other children at the nursery?

<table>
<thead>
<tr>
<th>A lot more severe</th>
<th>A little more severe</th>
<th>About average severe</th>
<th>A little less severe</th>
<th>A lot less severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Dear Parent,

I am carrying out a study in and around Greenwich looking at the effect that having a young child with learning disabilities has on families. Specifically I am interested in whether the family have been given a clear diagnosis for their child or not. The purpose of carrying out his research is to determine difficulties which the family experience around the time of their child’s diagnosis, or stresses caused by a lack of a clear diagnosis. I would therefore like to ask if you would be prepared to help out with this research.

If you were to take part, you would be asked to spend about an hour being interviewed on an informal basis about your child with learning disabilities and the family generally. This interview could take place at the school your child attends, at the Psychology Department in Eltham, or at your home if it difficult for you to get to these places. You will not be required to do anything yourselves.

Taking part in this research will not effect the care or schooling which your child is currently receiving, nor will it affect any decisions made about your child’s needs in the future. Your participation in this project is entirely voluntary, and you may withdraw at any time.

All information given by you during the interview will be entirely confidential, and your identity will not be revealed in the event of the data being published unless your consent is specifically requested.

If you would like more information about the research before making your decision, please contact me at the Psychology Department by phoning or writing to me at the above address.
Please could you complete the slip over page to let me know whether you are willing to take part in the research. If you decide to take part I will contact you on receiving your reply to arrange a time for the interview.

Please send your reply in the stamped addressed envelope enclosed.

Thank-you for your help
Yours sincerely

Louise Connor - Clinical Psychologist

Name of child __________________________  
Date__________________  
I would/would not * like to take part in the research project

If taking part please could your give your address and phone number:

Name ____________________________
Address ____________________________
________________________
________________________
Phone ____________________________

Signed ____________________

* please delete
## Table of Means and Standard Deviations for Coping Strategies of Mothers and Fathers in Both Diagnostic Groups

<table>
<thead>
<tr>
<th>Coping Strategies</th>
<th>Mothers Specific Diagnosis</th>
<th>Mothers Non-Specific Diagnosis</th>
<th>Fathers Specific Diagnosis</th>
<th>Fathers Non-Specific Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Accepting Responsibility</td>
<td>.69</td>
<td>.56</td>
<td>1.19</td>
<td>.78</td>
</tr>
<tr>
<td>Confrontative Coping</td>
<td>1.18</td>
<td>.42</td>
<td>1.10</td>
<td>.63</td>
</tr>
<tr>
<td>Distancing</td>
<td>1.29</td>
<td>.65</td>
<td>1.24</td>
<td>.77</td>
</tr>
<tr>
<td>Escape Avoidance</td>
<td>1.48</td>
<td>.61</td>
<td>1.39</td>
<td>.87</td>
</tr>
<tr>
<td>Planful Problem Solving</td>
<td>1.17</td>
<td>.72</td>
<td>1.43</td>
<td>.80</td>
</tr>
<tr>
<td>Positive Reappraisal</td>
<td>1.72</td>
<td>.50</td>
<td>1.16</td>
<td>.63</td>
</tr>
<tr>
<td>Self Controlling</td>
<td>1.70</td>
<td>.62</td>
<td>1.59</td>
<td>.35</td>
</tr>
<tr>
<td>Social Support Seeking</td>
<td>1.67</td>
<td>.52</td>
<td>1.61</td>
<td>.76</td>
</tr>
</tbody>
</table>