

**Stress and coping among parents of children with severe learning disabilities: Coping strategies and parents' well-being**

**HANNA LINK**

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## **Stress and coping among parents of children with severe learning disabilities: Coping strategies and parents' well-being**

**Hanna Link**

### **ABSTRACT**

The traditional approach of researchers exploring adjustment in families caring for a disabled child has been to examine and document the stressors they experience and the adverse effects of these stressors on the well-being of family members. The concept of "coping" has been introduced to the field in recent years. Lazarus and Folkman's (1984) process model of stress and coping, emphasising the importance of coping resources and coping strategies, is now incorporated in disability research. Recent research examining the ways parents of children with disabilities cope has focused primarily upon coping resources. Comparatively little research has explored coping strategies and the relationship between the use of coping strategies and parents' well-being (Beresford, 1994). Further, the results of Quine and Pahl's (1991) study of mothers caring for a child with severe learning disabilities (SLD) are inconsistent with previous research with related populations, warranting further research.

This thesis reports on a large-scale ( $N=123$ ) cross-sectional, correlational study of parents caring for a child with SLD. Lazarus and Folkman's (1984) process model provided the conceptual framework for the work. The study aimed to provide a detailed analysis of the coping strategies used by parents, by employing both quantitative and qualitative techniques, and aimed to investigate the relationship between use of individual coping strategies listed on the WC-R and parental well-being. As hypothesised, in contrast to Quine and Pahl's (1991) study, use of practical coping strategies and or emotional social support was associated with decreased stress and psychological distress, as measured by the QRS-F and GHQ-12 respectively. Further, as predicted, use of wishful thinking was associated with increased stress and psychological distress. The results are discussed in relation to previous research findings and theory. Clinical and policy implications are discussed. Finally, limitations of the study are outlined and suggestions for further research are offered.



## 1. Literature Review

### 1.1 Introduction

Until the mid-1970s, most research exploring the experiences of families caring for a disabled child adopted a “pathological” approach (Byrne & Cunningham, 1985). It was assumed that high levels of stress and psychological distress were inevitable among family members, particularly mothers. As Byrne & Cunningham (1985) note, these early studies remained within a conceptual vacuum, ignoring developments in the fields of early intervention, family functioning, stress and coping. Changes in policy and service provision over the years had similarly been largely overlooked. Consequently, numerous studies to date have examined the stressors associated with caring for a disabled child and the adverse effects of these stressors on parents’ well-being (e.g. Chetwynd, 1985; Quine & Pahl, 1985).

The results of such studies indeed indicate that, in general, parents of disabled children experience more stress and less psychological well-being than parents of non-disabled children. Miller, Gordon, Daniele & Diller (1992), for example, compared mothers of physically disabled children with mothers of non-disabled children. They found that 14.5 % of mothers of disabled children scored within the clinical range for depression, as measured by the Brief Symptom Inventory (Derogatis & Spencer, 1982) compared to 3.2 % of mothers of non-disabled children. Similarly, 38 % of mothers of disabled children had psychological well-being scores within the clinical range compared to only 16 % of mothers of non-disabled children.

Whilst it must be noted that levels of well-being were significantly lower in mothers of disabled children than in mothers of non-disabled children, the resilience of many of the mothers of disabled children cannot be ignored. These figures also show that 62 % of mothers of disabled children managed their stress effectively. Although it cannot be disputed that parents of disabled children face high levels of stress, it is also true to say that many such parents manage their stress effectively and *do not* develop psychological disorders.

The research focus must now move on from describing stressors and their effects. Research examining the ways in which parents of children with disabilities cope, with varying degrees of success, with the day-to-day care of their children is needed. As Beresford (1994, p. 171) comments, “such work has far greater implications for understanding and improving the ways that these families can be helped”.

This topic is of clinical importance not only because of the potentially harmful effects of stress on parents’ physical health, psychological well-being and personal relationships. The effects of parental stress on children and implications for service provision must also be considered. Parental stress has been shown to have a detrimental effect on the quantity and quality of parent-child interactions (e.g. Zussman, 1980), in turn stifling child development. Further, siblings of children with developmental disabilities have demonstrated lower self-concept when parental stress was high (Dyson, Edgar & Crnic, 1989). Moreover, parental stress is a well-known risk factor for neglect and child abuse (Johnson, 1990). Parents under stress are also more likely to seek professional support and request long-term care (e.g. Wilkin, 1979; Sherman & Coccozza, 1984).

Furthermore, this study comes at a time of reform in policy relating to carers. The Government has brought forward for the first time a national strategy for carers (Department of Health, 1999). The importance of supporting carers and understanding and meeting their health needs is now recognised.

### 1.1.1 Organisation and Scope of the Review

The current study explores stress and coping among parents of children with severe learning disabilities (SLD). As nomenclature is a major source of confusion in this field, after this introduction there is a short section clarifying the terminology used in this dissertation. Prevalence, causes of learning disability and associated disorders are also considered.

An overview of recent changes in UK community care policies is given next. Unmet service needs are considered as a source of parenting stress in a “common needs” model.

Recent research exploring parents’ ways of coping with the day-to-day stresses of rearing a disabled child is reviewed in following sections. The review draws together research findings from the fields of physical disability and learning disability.

The review is grounded in Lazarus & Folkman’s (1984) process model of stress and coping. This model has been deemed to be the most comprehensive (Beresford, 1994) and much of the research in this area is firmly rooted within this conceptual framework. A brief overview of the process model is given, introducing the concepts of coping resources and coping strategies. Then follows a review of research relating to the coping resources and coping strategies used by parents of children with disabilities to cope with the daily stresses of caring.

## 1.2 Learning Disability

### 1.2.1 Definition

The term “learning disability” is now used in the UK in preference to older terminology such as “mental handicap”, “mental retardation” and “mental subnormality”. It is assumed to be synonymous with the educational label of “learning difficulty”, which has replaced the older term “educational subnormality” (Turk, 1996), and is not to be confused with “specific learning difficulty”, such as dyslexia. It should, however, be noted that the label “mental retardation” is still in use in Northern America, where the term “learning disability” refers to specific learning difficulties.

The American Association on Mental Retardation (AAMR) definition and classification system has been deemed the most comprehensive (Hatton, 1998). Mental retardation (learning disability) is defined as “significantly subaverage intellectual functioning, existing concurrently with related limitations in two or

more...adaptive skill areas" with onset before age 18 (Luckasson, Coulter, Followay, Reiss, Schalock, Snell, Spitalnik & Stark, 1992).

Whilst the AAMR classification system does not define degrees of learning disability, as Hatton (1998) notes, the concept of levels of severity of learning disability is in common usage. These classifications are based upon standardised Intelligence Quotients (IQ scores). A widely used system is that of the International Classification of Diseases produced by the World Health Organisation (ICD-10). Four levels of learning disability are identified ranging from mild (50-70 IQ), moderate (35-49 IQ) to severe (20-34 IQ) and profound (< 20 IQ) (Hatton, 1998).

However, in the education system learning difficulties are presumed to lie on a continuum from mild (70-85 IQ) to moderate (55-70 IQ) and severe (< 55 IQ) (Montgomery, 1990). For many purposes (e.g. epidemiological studies, educational provision as above), all individuals with IQ < 50 / 55 are classified as having severe learning disabilities (SLD) (Hatton, 1998; Turk, 1996). Whilst this latter classification is used in the present study, it is in no way assumed that individuals with SLD form a homogeneous group.

### 1.2.2 Prevalence

It is estimated that there are 1.2 million people in the UK with a learning disability, 200 000 of whom have severe disabilities (Mencap, 1999). Whilst studies report a higher prevalence of mild learning disabilities in males than females (ratio 1.6:1), some studies have shown that this gender difference is less pronounced in people with severe learning disabilities (Hatton, 1998). Similarly, whilst a disproportionate number of people with mild learning disabilities come from socially disadvantaged backgrounds, people with severe learning disabilities come from a range of socio-economic backgrounds (Hatton, 1998).

### 1.2.3 Aetiology

In approximately 75 % of all cases of learning disability the cause is unknown (Davison & Neale, 1990). A specific biomedical cause is more often found in

individuals with severe learning disabilities. Identified causes of learning disability include chromosomal or genetic anomalies (e.g. Down's syndrome, fragile X), maternal malnutrition, illness, infection and / or substance abuse, oxygen deprivation, birth trauma, head injury, prematurity, lead poisoning and uncontrolled epilepsy (Turk, 1996; Davison & Neale, 1990; Hatton, 1998).

#### 1.2.4 Associated Disorders and Conditions

People with learning disabilities often have additional disorders or conditions that may interact with their disability. The number of additional disorders an individual is likely to have increases with the severity of the learning disability (Hatton, 1998). The most common disorders or conditions associated with learning disability include sensory impairments, motor disorders such as cerebral palsy, epilepsy, behaviour problems, and psychiatric disorders (Turk, 1996; Hatton, 1998).

### 1.3 Community Care and Service Provision

#### 1.3.1 The Policy Context

Since the advent of "care in the community" in the early 1970s, parents have become the main providers of services for children and adults with a learning disability (Madden, 1995). In Leicestershire, for example, parents are the largest single provider of accommodation for adults with learning disabilities, housing and supporting 39 % of all adults with a learning disability in the county (personal communication, Principal Computer Officer, Leicestershire Learning Disability Register, February 21, 2000). National policy relating to families of learning disabled children has altered considerably since the late 1980s, resulting in major changes in the organisation and provision of health, education and social services (Madden, 1995). The 1989 Children Act (Department of Health, 1991), for example, states that children with learning disabilities, as "children in need", require services which are integrated with mainstream services for non-disabled children. Local authorities are now obliged to provide services designed to give children with disabilities the opportunity to lead lives as normal as possible.

Similarly, the 1990 NHS and Community Care Act (HMSO, 1990) advocates individualised needs-led services. A key objective is the promotion of domiciliary, day and respite care services<sup>1</sup> to enable people with learning disabilities to live in their own homes wherever feasible. Practical support for carers is also noted as a high priority.

However, whilst there has been an escalating policy of greater community provision and in-home support, studies have shown that, in practice, many parents are unaware of respite services available (e.g. Stalker & Robinson, 1994). Further, access to respite care has been shown to be problematic, especially for those with severe disabilities, physical disabilities, behavioural problems and / or medical problems (Hayes, Cotterill, Sloper & Flynn, 1996). Consequently, many parents have experienced community care as the gradual erosion of support services and have in reality had to cope with the day-to-day care of their children with limited support if any (Lee, 1994; Beresford, 1996). As Madden (1995, p.90) notes, “without parents, learning disability “community care” would collapse”.

In recognition of the vital role all carers, including parents, play in keeping community care in existence, the Government has recently developed a national strategy for carers, “Caring About Carers” (Department of Health, 1999). The importance of supporting carers in their caring role is emphasised. Service providers are urged not to neglect the carer’s needs when assessing and meeting the needs of the patient or user. The well-being of the carer is given equal importance. A central tenet of this new approach to carers is “carers’ right to have their own health needs met” (Department of Health, 1999, p. 6). Research examining the ways in which parents of children with learning disabilities cope, with varying degrees of success, with the day-to-day care of their children is, therefore, essential if positive changes are to be made.

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<sup>1</sup> Respite care, also known as “short term breaks”, refers to services where children spend one or more nights away from their family in a staffed unit or with other families in family-link schemes.

### 1.3.2 Service Provision and Parents' Coping – The Common Needs Model

In recognition of the drawbacks of community care and often patchy service provision, several researchers have considered the unmet service needs of families to be the main source of stress (e.g. Wilkin, 1979, Carey, 1982). This position has been termed the “needs-deficit” or “common needs” model (Dale, 1996). The approach emphasises and explores the practical problems faced by families and suggests how services may be better organised to overcome them. Common needs identified include financial assistance, day care during school holidays and over weekends, babysitting services and help with transport (Byrne & Cunningham, 1985).

The common needs model continues to be widely endorsed by many parents and professionals in the child-care field (Dale, 1996) and has been helpful in moving the research focus away from seeing the child as a pathology, instead focusing upon families' practical and material needs. As the shortfall between families' perceived needs and available service provision and resources persists, the model remains relevant today.

However, the model has been criticised for its tendency to assume that all families experience the same amount and type of stress and have similar, homogeneous needs, regardless of their family resources and circumstances (Dale, 1996). It is assumed that all families need and will benefit in a similar way from the same range of services. Mainstream research on stress and coping challenges this view. One of the most widely used models in this field, that of Lazarus and colleagues (Lazarus & Folkman, 1984), is now incorporated in disability research (Knussen & Sloper, 1992). This model is outlined below.

## 1.4 Lazarus and Folkman's (1984) Process Model of Stress and Coping

Over the years, stress has been conceptualised in three ways:

- as a *stimulus or stressor* in the environment causing discomfort or tension

- a person's physiological and psychological *response* to a stressor (strain)
- as a *process* involving stressors, strains and continuous *transactions* between a person and the environment (Sarafino, 1990).

According to this latter view, the person is not merely a passive victim of stressors in the environment, but an active agent who can influence the impact of stressors through cognitive, behavioural and emotional strategies.

In their process model of stress and coping, Lazarus & Folkman (1984, p.19) define psychological stress as "...a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being". These researchers suggest that, through the process of primary appraisal, a potential stressor is categorised with respect to its significance for well-being as either irrelevant, benign-positive or stressful (see Figure 1).

Stress appraisals include *harm / loss*, *threat* and *challenge*. A situation is appraised as involving *harm / loss* if some damage to the person has already been sustained, such as physical loss, loss of self-esteem and illness. *Threat* concerns anticipated losses yet to take place, whereas *challenge* appraisals focus upon the potential for gain in an encounter. It must be noted that these three stress appraisals are not mutually exclusive.

Stress appraisals call for the mobilisation of coping efforts. A further form of appraisal, that of evaluating what might and can be done, then takes place. This secondary appraisal is said to be mediated by socio-ecological and personal coping resources. The process model, therefore, incorporates the strengths of the common needs model, acknowledging that socio-ecological resources, including service provision, impact upon parenting stress. The choice of coping strategies depends heavily on the resources available (see Figure 1). The chosen coping strategy is then put into practice and the outcome evaluated.



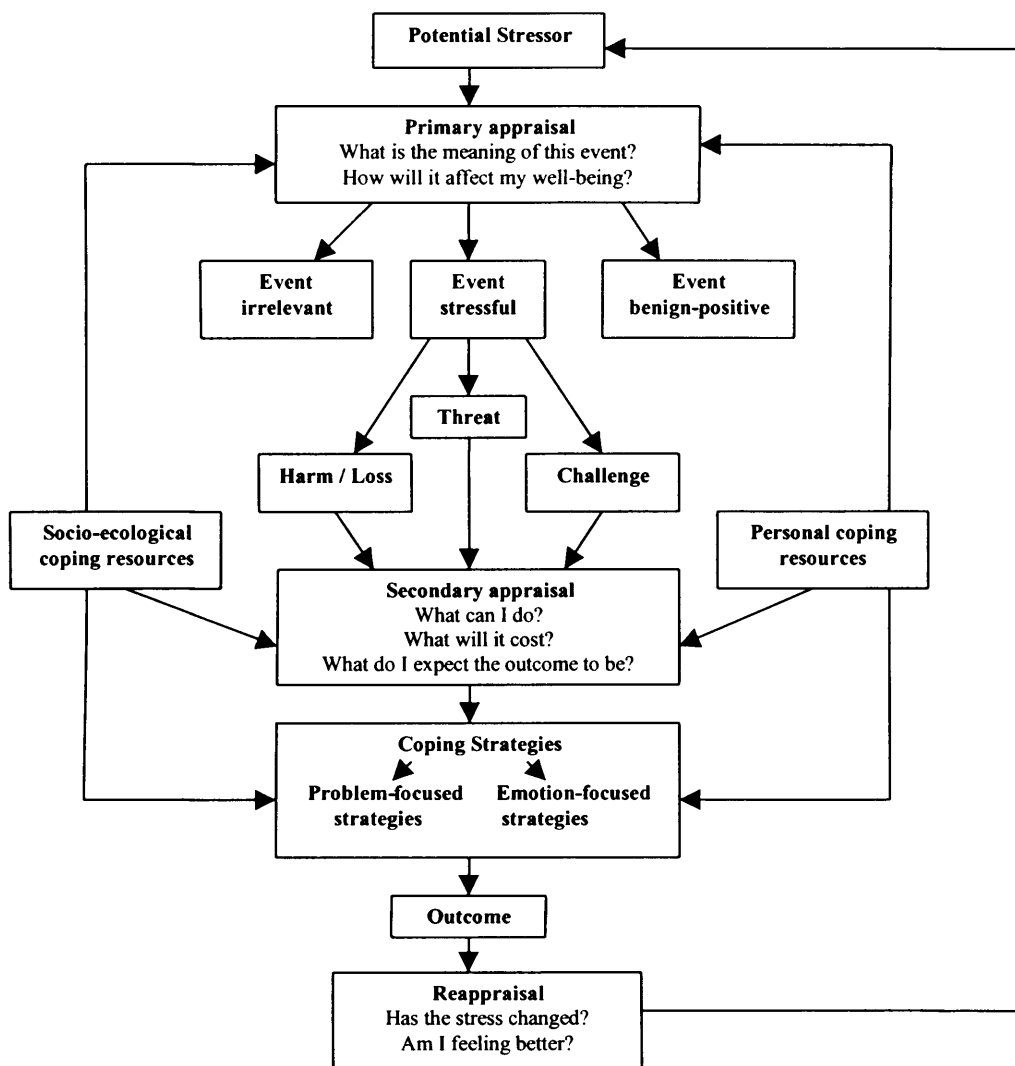


Figure 1. A representation of Lazarus & Folkman's (1984) process model of stress and coping (adapted from Beresford, 1994).

Strategies are either adhered to if judged to be effective, or altered, where possible, if considered ineffective. Outcome is monitored in a continuous feedback loop. Coping is defined as “constantly changing cognitive and behavioural efforts to manage specific external and / or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141).

By defining coping as “..efforts to manage..”, Lazarus & Folkman (1984) avoid confounding coping with mastery. A realistic view of stress is taken. The model recognises that not every problem can be mastered and allows for the fact that some coping efforts are not aimed at correcting the problem. In this respect the model is

particularly helpful when considering parents' ways of coping with a disabled child, as several sources of stress identified in this population, for example an over- or under-active child and behaviour problems (Chetwynd, 1985; Quine & Pahl, 1985; Sloper, Knussen, Turner & Cunningham, 1991), are either permanent or not easily eliminated.

According to Lazarus and Folkman (1984), coping can serve two main functions: it can alter the *problem* causing the stress (problem-focused coping) or, alternatively, it can regulate or reduce the *emotional response* to the problem (emotion-focused coping). These authors do, however, note that both types of coping may be used together and that some coping strategies may serve both functions. To illustrate this point, Knussen & Sloper (1992) give the example of a mother who has had a difficult day managing a child exhibiting behaviour problems. The mother may tell her husband or friend about her day to relieve pent up feelings (emotion-focused coping) and through discussing the problem a more practical solution may be identified (problem-focused coping).

Through factor analytic studies, using their Ways of Coping Questionnaire (Folkman & Lazarus, 1985), Lazarus and colleagues have identified several types of coping strategies, categorised as either primarily problem- or emotion-focused. A number of researchers have used factor analysis with responses to revised versions of this questionnaire (e.g. Miller *et al.*, 1992; Knussen, Sloper, Cunningham & Turner, 1992). Whilst the exact factor structure tends to vary between studies, strong problem-focused and emotion-focused coping factors are found, giving further support to the model.

Problem-focused coping is typified by a practical problem-solving strategy (e.g. "I try to analyse the situation in order to understand it better"), whereas emotion-focused coping is typified by strategies of "wishful thinking" (e.g. "I wish that the situation would go away or somehow be over with"). Other coping strategies identified include seeking emotional social support, passive acceptance, avoidance, stoicism, and positive reappraisal.

## 1.5 Research on Coping Resources

As outlined above, coping resources are an essential part of the coping process. Availability of resources affects the appraisal of the potential stressor and determines which strategies an individual can use. If resources are unavailable, the individual is more vulnerable to stress.

Recent research into the ways parents of children with disabilities cope has focused primarily upon coping resources, with an emphasis upon socio-ecological factors. As Lazarus and Folkman (1984, p. 159) note, it is not possible to list all the resources people draw upon to cope with the “myriad demands of living”. Rather, researchers have sought to identify the main categories of resources. As personal resources are more intangible, these are under-researched (Beresford, 1994).

Personal coping resources will be considered first followed by socio-ecological coping resources. As this field of research is too extensive to review comprehensively within the limits of this thesis, a summary of the main findings is given.

### 1.5.1 Personal Coping Resources

Personal coping resources identified by researchers as buffering the impact of parenting stress include physical resources, such as health, energy and stamina and psychological resources, such as personality, belief systems and problem-solving skills.

#### 1.5.1.1 Physical resources

Physical resources are relevant to coping in perhaps all stressful situations: an individual who is unwell, tired or otherwise incapacitated has less energy to expend on coping. Physical health is an important resource for parents of disabled children. Children with learning and or physical disabilities often need help with everyday tasks such as washing, dressing and undressing (Quine & Pahl, 1985), all of which can be physically demanding, particularly if lifting is involved.

However, whilst physical health is recognised in the wider coping literature as a valuable coping resource (Lazarus & Folkman, 1984), as discussed above, in studies of parents of disabled children it has usually been conceptualised as an outcome. For example, in their study of two hundred families with severely learning disabled children, Quine & Pahl (1985) found a positive correlation between the total burden of care and mothers' self-reported stress, as indicated on the Malaise Inventory (Rutter, Tizard & Whitmore, 1970). This outcome measure includes symptoms of both physical and mental ill health. Moreover, two-thirds of parents reported being woken up on "some" or "most" nights. Caring for a disabled child may, therefore, place extra demands upon parents' physical health and there may be little opportunity for renewal of this coping resource.

#### 1.5.1.2 Psychological Resources

Several researchers have investigated the impact of personality traits on parents' coping. For example, in their study of parents of children with severe physical disability, Sloper & Turner (1993) found a positive association between extraversion and maternal adaptation to the child. They note previous research suggesting that extraversion is related to effective coping efforts. Optimism and a sense of humour have also been found to be important coping resources (e.g. Venters, 1981; Libow, 1989).

In keeping with the general psychological literature, an internal locus of control (Mischel, 1993) has been shown to be a protective factor. Parents who believe that they can affect the course of their lives, those with an internal locus of control, are less vulnerable to the effects of stress (Frey, Greenberg & Fewell, 1989; Sloper et al., 1991; Sloper & Turner, 1993). Further, parents who believe in their own efficacy are more likely to achieve positive outcomes (Frey et al., 1989; Wiggs & Stores, 1998).

Parents' wider belief systems and ideologies have also been shown to be important resources. Studies have shown that parents adopting a flexible, day-to-day approach to life fare better (e.g. Bregman, 1980). Further, an ability to focus upon

the positive aspects of the parenting situation has been found to be positively associated with adjustment (Beresford, 1994). These two life philosophies may also be regarded as coping strategies (cf. problem-solving and positive reappraisal). The religious beliefs of families with a disabled child have rarely been examined and the findings are equivocal (Byrne & Cunningham, 1985; Yau & Li-Tsang, 1999).

Problem-solving skills are also important resources for coping (Lazarus & Folkman, 1984). This ability has, nevertheless, generally been conceptualised in the literature as a coping strategy as opposed to a coping resource. Previous coping and life experiences may also affect parents' appraisal of and approach to a stressful situation. However, this issue, whilst important, is methodologically problematic. Studies to date have explored the effects of prior coping experiences on how parents cope with caring using retrospective measures (Beresford, 1994). Whilst a history of positive coping experiences has been found to increase parents' perceptions of their coping efficacy and high self-efficacy has been found to be related to successful adaptation (e.g. Frey et al., 1989), retrospective measures are open to the problems of forgetting and reactivity (Elmes, Kantowitz & Roediger, 1992). As Beresford (1994) notes, longitudinal research is required to establish objectively parents' history of coping and the effects of this on adaptation.

Parenting skills are a further consideration, however, whilst studies have consistently shown that children with greater problems of management are more stressful (e.g. Quine & Pahl, 1985; Chetwynd, 1985; Sloper et al., 1991), few studies have examined parenting skills as a resource (Beresford, 1994).

### 1.5.2 Socio-ecological Coping Resources

As in the general psychological literature (Sarafino, 1990; Davison & Neale, 1990), a number of socio-ecological factors have been found to modify the impact of stressors on parents of disabled children. These include adequate income and housing, the availability of social support, parents' education and marital status and family characteristics, such as cohesion, expressed emotion and adaptability (e.g. Sloper *et al.*, 1991; Sloper & Turner, 1993).

A positive relationship between parental educational level and adaptation has been consistently reported: Quine & Pahl (1991) suggest that parents with a higher level of education have more access to information and more sophisticated problem-solving skills. The role of marital status remains a contentious issue. It is not yet clear whether being married or in a close partnership is itself a coping resource, or whether differences in the adaptation of lone parents (e.g. Quine & Pahl, 1985) reflect socio-economic circumstances and or levels of social support (Beresford, 1994).

Social support as a resource for families of disabled children has received considerable research attention (Byrne & Cunningham, 1985). Researchers have, for example, explored the availability, function and efficacy of formal, professional support, such as respite care, spouse support and support from extended family and friends (Beresford 1994). One important and consistent finding is the positive association between perceived social isolation and parental stress (e.g. Chetwynd, 1985; Quine & Pahl, 1991; Sloper *et al.*, 1991).

## 1.6 Research on Coping Strategies

There is comparatively little research on the coping strategies used by parents caring for a disabled child (Tunali & Power, 1993; Beresford, 1994). Much of the work in this area has been qualitative in nature detailing general coping strategies considered by parents to be adaptive.

Brown & Hepple (1989), for example, report parents' views as to how and why they cope with the care of their learning or multiply-disabled child. They interviewed twenty-nine families attending a Barnardo's Resource Centre in Gateshead, UK. Talking to one's spouse, to relieve emotional distress or decide upon a course of action, was the most frequently mentioned coping strategy. The extended family was also used for emotional and practical support, whereas formal support was said to be used as a last resort or in a crisis. "Thinking of how much worse it could be" and focusing on the positive characteristics of the child were common cognitive coping strategies. Some parents reported that a belief in God gave them hope.

Adopting a “take each day as it comes” approach and restructuring the situation using humour were further coping strategies.

In a somewhat unusual American study of “positive parental management” of childhood neuromuscular disease, Bregman (1980) reports a wide range of coping strategies used by parents. Bregman lived with each of six families from the New York City Metropolitan area for four days and nights to gain a deep understanding of parents’ coping tasks and strategies. Five patterns of management emerged:

First, the parents altered their perspective on time, adopting a “take each day as it comes” philosophy. They habitually scheduled activities day by day, set realistic goals and organised exciting and interesting activities for their children, to capitalise on the time available.

Second, parents aimed to maintain a lifestyle that was as normal as possible. For example, they encouraged contact with non-disabled children and maintained regularity in daily schedules. Parents were also involved in educating members of their community about their child’s condition to dispel stereotypes of handicapped people.

Third, parents attempted to minimise their families’ vulnerability by keeping well informed, monitoring the standard of services received and rectifying problems.

Fourth, parents actively developed their personal coping resources by, for example, identifying the ways in which they had helped their children, assisting other disabled individuals and engaging in “stress-reducing activities”, such as crying or participating in leisure activities.

Finally, parents cultivated their informal and formal support networks. They maintained the services of physicians and paediatricians and kept in regular contact with friends, relatives and other parents.

Qualitative research studies reporting parents' views of helpful coping strategies, such as those described above, have, therefore, provided rich data on the process of coping with caring for a disabled child. These studies have revealed a wide range of coping strategies used by parents and highlight the individuality of family responses to stress, as predicted by the process model. Similarly, the qualitative research has identified coping efforts not directly aimed at solving the problem, for example resource maintenance strategies, such as maintaining social and formal support networks and personal coping resources (Bregman, 1980).

However, whilst qualitative research has provided invaluable information about how parents cope, studies report only the strategies considered by *some* parents to be *adaptive*. Other less helpful strategies used by parents are not discussed. It is equally important to be aware of strategies that are unhelpful. With this knowledge clinicians will be better able to assist parents by, for example, providing coping skills training where needed and / or facilitating access to coping resources.

Moreover, in these studies the efficacy of the various coping strategies was measured subjectively by parents. In Bregman's (1980) study, only strategies considered by parents and Bregman herself to be helpful were reported. Although it has been shown that parents who believe in their own efficacy are more likely to achieve positive outcomes (Frey *et al.*, 1989; Wiggs & Stores, 1998), a more objective measure is required. Further, as the sample sizes are small, one cannot generalise with confidence from these findings. The studies have, nevertheless, been extremely helpful in generating testable hypotheses.

### 1.6.1 Coping Strategies and Parents' Well-being

As discussed above, Lazarus & Folkman's (1984) process model of stress and coping, emphasising coping "efforts" and the importance of focusing upon specific responses to specific encounters, has only recently been used in this field of research. Consequently, relatively little research has explored objectively the relationship between the use of coping strategies and parents' well-being. Research in this area has typically been multivariate, exploring the relationships between



potential stressors, coping resources, coping strategies and adjustment (Beresford, 1994).

#### 1.6.1.1 Parents of Children with Physical Disabilities

In a multivariate cross-sectional UK study, Sloper & Turner (1993) investigated coping among parents of children with severe physical disability. Coping strategies were measured using an adapted version of the Ways of Coping Questionnaire (Revised) (Folkman & Lazarus, 1985). Parental adjustment was assessed using measures of perceived satisfaction with current life circumstances (Sloper *et al.*, 1991) and adaptation to the child (Judson & Burden, 1980). The Malaise Inventory (Rutter *et al.*, 1970) was used to assess parental distress.

In their multiple regression analysis two types of coping strategy were identified as significant factors associated with adjustment. The strategy of seeking social support at the time of the diagnosis was positively related to satisfaction with life for mothers, whilst wishful thinking was found to be a less favourable strategy, accounting for 33.3 % of the variance in scores of mothers' and 27.9 % of fathers' adaptation to the child.

Using similar methodologies, American researchers Miller *et al.* (1992) and Thompson, Zeman, Fanurik & Sirotkin-Roses (1992) studied coping among parents of physically disabled children on a broader level by exploring the relationship between use of emotion-focused- or problem-focused coping and parental well-being. Miller *et al.* (1992) found a positive association between the use of emotion-focused strategies, such as distancing and escape-avoidance, and maternal distress. In contrast, problem-focused coping efforts such as problem solving and seeking social support were negatively associated with maternal distress.

Thompson *et al.* (1992) report similar findings. They collapsed scores from the Ways of Coping Questionnaire to generate two broad-band measures – “palliative coping” (avoidance, wishful thinking, self blame) and “adaptive coping” (cognitive restructuring, information seeking, seeking social support). Parental adjustment was assessed using the Symptom Checklist 90-Revised (Derogatis, 1977). Parents with

poor adjustment scores, those meeting the criteria for “caseness”, were found to use more palliative coping methods than parents with good adjustment scores. They also used a higher ratio of palliative to adaptive coping strategies.

#### 1.6.1.2 Parents of Children with Learning Disabilities

Several researchers have explored the coping strategies of parents of children with learning disabilities, although few have concentrated upon a specific severity level (Flynt & Wood, 1989). Sloper *et al.* (1991), for example, studied coping among 123 parents of children with Down’s syndrome living in Manchester, UK. “Practical coping” (problem solving) was found to be an adaptive strategy for mothers, whilst for fathers coping through passive acceptance was associated with greater dissatisfaction with life. For mothers use of wishful thinking was a significant predictor of poor physical and mental health.

In this study use of emotional social support was not significantly related to parental well-being. Whilst use of social support showed univariate relationships with outcome measures for both mothers and fathers, it lost its significance in the multivariate analysis after entry of personality, marital relationship and other coping factors. This finding suggests that the effect of social support is mediated by coping resources available, as predicted by the process model.

In contrast, in an American study of parents of children with various developmental disabilities Frey *et al.* (1989) found that the strategy of seeking social support was negatively associated with both psychological distress and parenting stress. Sixty percent of their sample were parents of children with Down’s syndrome. However, in both of these studies the source of social support was not considered and this may perhaps account for the different findings (Beresford, 1994). As Beresford (1994) notes, many of the coping questionnaires used cluster together a number of discrete strategies, such as use of professional support and use of informal support networks, into a single sub-scale.

Whilst researchers have studied coping among parents of children with primarily learning *or* physical disabilities, noting that “..a child with a major motor disorder..

may produce different demands to those of a child with mental handicap” (Sloper & Turner, 1993, p. 168), there has been little research specifically exploring the coping strategies of parents of children with severe learning disabilities (SLD, <50 IQ, Turk, 1996). As discussed above, children with SLD commonly have congenital physical abnormalities and sensorimotor deficits (Davison & Neale, 1990; Quine & Pahl, 1985) and often exhibit behavioural problems (Turk, 1996).

More research in this area is needed: Quine & Pahl (1985) found that children who have more impairments and / or behavioural problems produce more stress in those who care for them. Further, Sloper *et al.* (1991) found a positive correlation between child’s IQ and mothers’ perceived satisfaction with life. It would seem, therefore, that parents of children with SLD are at greater risk of parenting stress and psychological distress. What has not yet been fully established, however, is how such parents manage their stress.

Quine & Pahl (1991) report on a study of 166 mothers caring for a child with severe learning disabilities. Maternal stress was measured using the Malaise Inventory (Rutter *et al.* 1970). Coping strategies were assessed using the Measure of Daily Coping (MDC) (Stone & Neale, 1984). The MDC lists eight coping styles: distraction, direct action, catharsis, acceptance, seeking social support, relaxation, religion and situation redefinition.

In their univariate analysis, coping through catharsis was significantly related to *higher* stress scores. This finding contradicts previous research indicating that parents find venting of emotions beneficial (e.g. Bregman, 1980; Brown & Hepple, 1989). Parents in Bregman’s (1980) study cited “crying” as a stress-reducing activity. Further, as mentioned above, freedom to express emotions has been found to be an important coping resource (e.g. Sloper *et al.*, 1991).

This result may, perhaps, be an artefact of the measures used by Quine and Pahl. As Beresford (1994) notes, cathartic behaviours such as “crying” feature in the Malaise Inventory, and the MDC may not discriminate between maladaptive emotional release and therapeutic emotional discharge.

As the purpose of their study was to explore the relationships between stressors, coping resources, coping strategies and parents' adjustment, only the variables associated with Malaise scores are reported. Interestingly, in contrast to previous research, seeking social support and use of direct action (problem solving) were not associated with outcome. Unfortunately, Quine & Pahl (1991) do not give details of other coping strategies used by parents of children with SLD and do not give an indication of the proportion of parents adopting each type of coping strategy.

As in studies of related populations (e.g., Frey *et al.*, 1989), Quine & Pahl (1991) found a positive relationship between perceived coping skills and well-being. In their hierarchical regression analysis, perceived coping skills accounted for a higher proportion of the variance in mothers' well-being (18.7%) than any other variable, suggesting that this is a more important determinant than the severity of stressors encountered.

Wiggs & Stores (1998) report a similar association between perceived control and maternal stress in their study of sleep problems in children with SLD. As this was the main focus of their research, the relationship between coping strategies and well-being was not explored.

These findings again suggest that interventions aimed at preventing or reducing stress in parents and other members of the family system should incorporate work on training parents in the use of coping strategies associated with positive outcomes. Further research examining the types of coping strategies used and the relationship between parents' coping strategies and well-being in this population is, therefore, needed to guide such interventions.

## 1.7 Summary

The traditional approach of researchers exploring adjustment in families caring for a disabled child has been to examine and document the stressors they experience and the adverse effects of these stressors on the well-being of individual family members. Whilst this approach has raised awareness of the families' circumstances and their support needs, it has also served to stereotype such families, leading

researchers and professionals to assume inevitable distress (Byrne & Cunningham, 1985; Yau & Li-Tsang, 1999).

The concept of “coping” has been introduced to the field in recent years. The recognition that a negative outcome is not inevitable and that parents cope with varying degrees of success with the day-to-day care of their children, has led to a focus on models of stress and coping which can account for this variation in response. One such model, that of Lazarus & Folkman (1984), conceptualises stress as a process involving continuous transactions between a person and the environment. Within this conceptual framework, an individual’s appraisal of the event as stressful and its outcome are said to be dependent upon the availability and utilisation of coping resources and coping strategies.

Recent research examining the ways parents of children with disabilities cope has focused primarily upon coping resources. Personal coping resources found to buffer the impact of parenting stress include physical health, optimism, extraversion, a sense of humour and an internal locus of control. Adequate income and housing, a cohesive family environment and social support have been found to be important socio-ecological coping resources. There is relatively little research on the coping strategies used by parents (Tunali & Power, 1993; Beresford, 1994). Much of this work is qualitative in nature, reporting parents’ views of helpful coping strategies. Comparatively little research has explored objectively the relationship between the use of coping strategies and parents’ well-being (Beresford, 1994).

This topic is of importance to all health professionals concerned with promoting well-being. Whilst research examining coping resources has increased understanding of the coping process in parents of children with disabilities, many of the resources identified, such as personality variables and socio-economic circumstances, cannot readily be addressed by clinicians. However, with a greater understanding of parents’ coping and awareness of both adaptive and maladaptive coping strategies, clinicians will be better able to assist parents by, for example, providing coping skills training where needed or facilitating access to coping resources.

Moreover, the escalating policy of greater community provision and, albeit limited, in-home support for families with a disabled child has made it increasingly important that parents effectively manage the day-to-day stresses of caring. Further, with recent changes in national policy, professionals are obliged to meet the needs of carers and promote their well-being (Department of Health, 1999). Research examining parents' current ways of coping and well-being is an essential part of this process.

Researchers exploring the coping strategies used by parents caring for a disabled child have investigated, defined and categorised coping strategies in a variety of ways, making it difficult to draw firm conclusions regarding the efficacy of different coping strategies (Beresford, 1994). There are, however, some commonalities in the research findings to date. In both quantitative and qualitative studies of parents' coping practical coping strategies such as planning, direct problem-solving and information seeking have generally been found to be associated with higher levels of well-being (e.g. Bregman, 1980; Sloper *et al.*, 1991; Miller *et al.*, 1992; Thompson *et al.*, 1992). Further, the strategy of using wishful thinking to manage stressful parenting situations has been consistently found to be associated with less favourable outcomes (Frey *et al.*, 1989; Sloper *et al.*, 1991; Thompson *et al.*, 1992; Sloper & Turner, 1993).

The utility of seeking social support, however, needs to be clarified. Whilst social support has been found to be an important coping resource, in their multivariate analyses both Sloper *et al.* (1991) and Quine and Pahl (1991) found that use of social support was not significantly associated with parental well-being. These findings conflict with those of previous studies using similar methodologies with related populations, in which a positive association between use of social support and adjustment was found (e.g. Frey *et al.*, 1989; Miller *et al.*, 1992; Thompson *et al.*, 1992; Sloper & Turner, 1993). Researchers investigating the use of social support as a coping strategy have, however, not considered the source of the support sought (e.g. informal, formal) which may perhaps account for the different findings (Beresford, 1994).

Further, whilst several researchers have studied coping among parents of children with either learning *or* physical disabilities, there has been little research specifically exploring the coping strategies of parents of children with severe learning disabilities (SLD), who often face the challenge of multiple impairments, including learning *and* physical disability. As Flynt & Wood (1989) note, although researchers have identified severity of condition as a stressor contributing to the demands placed upon the family, many investigators have nevertheless tended to view learning disabled children as a homogeneous group and, subsequently, few have focused upon a specific severity level. Whilst Quine and Pahl (1991) report on a large-scale quantitative study of mothers caring for a child with SLD, their findings are inconsistent with previous research with related populations. In their study, seeking social support and use of direct action (problem-solving) were not associated with parental well-being. Further research is required to ascertain whether these inconsistent findings can be replicated.

Whilst studies using purely qualitative techniques have identified a wide variety of coping strategies used by parents of children with disabilities (e.g. Bregman, 1980, Brown & Hepple, 1989), these studies report only the strategies considered to be *adaptive*, based upon *subjective* ratings. Less helpful coping strategies used by parents are not discussed. However, paradoxically, studies using strictly quantitative methods and standardised coping questionnaires consisting of a limited list of strategies restrict parents' responses. Such measures cannot be taken to include *all* coping strategies parents use and will not provide detailed information. The research literature, therefore, indicates the importance of combining both qualitative and quantitative techniques.

## 1.8 Aims of the Current Study

The reviewed literature on parenting stress, psychological distress and coping in parents of disabled children, therefore, highlights a need to explore further the strategies parents of children with severe learning disabilities (SLD) use to manage the daily stresses and chronic strains of caring. Further research examining the types of coping strategies used and the relationship between parents' coping

strategies and well-being in this population is needed. The present study aims to address this need.

The study aims to add to the growing body of knowledge on stress and coping among parents of children with disabilities in four main respects:

Firstly, the study will add to the limited research exploring the relationship between use of coping strategies and parents' well-being. Correlations between parents' scores on a measure of coping strategies and two measures of well-being will be examined.

Secondly, in contrast to previous studies of coping strategies and well-being, the source of social support used by parents of children with disabilities to manage stressful situations will be taken into account and controlled for by the use of a coping questionnaire measuring primarily parents' use of informal support. Correlations between parents' scores on a measure of use of informal social support and two measures of well-being will be examined.

Thirdly, the study will add to the limited research on the coping strategies of parents of children with severe learning disabilities (SLD). The findings of Quine and Pahl's (1991) study of coping in mothers of children with SLD are inconsistent with previous research, warranting further confirmatory or disconfirmatory research.

Finally, the study will go beyond previous studies of parents' coping strategies by using both quantitative and qualitative measures of coping. The coping questionnaire to be used includes an optional open-ended item, allowing parents to describe other idiosyncratic strategies they use not otherwise listed.



## 1.9 Research Questions and Hypotheses

Based upon the cognitive-behavioural process model of stress and coping outlined (Lazarus & Folkman, 1984) this research, therefore, aims to address the following questions:

- What level of parenting stress and psychological distress do parents of children with SLD experience?
- What proportion of parents of children with SLD experience psychological distress at clinically significant levels (i.e. warranting professional assistance)?
- Which types of coping strategies do parents of children with SLD employ to manage parenting stress?
- What is the nature of the relationship between use of individual coping strategies and parents' well-being?

Further, drawing upon the consistent empirical data from related populations, six hypotheses are proposed:

### *Hypothesis One*

The use of practical coping to manage stressful parenting situations is associated with lower levels of psychological distress.

### *Hypothesis Two*

The use of practical coping to manage stressful parenting situations is associated with lower levels of parenting stress.

*Hypothesis Three*

The use of emotional social support to manage stressful parenting situations is associated with lower levels of psychological distress.

*Hypothesis Four*

The use of emotional social support to manage stressful parenting situations is associated with lower levels of parenting stress.

*Hypothesis Five*

The use of wishful thinking to manage stressful parenting situations is associated with higher levels of psychological distress.

*Hypothesis Six*

The use of wishful thinking to manage stressful parenting situations is associated with higher levels of parenting stress.

## **2. Method**

### 2.1 Ethical Approval

The research proposal was submitted to and approved by the University of Leicester Doctor of Clinical Psychology Course Research Subcommittee. As the study was to be conducted in Derbyshire, the proposal was submitted to the North Derbyshire Local Research Ethics Committee and Southern Derbyshire Ethics Committee of the National Health Service (NHS). The Committees both advised that NHS Ethics Committee approval was not required, as the research was to involve a community sample and was not to be conducted in NHS settings (Appendix 1).

The proposal was also submitted to and approved by the Leicestershire and Rutland Healthcare NHS Trust Research and Development Operational Group. The Group confirmed that the Leicestershire and Rutland Healthcare NHS Trust would provide indemnity for the study.

The Group recommended that the covering letter include a more explicit offer for any parents who were distressed or wished to talk about issues raised by the study to contact the researcher (Appendix 1). These suggested changes to the covering letter were made.

### 2.2 Sample

#### 2.2.1 Eligibility Criteria

Respondents were required to be the natural parent of a child with severe learning disabilities (SLD) under the age of eighteen, whose child lived at home, was not in long-term care, and attended a special school in Derbyshire. As in other education authorities (Caine, Hatton & Emerson, 1998), almost all pupils with SLD in Derbyshire receive segregated education in special schools, which may include pupils with moderate learning difficulties. Only a very small number of pupils with SLD in Derbyshire, for example approximately 20 in Derby City, attend Enhanced

Resource or mainstream schools (personal communication, Statementing Officer, Derby City Education Service, February 17, 2000). These schools were not included in the study as parents of pupils with SLD attending the schools were not readily identifiable. The Education Service does not collect data documenting the number and location of pupils with SLD who are mainstreamed.

Foster parents were excluded from participation in the study as it was felt that their experiences of parenting a child with SLD would differ from those of natural parents. Unlike natural parents, foster parents *chose* to care for a child with SLD and may have a different attitude or approach to the child. Foster parents also do not have final responsibility for children in their care. Further, previous experience of caring for a child with difficulties may influence foster parents' ways of coping and experiences of parenting stress.

### 2.2.2 Sampling

The analysis is based upon a non-random, self-selected sample of 123 parents of children with SLD drawn from the wider population of parents of children with SLD whose children attend special schools in Derbyshire. A community sample as opposed to a clinical sample was used as it was felt that this would represent more closely the range of parents' experiences and coping strategies, including those of parents seeking professional support.

### 2.2.3 Sample Size

Power calculations for Pearson's  $r$  correlation coefficients were performed, on the assumption that parametric tests were to be used, to ascertain the required sample size (Howell, 1992). The correlation between relative coping scores on the coping questionnaire and outcome measures (effect size) was estimated as being between .20 and .40, based upon findings of previous studies using similar measures (Frey *et al.*, 1989; Miller *et al.*, 1992). An estimated effect size of .30 was, therefore, used to calculate the sample size required for a high power level of .80. The power analysis revealed that a sample size of 88 was required for an effect size of .30 to obtain a power level of .80.

As postal surveys are generally cheaper and quicker, especially when respondents are widely distributed (Mathers, Fox & Hunn, 1998), a postal survey was used to achieve a large sample within budgetary and time constraints.

Based upon the results of previous postal surveys, a response rate of between 20 % and 40 % was expected. Fink (1995) reports a 20 % response rate for first mailings and Wiggs & Stores (1996) report a 43 % response rate for their postal survey of sleep disturbance in children with SLD, which involved some repeat mailings. To allow for the expected response rate oversampling was used (Fink, 1995) to achieve a minimum sample size of 88.

#### 2.2.4 Response Rate

Questionnaire packs were distributed to 317 households of children with SLD (see Procedure below). Participation was on a voluntary basis. A total of 139 questionnaire packs were returned (44 %). Of these, seven (5 %) were returned blank. One blank return was from a Social Services Hostel Keyworker, who advised that the child concerned lives at the Hostel and has no contact with her parents. Nine (6.8 %) of the completed questionnaire returns were from female foster parents. These were excluded from the analysis. The final sample therefore consisted of 123 parents.

The overall response rate was, therefore, 40 % (123 / 307 eligible respondents).

#### 2.2.5 Characteristics of the Sample

Of the 123 respondents, 113 (91.9 %) were mothers and 10 (8.1 %) were fathers of a child or children with SLD. In two cases the respondent was the natural parent of two children with SLD. In one of these cases only one child with SLD lived at home and, therefore, data regarding this child were entered for analysis. In the second case data concerning the eldest child was arbitrarily chosen and entered for analysis.

Demographic characteristics of the sample are given in Table 1. Table 1 shows that participants were predominantly White (86.2 %) and married (74.0 %). Participants came from the full range of social classes. Most participants (64 %) were caring for a male child with SLD.

Table 1. Demographic characteristics of the sample

Parental age:	Mean	40.0 years	(SD = 7.49, range 21-68)		
Child age:	Mean	10.8 years	(SD = 3.89, range 3-17)		
Child gender:	Male	79	(64 %)	Female	44 (36 %)
Marital status of parent:	Single	5	(4.1 %)	Separated	1 (0.8 %)
	Married	91	(74.0 %)	Divorced	18 (14.6 %)
	Cohabiting	8	(6.5 %)		
Social class: <sup>a</sup>					
	I / II	40	(32.5 %)		
	III	33	(26.8 %)		
	IV	15	(12.2 %)		
	V	4	(3.3 %)		
	Economically inactive	30	(24.4 %)		
	Missing data	1	(0.8 %)		
Ethnic origin:					
	White	106	(86.2 %)		
	Black-Caribbean	5	(4.1 %)		
	Indian	4	(3.2 %)		
	Pakistani	6	(4.9 %)		
	Bangladeshi	1	(0.8 %)		
	Chinese	1	(0.8 %)		

N = 123

<sup>a</sup> Social class is based on the occupation of the main wage earner in the household using National Census occupational categories (HMSO, 1998).

The median number of children in the family, including children without disabilities, was two (range 1-10). In twenty cases (16.3 %) participants had one child, a child with SLD. Eighty-three percent of the children with SLD were classified by their parent as being mobile, although in some cases the child's mobility was noted to be restricted. In 80.5 % of cases the child had other disabilities in addition to SLD. A breakdown of these additional disabilities, as reported by parents, is given in Table 2.

Table 2. Additional disabilities of children in the sample as reported by parents

Disability	Frequency <sup>a</sup>	% of children
Autism	10	8.1
Behaviour problems	41	33.33
Cerebral Palsy	6	4.9
Communication problems	17	13.8
Epilepsy	15	12.2
Hearing loss / deaf	11	8.9
Visually impaired / blind	14	11.4
Other physical / medical conditions (e.g. tracheostomy, scoliosis, heart defect)	23	18.7

*N* = 123

<sup>a</sup> Column total does not add up to 123 as some children had multiple disabilities.

In five cases (4.1 %) the child made use of the school's residential facility. Twelve participants (9.8 %) indicated that they were using psychological or mental health services to manage their child with SLD at the time of the study.

Ten participants (8.1 %) indicated that they acted as the sole carer of their child with SLD. However, in most cases (69.9 %) participants shared the care of their child with one other person or agency. Twenty-two participants (17.9 %) indicated that they received practical support from two other sources, four (3.3 %) noted three sources and one participant (0.8 %) listed six other sources of support. Current or ex-spouses / partners were the most commonly cited sources of support ( *N* = 102, 90.3 %). Other family members, such as grandparents and siblings of the child with SLD, were cited in 23 cases (20.4 %). Twelve participants (10.6 %) indicated use

of formal respite care, such as link family schemes and domiciliary services. Three participants (2.7 %) employed their own child minder or carer. Friends were cited as sources of practical support in four cases (3.5 %).

## 2.3 Measures

### 2.3.1 You & Your Family Background Questionnaire

A questionnaire entitled “You & Your Family” was developed for the collection of demographic data and information regarding the families’ circumstances (Appendix 2).

Categories used to determine the ethnic origin of participants followed those used in the National Census (HMSO, 1998). These categories are known to be acceptable to the ethnic minorities concerned. The occupation of the main wage earner in the household was used to determine social class. Occupational categories used on the questionnaire were also based upon those used in the National Census (HMSO, 1998). For simplicity, Social Class I (Professional) and Social Class II (Managerial and Technical) were combined into one category named “Professional”. The categories “Housewife / husband”, “Student”, “Unemployed” and “Never had occupation” were added as it was felt that they would be more acceptable to participants than the Census category “Economically inactive”. Social class based upon occupation as indicated by participants on the questionnaire was, therefore, categorised as follows:

- I/II Professional / Managerial and Technical occupations
- III Skilled occupations (including manual and non-manual)
- IV Partly skilled occupations
- V Unskilled occupations
- Economically inactive (e.g. carer, housewife / husband, student, unemployed)

The question “Who shares the care of your child / children?” was included to provide an indicator of the amount and source of practical social support available to the respondent. The choice of categories of support, “Spouse / Partner”, “Other



family member”, “Friend”, “Other” was informed by a review of the literature. As two of the six participating schools have a residential facility, respondents were asked whether or not their child with SLD was a boarder at their school. Respondents were also asked whether or not they currently use psychological and or mental health services to manage their child with SLD to determine use of this coping strategy.

The “You & Your Family” questionnaire was piloted with a small number of people known to the researcher ( $N = 3$ ) along with the covering letter and other measures in the questionnaire pack to determine ease of completion and the approximate time taken to participate. All participants in the pilot study reported that they found the questionnaire pack easy to complete. As these participants were not parents of children with SLD, their responses were not included in the study. The approximate time taken to complete the questionnaire pack (10 minutes), as reported by participants in the pilot study, was indicated on the covering letter (Appendix 3).

### 2.3.2 Measures of Well-Being

#### 2.3.2.1 Measure of Parenting Stress

The Questionnaire on Resources and Stress – Friedrich Short-Form (QRS-F) (Friedrich, Greenberg and Cmic, 1983, Appendix 4) was used as a measure of parenting stress. Whilst several other measures of parenting stress exist, including the Malaise Inventory (Rutter *et al.*, 1970) and Parenting Stress Index (Abidin, 1983), the QRS-F was chosen in preference because it was specifically designed to measure the impact of a developmentally delayed, learning disabled or chronically ill child on other family members. The QRS-F also benefits from its simple true / false format, use of both positively and negatively phrased items and good psychometric properties. Further, unlike the Malaise Inventory, the QRS-F does not include cathartic behaviours, such as “crying” and “getting angry”, as indicators of parenting stress. As discussed above, these behaviours are often reported as coping strategies.

### 2.3.2.1.1 Description

The QRS-F is a self-administered 52-item true / false instrument developed from the 285-item Questionnaire on Resources and Stress (Holroyd, 1974). It consists of four factorially analysed subscales, which assess parental perceptions about:

Parent and family problems (20 items)

Pessimism (11 items)

Child characteristics (15 items)

Physical Incapacity (6 items)

Parents are required to give true or false answers to statements concerning themselves and their family. As the QRS-F is an American questionnaire, an anglicised version was used in the present study (McConachie & Waring, 1997).

### 2.3.2.1.2 Scoring

Total factor scores were calculated by summing responses to items in each sub-scale using the scoring keys provided with the questionnaire. The four factor scores were added together to obtain a total QRS-F score for perceived stress (maximum 52). QRS-F total scores were used as a measure of parenting stress. Higher scores are taken to be indicative of greater distress within a family (Dyson *et al.*, 1989).

### 2.3.2.1.3 Psychometric Properties

The QRS-F has a correlation of .997 with the original longer form (Friedrich *et al.*, 1983). The Kuder-Richardson-20 reliability coefficient for the scale is .95, with item-total correlations ranging from .15 to .63 and a mean inter-item correlation of .26. Scott, Sexton, Thompson & Wood (1989) have also examined the psychometric properties of the QRS-F. They concluded that the QRS-F demonstrated satisfactory convergent, divergent and construct validity.

The QRS-F has been used in several studies of adaptation of families with a disabled child as a measure of outcome (e.g. Frey *et al.*, 1989; Flynt & Wood, 1989;

Donovan, 1988; Dyson, 1997) and an American study of stress in parents of children with severe learning disabilities (Rousey, Best & Blacher, 1992). These studies have provided evidence of its construct, discriminant and predictive validity.

### 2.3.2.2 Measure of Psychological Distress

The General Health Questionnaire-12 (GHQ-12) (Goldberg, 1992, Appendix 5) was used as a measure of psychological distress. Whilst there are a number of other measures available, such as the Symptom Checklist-90 (Derogatis, 1977) and Brief Symptom Inventory (Derogatis & Spencer, 1982), the GHQ-12 was chosen for its brevity, simplicity, good psychometric properties and ability to detect psychiatric cases.

#### 2.3.2.2.1 Description

The GHQ-12 is a self-administered 12-item shortened version of the General Health Questionnaire (Goldberg, 1978) designed to detect non-psychotic psychiatric disorder in people in community and medical settings. For each item respondents are required to rate how much they feel their present state is similar to or different from their usual state.

#### 2.3.2.2.2 Scoring

Participants' responses to the GHQ-12 were scored using the GHQ method (0-0-1-1, e.g. Not at all = 0, No more than usual = 0, Rather more than usual = 1, Much more than usual = 1) which produces a symptom count, as opposed to Likert scoring where responses score 0, 1, 2 and 3 respectively. GHQ scoring was used as, whilst this produces a skewed distribution, it is appropriate for detecting cases (Johnston, Wright & Weinman, 1995). Further, a recent large scale ( $N = 25916$ ) World Health Organisation (WHO) study found the GHQ method to be superior to the Likert method for the GHQ-12 with regard to its effect upon validity coefficients (Goldberg, Gater, Sartorius, Ustun, Piccinelli, Gureje & Rutter, 1997).

Scores were summed to give a GHQ-12 total score (maximum 12). This score was used in the current study as a measure of psychological distress. Higher scores are taken to be indicative of greater psychological distress.

Johnston *et al.* (1995) state that the recommended cut-off threshold for psychiatric disorder or “caseness”, as assessed by the GHQ-12, is 2 / 3 using the GHQ method. However, the threshold used varies between studies and in the WHO study the best threshold for the UK (Manchester) was found to be 3 / 4 (Goldberg *et al.*, 1997). A score of three or higher was therefore used in the current study to detect parents experiencing psychological distress at clinically significant levels.

#### 2.3.2.2.3 Psychometric Properties

The internal consistency of the GHQ-12 as assessed by Cronbach’s alpha ranged from 0.82 to 0.90 in a series of studies; the GHQ-12 also has good split-half reliability (0.83) and test-retest reliability (0.73) (Johnston *et al.*, 1995). The validity of the GHQ-12 has been examined and confirmed in several studies by assessing its sensitivity in detecting psychiatric cases. In the WHO study, for the UK sample, sensitivity was 84.6 % and the specificity in detecting cases of disorder was 89.3 % (Goldberg *et al.*, 1997).

### 2.3.3 Measures of Coping

#### 2.3.3.1 Ways of Coping (Revised) Questionnaire

The Ways of Coping (Revised) Questionnaire (WC-R) (Knussen *et al.*, 1992, Appendix 6) was used as a quantitative measure of coping strategies employed by parents. Whilst there are several other measures of coping strategies available, such as the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983), MDC (Stone & Neale, 1984), COPE (Carver, Scheier & Weintraub, 1989) and Coping Responses Inventory (Moos, 1993), the WC-R was chosen in preference for a number of reasons.

Firstly, the WC-R was adapted from the original Ways of Coping (Revised) Questionnaire (Folkman & Lazarus, 1985) to specifically measure coping in parents of children with learning disabilities (Down's syndrome) and has been successfully used with this population (Sloper *et al.*, 1991). Secondly, the Ways of Coping is the most widely used measure in the field (McConachie & Waring, 1997) and use of the WC-R therefore allows more direct comparison of the results with previous findings. Thirdly, the WC-R emerged from Lazarus & Folkman's (1984) process model of stress and coping, the theoretical model used to inform the current study. Fourthly, the WC-R has demonstrated adequate internal reliability and psychometric properties (Knussen *et al.*, 1992; Hatton, Knussen, Sloper & Turner, 1995). Finally, unlike the CHIP (McCubbin *et al.*, 1983) which assesses parents' perceptions of the *helpfulness* of coping strategies listed, the WC-R requires parents to indicate the coping strategies that they *use* and thus allows outcome to be measured more objectively.

#### 2.3.3.1.1 Description

The WC-R is a 48-item self-administered questionnaire developed from the Ways of Coping (Revised) Questionnaire (Folkman & Lazarus, 1985). The 48 items represent thoughts and actions which may be used to manage the demands of a stressful encounter. Knussen *et al.* (1992) controlled the source of the encounter by specifying that respondents complete the WC-R in relation to "problems in bringing up your child with Down's syndrome". All items taken from the original questionnaire were re-phrased in the present tense to encourage respondents to relate the items to a current or recent stressful encounter and some words were anglicised for use with a British sample (Knussen *et al.*, 1992).

In the current study the source of the encounter was controlled by specifying that respondents complete the WC-R in relation to "problems in bringing up your child with severe learning disabilities (SLD)".

Respondents are required to rate each item on a four-point Likert scale, from "not used" to "used a great deal".

The WC-R consists of five factorially analysed subscales representing five distinct coping strategies:

1. Practical Coping (17 items) e.g. “I make a plan of action and follow it.”
2. Wishful Thinking (18 items) e.g. “I hope a miracle will happen.”
3. Stoicism (5 items) e.g. “I maintain my pride and keep a stiff upper lip”.
4. Seeking Emotional Social Support (5 items) e.g. “I talk to someone about how I am feeling”
5. Passive Acceptance (3 items) e.g. “I accept it, since nothing can be done.”

### 2.3.3.1.2 Scoring

Relative coping scores – the proportion of total coping efforts used on a specific strategy, as opposed to raw scores – the frequency of efforts used on a specific strategy, were obtained for each subscale, as recommended by Vitaliano, Maiuro, Russo & Becker (1987). The use of relative scores is recommended as they take into account individual differences in the relative use of ways of coping, controlling for both inequality in the numbers of items in each subscale and individual differences in overall response rates (Vitaliano *et al.*, 1987).

Relative scores were computed by first calculating the mean item scores for each of the five subscales. Mean item scores were obtained by dividing the sum of the ratings (raw score) by the number of items in the subscale (e.g. 17 on Practical Coping, 18 on Wishful Thinking, etc.). Relative scores were then obtained by dividing the mean item scores by the sum of the mean item scores for each of the subscales. By way of example, participants’ relative coping scores for the Practical Coping subscale (1) in relation to the other four subscales (2, 3, 4, and 5) were calculated as follows.

Relative score (1)

$$= \frac{\text{mean item score (mis) (1)}}{\text{mis (1) + mis (2) + mis (3) + mis (4) + mis (5)}}$$

### 2.3.3.1.3 Psychometric Properties

In their study of 182 parents of children with Down's syndrome, Knussen *et al.* (1992) found that coefficients of reliability (alpha) for the five subscales on the WC-R were 0.90, 0.89, 0.65, 0.77 and 0.53 respectively. The stability of the WC-R over time has also been assessed by comparing the scores of mothers and fathers of children with Down's syndrome over a three-year time interval (Hatton *et al.*, 1995). Paired samples *t* tests revealed that parents' scores on the five coping strategy subscales had not changed significantly over the three-year period. Test-retest reliability was found to be adequate for all subscales, with the exception of mothers' scores on the Passive Acceptance subscale and fathers' scores on the Stoicism subscale. The three WC-R subscales hypothesised in the current study to be associated with parental well-being - Practical Coping, Wishful Thinking and Seeking Emotional Social Support - have, therefore, demonstrated both adequate internal reliability and test-retest reliability.

The validity of the WC-R has also been assessed and shown to be acceptable. Knussen *et al.* (1992), for example, compared the subscales resulting from their factor analysis with those reported in earlier studies and found them to be similar. Further, the WC-R has been used in studies of adaptation of parents of children with Down's syndrome (e.g. Sloper *et al.*, 1991) and parents of children with severe physical disability (Sloper & Turner, 1993), demonstrating validity in its pattern of associations with outcome variables, such as parenting stress, as discussed above.

### 2.3.3.2 Open-ended item

"I tried something entirely different from any of the above. (Please describe)."

As discussed above, an optional open-ended item was added to the end of the WC-R to allow parents to describe additional idiosyncratic coping strategies that they use to manage stressful parenting situations. This item, therefore, provided a second qualitative measure of coping. The wording of the open-ended item was taken directly from item 67 of the Ways of Coping (Revised) Questionnaire (Lazarus & Folkman, 1984).

## 2.4 Design

A cross-sectional, predominantly quantitative and correlational research design was employed to address the research questions posed. As the relationship between parents' use of individual coping strategies and their well-being was the subject of investigation, this necessitated use of a correlational design to explore the association between variables.

Hypotheses regarding associations between coping strategies used and psychological distress were tested by examining correlations between Practical Coping, Wishful Thinking and Seeking Emotional Social Support WC-R relative coping scores and GHQ-12 total scores.

Hypotheses regarding associations between coping strategies used and parenting stress were tested by examining correlations between Practical Coping, Wishful Thinking and Seeking Emotional Social Support WC-R relative coping scores and QRS-F total scores.

## 2.5 Procedure

### 2.5.1 Discussion of Research Proposal with Headteachers

School lists giving details of special school placements funded for children with SLD were obtained from Derby City Council and Derbyshire County Council Education Departments (January 1998 figures). These lists indicated that there are seven special schools offering placements to pupils with SLD located across Derbyshire. Three of these are mixed ability schools offering placements to pupils with both moderate and severe learning disabilities.

The research proposal was discussed over the telephone in the summer or autumn term of 1999 with Headteachers of each of the seven schools. Headteachers of three schools gave their approval for the project over the telephone and did not wish to meet to discuss the proposal further. One Headteacher expressed an interest in the project but decided not to involve parents of children attending his school as the



future of the school is uncertain due to amalgamation. He felt that parents are currently experiencing unusual levels of stress which would confound the results.

Meetings were held with three Headteachers at their respective schools to discuss the proposal further and the requirements of the study. All three Headteachers expressed an interest in the project and gave their approval.

One Headteacher enlisted the services of his bilingual assistant to translate the questionnaires over the telephone for non-English-speaking illiterate parents wishing to participate. The Headteacher advised that this would be required for three families. The same Headteacher also requested that the educational term “significant learning difficulties” be used on questionnaires sent out by his school as opposed to “severe learning disabilities”, as this term is used by the school to refer to SLD. The Ways of Coping – Revised (WC-R) questionnaire and covering letter were altered for this school as requested.

In summary, six out of the seven special schools in Derbyshire offering placements to pupils with SLD participated in the study. Headteachers of each participating school provided approximate numbers of pupils stated as having SLD attending their schools and details of term dates.

All seven Headteachers expressed an interest in the project and requested a summary of the results.

### 2.5.2 Questionnaire Distribution

The measures described above were distributed in a clear plastic wallet with a stamped addressed envelope for the return of questionnaires, accompanied by a covering letter explaining the purposes and requirements of the study (Appendix 3).

Coloured headed paper was used for the covering letter as this has been shown to increase response rates (Mathers *et al.* 1998). The literacy level of the covering letter was ascertained by calculating the Flesch Reading Ease Score. The Flesch Reading Ease Score computes readability based upon the average number of

syllables per word and the average number of words per sentence. Scores range from 0 to 100, with higher scores indicating greater readability. The Flesch Reading Ease Score of the covering letter was 60, which is typical of standard writing (Mathers *et al.*, 1998).

The covering letter reassured respondents of their confidentiality and emphasised that participation was on a voluntary basis. To stress this latter point, parents were asked to return their questionnaires blank if they did not wish to participate in the study. To ensure confidentiality, returns were mailed directly to the researcher.

The questionnaires were placed in clear plastic wallets to protect them from accidental damage or spillage when taken home by pupils. Respondents were asked not to return the wallets to reduce postage costs. However, it is possible that provision of the plastic wallets also unintentionally served as a small incentive to participate, as one participant expressed their gratitude for the wallet on their questionnaire return.

The questionnaire pack was designed to be inviting and self-completed without assistance. Measures were chosen for their psychometric properties, sensitivity to participants' feelings and ease of completion. All measures were anonymous.

Each participating school was provided with a box of questionnaire packs and a contact telephone number in the case of any difficulties. Distribution was carried out by Class Teachers: pupils with SLD were given a questionnaire pack to take home to their parents. The distribution took place in the autumn term of 1999. To maximise the response rate packs were not distributed over holiday periods (Mathers *et al.*, 1998).

Headteachers were contacted to obtain the precise number of questionnaire packs distributed and response rate. Return envelopes were numbered to allow identification of the school from which it was distributed, to monitor progress and to calculate the response rate for each school. Headteachers were informed of the response rate for their school and thanked for their participation in the study.

### 2.5.3 Thank You and Reminder

Whilst a higher response rate may be achieved if repeated mailings are sent out to eligible non-respondents (Fink, 1995; Mathers *et al.*, 1998), this method was not used for several reasons. First and foremost, it was felt that this would aggravate parents and increase their stress. This would be highly insensitive given the nature of the study and would perhaps confound the results.

Secondly, it was felt that parents would question their anonymity as schools would be required to keep a record of parents' names and the numbers of their questionnaire packs to facilitate this process. Anonymity was felt to be important given the sensitive topic. In support of this argument, two respondents blanked out the number on their return envelope and one respondent emphasised the need for their answers to remain confidential. Further, it has been suggested that anonymity may reduce possible social desirability response bias in the WC-R (Knussen *et al.*, 1992).

Thirdly, use of repeated mailing would have increased the schools' involvement in the study and the workload of Class Teachers, which may perhaps have reduced their participation.

In view of the above, Headteachers were instead contacted and asked to place a thank you and reminder to parents in the school newsletter. In three cases the content of the message to parents was discussed over the telephone. In the remaining three cases letters were sent to Headteachers (Appendix 7). The reminders expressed gratitude to parents for their participation and the well wishes received from a number of participants (Appendix 8). Parents were informed that there was still time to participate and return their questionnaires if they had yet to do so.

A minimum of six weeks was allowed for the first wave of questionnaires to be returned, as recommended by Mathers *et al.* (1998), before Headteachers were contacted and the messages sent out in the newsletters. A second wave of questionnaires was received, indicating that the message had been effective.

#### 2.5.4 Contact with Participants

The covering letter encouraged respondents to contact the researcher for any further information required about the study. Further, as stress and coping is a sensitive topic and some of the questionnaire items were potentially distressing, participants were encouraged to contact the researcher if they wished to discuss issues raised by the study.

In two cases telephone contact was established with participants, issues or queries addressed and suggestions given regarding possible sources of support where applicable.

Written comments received from participants can be found in Appendix 8.

### 3. Results

#### 3.1 Organisation of the Results

For clarity, the results of the study are presented following the order of the research questions and hypotheses set in chapter one. The raw data from the QRS-F, GHQ-12 and WC-R may be found in Appendix 9. A copy of the summary of results sent to the schools is given in Appendix 10. As both quantitative and qualitative measures of coping strategies were employed, to avoid confusion, quantitative data are presented first and qualitative data presented separately in a later sub-section. As few fathers participated in the study ( $N = 10$ ), all data obtained from fathers were analysed together with the data from mothers

#### 3.2 Quantitative Data

##### 3.2.1 Levels of Parenting Stress Reported by Parents

Summary data from the QRS-F indicating levels and sources of parenting stress, as reported by parents, are given in Table 3. The mean total score of 30.05 ( $SD = 9.31$ ) is considerably higher than that reported by Dyson (1996) with regard to parents of non-disabled children (mean QRS-F total score 3.5,  $SD = 4.5$ ,  $N = 55$ ),

Table 3. Breakdown of parents' QRS-F scores

Subscale <sup>a</sup>	Mean	SD	Minimum	Maximum
Parent and family problems (20)	10.31	5.18	0	20
Pessimism (11)	8.14	2.18	1	11
Child characteristics (15)	9.02	2.95	0	14
Physical Incapacity (6)	2.72	1.87	0	6
Total score (52)	30.05	9.31	7	48

$N = 123$

<sup>a</sup>Number of items in parenthesis.

indicating that, on average, parents in the current study reported high levels of stress. However, whilst on average parents reported high levels of stress, it can be seen that parents' levels of stress varied considerably between individuals, with some parents reporting very low levels of parenting stress

### 3.2.2 Levels of Psychological Distress Reported by Parents

Summary data from the GHQ-12 indicating levels of psychological distress, as reported by parents, are given in Table 4. The mean GHQ-12 total score (3.61) is above the threshold for psychiatric caseness - a score of three or higher.

Table 4. Breakdown of parents' GHQ-12 scores

Mean	SD	Median	Minimum	Maximum
3.61	3.68	2.00	0	12

$N = 121$

Of the 121 participants who completed the GHQ-12, 60 (49.59 %) scored above the threshold for caseness, indicating that they experienced psychological distress at clinically significant levels warranting professional assistance. The distribution of parents' GHQ-12 total scores is illustrated in Figure 2.

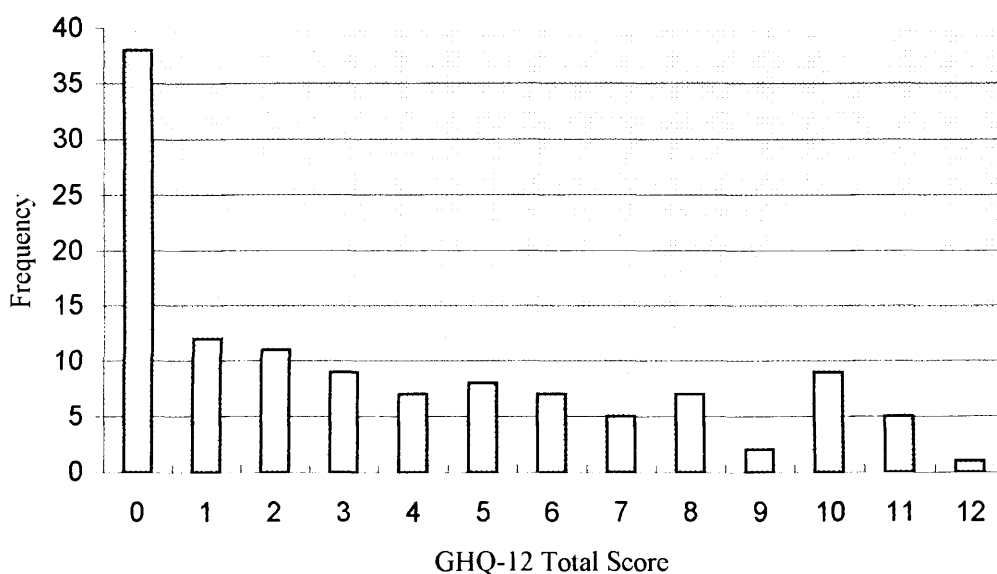


Figure 2. Distribution of parents' GHQ-12 total scores.  
 $N = 121$

### 3.2.3 Parents' Coping Strategies

Summary data from the WC-R, indicating parents' self-reported use of the five coping strategies listed to manage stressful parenting situations with their child with SLD, are presented in Table 5. As discussed above, relative coping scores (the proportion of total coping efforts used on a specific strategy), as opposed to raw scores (the frequency of efforts used on a specific strategy), were used. The minimum and maximum relative coping scores for each coping strategy which could be obtained by participants were, therefore, 0 (0 % of all coping efforts) and 1 (100 % of all coping efforts), respectively.

Table 5. Breakdown of parents' WC-R relative coping scores

WC-R Subscale	Mean	SD	Median	Minimum	Maximum	Range
Practical Coping	.2205	.0055	.2200	.10	.37	.27
Wishful Thinking	.1621	.0069	.1500	.01	.33	.32
Stoicism	.1920	.0062	.2000	.05	.33	.28
Seeking Emotional Social Support	.1956	.0093	.1900	.00	.46	.46
Passive Acceptance	.2311	.0089	.2400	.00	.42	.42

*N* = 122

It can be seen that relative use of each coping strategy varied greatly between individuals. All parents who completed the WC-R indicated that they used strategies of practical coping, wishful thinking and stoicism at least to a small extent. However, Table 5 shows that the coping strategies of seeking emotional social support and passive acceptance of the stressful parenting situation were not used by all parents. Parents' use of these two coping strategies varied most widely. The minimum and maximum relative coping scores for these two subscales show that whilst some parents did not use these strategies at all, for other parents strategies of seeking emotional social support or passive acceptance accounted for over 40 % of their total coping efforts.

To investigate further parents' relative use of WC-R coping strategies, participants were classified according to their highest relative coping score, that is, the strategy accounting for the largest proportion of their coping efforts. Where participants' relative coping scores were equally high on two or more coping strategies (e.g. wishful thinking and passive acceptance) and no one strategy accounted for most of the coping efforts, new combined categories (e.g. wishful thinking / passive acceptance) were used. A breakdown of the coping strategies used by parents accounting for the largest proportion of total coping efforts is given in Figure 3.

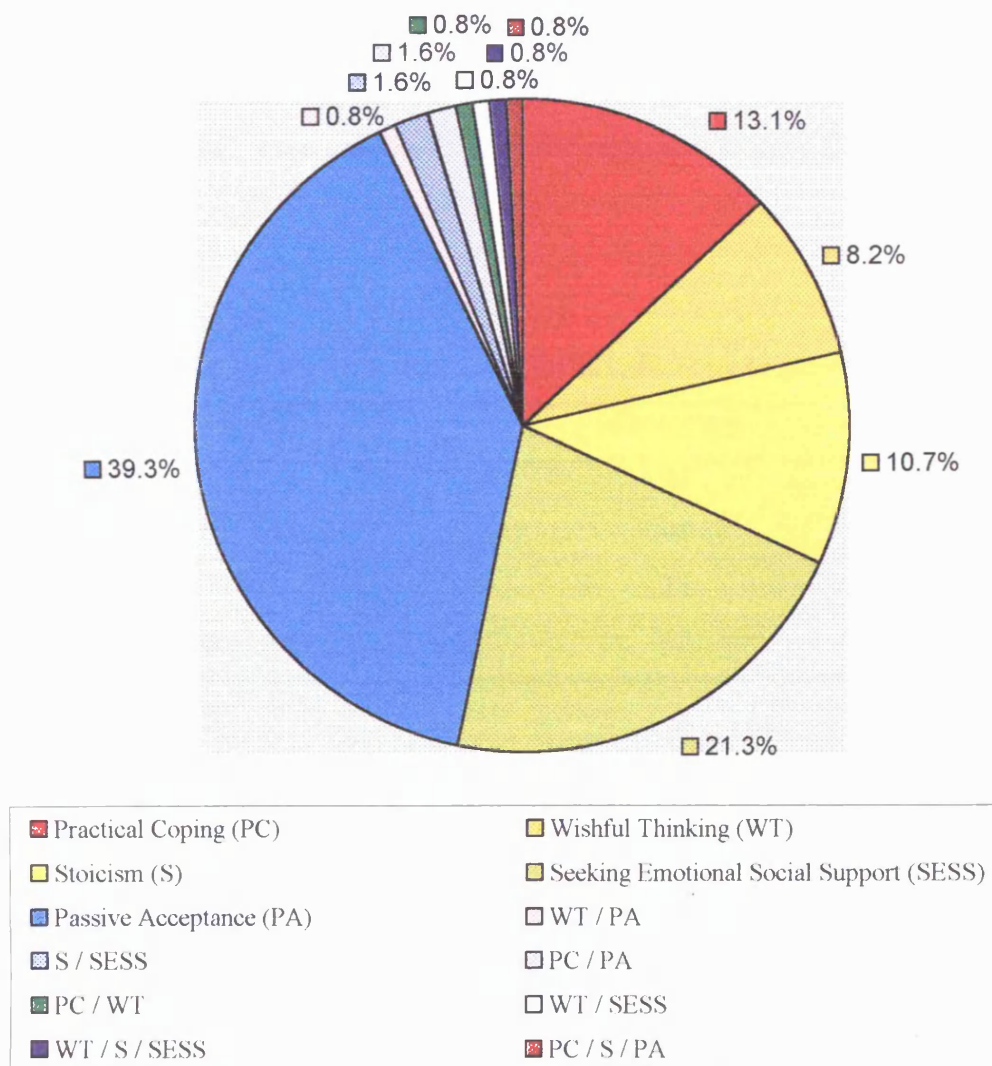


Figure 3. Parents' relative use of WC-R coping strategies. Coping strategy accounting for largest proportion of parents' coping efforts based upon highest relative coping score(s).

N=122



It can be seen that passive acceptance of the stressful parenting situation accounted for the largest proportion of parents' coping efforts, followed by the strategy of seeking emotional social support, use of practical coping, stoicism and wishful thinking.

In contrast to previous studies of coping strategies and well-being, the current study aimed to take into account and control for the source of social support used by parents to manage stressful parenting situations. On the WC-R the strategy of seeking emotional social support refers to the use of support from informal sources, such as family and friends. Use of professional support (item 13) falls within the practical coping subscale and, therefore, to investigate parents' attitudes towards use of formal sources of support, responses to item 13 of the WC-R, "I try to get professional help", were examined. Parents' responses to item 13 are summarised in Table 6.

Table 6. Parents' responses to item 13 of the WC-R, "I try to get professional help"

Rating	Frequency	Percent (%)
Not used	43	35.0
Used somewhat	41	33.3
Used quite a bit	21	17.1
Used a great deal	18	14.6

$N = 123$

#### 3.2.4 Coping Strategies and Parents' Well-being

The distributions of data obtained from the QRS-F, GHQ-12 and WC-R were first examined using histogram plots, tests of skewness and kurtosis and Kolmogorov – Smirnov one-sample tests of normality. These exploratory analyses indicated that, with the exception of parents' relative coping scores on the seeking emotional social support and stoicism subscales of the WC-R, population distributions of the measures used could not be regarded as normal. A non-parametric measure of correlation, Spearman's rho ( $r_s$ ), was therefore used to examine the relationship between use of individual coping strategies and parents' well-being.

### 3.2.4.1 Tests of Hypotheses

Spearman's rho bivariate correlations between parents' WC-R relative coping scores and GHQ-12 total scores were calculated to examine the association between coping strategies used and psychological distress. Spearman's rho bivariate correlations between parents' WC-R relative coping scores and QRS-F total scores were calculated to examine the association between coping strategies used and parenting stress. Where hypotheses regarding the direction of the relationship between variables were proposed, tests were reported as one-tailed (Howell, 1992). All other correlations were reported as two-tailed. As there is an increased probability of Type I errors when making repeated use of correlations, correlations apparently significant at  $p < .05$  should be treated tentatively.

Table 7 presents the inter-correlations between WC-R subscales. It can be seen from Table 7 that use of practical coping is inversely related to use of wishful thinking and passive acceptance. Similarly, it can be seen that the strategy of seeking emotional social support is inversely related to use of wishful thinking, stoicism and passive acceptance. Further, use of stoicism is inversely related to use of passive acceptance. Whilst several of the subscales are inversely correlated at levels reaching statistical significance ( $p < .01$ ), none of the subscales are strongly positively correlated. The inter-correlations displayed in Table 7 therefore confirm that the WC-R subscales measure discrete coping strategies.

Table 7. Inter-correlations ( $r_s$ ) between subscales of the WC-R.

WC-R Subscale relative score	1	2	3	4	5
1. Practical Coping	-	-.447 *	.019	.084	-.352 *
2. Wishful Thinking	-.447 *	-	-.081	-.389 *	.026
3. Stoicism	.019	-.081	-	-.318 *	-.248 *
4. Seeking Emotional Social Support	.084	-.389 *	-.318 *	-	-.553 *
5. Passive Acceptance	-.352 *	.026	-.248 *	-.553 *	-

$N = 122$

\*  $p < .01$ . (Two-tailed)

The correlation between the GHQ-12 total score and QRS-F total score was .574 ( $p < .01$ ) indicating that they acted as two related but conceptually distinct measures of well-being. The correlations between relative coping scores and the two measures of well-being are presented in Table 8.

Table 8. Spearman's rho correlations between WC-R relative coping scores and measures of well-being.

WC-R Subscale relative score	GHQ-12 total score	QRS-F total score
1. Practical Coping	-.199* <sup>a</sup>	-.193* <sup>a</sup>
2. Wishful Thinking	.391** <sup>a</sup>	.351** <sup>a</sup>
3. Stoicism	-.019	-.091
4. Seeking Emotional Social Support	-.284** <sup>a</sup>	-.292** <sup>a</sup>
5. Passive Acceptance	.185*	.237**

$N = 122$

\*  $p < .05$ ; \*\*  $p < .01$ .

<sup>a</sup> One-tailed test, all other tests were two-tailed.

#### 3.2.4.1.1 Hypotheses One and Two

As proposed in hypotheses one and two, the use of practical coping to manage stressful parenting situations was found to be associated with lower levels of psychological distress and parenting stress (Table 8). Weak but statistically significant negative correlations between parents' practical coping relative coping scores and the GHQ-12 total scores and QRS-F total scores were found ( $r_s = -.199$ ,  $p < .05$ ;  $r_s = -.193$ ,  $p < .05$  respectively).

#### 3.2.4.1.2 Hypotheses Three and Four

Hypotheses three and four were also supported: highly statistically significant negative correlations between parents' WC-R relative coping scores on the seeking emotional social support subscale and the two measures of well-being were found (Table 8). Use of emotional social support from informal sources was, therefore,

associated with lower levels of psychological distress ( $r_s = -.284, p < .01$ ) and parenting stress ( $r_s = -.292, p < .01$ ) as predicted.

#### 3.2.4.1.3 Hypotheses Five and Six

Hypotheses five and six stated that use of wishful thinking to manage stressful parenting situations would be associated with higher levels of psychological distress and parenting stress. It can be seen from Table 8 that positive, highly statistically significant, correlations between parents' WC-R relative coping scores on the wishful thinking subscale and the two measures of well-being were indeed found. Use of wishful thinking was, therefore, found to be associated with higher levels of psychological distress ( $r_s = .391, p < .01$ ) and parenting stress ( $r_s = .351, p < .01$ ) as hypothesised.

#### 3.2.4.2 Use of Passive Acceptance and Parental Well-being

Table 8 shows that passive acceptance of stressful parenting situations was also positively associated with measures of parental well-being. The Spearman's rho correlation between parents' WC-R relative coping scores on the passive acceptance subscale and GHQ-12 total scores was .185 ( $p < .05$ ). The correlation between passive acceptance relative coping scores and QRS-F total scores was .237 ( $p < .01$ ). Thus, passive acceptance, the most frequently used coping strategy (Figure 3), was found to be associated with higher levels of psychological distress and parenting stress.

### 3.3 Qualitative Data

#### 3.3.1 Parents' Coping Strategies

##### 3.3.1.1 Content Analysis

Parents' responses to the optional open-ended item added to the end of the WC-R were content analysed using the method described by Fink (1995). Content analysis was used as this technique allows raw qualitative data to be categorised, coded and

summarised with relative ease, permitting the identification of discrete coping strategies and clustering of responses pertaining to the same coping strategy. Of the 123 participants, 23 (18.7 %) chose to complete the open-ended item, indicating that they used other coping strategies which they felt were not otherwise listed on the WC-R. Parents' verbatim responses to this item may be found in Appendix 10.

The raw qualitative data were first reviewed and 39 statements or clauses describing coping strategies were identified from parents' responses. Categories representing discrete coping strategies were then created, based upon the review of parent's responses. A total of 12 categories was created. Each category was assigned a numerical code (1-12). The response categories and codes are presented in Table 9. Parents' verbatim responses were then categorised and coded.

Table 9. Content analysis response categories and codes

Category (coping strategy)	Code
Maintain a positive attitude, get on with life	1
Use of distraction (e.g. engagement in other activity)	2
Make time for self	3
Relaxation	4
Exercise	5
Catharsis (e.g. crying, anger)	6
Take one day at a time	7
Cognitive reappraisal of situation (e.g. acknowledge own limitations, value child with SLD, think of how much worse it could be)	8
Support from family / partner	9
Use of professional support (e.g. counselling)	10
Use of religious belief / faith	11
Practical problem-solving approach (e.g. use of routine, turn-taking, try to make things better)	12

### 3.3.1.2 Inter-rater Reliability

As content analysis is a subjective data reduction technique open to researcher bias, at this stage a second independent rater was introduced to establish the inter-rater

reliability of coding. The second rater was given the raw qualitative data and response categories and asked to code the data.

The inter-rater reliability of codings was assessed statistically using Cohen's kappa. Cohen's kappa was used as this is a chance-corrected measure of agreement for use with categorical scales (Howell, 1992; Dewey, 1995). Whilst percentage agreement is a more straightforward measure of inter-rater reliability, this does not control for agreement reached by chance alone (Howell, 1992). Further, Cohen's kappa treats all disagreements as equally serious, providing a robust measure of agreement (Dewey, 1995).

Cohen's kappa for each category ranged from .623 to 1, indicating substantial to perfect agreement (Dewey, 1995). The results of the inter-rater reliability check are given in more detail in Appendix 11. As agreement between raters was found to be very high the categories and codes were left as above. The codes of the author were used in the analysis.

### 3.3.1.3 The Relative Use of Coping Strategies

The results of the content analysis are summarised in Table 10.

It can be seen from Table 10 that the most frequently cited coping strategy, adopted by over 30 % of the participants completing the open-ended coping item, was that of maintaining a positive attitude and getting on with life (code 1). The second most popular strategy, cognitive reappraisal of the stressful parenting situation (code 8) incorporated raw data themes such as acknowledging one's own limitations as a parent, thinking of how much worse things could be and focusing upon the positive aspects of rearing a child with SLD. Whilst use of this latter strategy appears to some extent dependent upon a positive attitude, it was felt that the two strategies were conceptually distinct as parents' deliberate efforts to reframe their negative experiences were evident in the raw data.

The remaining ten coping strategies identified in the content analysis are self-explanatory. It must, however, be noted that use of religious belief / faith (code 11),

Table 10. Summary of responses to the open-ended coping item

Response Category Code	Frequency	% 39 Responses Assigned to Each Code	% 23 Participants Assigned to Each Code
1	7	17.95	30.43
2	4	10.26	17.39
3	2	5.13	8.70
4	3	7.69	13.04
5	2	5.13	8.70
6	2	5.13	8.70
7	2	5.13	8.70
8	5	12.82	21.74
9	3	7.69	13.04
10	3	7.69	13.04
11	2	5.13	8.70
12	4	10.26	17.39

a strategy reported by two of the participants, is non-specific and incorporates raw data themes of faith in God providing strength and the belief that the child with SLD chose to enter life with a disability.

### 3.3.2 Coping Strategies and Parents' Well-being

Parents choosing to complete the optional open-ended coping item were asked to describe any other coping strategies which they used not otherwise listed. Parents were not asked to indicate how helpful they found these strategies to be. However, from inspection of the raw data (Appendix 10) it would appear that parents listed only the strategies used that they felt were adaptive. The second rater was of the same opinion. Several participants commented upon the efficacy of their coping strategies in reducing parenting stress and aiding relaxation (Appendix10). It would appear, therefore, that the coping strategies identified in the content analysis were considered by participants to increase their sense of well-being.

## 4. Discussion

### 4.1 Organisation of the Discussion

In the next sub-section the results of the study are discussed in relation to previous research findings in the field of stress and coping, with an emphasis upon studies examining stress and coping in parents with a disabled child. The results are also discussed in relation to Lazarus and Folkman's (1984) process model of stress and coping, the theoretical framework underpinning the work. Clinical and policy implications of the study are discussed in later sub-sections. Finally, possible limitations of the study are discussed and suggestions for future research are offered.

### 4.2 Discussion of Results in Relation to Previous Research Findings and Theory

The study aimed to add to the growing body of research on stress and coping among parents of children with disabilities in several respects, as outlined in chapter one. For clarity, the results of the study are discussed following the order of the research questions and hypotheses set.

#### 4.2.1 Levels of Parenting Stress and Psychological Distress Reported by Parents

As in previous studies of stress among parents of children with disabilities, in the current study, on average, parents reported high levels of parenting stress (Table 3). Parents' scores on the QRS-F are comparable to those reported by Rousey *et al.* (1992) in their American study of stress in parents of children with "severe developmental disabilities" (SLD). Rousey *et al.* (1992) report mean QRS-F total scores of 27.06 (SD = 8.40) for mothers and 26.21 (SD = 9.61) for fathers. In the current study the mean QRS-F total score was marginally higher, 30.05 (SD = 9.31). However, it can be seen from the standard deviations that this difference is not statistically significant.



Similarly, in accordance with previous research findings, on average, parents reported high levels of psychological distress (Table 4). The mean GHQ-12 total score of 3.61 (SD = 3.68) is considerably higher than that reported by Goldberg, Oldehinkel and Ormel (1998) with regard to UK general practice patients. In their WHO study Goldberg *et al.* (1998) found that these patients had a mean GHQ-12 total score of 2.78 (no SD given,  $N = 1523$ ). In the current study almost half of the parents who completed the GHQ-12 (49.59 %) scored above the threshold for caseness, indicating that they experienced psychological distress at clinically significant levels, warranting professional assistance.

As the GHQ-12 has not been used previously in studies of families caring for a disabled child, the results of the current study cannot be compared directly with previous research findings in this field. However, the levels of psychological distress reported by parents can perhaps be put into perspective by comparison with studies in other fields using the GHQ-12. For example, in their cross-national study of co-resident spouse carers for people with Alzheimer's disease, Schneider, Murray, Banerjee and Mann (1999), found that between 40 % and 75 % of carers scored above the GHQ-12 threshold. Similarly, McGilloway, Donnelly and Mays (1997) administered the GHQ-12 in their study of the experiences of informal carers of former long-stay psychiatric patients. McGilloway *et al.* (1997) found that 45 % of the informal carers, most of whom were relatives, had GHQ-12 total scores above the threshold for caseness. By way of comparison, Kisely and Goldberg (1996) report on a study of psychiatric morbidity among general practice patients. They found that 40 % of patients were GHQ-12 "cases".

The proportion of parents in the current study experiencing psychological distress outside of the normal range is higher than that reported by Miller *et al.* (1992) with regard to mothers of physically disabled children. As discussed above, Miller *et al.* (1992) found that 38 % of mothers of physically disabled children had psychological well-being scores within the clinical range, as measured by the Brief Symptom Inventory. It must be noted, however, that the children of parents in Miller *et al.*'s (1992) study did not have learning disabilities and, as a positive correlation between child's IQ and parental satisfaction with life has been found (Sloper *et al.*, 1991), this may perhaps account for the different findings. However,

as a different measure of psychological distress was used, it may not be possible to make valid comparisons with Miller *et al.*'s (1992) study.

The result is, nevertheless, consistent with Quine and Pahl's (1985) finding that children who have more impairments and or behavioural problems produce more stress in those who care for them. In the current study 80.5 % of the children with SLD had other additional disabilities, a third of which were behavioural problems.

Whilst on average parents reported high levels of parenting stress and psychological distress, it can be seen from Table 3, Table 4 and Figure 2 that levels of well-being varied considerably between individuals. Whilst some parents reported very low levels of parenting stress, others approached the top of the measurement scale (Table 3). Similarly, the minimum and maximum GHQ-12 total scores obtained by parents were 0 and 12 respectively (Table 4). Whilst one parent obtained the highest possible score on the GHQ-12, 38 parents (31.4 %) indicated that they did not experience any psychological distress (Figure 2).

The results of the current study, therefore, provide support for models of stress and coping that can account for this variation in response, such as Lazarus and Folkman's (1984) process model. Assumptions that high levels of distress and parenting stress are inevitable among families caring for a disabled child, as predicted by the "pathological" model of family functioning (Byrne & Cunningham, 1985), are once more rejected. Similarly, the results suggest that a "needs-deficit" or "common needs" model of stress and coping (e.g. Wilkin, 1979), discussed above, is inappropriate, as parents clearly do not all experience the same amount of stress and, therefore, do not have homogeneous needs.

#### 4.2.2 Parents' Coping Strategies

In contrast to previous research examining parents' self-reported ways of coping with caring for a disabled child, the current study used both quantitative and qualitative measures to provide a broad overview of the coping strategies employed by parents to manage parenting stress. Results from the WC-R and content analysis are considered in turn.

#### 4.2.2.1 Quantitative Data

Parents' scores on the WC-R indicate that each of the five coping strategies listed was used by at least one parent (Table 5). However, use of each coping strategy varied considerably between individuals. Strategies of practical coping, wishful thinking and stoicism were used to some extent by all parents completing the WC-R. In contrast, whilst strategies of seeking emotional social support and passive acceptance of the stressful parenting situation were not used at all by some parents, for other parents these strategies featured highly in their coping repertoire, in some cases accounting for over 40 % of their total coping efforts (Table 5). These results, therefore, demonstrate the range of individual differences in the self-reported use of coping strategies, despite the fact that the parents were all facing similar stressors, as predicted by the process model. Further, in accordance with Lazarus and Folkman's (1984) model of stress and coping, parents were found to use coping strategies that were problem- and or emotion-focused.

In the current study passive acceptance of the stressful situation accounted for the largest proportion of parents' coping efforts, as measured by the WC-R (Figure 3). Seeking emotional social support was found to be the second most popular WC-R coping strategy, followed by use of practical coping, stoicism and wishful thinking. Unfortunately, it is not possible to determine whether parents' relative use of WC-R coping strategies in this study is comparable to that observed in previous related studies using the WC-R, as researchers have not reported this information.

Whilst in the current study passive acceptance was the most frequently used WC-R coping strategy, interestingly, use of this strategy has not been reported in previous, qualitative, studies of parents' coping. However, as discussed below, in the current study passive acceptance was found to be associated with higher levels of parenting stress and psychological distress (Table 8) and, as qualitative studies have tended to report only parents' views of *helpful* coping strategies, this may perhaps account for the different findings. Similarly, qualitative studies have not revealed parents' use of wishful thinking to manage their stress – a second less favourable coping strategy (Table 8).

The relatively high use of emotional social support to manage parenting stress found in the current study is, however, consistent with previous research findings. On the WC-R this subscale refers to the use of support from informal sources, such as family and friends. As discussed above, use of informal social support – talking to one’s spouse – was the most frequently mentioned coping strategy in Brown and Hepple’s (1989) study of parents caring for a learning or multiply-disabled child. Further, parents in this study indicated that they used and valued emotional and practical support from their extended family, listing this as a separate coping strategy. Similarly, as discussed above, parents in Bregman’s (1980) American study invested time cultivating both their informal and formal support networks. This study therefore provides quantitative data from a large sample supporting the conclusions suggested by smaller scale qualitative research.

Whilst parents in Bregman’s (1980) study were found to actively seek out and maintain contact with professionals, such as physicians and paediatricians, this finding is atypical. As Beresford (1994) notes, Bregman used a select sample of parents who had successfully adapted to the demands of caring for a child with muscular dystrophy and this may perhaps account for the different findings. Further, as mentioned above, the small sample size of six families limits the generalisability of Bregman’s results.

In general, researchers examining parents’ use of informal and formal support networks have found that formal support is used most often only at times of crisis, or as a last resort, after other sources of support have been exhausted (e.g. Brown & Hepple, 1989). The relatively low use of formal support observed in the current study is, therefore, consistent with the research literature. Whilst almost half of the parents completing the GHQ-12 indicated that they were experiencing psychological distress at clinically significant levels and, on average, parents reported high levels of parenting stress, at the time of the study only 9.8 % of the sample were using psychological or mental health services to manage their child with SLD. Further, only 10.6 % indicated that they used formal respite care. Moreover, 35 % of parents revealed that they did not use professional help of any kind to manage stressful parenting situations (Table 6).

However, whilst the relatively low use of professional support observed in the current study is consistent with previous research in this field, it is not possible to determine the reasons for this as this was not the subject of investigation. One cannot, for example, assume that parents in the sample used formal support only at times of crisis. Further research would be required to ascertain parents' reasons for using and not using formal support services.

As use of professional support falls within the practical coping subscale of the WC-R, this may perhaps partly explain parents' relatively low use of practical coping strategies in general. "Practical coping" was the coping strategy most frequently used by 13.1 % of the sample (Figure 3). Parents' use of practical coping strategies other than use of formal support, such as information seeking, planning and direct-problem solving, has also been identified in qualitative studies (e.g. Bregman, 1980; Beavers, 1989).

Whilst use of "stoicism" *per se* has not been reported in qualitative studies of parents' coping strategies, this strategy appears to encompass a range of individual coping strategies identified in such studies. The stoicism WC-R subscale consists of items implying control over negative emotions, such as "I go on as if nothing has happened", "I remind myself how much worse things could be" and "I maintain my pride and keep a stiff upper lip". As discussed above, a number of parents in Brown and Hepple's (1989) study also employed the cognitive strategy of "thinking of how much worse it could be". Further, in this study two families indicated that others' expectations that they would not manage had made them all the more determined to do so. This latter strategy appears similar to that of maintaining a "stiff upper lip". It would seem, therefore, that parents' use of stoicism to manage stressful parenting situations, found in the present study, is again consistent with previous research findings. This study, therefore, again provides quantitative data from a large sample supporting the conclusions suggested by previous small-scale qualitative research.

#### 4.2.2.2 Qualitative Data

Whilst an open-ended item was included to allow parents to describe coping strategies used not otherwise listed on the WC-R, the content analysis of responses

to this item identified three coping strategies which are in fact included on the coping questionnaire; use of informal social support, use of professional support and use of a practical coping strategy. In this way the results of the content analysis, therefore, provide further evidence of the validity of the WC-R results. Whilst in their responses to the open-ended item parents gave additional and more detailed examples of the three strategies than those listed on the WC-R (Appendix 10), as each of these strategies has already been discussed above, to avoid repetition the corresponding qualitative data will not be discussed further.

The content analysis revealed nine further coping strategies used by parents not listed on the WC-R, again highlighting the importance of combining both qualitative and quantitative techniques when researching coping strategies (Beresford, 1994). As discussed above, parents' comments suggest that each of the twelve strategies identified were found to be adaptive. However, it must be noted that as the efficacy of these strategies was not measured objectively and parents were not specifically asked to indicate the helpfulness of the strategies they described, assumptions regarding the perceived efficacy of the strategies identified in the content analysis are made with caution.

The strategy occurring most frequently in the content analysis, that of maintaining a positive attitude and getting on with life, has been reported in various guises as both a psychological coping resource and coping strategy in previous studies of family functioning (e.g. Venters, 1981; Libow, 1989, Beavers, 1989). Beavers (1989), for example, reports on a longitudinal study of families caring for a child with developmental disabilities. As in the current study, maintaining a positive outlook was said to be an effective coping strategy. Parents adopting this strategy were said to have "infectious optimism". Similarly, parents in Brown and Hepple's (1989) study reported a need to maintain a positive attitude to manage parenting stress.

Cognitive reappraisal of the stressful parenting situation, a related but conceptually distinct coping strategy, has also been cited in previous research studies. For example, as discussed above, parents in Bregman's (1980) study were found to capitalise on their personal strength and, rather than focusing upon the difficulties they faced, they were said to actively identify the ways in which they helped their

children. Similarly, as mentioned previously, Brown and Hepple (1989) note how several parents in their study adopted the strategy of reminding themselves how much worse things could be. This stoic attitude also demands use of cognitive restructuring and may, therefore, be considered an example of both coping strategies.

Further, in keeping with the results of the current study, Beavers (1989) describes parents' use of cognitive reappraisal of the role of the child with the disability as an effective coping pattern. For example, Beavers describes how some families in her study focused upon the loveable aspects of their child as opposed to their lack of academic achievement, whilst others defined their child as "endearingly fragile" or as a "family pet" prone to exhibiting behavioural problems.

The efficacy of cognitive reappraisal as a coping strategy may be readily explained by Lazarus and Folkman's (1984) process model. As discussed above, within this conceptual framework psychological stress is said to occur when an individual appraises an event or potential stressor as taxing or exceeding available resources and jeopardising well-being. Through cognitive restructuring the person-environment relationship is re-evaluated and the potential stressor is no longer categorised as endangering well-being and, thus, psychological stress is reduced. Similarly, drawing upon the process model, parents' strategy of maintaining a positive attitude may encourage them to categorise potentially stressful parenting situations as either irrelevant to their well-being or benign-positive in the primary appraisal. In this way, parents adopting this strategy may perhaps be buffered from the experience of stress.

Use of distraction, physical exercise, relaxation and making time for one's self have been widely reported in the general psychological literature on anxiety and stress management as being effective ways of reducing stress (e.g. Sarafino, 1990, Clark, 1996). However, in contrast to the current study, these coping strategies have seldom been reported in previous studies of parents' coping.

There are several possible explanations for this and further research is required to determine the true frequency with which these strategies are used. For example, it

may be that use of these coping strategies is taken for granted by parents and consequently not reported or, alternatively, parents may perhaps have insufficient time to actively engage in such stress-reducing activities. It must nevertheless be noted that whilst parents may not actively use these strategies they may, for example, benefit from relaxation and time out indirectly when their children are asleep, at school or otherwise occupied. Further, as discussed above, caring for a child with learning and or physical disabilities can be physically demanding (e.g. Quine & Pahl, 1985) and subsequently many parents will already engage in much physical exercise, although not through choice.

In contrast, the strategy of taking each day as it comes, identified in the content analysis, has been found to be a common successful approach (Beavers, 1989). As discussed above, parents in Bregman's (1980) study, for example, were found to habitually schedule activities day by day. Similarly, Brown and Hepple (1989) report how some parents in their sample talked of the need to live day by day. This approach may be regarded as a specific example of practical problem-solving (Beavers, 1989; Hawton & Kirk, 1996), a strategy most often found to be adaptive in quantitative studies (e.g. Sloper *et al.*, 1991; Miller *et al.*, 1992; Thompson *et al.*, 1992). Parents adopting this strategy have a deliberate focus on the present and specific and concentrate upon small goals (Beavers, 1989). Further, as mentioned above, the ability to focus solely on the present may also be considered a psychological coping resource (Beresford, 1994).

Similarly, whilst freedom to express emotions has been found to be an important coping resource (e.g. Sloper *et al.*, 1991), as discussed above, as in the current study, use of catharsis has also been identified as a coping strategy (e.g. Bregman, 1980; Brown & Hepple, 1989; Quine & Pahl, 1991). For example, as mentioned above, parents in Bregman's (1980) study cited "crying" as a stress-reducing activity. As noted previously, in the current study no firm conclusions regarding the perceived and actual efficacy of catharsis can be drawn, as the efficacy of strategies identified in the content analysis was not measured objectively. However, as discussed above, from inspection of the raw data parents appeared to list only the strategies they used that they considered adaptive. It would seem, therefore, that the



two parents citing catharsis as a coping strategy found this strategy to be helpful in reducing parenting stress.

Whilst this finding is consistent with the results of previous, related studies identifying emotion release as an important coping resource and coping strategy (e.g. Bregman, 1980; Brown & Hepple, 1989, Sloper *et al.*, 1991), this result is inconsistent with that of Quine and Pahl (1991) with regard to mothers of children with SLD. As discussed above, Quine and Pahl found coping through catharsis to be significantly related to *poor* adjustment. The present results, therefore, lend support to Beresford's (1994) argument that Quine and Pahl's finding is an artefact of the measures they used. Quine and Pahl used the MDC to measure coping strategies and the Malaise Inventory as a measure of parents' adjustment. As discussed above, cathartic behaviours such as "crying" feature in the Malaise Inventory, and the MDC may perhaps not discriminate between maladaptive and therapeutic emotional discharge.

Finally, use of religious faith as a coping strategy, mentioned by two participants, has also been reported in previous studies of parental coping (e.g. Brown & Hepple, 1989; Libow, 1989; Venters, 1981) although, as mentioned above, the ideological beliefs of families with a disabled child have received little research attention (Beresford, 1994). In their study of families caring for a child with learning or multiple disabilities Brown and Hepple (1989) examine the role of philosophical and religious beliefs in some depth. They found that when asked specifically about their beliefs the majority of parents could articulate a religious belief that served to reframe potentially negative situations into positive experiences. Religious faith may, therefore, encourage parents to use cognitive reappraisal.

Venters (1981) and Libow (1989) suggest that a further positive function of religious faith is the ability to attribute some meaning to the child's condition, even if the meaning is unknown and accessible only to a higher being, such as God. The belief that the child with SLD chose to enter life with a disability, described by one parent in the current study, appears to fulfil this function.

However, whilst religious beliefs may be a source of inner strength, as indicated by the second parent in the present study, for others religious beliefs may be detrimental to well-being. Brown and Hepple (1989), for example, note that whilst Catholic doctrine teaches parents to accept a disabled child as a gift from God, other religious faiths view disability as a punishment for guilt.

The low use of religious faith as a coping strategy indicated by the present study is somewhat inconsistent with previous research in this field. Turnbull, Brotherson and Summers (1985, p. 119), for example, found that religion was “mentioned with unanticipated frequency as an important coping strategy”. However, as parents were not explicitly asked about their religious beliefs this may perhaps account for the different findings. Alternatively, the result may perhaps reflect a change in religiosity over time. Much of the limited research in this field was conducted several decades ago and may be outdated. Further, more recent, research examining the role of parents’ ideological beliefs is needed.

It can again be seen from the above discussion of coping strategies revealed by the content analysis that, in accordance with Lazarus and Folkman’s (1984) process model, parents employ strategies which are either problem-focused and or emotion-focused in their function. Strategies of taking each day at a time, use of professional support and practical problem solving have a predominantly problem-focused function and may be considered further examples of practical coping. In contrast, strategies of maintaining a positive attitude, use of religious faith, distraction, relaxation, exercise, making time for one’s self, cognitive reappraisal and catharsis have a predominantly emotion-focused function, aiming to regulate the emotions tied to the stressful parenting situation. Use of informal social support may perhaps serve both functions, as described above.

The higher use of emotion-focused strategies relative to problem-focused strategies, seen in both the content analysis of responses to the open-ended coping item and parents’ responses to the WC-R, may perhaps reflect the nature of the stressful parenting situation faced by parents. As discussed above, several sources of stress identified in this population, for example an over- or under-active child and

behaviour problems (Quine & Pahl, 1985) are either permanent or not amenable to change.

#### 4.2.3 Coping Strategies and Parents' Well-being

As described above, hypotheses regarding associations between parents' self-reported use of individual coping strategies listed on the WC-R and the two measures of well-being were tested using Spearman's rho correlations. As hypothesised, use of practical coping was found to be associated with lower levels of psychological distress and parenting stress (Table 8). This result is consistent with the content analysis findings and those of qualitative studies reported by Bregman (1980) and Brown and Hepple (1989), discussed above, in which the efficacy of this method of coping was measured subjectively by parents. Further, the association of practical coping strategies with decreased psychological distress and parenting stress confirms the results of numerous previous large-scale quantitative studies of parental coping with related populations (e.g. Frey *et al.*, 1989; Sloper *et al.*, 1991; Miller *et al.*, 1992; Thompson *et al.*, 1992, Sloper & Turner, 1993). This study has, therefore, shown that the positive relationship between use of practical coping and well-being previously found in families of children with other disabilities also occurs in families of children with SLD.

Quine and Pahl's (1991) finding of no association between use of practical coping and outcome in mothers of children with SLD is not supported. As discussed above, in their cross-sectional UK study of 166 mothers caring for a child with SLD Quine & Pahl used the Malaise Inventory to measure parenting stress and the MDC to provide information about the coping strategies utilised by parents. The MDC lists eight coping strategies including a practical coping strategy, "direct action", described as "thought about solutions to the problem, gathered information about it, or actually did something to try to solve it" (Stone & Neale, 1984). In Quine and Pahl's study use of direct action was not significantly related to parenting stress in the univariate analysis.

Whilst the current study employed different measures of coping strategies to Quine and Pahl (1991), it appears from the above description of "direct action" that this

MDC coping category is very similar to that of “practical coping” on the WC-R. It seems unlikely, therefore, that this can account for the conflicting findings. Further research comparing use of the MDC with the WC-R would shed more light on this issue.

Similarly, whilst the present research utilised different measures of outcome to Quine and Pahl, the measures used in both studies are of established reliability and validity. Moreover, the Malaise Inventory, used by Quine and Pahl, has also been used to measure outcome in several previous studies cited above whose findings support the present research (e.g. Sloper *et al.*, 1991; Sloper & Turner, 1993). It seems again unlikely, therefore, that the conflicting findings are an artefact of the measures used.

As in the present study, mothers in Quine and Pahl’s (1991) study reported high levels of parenting stress. The mean Malaise score of mothers in their sample was outside of the normal range. Further, the range of disabilities of children in their sample is comparable with that reported in the present study (Table 2), although it appears that children in Quine and Pahl’s sample were more seriously impaired. For example, one third of their sample were unable to walk, whereas 83 % of children with SLD in the current study were classified by their parent as being mobile. However, whilst there are some differences in the sample characteristics of the two studies, this does not appear to account for the inconsistent findings. For example, as discussed above, Sloper and Turner (1993) found a positive association between use of practical coping and parental well-being in their study of parents of children with severe physical disability.

There are no theoretical reasons why mothers of children with SLD should differ in their response to coping strategies they employ from mothers caring for children with other disabilities. The results of the present study illustrate this point; over 90 % of the sample were mothers caring for a child with SLD. As discussed above, parents caring for a child with SLD may face multiple stressors (Quine & Pahl, 1985; Turk, 1996), and subsequently may have fewer personal coping resources to draw upon (e.g. clarity of thought) to permit the *use* of practical coping strategies where feasible. However, there is no obvious reason why parents managing to use a

practical coping strategy nevertheless would not find the strategy of benefit. Unfortunately, Quine and Pahl (1991) do not discuss their results in relation to previous research in this area (e.g. Frey *et al.*, 1989) or offer possible explanations for their inconsistent findings.

Lazarus and Folkman's (1984) process model of stress and coping offers one possible explanation for the contradictory results. According to the model stress is reduced only if there is a fit between an individual's appraisal of a potential stressor or event and the coping strategies employed. Subsequently, a coping strategy that is effective in one appraised situation may be ineffective in another. For example, levels of depression are found to be lower in situations appraised as changeable when problem-focused coping is used. In contrast elevated depression scores are found when emotion-focused coping is used in situations appraised as changeable (Miller *et al.*, 1992).

It may be that practical coping strategies were a poor fit with the appraisals of mothers in Quine and Pahl's (1991) study and a better match for the appraisals of parents in the current study. Parents in Quine and Pahl's study may, for example, have appraised the situation as unchangeable. This may possibly account for their use of catharsis, perhaps in despair, and the associated higher stress scores. However, as parents' appraisals of stressful parenting situations were not measured in either the current study or that of Quine and Pahl it is not possible to verify this. Further research examining stress, appraisal and the coping strategies of mothers caring for a child with SLD, employing methodology such as that used by Miller *et al.* (1992), would be required to test this hypothesis.

Alternatively, Quine and Pahl's (1991) inconsistent finding that use of a practical coping strategy, "direct action", was not associated with outcome in mothers caring for a child with SLD may perhaps be an effect of range restrictions (Howell, 1992). It may be that parents' scores on either or both of the measures used in the univariate analysis, the Malaise Inventory and MDC, had a restricted range. The effect of such range restrictions is to alter the correlation between variables. Whilst, depending upon the nature of the data, the correlation may either rise or fall as a result of a range restriction, most commonly the correlation is reduced (Howell,

1992). In contrast to the present study, Quine and Pahl (1991) do not give an indication of parents' relative use of individual coping strategies and do not give a breakdown of parents' scores on the coping questionnaire and, therefore, unfortunately it is not possible to eliminate this possibility.

Hypotheses three and four, which predicted a positive relationship between use of emotional social support and parental well-being were also supported. Significant negative correlations between parents' relative coping scores on the seeking emotional social support WC-R subscale and their total scores on both the GHQ-12 and QRS-F were found (Table 8), indicating that use of emotional social support from informal sources was associated with lower levels of psychological distress and parenting stress. This result is again consistent with the content analysis findings and those of qualitative studies discussed above reporting parents' views of helpful coping strategies. Further, the association of seeking emotional social support with lower levels of psychological distress and parenting stress again confirms the results of several previous large-scale quantitative studies with related populations (e.g. Frey *et al.*, 1989; Miller *et al.*, 1992; Thompson *et al.*, 1992; Sloper & Turner, 1993).

This study has, therefore, shown that the positive relationship between use of emotional social support and well-being previously found in families of children with physical disabilities also occurs in families of children with SLD. Further, this study provides quantitative data from a large sample supporting the conclusions suggested by Bregman's (1980) and Brown and Hepple's (1989) small-scale qualitative research.

In contrast, as discussed above, in their studies of parents caring for children with learning disabilities both Quine and Pahl (1991) and Sloper *et al.* (1991) found that use of social support was not significantly associated with parental well-being. However, whilst Quine and Pahl did not find any association between use of social support and outcome, as mentioned above, in Sloper *et al.*'s study use of social support showed univariate relationships with outcome measures, as in the current study. As discussed above, Sloper *et al.* found that use of social support lost its significance in their multivariate analysis after entry of personality, marital

relationship and other coping factors. The present results, therefore, again do not support those of Quine and Pahl with regard to mothers caring for a child with SLD, but are consistent with those of Sloper *et al.*'s univariate analysis.

The results of Sloper *et al.*'s (1991) multivariate analysis, indicating no significant relationship between outcome measures and social support, are inconsistent with those of other multivariate studies of parental coping (e.g. Frey *et al.*, 1989; Miller *et al.*, 1992; Thompson *et al.*, 1992). However, as Sloper *et al.* note, studies finding a relationship between use of social support and stress have not included personality factors in multivariate analyses and this may perhaps account for the different findings. Sloper *et al.* cite previous studies which suggest that social support may be related to personality. Quine and Pahl's (1991) finding with regard to use of social support cannot, however, be explained in this way, as personality variables were not considered.

As discussed above, whilst there are both informal and formal sources of social support, many of the coping questionnaires used in studies of parental adaptation do not distinguish the source of support. Instead a number of discrete coping strategies are clustered together into a single subscale. It was noted above that Beresford (1994) suggests that this practice may mask the impact of individual strategies on parental well-being and perhaps account for the inconsistent findings of Quine and Pahl (1991) and Sloper *et al.* (1991). To avoid this ambiguity, in the current study the source of social support (i.e. informal vs. formal) was controlled for by the use of a coping questionnaire which measures parents' use of informal sources of support.

As mentioned above, on the WC-R the strategy of seeking emotional social support, found to be associated with lower levels of psychological distress and parenting stress, refers to support from informal sources such as family and friends. Different sources of informal social support are, however, clustered together and, unfortunately, it is not possible to separate out the impact of social support from different informal sources (e.g. partner, relative, friend).

Parents' responses to the question "Who shares the care of your child / children?" on the background questionnaire suggest that current or ex-spouses / partners were the most frequently used source of practical support. As mentioned above, this source of support was cited by over 90 % of participants. Use of family members for practical support was cited by over 20 % of the sample, whereas friends were cited in only four cases. However, whilst these figures provide some information about informal sources of practical support used by parents, one cannot assume that parents use the same informal sources in the same proportions for emotional social support. Further research using a measure of parents' social support networks, such as The Social Support Resources Scale (Vaux & Harrison, 1985), would be required to determine the impact of different sources and types (e.g. emotional, practical) of informal support on parental adjustment.

The WC-R does, however, permit discrimination of parents' use of social support from formal sources from their use of informal social support. As mentioned above, on the WC-R use of professional support (item 13) falls within the practical coping subscale. The breakdown of parents' responses to this item, presented in Table 6, shows that 65 % of parents reported that they used professional support to manage stressful parenting situations at least to some extent. It appears, therefore, that parents' responses to item 13 most often added to their practical coping relative scores. As discussed above, use of practical coping was found to be positively related to parental well-being. Hence, as use of professional support falls within the practical coping subscale, it appears that use of professional support is related to a coping style associated with lower levels of psychological distress and parenting stress. Further research using a standardised measure of formal support would nevertheless be required to verify this.

The results of the present study, therefore, tentatively suggest that, in general, use of social support from both informal and formal sources is positively associated with parental adjustment. It would appear therefore that the practice of combining different *sources* of social support on measures of coping strategies cannot account for the fact that neither Quine and Pahl (1991) nor Sloper *et al.* (1991) found social support to be an adaptive strategy. Whilst, as discussed above, Sloper *et al.*'s inconsistent findings may perhaps be explained by their inclusion of personality



variables in their multivariate analysis, Quine and Pahl's findings remain, for the time being, unaccounted for. As with their findings with regard to use of practical coping, it may be that the strategy of seeking emotional support was a poor fit with the appraisals of mothers in Quine and Pahl's study or, alternatively, their contradictory results may be an effect of range restrictions.

It must be noted, however, that the *type* of support sought by parents (e.g. emotional, practical) in the present study was not differentiated on the WC-R. For example, use of professional support, whilst part of the practical coping subscale may also encompass parents' use of emotional support from professional sources, such as counselling, identified in the content analysis. Further, whilst the WC-R social support subscale is labelled "seeking emotional social support", it includes items indicating use of practical support, such as "I ask relatives or friends I respect for advice". It is possible, therefore, that Quine and Pahl's (1991) finding of no association between use of social support and outcome in mothers caring for a child with SLD reflects their use of different and inferior *types* of support. The strategy of "seeking social support" on the MDC, used by Quine and Pahl, refers to *emotional* support "from loved ones, friends, or professionals" (Stone & Neale, 1984).

Hypotheses five and six, stating that use of wishful thinking to manage stressful parenting situations would be associated with higher levels of psychological distress and parenting stress, were also supported. Significant positive correlations between parents' relative coping scores on the wishful thinking WC-R subscale and their total scores on the GHQ-12 and QRS-F were found (Table 8). This result is consistent with those of previous large-scale quantitative studies with related populations measuring this method of coping (e.g. Frey *et al.*, 1989; Sloper *et al.*, 1991; Thompson *et al.*, 1992; Sloper & Turner, 1993). This study has therefore confirmed that the negative relationship between use of wishful thinking and well-being previously found in families of children with physical disabilities also occurs in families of children with SLD. As wishful thinking does not feature on the MDC, it is not possible to compare this result with Quine and Pahl's (1991) study of mothers of children with SLD.

The association of wishful thinking with higher levels of psychological distress and parenting stress may again be explained by the process model. Parents adopting this strategy attempt to regulate emotions tied to the stressful parenting situation by avoiding the situation, pretending it is not there or avoiding thinking about it, without changing the realities of the situation. Subsequently problems occurring are not dealt with and remain as stressors, draining personal coping resources. The parent may then be more likely to appraise future stressors as taxing or exceeding coping resources, resulting in the experience of stress. Use of wishful thinking may, therefore, keep the parent in a cycle of withdrawal, resulting in poor adjustment, rather than freeing up energies for problem-solving. In support of this argument, Sloper and Turner (1993) cite longitudinal data indicating that use of wishful thinking does lead to distress.

The association of passive acceptance with higher levels of psychological distress and parenting stress found in the current study (Table 8) may be explained in a similar fashion. Parents adopting this coping strategy also avoid dealing directly with potential stressors they face and instead take the view that nothing can be done. Problems occurring again mount up, draining personal coping resources further. All potential stressors are categorised as stressful in the primary appraisal. Further, as parents using this strategy perceive themselves as having insufficient coping resources to manage the situation differently, an experience of stress results, leading to poor adjustment.

As passive acceptance does not feature on previous versions of the Ways of Coping Questionnaire, the results of the present study may only be compared directly to those of Sloper *et al.* (1991) who also used the WC-R to measure coping strategies. In their study of parents caring for a child with Down's syndrome Sloper *et al.* found use of passive acceptance to be negatively associated with parents' perceived satisfaction with life. However, in contrast to the present study, use of this strategy was not significantly associated with parental stress (Malaise scores) in their univariate analyses.

Similarly, Quine and Pahl (1991) found that use of acceptance, as measured by the MDC, was not associated with Malaise scores. The MDC coping category of

acceptance, “Accepted that the problem had occurred, but that nothing could be done about it” (Stone & Neale, 1984), appears synonymous with passive acceptance on the WC-R. These conflicting findings may, perhaps, reflect the different measures of outcome used. As Sloper *et al.* note, some of the symptoms of stress measured by the Malaise Inventory may be the result of the cumulative effects of stress on health over time. In contrast, the two measures of well-being in the present study indicate the respondent’s current feelings.

The association between passive acceptance of stressful parenting situations and poor adjustment found in the current study is, however, consistent with the wider psychological literature on clinical depression. Individuals suffering from depression view themselves as incapable of surmounting obstacles they face (Young, Beck & Weinberger, 1993) and may stop trying. Helplessness and hopelessness are common features (Fennell, 1996).

### 4.3 Implications of the Results for Clinical Practice

The results of the study have strong implications for clinical practice. For clarity, each of the clinical implications are considered separately below. It should, however, be noted that the multiplicity of factors associated with parental outcome, indicated by the research literature to date and Lazarus and Folkman's (1984) process model, highlights the importance of undertaking comprehensive, multi-faceted assessments and interventions (Quine & Pahl, 1991; Knussen & Sloper, 1992). Hence, whilst each of the recommendations for clinical practice are presented separately, it is proposed that they all form part of an individualised, multi-agency, co-ordinated approach.

#### 4.3.1 Coping Skills Training

Firstly, as discussed above, in accordance with previous research, the results of the study indicate that parents in the sample experienced high levels of parenting stress and psychological distress. Almost half of the parents who completed the GHQ-12 scored above the threshold for psychiatric caseness, indicating that they experienced psychological distress at clinically significant levels, warranting professional assistance.

Secondly, the results are consistent with the suggestion that certain ways of coping with stressful parenting situations are more effective than others: a finding which replicates those of previous large-scale research studies with related populations (e.g. Frey *et al.*, 1989; Sloper *et al.*, 1991, Miller *et al.*, 1992; Thompson *et al.*, 1992; Sloper & Turner, 1993). The present results confirm those of previous studies of families caring for a disabled child indicating a positive relationship between use of practical coping strategies and use of social support and parental well-being. The conflicting findings of Quine and Pahl (1991) are not supported. In contrast, as discussed above, the present research indicates that, as would be expected, parents caring for a child with SLD do not differ in their response to coping strategies they employ from parents caring for children with other

disabilities. Further, the present results confirm those of previous studies indicating a negative relationship between use of wishful thinking and parental well-being.

Thirdly, the detailed breakdown of parents' relative use of coping strategies given in the present study indicates that the strategy accounting for the largest proportion of parents' coping efforts was passive acceptance, a strategy found to be associated with higher levels of psychological distress and parenting stress. Previous research examining ways of coping indicates that people prefer particular coping strategies regardless of the specific nature of the stressor (e.g. Lazarus & Folkman, 1984). Further, Hatton *et al.* (1995) showed that the pattern of parental responses to the WC-R is generally highly stable over time. It is likely, therefore, that without intervention parents in this study will continue to use coping strategies in the proportions seen, and continue to experience the high levels of stress and distress reported.

The results, therefore, suggest that parents may benefit from the opportunity to learn alternative and more effective ways of coping with the demands of caring for a disabled child. Coping skills training could form part of a comprehensive cognitive-behaviourally based intervention programme offered to parents.

Such a programme could involve instruction in the use of those strategies found to be associated with lower levels of parenting stress and psychological stress, namely practical coping and social support. Further, such a programme would need to address the factors influencing parents' access to and use of adaptive coping strategies. For example, some parents may require social skills training to facilitate access to social support. Moreover, following the process model (Lazarus & Folkman, 1984), stress is said to result from a mismatch between an individual's appraisal of a potential stressor and the coping strategies employed. Parents may, therefore, also benefit from appraisal training (Miller *et al.*, 1992), helping them to distinguish between changeable and unchangeable stressors and make appropriate matches between appraisals and coping strategies.

The results also suggest that cognitive reappraisal is a particularly helpful coping strategy for parents of children with disabilities. As discussed above, the sources of

stress identified in this population, for example an over- or under-active child and behaviour problems (Quine & Pahl, 1985; Sloper *et al.*, 1991), are either permanent or not easily mastered. For parents faced with stressors not amenable to change effective coping involves coming to terms with problems rather than mastering them. Cognitive reappraisal appears suited to this task. Training in the use of cognitive restructuring may, therefore, form an important part of coping skills training. Additional stress-reducing strategies to be taught could include use of distraction, physical exercise and relaxation, also identified in the content analysis.

Coping skills training is a relatively new intervention approach (Beresford, Sloper, Baldwin & Newman, 1996) and, to date, reports of its use are limited to the American literature. The research in this area suggests that interventions of this nature are indeed effective. For example, Kirkham (1993) found that, compared to a control group, at two-year follow-up mothers of disabled children who had taken part in a coping skills training programme had maintained lower depression scores and improvements in their coping skills. Further, the intervention group reported greater satisfaction with their relationship with their child than the control group.

Similarly, Gammon and Rose (1991) showed that parents of children with various developmental disabilities benefited from their comprehensive "Coping Skills Training Program" (CSTP). The CSTP involved ten two-hour sessions with groups of four to eight parents over a ten-week period. The programme consisted of several components, including cognitive restructuring (positive self-statements), problem-solving, individual goal attainment (setting realistic goals) and interpersonal skills training. Post-intervention parents showed significant improvements in their problem-solving abilities and the achievement of individualised goals, and more modest, though statistically significant, improvements in expressions of positive self-regard and interpersonal communication skills.

Whilst further research is needed to establish the viability and efficacy of coping skills training with a UK population, the American research suggests that this approach may be a productive and cost-effective way of reducing the high levels of stress experienced by parents. Whilst there are examples of coping skills training

on a one-to-one basis (e.g. Zeitlin, Rosenblatt & Williamson, 1986), this form of intervention is most often group-based (Beresford, *et al.*, 1996) and, therefore, less expensive. Further, as discussed above, researchers have shown that parents who believe in their own coping efficacy are more likely to achieve positive outcomes (e.g. Frey *et al.*, 1989; Quine & Pahl, 1991; Wiggs & Stores, 1998). Provision of coping skills training may, therefore, in itself increase parents' perceived, if not actual, coping skills and subsequently increase parental well-being.

#### 4.3.2 Assessment of Coping Skills and Well-being

Clinicians would first need to assess objectively parents' coping skills and well-being to determine the need for clinical intervention such as coping skills training. The results indicate the need for objective rather than subjective measurement. For example, for over 10 % of the sample stoicism was the most frequently used coping strategy. Parents using stoicism to manage parenting stress may present as well adjusted and not in need of intervention. The present results, however, indicate that use of this strategy is not significantly associated with outcome (Table 8). It is possible that distress experienced by such parents may be hidden. The results, therefore, suggest that parental coping and well-being should be assessed objectively and routinely.

Similarly, parents' responses to the open-ended coping item suggest that parents may report only adaptive strategies if asked about their ways of coping in a clinical interview. Understandably, in the present study parents appeared to use the dictionary definition of coping, which considers coping as synonymous with mastery. Subsequently, parents' relative use of adaptive versus maladaptive coping strategies may be more difficult to determine in an interview.

The main findings of the current study are consistent with those of previous large-scale studies with related populations using other measures of coping strategies and well-being (e.g. Frey *et al.*, 1989; Miller *et al.*, 1992; Thompson *et al.*, 1992). The WC-R used in the present study appears, therefore, to be a useful and valid objective measure of parents' coping strategies. Further, the intercorrelations between WC-R subscales (Table 7) indicate that the WC-R reliably measures five

distinct coping strategies. Moreover, as the WC-R was specifically adapted for use with parents of children with disabilities (Knussen *et al.*, 1992), it would seem to be the instrument of choice. The WC-R allows assessment of both adaptive and maladaptive coping strategies and, furthermore, through calculation of relative coping scores, parents' relative use of individual coping strategies can be ascertained. The clinician can, thus, gain an impression of the extent of parents' use of coping strategies associated with poor adjustment.

However, whilst the results suggest that the WC-R may be a useful assessment tool, as discussed above, coping questionnaires consist of a limited list of strategies and cannot, therefore, be taken to include all strategies parents use (Beresford, 1994). The content analysis identified nine further coping strategies. The results suggest, therefore, that clinicians wishing to obtain a more comprehensive overview of parents' coping strategies should include an open-ended coping item, as in the present study.

The two measures of well-being used in the current study, the QRS-F and GHQ-12, were found to be correlated at .574 ( $p < .01$ ) and produced significant correlations with WC-R relative coping scores in the same directions. These results, therefore, suggest that either one of these questionnaires would serve as a suitable measure of well-being for clinical practice. As the GHQ-12 is shorter than the QRS-F and less time-consuming, use of this measure may be preferable. Clinicians may, however, wish to administer the QRS-F in addition to the GHQ-12 to gain an impression of the sources of parenting stress experienced and identify possible areas for intervention.

It must, however, be noted that the use of standardised measures, such as the WC-R and GHQ-12, is recommended here as an adjunct to and not a substitute for comprehensive clinical assessment. Whilst it is proposed that clinicians working with families with disabled children assess parental coping and well-being routinely, using standardised measures, clinicians need to remain aware of the limitations of such self-report measures, such as the possibility of human and measurement error (Johnston *et al.*, 1995), and exercise clinical judgement when



interpreting scores. It is not recommended that clinical decisions be made solely upon the basis of a parent's scores on such measures.

#### 4.3.3 Use of Formal Support Services

Whilst the results suggest a need for routine assessment of parental coping and well-being and provision of coping skills training, as discussed above, they also highlight a wider issue, reported previously in the research literature, of parents' low usage of formal support services. Clinicians cannot help parents who are not accessing their services. It is, therefore, of paramount importance that this issue is addressed.

As discussed above, on average, parents in the current study reported high levels of parenting stress and psychological distress. Almost half of the parents completing the GHQ-12 indicated that they were experiencing psychological distress at clinically significant levels. However, in spite of these high levels of stress and distress, at the time of the study only 9.8 % of the sample were using psychological or mental health services to manage their child. Further, only 10.6 % indicated that they used formal respite care. Moreover, 35 % of parents revealed that they did not use professional help of any kind to manage stressful parenting situations (Table 6).

Whilst, as mentioned above, it is not possible to determine the reasons for parents' relatively low usage of formal support services, as this was not the subject of investigation, previous research in this area indicates several potential areas for intervention.

Firstly, parents need to be aware of the range of services available to them. As discussed above, previous research has shown that many families caring for a child with disabilities are unaware of services provided (e.g. Sloper & Turner, 1993; Stalker & Robinson, 1994; Hayes *et al.*, 1996). For example, in their study of parents' views of different respite care services, Stalker and Robinson (1994) found that 76 % of families using residential homes and 42 % of families using health authority provision thought that they had no choice of respite facility and were not aware of alternative family-based facilities available. Further, levels of satisfaction with these services were found to be lower than that of parents using family-based

schemes. Nevertheless, the principal effect of respite care, identified by parents in all three groups, was the opportunity to relax and reduced levels of parenting stress. Clinicians, therefore, have a role in facilitating parents' access to services by providing information and the opportunity to discuss the options available (Sloper & Turner, 1993).

Secondly, services provided need to meet parents' requirements. As Stalker and Robinson's (1994) study illustrates, many services do not meet parents' needs. Parents who are dissatisfied with services received may choose to opt out. Whilst the present results suggest that parents accessing professional support find this to be of benefit, as indicated by the content analysis findings and positive relationship between use of practical coping strategies and well-being, one cannot assume that parents not accessing professional support would benefit from using it. Beresford (1994), for example, cites research identifying formal support as a *source* of stress. Further, research has shown that parents' interactions with professionals are sometimes less than optimal. For example, in their study of doctor-parent communication at first diagnosis of SLD, Quine and Rutter (1994) found that 58 % of parents were dissatisfied with the communication.

Clinicians, therefore, have a role in assessing parents' needs and evaluating their services in view of these.

Thirdly, clinicians have a role to play in normalising parents' experience of stress and the use of formal support services. As discussed previously, for over 10 % of the sample stoicism was the most frequently used coping strategy. Parents with a tendency to "keep a stiff upper lip" may, perhaps, find it more difficult to access services when needed. Similarly, parents passively accepting stressful parenting situations, the most frequently used WC-R coping strategy, may perhaps be less likely to seek professional help out of a belief that nothing can be done. Further, clinicians working in the disabilities field have a role in advertising and normalising the use of adult mental health services, such as professional counselling, identified by some parents in the content analysis as being a helpful coping strategy.

#### 4.4 Policy Implications

It can be seen from the above discussion of clinical implications that the current study lends support to recent policy initiatives relating to carers. As mentioned above, the Government has recently developed a national strategy for carers, "Caring about Carers" (Department of Health, 1999). The importance of supporting carers in their caring role is emphasised, in the recognition that "helping carers is one of the best ways of helping people they are caring for" (Department of Health, 1999, p.6). This new approach to carers has three strategic elements: provision of information, support and care for carers.

Firstly, the Government emphasises the need for carers to receive wider and more accessible information with regard to the sources of help and services available to them. As discussed above, studies have shown that many families caring for a disabled child are unaware of services provided (e.g. Stalker & Robinson, 1994). The relatively low use of formal support reported in the present study may perhaps in part reflect parents' lack of awareness of service provision. Further, as mentioned previously, the relatively high use of passive acceptance to cope with stressful parenting situations reported in the current study indicates that many parents feel that nothing can be done to alleviate their stress. This would also suggest that many parents in the sample were unaware of possible sources of help.

Moreover, the Government's new approach emphasises the need for provision of information to carers to be part of a two-way process. Statutory services are encouraged to collect information about carers and their needs and to use it to respond with relevant information (Department of Health, 1999). As discussed above, the assessment tools used in the current study offer a means by which clinicians can assess parents' well-being and needs with regard to coping skills training. Such an assessment may form a valuable part of a wider assessment of carers' needs.

Secondly, the "Caring about Carers" strategy emphasises the need to support carers in carrying out their caring responsibilities. Service providers are encouraged to view carers as partners in the provision of care and involve carers in service

planning and delivery, to ensure that services provided are relevant and responsive (Department of Health, 1999). As discussed above, the relatively low use of formal support reported by parents in the present study may also partly reflect a degree of dissatisfaction with services.

Clinicians will be better able to support parents and meet their needs if, as suggested above, these are routinely assessed. Provision of coping skills training is one means by which parents can be supported directly by clinicians. As discussed above, clinicians can also support parents through facilitating access to coping resources and providing emotional support in addition to practical advice. Further, the present results suggest that for many parents routine assessment of their coping skills and well-being would provide an opportunity for reflection on their *expertise* as a carer and, thus, act as an indirect source of emotional support.

Thirdly, the Government's new approach to carers emphasises the need to care for carers and recognise carers as individuals with their own aspirations and needs independent of the person being cared for (Department of Health, 1999). Maintenance of carers' physical and emotional health is noted as a priority. Further, stress-related illness in carers is cited as a cause for concern. The present results are, therefore, of particular policy relevance.

The current study provides up-to-date information about levels of stress and distress experienced by parents of children with SLD and, furthermore, indicates practical ways in which such parents may be assessed and helped. Moreover, as discussed above, the results are consistent with those of several previous large-scale studies with related populations (e.g. Frey *et al.*, 1989; Sloper *et al.*, 1991; Sloper & Turner, 1993), suggesting that the intervention approaches outlined above may also be usefully applied to parents of children with other disabilities. Whilst further research with a UK population is required, the American research into coping skills training to date suggests that this approach is effective (e.g. Gammon & Rose, 1991; Kirkham, 1993). Coping skills training may, therefore, in future form an important part of evidence-based clinical practice.

Further, in line with recent policy (Department of Health, 1999), the present results indicate the importance of viewing the disabled child as part of family and wider social systems. As discussed above, parenting stress can have a damaging effect on not only parents' well-being but that of their child or children (e.g. Dyson *et al.*, 1989), impacting upon family relationships. Further, as mentioned above, parents under stress are more likely to request long-term care (e.g. Sherman & Coccozza, 1984). It is, therefore, essential that statutory services concerned with promoting well-being take an inclusive approach and consider and address the needs of parents alongside those of the child. The present results support recent Government policy calling for the comprehensive assessment of both the carer and cared for and intervention where indicated (Department of Health, 1999).

Services for families of children with disabilities may, therefore, need to reorganise so that the focus is truly on the needs of *families* and not solely on those of the child. The escalating policy of greater community provision and home-based support for families with a disabled child has made it increasingly important that parents effectively manage the day-to-day stresses of caring. The present results suggest that whilst some parents are managing the demands placed upon them, the majority are not and tend to rely upon less favourable coping strategies. Services need to be organised to support parents in their caring role.

## 4.5 Limitations of the Study

Several limitations of the study require qualification of these conclusions. Limitations of the design, measures and procedure are considered in turn below. Possible improvements to the methodology used are suggested.

### 4.5.1 Design

The cross-sectional correlational design of the present study prevents conclusions about cause and effect (Barker, Pistrang & Elliott, 1994). Whilst a fuller longitudinal investigation of links between use of individual coping strategies and outcome variables would perhaps help to elucidate the important resistance and risk factors, such an investigation is unfortunately outside the scope of doctoral research, given time and budgetary constraints.

The use of two outcome measures in the current study allowed the results to be cross-checked. The two measures of well-being, the QRS-F and GHQ-12, produced significant correlations with WC-R relative coping scores in the same directions, providing evidence of the validity of the results. Whilst the use of more than one outcome measure in studies of parental coping has been recommended (Beresford, 1994), in hindsight it may perhaps have been better to have included an outcome measure with both a positive and negative pole, such as the satisfaction with life measure used by Sloper *et al.* (1991) and Sloper and Turner (1993).

The satisfaction with life measure incorporates both a positive pole (high satisfaction) and a negative pole (low satisfaction) whereas the QRS-F and GHQ-12 measure only negative outcome, that is, symptoms of parenting stress and psychological distress respectively. As Sloper and Turner (1993, p. 169) note, “lack of distress may not be an adequate measure of successful outcome”. Further, both Sloper *et al.* (1991) and Sloper and Turner (1993) found that the five subscales of the WC-R were significantly associated with at least one, but not necessarily all, outcome measures, suggesting that different coping strategies affect different aspects of parental adjustment.

However, whilst it would perhaps have been beneficial to have measured parental well-being more fully, using the satisfaction with life measure, this index is computed from a range of measures and comprises twenty questions (Sloper *et al.*, 1991). Inclusion of this additional measure of well-being would, therefore, have increased the time taken to participate in the study substantially and subsequently may have lowered the response rate. Whilst, to overcome this problem, the satisfaction with life measure could have been used in place of one of the two measures of negative outcome, valuable information obtained in the present study regarding current levels of parenting stress or psychological distress would then have been forfeited.

In spite of its limitations, the three-variable, cross-sectional, correlational design used allowed the research questions to be answered and the hypotheses to be tested.

#### 4.5.2 Measures

Whilst the study benefited from the use of standardised questionnaires of established reliability and validity, its reliance on self-report data may be considered a further limitation. By definition self-report measures are subjective and open to the problems of bias, retrospective falsification and inadequate memory (Barker *et al.*, 1994). Whilst it is advisable to supplement self-report data with observational data (Barker *et al.*, 1994), this would perhaps have been impractical given time constraints.

However, whilst the research relied upon parental perceptions of all variables, it is argued that these perceptions are the most important factors in the coping process (Lazarus, 1999). The essence of Lazarus and Folkman's (1984) model is the process of *appraisal*, referring to the way individuals *construe* the significance for their well-being of what is happening and what might be done, which refers to the coping process. Further, as Lazarus and Folkman (1984, p. 320) argue, retrospective falsification is itself a process of coping. Within this conceptual framework, individual, subjective experience of stress and coping was, therefore, the subject of study.

As discussed above, standardised coping questionnaires, such as the WC-R, include both adaptive and maladaptive coping strategies, whereas researchers using qualitative techniques to investigate parental coping have tended to uncover only the coping strategies considered by parents to be adaptive (e.g. Bregman, 1980; Brown & Hepple, 1989). However, standardised coping questionnaires list only a limited number of coping strategies and, therefore, restrict parents' responses. The present study, therefore, benefited from combining both quantitative and qualitative techniques: the content analysis of responses to the open-ended coping item revealed nine coping strategies not listed on the WC-R.

It could, nevertheless, be argued that use of content analysis is a less rigorous method than using standardised measures such as the WC-R. Use of a second rater, however, allowed the reliability of categorisation of raw data themes to be ascertained and, as discussed above, the inter-rater reliability was found to be very high. However, as the content analysis reflects parents' individual and unique responses it is more difficult to relate the findings to those of previous studies.

In hindsight, it would have been better to have asked parents responding to the open-ended item to indicate the perceived helpfulness of the coping strategies they described. As discussed above, from inspection of the raw data (Appendix 10) it appeared that parents listed only the strategies used that they felt were adaptive. The second rater shared this opinion. In further support of this argument, as mentioned above, several participants spontaneously commented upon the efficacy of their coping strategies in reducing stress or aiding relaxation. However, as parents were not asked explicitly to rate the efficacy of their additional coping strategies it is unfortunately not possible to verify this.

Similarly, in hindsight, two of the questions on the "You and Your Family" background questionnaire (Appendix 2) were not specific enough. Whilst parents were asked whether or not their child with SLD was a boarder at their school, they were not explicitly asked about use of other forms of respite care. The question "Who shares the care of your child / children?" allowed parents to indicate their use of "Other", formal sources of practical support, and twelve participants (10.6 %) indicated use of formal respite care by this means. However, as parents were not



explicitly asked whether or not they used respite care, the present study may perhaps underestimate use of this as a coping strategy.

Likewise, whilst parents were asked whether or not they were using psychological and or mental health services at the time of the study to manage *their child with SLD*, they were not asked to indicate their own use of adult mental health services to combat parenting stress. The present study may therefore underestimate parents' use of formal support services in general. The breakdown of parents' responses to item 13 of the WC-R (Table 6) nevertheless conclusively indicates that 35 % of parents reported that they did not use professional support to manage stressful parenting situations. Further still, Table 6 shows that the majority of parents using professional support did so only occasionally (33.3 % used professional support "somewhat", Table 6). Whilst these data provide evidence of parents' relatively low use of formal support, the background questionnaire could be improved by asking more specific and direct questions about parents' use of formal support services.

Finally, it may perhaps have been beneficial to have included a measure of social desirability, such as the short version of the Marlow-Crowne Social Desirability Scale (Strahan & Gerbasi, 1972), within the questionnaire pack completed by parents. Knussen *et al.* (1992) found a significant inverse association between scores on the Marlow-Crowne Social Desirability Scale and wishful thinking WC-R relative scores for fathers, indicating that fathers with higher social desirability scores were likely to have a lower proportion of total endorsements on the wishful thinking subscale. Whilst a significant inverse association between mothers' social desirability scores and wishful thinking WC-R *raw* scores was also found, no association was found between mothers' social desirability scores and their wishful thinking *relative* scores.

As discussed above, in the current study WC-R relative scores as opposed to raw scores were used. Drawing upon Knussen *et al.*'s (1992) findings, the present study may, therefore, underestimate fathers' use of wishful thinking. However, as 91.9 % of the sample were mothers and mothers' WC-R relative scores were not found by Knussen *et al.* (1992) to be related to social desirability scores, it is unlikely that the

present results are affected greatly by social desirability. Further, Knussen *et al.* (1992) suggest that their results were affected by the lack of anonymity in their study. As discussed above, in the present study participants remained anonymous and this may, therefore, have reduced possible response bias in the WC-R further.

Whilst it may have been better to have included a measure of social desirability as a control in the present study, this would again have increased the time required to participate in the study and may have reduced the response rate. As discussed above, it was desirable to keep the research demands placed upon parents to a minimum.

#### 4.5.3 Procedure

Whilst low, the response rate of 40 % was comparable to that reported in other similar UK postal surveys and good considering that a one-stage recruitment procedure was used. Wiggs and Stores (1996), for example report a 43 % response rate in their postal survey of sleep disturbance and challenging behaviour in children with SLD. As in the present study Wiggs and Stores distributed questionnaire packs to parents through special schools. However, in contrast, reminder letters were sent to those who had not replied.

Whilst, for the reasons given in section 2.5.3, repeated mailings were not used in the present study, in hindsight the response rate may perhaps have been improved upon if parents had been given advance notice of the study. This has been found to increase response rates (Fink, 1995; Mathers *et al.*, 1998). Parents could perhaps have been informed about the study by the researcher on parents' evenings or at P.T.A. meetings. However, this would have been time-consuming and perhaps impractical. Further, this would have delayed the distribution of questionnaire packs and newsletter reminders, reducing the time available for the return of questionnaires within the time constraints of the study. Use of advance letters, whilst more feasible, would nevertheless have increased the cost of the study.

As discussed above, as postal surveys are generally cheaper and quicker, especially when respondents are widely distributed (Mathers *et al.*, 1998), a postal survey was

used to achieve the large sample size required within budgetary and time constraints. However, postal surveys have several limitations. Firstly, there is a lack of personal contact between the potential respondent and researcher and, in general, postal surveys tend to have lower response rates than face-to-face interviews (Mathers *et al.*, 1998). Secondly, postal surveys usually take longer than either telephone or face-to-face surveys (Mathers *et al.*, 1998) and consequently, as mentioned above, sufficient time needs to be allocated to allow respondents to reply. Thirdly, postal surveys are not suitable for people with literacy problems. Whilst the literacy level of the covering letter was ascertained and found to be typical of standard writing, and the measures were chosen for their brevity and simplicity, some parents may perhaps have had difficulty understanding and completing the standardised questionnaires. However, all social classes were represented in the sample, suggesting indirectly that the questionnaire pack was accessible to participants from a range of socio-economic and academic backgrounds.

However, it must be noted that in the present study all of the questionnaires were sent out in English. Whilst one school enlisted the services of an interpreter to allow non-English speaking parents to participate, other such parents of children attending the other five schools involved in the study did not have the benefit of this service. Strictly speaking these parents were not, therefore, eligible respondents and thus the true response rate may perhaps be underestimated. However, there were only three non-English-speaking families identified in the school using the interpreter and it is likely that the numbers of such families in the other five schools were equally low. In hindsight, it would have been wise to have asked the Headteachers of the other five schools whether any of the families to be targeted were non-English-speaking. It would also have been preferable to provide questionnaire packs to non-English speaking families in their first language. For financial reasons this was not possible. However, the three non-English speaking families who were offered the services of an interpreter were also illiterate and, therefore, would have been unable to read questionnaires translated into their first language.

In the current study non-probability convenience sampling was used (Fink, 1995). All parents of children with SLD attending the participating special schools were invited to take part in the study. Participants were not randomly selected but self-selected. A major disadvantage of non-probability samples, however, is that they do not guarantee that all eligible participants have an equal chance of being selected (Fink, 1995). To the extent that the sample in the current study varies from the general population generalisability may be limited. The sample were predominantly White (86.2 %), married (74.0 %) and female (91.9 %).

However, whilst the majority of participants were White, this is typical of Derbyshire, although, interestingly, the proportion of White participants (86.2 %) is lower than would be expected from Census statistics for the population of Derbyshire (97.0 %) (HMSO, 1992; HMSO, 1993). This finding may perhaps reflect an increased prevalence of SLD among British Asians (Emerson, Azmi, Hatton, Caine, Parrott & Wolstenholme, 1997). Emerson *et al.* (1997) found that the prevalence of SLD is approximately three times higher among the Asian community when compared to the non-Asian community.

Whilst the sample deviates from the normal population in terms of ethnicity, marital status and gender, the results of the study may, nonetheless, be reliably compared to those of previous studies of parental coping. Such studies have also tended to use samples with these characteristics (e.g. Miller *et al.*, 1992; Thompson *et al.*, 1992). However, whilst most studies have concentrated upon the mother as the main respondent, some researchers have specifically sought the views of fathers and explored the factors relating to stress for fathers in comparison to mothers (e.g. Frey *et al.*, 1989; Sloper *et al.*, 1991; Sloper & Turner, 1993). Findings from these multivariate studies suggest that the relationship between use of certain coping strategies and parental well-being is less pronounced for fathers than mothers. These results, therefore, suggest that the associations between use of individual coping strategies and parental well-being found in the present study may have been weakened by the pooling of responses from fathers and mothers.

Whilst as only ten fathers participated in the current study it seemed unlikely that the results would have been affected greatly, to check for this post-hoc correlational

analyses were conducted on mothers' responses. These analyses revealed that the associations between individual coping strategies and parental well-being found were not affected significantly by the pooling of fathers' and mothers' responses (Appendix 12). As the number of fathers taking part in the study was very low it was not statistically viable to treat fathers as a separate group.

Beresford (1994) suggests that whilst previous research has identified gender differences in preferred coping strategies, the different findings with respect to fathers' and mothers' coping strategies and adjustment are more likely to reflect gender differences in what is experienced as stressful in relation to caring for a disabled child. Beresford notes that, in spite of this, researchers exploring mothers' and fathers' stress and coping have administered identical stress and coping measures designed for use with mothers. Beresford suggests that data obtained from fathers' responses to such measures may be invalid. In contrast, the measures used in the present study were designed for use with both male and female respondents (Friedrich *et al.*, 1983; Goldberg, 1992; Knussen *et al.*, 1992) and, therefore, there is no reason to believe that data obtained from fathers in the current study is invalid.

#### 4.6 Contribution of the Study to the Research Area

In spite of its limitations, it can be seen from the above discussion that the present study adds to the research literature in several broad respects, meeting the aims set in chapter one.

Firstly, the study adds to the limited research exploring the relationship between use of individual coping strategies and parental well-being. Hypotheses regarding associations between coping strategies used, psychological distress and parenting stress were tested using univariate correlational analyses. The findings support those of previous multivariate studies with related populations.

Secondly, in contrast to previous studies of coping strategies and well-being, the source of social support used by parents to manage stressful parenting situations was considered and controlled for by the use of a coping questionnaire measuring parents' use of informal support. In keeping with previous research, the results suggest that informal sources of support were used more often than formal sources.

As discussed above, in contrast to previous research, Sloper *et al.* (1991) and Quine and Pahl (1991) did not find social support to be an adaptive coping strategy. The present results do not support Beresford's (1994) suggestion that these conflicting findings may be accounted for by the researchers' use of coping questionnaires that cluster various sources of social support into a single strategy. The results suggest that use of social support was positively associated with well-being irrespective of whether formal or informal sources were used. Other possible reasons for the conflicting findings of Sloper *et al.* (1991) and Quine and Pahl (1991) were offered.

Thirdly, the study adds to the limited research examining the self-reported coping strategies of parents of children with SLD. Few researchers exploring stress and coping in parents of children with learning disabilities have focused upon a specific severity level (Flynt & Wood, 1989). Some researchers have acknowledged that children with physical disabilities may produce different demands to children with learning disabilities and have, therefore, examined parents' ways of coping with these difficulties separately (e.g. Sloper & Turner, 1993; Sloper *et al.*, 1991).

However, as discussed above, there has been little research specifically exploring the coping strategies of parents of children with SLD, who often face the challenge of multiple impairments, including both learning and physical disability.

Further, the findings of Quine and Pahl's (1991) UK study of coping in mothers of children with SLD are inconsistent with previous research with related populations, warranting further confirmatory or disconfirmatory research. The present study addressed this need.

The results of the current study on stress and coping in parents of children with SLD do not support those of Quine and Pahl (1991). The present findings are consistent with those of previous large-scale studies with related populations. This study has shown that the positive relationships between use of practical coping and emotional social support and well-being also occur in families of children with SLD. Possible reasons for Quine and Pahl's inconsistent findings were offered.

Fourthly, the study went beyond previous studies of parents' self-reported coping strategies by using both quantitative and qualitative measures of coping. The content analysis of parents' responses to the open-ended item revealed nine further coping strategies not listed on the WC-R. The study provides a detailed analysis of the coping strategies used by parents of children with SLD.

#### 4.7 Areas for Further Research

Whilst the current study can be seen to make a significant contribution to the body of literature on stress and coping in families with a disabled child, there remain several areas in need of further research, some of which are outlined below.

Firstly, whilst the findings of the univariate correlational analyses are consistent with those of previous large-scale studies with related populations, as discussed above, the current results do not support those of Quine and Pahl (1991) with regard to mothers of children with SLD. In contrast to Quine and Pahl's study, in the present study use of a practical coping strategy and use of social support were found to be positively associated with parental well-being. Similarly, catharsis was indicated to be a further helpful coping strategy.

As discussed above, there are several possible explanations for these inconsistent findings, which may perhaps form the basis for further research. For example, as mentioned previously, the disparate findings may perhaps reflect differences in parents' appraisal of parenting situations. It was noted that, according to the process model, stress is reduced only if there is a fit between an individual's appraisal of a potential stressor and the coping strategy employed. It was therefore suggested that the strategies of seeking social support, catharsis and practical coping were perhaps a poor fit for the appraisals of mothers in Quine and Pahl's (1991) study and a better match for the appraisals of parents in the current study. As discussed above, further research examining stress, appraisal and the coping strategies of parents caring for a child with SLD, employing methodology such as that used by Miller *et al.* (1992), is needed to test this hypothesis.

Alternatively, the inconsistent findings may perhaps be an artefact of the coping measure used by Quine and Pahl (1991). As mentioned above, in contrast to previous studies in this field, Quine and Pahl used the MDC (Stone & Neale, 1984) to measure parents' coping strategies. The present results therefore suggest that research comparing the use of the MDC and WC-R is warranted.



Secondly, the range of coping strategies reported by parents in the current study is, in general, consistent with previous qualitative studies with related populations. However, as discussed above, the low use of religious faith as a coping strategy indicated by the present study is somewhat inconsistent with previous, albeit limited, research in this field (e.g. Turnbull *et al.*, 1985). Although it was noted that parents in the current study were not explicitly asked about their religious beliefs, and that this may have led to underreporting of use of religion, the possibility of a change in religiosity over time was also considered. The present results therefore suggest a need for further, more up-to-date research examining the role of parents' ideological beliefs in their management of parenting stress.

Conversely, in the current study several parents reported use of traditional stress-management techniques, such as physical exercise and relaxation, to manage parenting stress. However, as discussed above, whilst such techniques have been widely reported in the general psychological literature, these coping strategies have seldom been reported in previous studies of parents caring for a disabled child. The present results therefore suggest a need for further research examining the extent to which such strategies are used by parents.

Thirdly, as mentioned above, studies employing a correlational design, as in the present research, cannot be used to make unequivocal causal inferences (Barker *et al.*, 1994). Longitudinal research examining the effect of coping strategies over time is much needed to uncover factors predictive of parental stress and, thus, inform clinical interventions aimed at improving parental well-being. Multivariate studies such as those of Frey *et al.* (1989), Quine and Pahl (1991) and Miller *et al.* (1992) have identified a wide range of factors predictive of parental adjustment. Longitudinal research in this area will, therefore, need to encompass the measurement of a wide range of variables, including perceived coping efficacy and coping strategies.

Fourthly, whilst researchers have started to explore gender differences in parental coping, possible racial differences have not generally been considered. As in the current study, the samples used have been predominantly white. Whilst in their American study Flynt and Wood (1989) found that black mothers of children with

moderate learning disabilities reported lower perceived family stress levels and used a greater amount of coping strategies centred around intrafamily resources than did white mothers, comparable UK studies are lacking. The present results suggest that parents from ethnic minority groups would need to be specifically targeted to maximise their participation in such research.

Fifthly, further research examining possible gender differences in the use and efficacy of different coping strategies is required. As discussed above, the results of studies to date (e.g. Sloper *et al.*, 1991; Sloper & Turner, 1993), may be invalid as measures administered to fathers had often been tailored for use with mothers. Researchers investigating this area would need to ensure that all measures used were suited to the respondents regardless of their gender. The effect of role differences would also need to be controlled for. Further, whilst it is recognised that family members form a mutually influencing system, little research has explored the effect of congruence of parents' coping styles on their adaptation (Beresford, 1994). There is also a need for continued study of other family members' modes of coping, including siblings of the disabled child, a group shown to be greatly affected by parenting stress (e.g. Dyson *et al.*, 1989).

Finally, to further move the research focus away from pathological models of family functioning, there is a need for continued research exploring the beneficial effects of having a child with a disability in the family. Brown and Hepple (1989), for example, found that whilst parents in their study identified several negative effects, such as restrictions in their lifestyle, relationship problems, anxiety and other emotional problems, they also identified positive benefits, such as feeling a better person and less selfish, and increased family cohesion. Whilst the present study revealed parents' coping strengths as well as their weaknesses, research specifically focusing upon strengths and benefits is needed to counterbalance the disparaging research of the past few decades.

## **5. Appendices**

### **APPENDIX 1**

#### **Letters to and from NHS Ethics Committees**

(Letter sent to North Derbyshire Ethics Committee not given as identical to one sent to Southern Derbyshire Ethics Committee)

21 May 1999

Dr A Mellersh  
Chairman  
Southern Derbyshire Ethics Committee  
Dept. of Public Health (Medical Admin)  
Southern Derbyshire Health  
Derwent Court  
Stuart Street  
Derby  
DE1 2FZ

University of Leicester  
Centre for Applied Psychology  
(Clinical Section)  
University Road  
Leicester  
LE1 7RH

Dear Dr Mellersh,

**Re: Ethical Approval for Third Year D. Clin. Psy. Research**

I am a second year Trainee Clinical Psychologist with the University of Leicester D. Clin. Psy. Course, employed by Leicestershire & Rutland Healthcare NHS Trust. I write to ask your advice regarding ethical approval for my third year research project.

For my third year research, I intend to explore the coping strategies which parents of children with severe learning disabilities (SLD) use to manage the day-to-day care of their children. I plan to access participants via Special Schools offering placements for children with SLD in Northern and Southern Derbyshire. Participation will be on a voluntary basis. I intend to give questionnaire packs to the Schools for distribution to pupils' parents via Class Teachers. The approval of the Headteachers will of course be sought prior to this. I enclose a copy of the research protocol for your information. This has been submitted to the University Ethics Committee for approval.

I am unclear whether it is appropriate for me to submit my proposal to NHS Ethics Committees, as the research will not be conducted in NHS settings. I would appreciate your advice with regards to this. Whilst I hope to be on placement in Derbyshire, the research will be independent of my clinical placement.

I would appreciate your advice on the above at your earliest convenience.

Yours sincerely,

**Mrs Hanna Link BSc (Hons)**  
**Clinical Psychologist in training**



Scarsdale, Newbold Road  
Chesterfield S41 7PF  
Tel: 01246 231255  
Fax: 01246 206672

**NORTH DERBYSHIRE LOCAL RESEARCH ETHICS COMMITTEE**

**CHAIRMAN: Revd. David C. Pickering**

DCP/AB

30<sup>th</sup> May, 1999

Mrs. H. Link, B.Sc.(Hons.),  
Clinical Psychologist in Training,  
Centre for Applied Psychology (Clinical Section),  
University of Leicester,  
University Road,  
Leicester,  
LE1 7RH

Dear Mrs. Link,

Thank you for your letter dated 21<sup>st</sup> May seeking advice as to whether your third year research project (in which you intend to explore the coping strategies which parents of children with severe learning disabilities use to manage the day-to-day care of their children) needs to be submitted to NHS Ethics Committees.

Having read your proposal I do not consider it requires NHS Ethics Committee approval but I will report the background to your study to the North Derbyshire Local Research Ethics Committee for their information.

Thank you for bringing your proposal to our attention.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'David C. Pickering', with a long, sweeping flourish extending to the right.

REVD. DAVID C. PICKERING  
Chairman, North Derbyshire LREC

**Michael Marchment**  
Chief Executive  
Southern Derbyshire Health Authority

Please reply to:- Jill Marshall  
SDEC Administrator  
ext 6420 (direct dial from Derby hospitals 16-6420)



Southern Derbyshire Health Authority,  
Derwent Court, Stuart Street,  
Derby DE1 2FZ.  
DX 709391 Derby 9.

Tel: (01332) 626300. Fax: (01332) 626350.  
website: [www.sdhealth.demon.co.uk](http://www.sdhealth.demon.co.uk)

## **SOUTHERN DERBYSHIRE ETHICS COMMITTEE**

Your Ref:  
Our Ref: AWAC/JM

Chairman: Dr A W A Crossley MB ChB FRCA  
Direct fax: 01332 363963

24 May 1999

Mrs H Link  
Clinical Psychologist in Training  
University of Leicester  
Centre for Applied Psychology (Clinical Section)  
University Road  
LEICESTER  
LE1 7RH

Dear Mrs Link

### **ETHICAL APPROVAL FOR THIRD YEAR D CLIN PSY RESEARCH**

Thank you for your letter about the above study, which I have reviewed today. I would take the view that this does not need ethics committee approval from an NHS committee, for the reasons which you have outlined.

Yours sincerely

A handwritten signature in black ink, appearing to read 'A W A Crossley', written over a horizontal line.

A W A Crossley  
Chairman  
Southern Derbyshire Ethics Committee

**NHS**

*working together for health*

LEICESTERSHIRE + RUTLAND

# Healthcare



Community Hospitals Mental Health Community Health Learning Disability

Ref: EB/AC1106/cm

06 August 1999

Mrs Hanna Link  
Clinical Psychologist in Training  
Centre for Applied Psychology (Clinical Section)  
New Building  
University of Leicester  
University Road  
Leicester  
LE1 7RH

**Headquarters**

George Hine House  
Gipsy Lane  
Leicester LE5 0TD

Tel: 0116 225 6000  
Fax: 0116 225 3684

Direct dial number: (0116) 246 3462

Dear Mrs Link

**Stress and Coping Among Parents of Children With Severe Learning Disabilities (S.L.D)  
Coping Strategies and Parents Well Being**

I am pleased to inform you that your study was approved by the Leicestershire and Rutland Research and Development Operational Group on 3 August 1999.

The group felt it important that you make an offer, within your study information leaflet, for any parents to contact you that are distressed or wish to talk about issues raised by your study.

I can confirm the Trust is willing to provide indemnity for your study.

May I take this opportunity to wish you all the best for your research study.

Yours sincerely

Dr Eric Button  
Director of Research and Development

**APPENDIX 2**

**You and Your Family Background Questionnaire**



## You & Your Family

Please tick boxes as appropriate.

### Your Details

1. Relationship to child with SLD: Mother Father  
Female Guardian Male Guardian
2. Ethnic group: White Black-Caribbean Black-African Black-other Indian  
Pakistani Bangladeshi Chinese Any other ethnic group \_\_\_\_\_
3. What is your age? \_\_\_\_\_
4. What is your marital status? Single Married Cohabiting Separated  
Divorced Widowed
5. What is the occupation of the main wage earner in your household?  
Professional Clerical non-manual Skilled manual Semi-skilled Unskilled  
Armed forces Police Housewife/husband Student Unemployed  
Never had occupation
6. How many children do you have? \_\_\_\_\_
7. Who shares the care of your child / children? (tick all that apply) Spouse / Partner  
Other family member Friend Other(s) \_\_\_\_\_ (please specify)

### Your Child with S.L.D.

1. What is your child's a). age? \_\_\_\_\_ b). gender? \_\_\_\_\_
2. How would you describe your child's mobility? Mobile Immobile
3. Does your child have additional disabilities (e.g. sensory impairments, behaviour problems)?  
Yes (please specify) \_\_\_\_\_ No
4. Is your child a boarder at his / her school? Yes No
5. Do you *currently* use Psychological / Mental Health Services to manage your child? Yes No

**APPENDIX 3**

**Covering letter**



UNIVERSITY OF LEICESTER  
CENTRE FOR APPLIED PSYCHOLOGY · UNIVERSITY ROAD · LEICESTER LE1 7RH · UK

Dear Parent,

**STUDY OF PARENTS' MANAGEMENT OF PARENTING STRESS**

In recognition of the numerous pressures facing today's parents of children with severe learning disabilities (S.L.D.), I am conducting a study examining the ways in which parents cope, with varying degrees of success, with the day-to-day care of their children. As each parent's experience of raising a child with S.L.D. is unique, I would like to sample the views of a wide range of parents and would very much like you to take part in this research. Your child's school has kindly agreed to distribute this research pack to all parents of children with S.L.D.

***What are the aims of the research?***

This research will add to the growing body of literature on stress and parents' coping. With a greater understanding of parenting stress and coping, professionals will be better able to assist parents.

***What do I have to do to take part?***

If you would like to take part, please complete the following enclosed questionnaires:

- You & Your Family** – a questionnaire seeking to obtain a general picture of your family
- QRS-F** – a questionnaire on parenting stress
- GHQ-12** – a General Health Questionnaire
- WC-R** – a questionnaire exploring the coping strategies you use to manage parenting stress

The questionnaires take approximately 10 minutes in total to complete. All questionnaires are confidential and anonymous. The answers will be analysed by computer and only the broad pattern of results will be reported. If you do not wish to take part, please return the questionnaires blank. Please return questionnaires to me in the prepaid envelope provided as soon as possible (do not return the plastic wallet).

If you have any queries or wish to talk about issues raised by the study, I may be contacted at the above address. Please do not hesitate to do so.

Thanking you in anticipation for your time.

Yours sincerely,

**Hanna Link**  
**Clinical Psychologist in training**

**CENTRE DIRECTOR**

Professor E. MILLER  
Tel: 0116 252 2466  
Fax: 0116 252 2503  
E-mail: em22@le.ac.uk

**COURSE DIRECTOR**

(D.Clin.Psy.Course)

Dr C McCREA  
Tel: 0116 252 2466  
Fax: 0116 252 2503

**CLINICAL STAFF**

Mr A LAHER  
Dr K LOUMIDIS  
Dr B J PILLAY  
Tel: 0116 252 2466  
Fax: 0116 252 2503

**CLINICAL TUTORS**

Dr F FURNISS  
Dr J HUGHES  
Tel: 0116 252 2492  
Fax: 0116 252 2503

**APPENDIX 4**

**Short-Form of the Questionnaire on Resources and Stress (QRS-F)**

## A SHORT-FORM OF THE QUESTIONNAIRE ON RESOURCES AND STRESS (QRS-F)



This questionnaire asks about your feelings about a child in your family. There are many blanks in the questionnaire. Imagine the child's name filled in on each blank. Give your honest feelings and opinions. Please answer all the questions, even if they do not seem to apply. If it is difficult to decide whether to circle True (T) or False (F), answer in terms of what you or your family feel or do *most* of the time. Sometimes the questions refer to problems your family does not have. Nevertheless, they can be answered True or False, even then. Please remember to answer all of the questions.

1. \_\_\_\_\_ doesn't communicate with others of his/her age group  T  F
2. Other family members do without things because of \_\_\_\_\_  T  F
3. Our family agrees on important matters  T  F
4. I worry what will happen to \_\_\_\_\_ when I can no longer take care of him/her  T  F
5. Constant demands to care for \_\_\_\_\_ limit the growth and development of someone else in our family  T  F
6. \_\_\_\_\_ is limited in the kind of work he/she can do to make a living  T  F
7. I have accepted that \_\_\_\_\_ might have to live out his/her life in a special setting (e.g. institution or group home)  T  F
8. \_\_\_\_\_ can feed himself/herself  T  F
9. I have given up things I really wanted to care for \_\_\_\_\_  T  F
10. \_\_\_\_\_ is able to fit into the family social group  T  F
11. Sometimes I avoid taking \_\_\_\_\_ out in public  T  F
12. In the future, our family's social life will suffer because of increased responsibilities and financial stress  T  F
13. It bothers me that \_\_\_\_\_ will always be this way  T  F
14. I feel tense whenever I take \_\_\_\_\_ out in public  T  F
15. I can go to visit friends whenever I want  T  F
16. Taking \_\_\_\_\_ on holiday spoils pleasure for the whole family  T  F
17. \_\_\_\_\_ knows his/her own address  T  F
18. The family does as many things together now as we ever did  T  F



2

- 19. \_\_\_\_\_ is aware of who he/she is  T  F
- 20. I get upset with the way my life is going  T  F
- 21. Sometimes I feel very embarrassed because of \_\_\_\_\_  T  F
- 22. \_\_\_\_\_ doesn't do as much as he/she should be able to do.  T  F
- 23. It is difficult to communicate with \_\_\_\_\_ because he/she has difficulty understanding what is being said to him/her  T  F
- 24. There are many places we can enjoy ourselves as a family when \_\_\_\_\_ comes along  T  F
- 25. \_\_\_\_\_ is over-protected  T  F
- 26. \_\_\_\_\_ is able to take part in games or sports  T  F
- 27. \_\_\_\_\_ has too much time on his/her hands  T  F
- 28. I am disappointed that \_\_\_\_\_ does not lead a normal life  T  F
- 29. Time drags for \_\_\_\_\_, especially free time  T  F
- 30. \_\_\_\_\_ can't pay attention for very long  T  F
- 31. It is easy for me to relax  T  F
- 32. I worry what will happen to \_\_\_\_\_ when he/she gets older  T  F
- 33. I get almost too tired to enjoy myself  T  F
- 34. One of the things I appreciate about \_\_\_\_\_ is his/her confidence  T  F
- 35. There is a lot of anger and resentment in our family  T  F
- 36. \_\_\_\_\_ is able to go to the bathroom alone  T  F
- 37. \_\_\_\_\_ can't remember what he/she says from one moment to the next  T  F
- 38. \_\_\_\_\_ can ride on a bus  T  F
- 39. It is easy to communicate with \_\_\_\_\_  T  F
- 40. Constant demands to care for \_\_\_\_\_ limit my growth and development  T  F



3

41. \_\_\_\_\_ accepts himself/herself as a person

T F

42. I feel sad when I think of \_\_\_\_\_

T F

43. I often worry what will happen to \_\_\_\_\_ when I can no longer take care of him/her

T F

44. People can't understand what \_\_\_\_\_ tries to say

T F

45. Caring for \_\_\_\_\_ puts a strain on me

T F

46. Members of our family get to do the same kinds of things that other families do

T F

47. \_\_\_\_\_ will always be a problem to us

T F

48. \_\_\_\_\_ is able to express his/her feelings to others

T F

49. \_\_\_\_\_ has to use a bedpan or a nappy

T F

50. I rarely feel blue

T F

51. I am worried much of the time

T F

52. \_\_\_\_\_ can walk without help

T F



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**APPENDIX 5**

**General Health Questionnaire – 12 (GHQ-12)**



# GENERAL HEALTH QUESTIONNAIRE (GHQ-12)



Name: ..... Date: .....

Please read this carefully.

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Have you recently . . .

1. been able to concentrate on whatever you're doing?	Better than usual	Same as usual	Less than usual	Much less than usual
2. lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual
3. felt that you are playing a useful part in things?	More so than usual	Same as usual	Less useful than usual	Much less useful
4. felt capable of making decisions about things?	More so than usual	Same as usual	Less so than usual	Much less than usual
5. felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual
6. felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual
7. been able to enjoy your normal day-to-day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual
8. been able to face up to your problems?	More so than usual	Same as usual	Less so than usual	Much less able
9. been feeling unhappy and depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual
10. been losing confidence in yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual
11. been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual
12. been feeling reasonably happy, all things considered?	More so than usual	About same as usual	Less so than usual	Much less than usual

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**APPENDIX 6**

**Ways of Coping Questionnaire (Revised) (WC-R)**

**Ways of Coping (Revised) - WC-R**

Please read each item and think about whether you use this way of dealing with problems in bringing up your child with severe learning disabilities (S.L.D.). By problems we mean such things as sleeping difficulties, embarrassing behaviours, worries about the child's future, your own feelings about having a child with severe learning disabilities or anything which you yourself feel to be a problem.

Please tick one of the spaces opposite each item to show whether you DO or DO NOT use this way.

	Not used	Used some- what	Used quite a bit	Used a great deal
1. I try to analyse the situation in order to understand it better.	_____	_____	_____	_____
2. I turn to work or substitute activity to take my mind off things.	_____	_____	_____	_____
3. I do something which I don't think will work, but at least I feel I'm doing something.	_____	_____	_____	_____
4. I talk to someone to find out more about the situation.	_____	_____	_____	_____
5. I criticise or lecture myself.	_____	_____	_____	_____
6. I try not to burn my bridges but leave things somewhat open.	_____	_____	_____	_____
7. I hope a miracle will happen.	_____	_____	_____	_____
8. I go on as if nothing has happened.	_____	_____	_____	_____
9. I look for the silver lining, so to speak; try to look on the bright side of things.	_____	_____	_____	_____
10. I accept sympathy and understanding from someone.	_____	_____	_____	_____
11. I tell myself things that help me to feel better.	_____	_____	_____	_____
12. I am inspired to do creative things.	_____	_____	_____	_____
13. I try to get professional help.	_____	_____	_____	_____
14. I try to change or grow as a person in a good way.	_____	_____	_____	_____
15. I make a plan of action and follow it.	_____	_____	_____	_____
16. I accept the next best thing to what I want.	_____	_____	_____	_____

	Not used	Used some- what	Used quite a bit	Used a great deal
17. I let my feelings out somehow.	___	___	___	___
18. I accept that I bring problems on myself.	___	___	___	___
19. I try to come out of experiences better than when I went in.	___	___	___	___
20. I talk to someone who can do something concrete about the problem.	___	___	___	___
21. I try not to act too hastily or follow my first hunch.	___	___	___	___
22. I find new faith.	___	___	___	___
23. I maintain my pride and keep a stiff upper lip.	___	___	___	___
24. I rediscover what is important in life.	___	___	___	___
25. I avoid being with people in general.	___	___	___	___
26. I ask relatives or friends I respect for advice.	___	___	___	___
27. I make light of the situation; I refuse to get too serious about it.	___	___	___	___
28. I talk to someone about how I am feeling.	___	___	___	___
29. I stand my ground and fight for what I want.	___	___	___	___
30. I take it out on other people.	___	___	___	___
31. I draw on my past experiences.	___	___	___	___
32. I usually know what has to be done, so I keep up my efforts to make things work.	___	___	___	___
33. I refuse to believe that it has happened.	___	___	___	___
34. I make a promise to myself that things will improve next time.	___	___	___	___
35. I think up a couple of different solutions to problems.	___	___	___	___
36. I accept it, since nothing can be done.	___	___	___	___
37. I try to keep my feelings from interfering with other things too much.	___	___	___	___

	Not used	Used some- what	Used quite a bit	Used a great deal
38. I wish that I could change what has happened.	_____	_____	_____	_____
39. I wish that I could change how I feel.	_____	_____	_____	_____
40. I try to change something about myself.	_____	_____	_____	_____
41. I daydream or imagine a better time or place than the one I am in.	_____	_____	_____	_____
42. I wish that the situation would go away or somehow be over with.	_____	_____	_____	_____
43. I have fantasies or wishes about how things might turn out.	_____	_____	_____	_____
44. I prepare myself for the worst.	_____	_____	_____	_____
45. I go over in my mind what I might say or do.	_____	_____	_____	_____
46. I try to see things from the other person's point of view.	_____	_____	_____	_____
47. I remind myself how much worse things could be.	_____	_____	_____	_____
48. I try to make myself feel better by exercising or getting involved in something.	_____	_____	_____	_____

*Optional:*

I try something entirely different from any of the above. (Please describe).

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**APPENDIX 7**

**Example of Thank you and Reminder Letter  
Placed in School Newsletters**

26<sup>th</sup> October 1999

Mrs XXXXX Headteacher  
XXXXX School  
Address

Dear Mrs XXXXX ,

**Re: STUDY OF PARENTS' MANAGEMENT OF PARENTING STRESS**

Many thanks for distributing questionnaire packs to pupils' parents. The overall response rate from XXXXX School so far is X %.

I would like to thank parents for taking part in the study and wondered if the school has a newsletter which I could place a message in? If so, my message to parents would be as follows:

**STUDY OF PARENTS' MANAGEMENT OF PARENTING STRESS**

Several weeks ago questionnaire packs for the above study were distributed to all parents of children with severe learning disabilities. Six schools across Derbyshire are taking part in this large-scale research project. The response from parents has been excellent. Thank you to all of you who returned questionnaires to me and for your useful and interesting comments and well wishes. There is still time if you have not yet returned your questionnaires.

Thank you once again,

Hanna Link  
Clinical Psychologist in training

I also wondered if you could let me know how many questionnaire packs were distributed, or alternatively, whether you had any left over, to determine a precise response rate. My work telephone number is now (01332) 293474.

Thank you once again for your assistance. I expect to have the results of the study by Summer 2000 and will send you a brief summary for your information.

Yours sincerely,

**Hanna Link**  
**Clinical Psychologist in training**

**APPENDIX 8**

**Comments from Participants**



1. Participant 15 (mother)

“This information should not be passed on to someone else. Wishes to remain anonymous.”

2. Participant 60 (father)

“Dear Hanna,  
I’ve filled in your questionnaire as honestly as possible. Some of the questions were difficult because of the broad spectrum of possible answers. I found myself saying Yes but, well maybe, that doesn’t apply to our (CHILD’S NAME), well only sometimes. Hope my very small contribution is helpful and good luck with your project.” NAME AND ADDRESS SUPPLIED.

3. Participant 67 (mother)

“To really know what it’s like with someone with SLD you have to live with them, my husband had a breakdown with it, you’re screwed up all the time, never knowing what is coming.”

4. Participant 80 (mother)

“Hanna,  
I found your questionnaire very interesting, if you would like any more questions answering I do not mind at all. I would like to talk about the problems and general up bringing of a child with SLD.” NAME AND TELEPHONE NUMBER SUPPLIED.

5. Participant 85 (mother)

“Happy to take part in any follow-up.” NAME AND TELEPHONE NUMBER SUPPLIED.

6. Participant 100 (father)

“Returned, completed as requested. Good luck with the research!!”

**APPENDIX 9**

**Raw data from QRS-F, GHQ-12 and WC-R**

**Key to variables:**

- 1 = QRS-F Total Score      7 = Practical Coping Relative Coping Score  
 2 = QRS-F Factor 1 Score    8 = Wishful Thinking Relative Coping Score  
 3 = QRS-F Factor 2 Score    9 = Stoicism Relative Coping Score  
 4 = QRS-F Factor 3 Score    10 = Social Support Relative Coping Score  
 5 = QRS-F Factor 4 Score    11 = Passive Acceptance Relative Coping Score  
 6 = GHQ-12 Total Score

Table 11. Raw data from the QRS-F, GHQ-12 and WC-R

Participant No.	Variable										
	1	2	3	4	5	6	7	8	9	10	11
1	32	15	7	8	2	7	0.22	0.19	0.17	0	0.42
2	13	1	6	6	0	0	0.23	0.16	0.15	0.22	0.24
3	18	4	6	8	0	0	0.21	0.11	0.19	0.23	0.26
4	40	15	11	12	2	1	0.27	0.06	0.16	0.29	0.22
5	31	12	11	8	0	5	0.22	0.18	0.16	0.16	0.27
6	21	4	7	8	2	0	0.29	0.17	0.26	0.21	0.07
7	27	11	8	7	1	0	0.19	0.1	0.11	0.42	0.18
8	37	17	7	11	2	5	0.27	0.16	0.1	0.19	0.28
9	35	15	7	10	3	10	0.21	0.2	0.21	0.16	0.23
10	15	2	5	7	1	0	0.31	0.12	0.2	0.37	0
11	45	16	11	14	4	3	0.19	0.22	0.14	0.3	0.15
12	11	5	4	0	2	0	0.21	0.09	0.26	0.17	0.28
13	30	6	10	13	1	3	0.19	0.11	0.22	0.25	0.23
14	21	6	7	8	0	4	0.17	0.21	0.2	0.2	0.22
15	40	14	11	11	4	11	0.25	0.29	0.17	0	0.29
16	21	7	8	4	2	8	0.2	0.09	0.22	0.2	0.3
17	31	12	8	8	3	8	0.13	0.18	0.17	0.19	0.32
18	34	12	10	11	1	1	0.23	0.09	0.24	0.31	0.13
19	20	3	9	7	1	0	0.17	0.33	0.2	0.2	0.11
20	45	18	11	13	3	10	0.14	0.31	0.22	0.06	0.28
21	17	2	6	6	3	0	0.23	0.25	0.21	0.13	0.18
22	38	12	11	12	3	6	0.21	0.16	0.18	0.13	0.33
23	27	10	9	8	0	3	0.19	0.12	0.33	0.15	0.22
24	25	6	9	8	2	2	0.14	0.15	0.1	0.26	0.35
25	38	13	11	11	3	3	0.16	0.21	0.26	0.09	0.29
26	29	11	3	10	5	5	0.28	0.14	0.29	0.29	0
27	41	17	11	12	1	6	0.16	0.27	0.28	0.06	0.24
28	23	10	7	11	5	0	0.14	0.29	0.08	0.08	0.4
29	20	3	10	6	1	0	0.29	0.03	0.11	0.26	0.31
30	36	15	10	10	1	8	0.17	0.28	0.06	0.24	0.25
31	39	11	9	14	5	2	0.24	0.14	0.18	0.07	0.37
32	31	12	9	8	2	0	0.21	0.15	0.25	0.17	0.21

Table 11. Raw data from the QRS-F, GHQ-12 and WC-R (cont.)

Participant No.	Variable										
	1	2	3	4	5	6	7	8	9	10	11
33	41	18	8	11	4	3	0.21	0.12	0.19	0.14	0.35
34	41	17	10	12	2	11	0.24	0.12	0.16	0.16	0.32
35	25	6	7	10	2	1	0.16	0.16	0.21	0.24	0.23
36	21	5	6	7	3	0	0.3	0.14	0.27	0.17	0.12
37	20	6	4	6	4	0	0.31	0.09	0.2	0.11	0.28
38	34	12	10	9	3	9	0.22	0.11	0.22	0.19	0.26
39	36	16	8	12	2	8	0.19	0.23	0.16	0.32	0.11
40	36	15	6	11	4	1	0.2	0.19	0.25	0.22	0.14
41	36	14	9	9	4	2	0.21	0.14	0.17	0.06	0.42
42	47	19	10	13	5	1	0.22	0.2	0.15	0.12	0.31
43	24	8	6	6	4	0	0.23	0.29	0.07	0.07	0.34
44	17	5	8	4	0	0	0.21	0.14	0.2	0.23	0.22
45	8	0	4	3	1	0	0.22	0.13	0.25	0.21	0.21
46	28	7	9	10	2	5	0.15	0.2	0.17	0.27	0.21
47	24	9	7	7	1	1	0.36	0.1	0.23	0.23	0.08
48	16	1	7	6	2	0	0.23	0.1	0.15	0.46	0.06
49	35	14	8	10	3	11	0.15	0.22	0.12	0.18	0.34
50	37	16	8	11	2	5	0.21	0.18	0.2	0.15	0.25
51	38	16	9	11	2	4	0.27	0.15	0.22	0.16	0.2
52	28	6	7	10	5	0	0.21	0.09	0.22	0.28	0.21
53	25	8	11	5	1	0	0.22	0.23	0.23	0.23	0.1
54	28	8	9	7	4	0	0.19	0.04	0.23	0.23	0.32
55	30	13	9	6	2	6	0.15	0.2	0.22	0.12	0.31
56	13	2	5	4	2	0	0.19	0.09	0.17	0.33	0.22
57	44	19	10	12	3	8	0.16	0.18	0.29	0.11	0.27
58	38	15	8	12	3	6	0.23	0.25	0.11	0.18	0.24
59	38	14	8	10	6	8	0.3	0.17	0.14	0.27	0.11
60	14	1	7	6	0	0	0.24	0.09	0.23	0.2	0.24
61	42	19	10	9	4	10	0.2	0.21	0.33	0.2	0.06
62	28	10	10	8	0	2	0.3	0.08	0.23	0.26	0.13
63	36	12	10	11	3	3	0.18	0.12	0.18	0.25	0.27
64	45	19	11	13	2	10	0.21	0.22	0.15	0.24	0.18
65	20	0	7	8	5	0	0.34	0.13	0.18	0.22	0.12
66	21	5	2	9	5	9	0.24	0.16	0.24	0.12	0.24
67	34	15	8	11	0	1	0.25	0.14	0.15	0.2	0.25
68	33	9	8	10	6	2	0.36	0.08	0.33	0	0.23
69	17	5	9	3	0	3	0.23	0.11	0.18	0.29	0.18
70	22	8	6	8	0	4	0.33	0.13	0.08	0.36	0.09
71	30	13	7	7	3	1	0.11	0.17	0.22	0.17	0.33
72	22	8	7	10	4	1	0.25	0.21	0.29	0.17	0.08
73	17	2	6	7	2	0	0.33	0.09	0.15	0.28	0.15
74	36	16	9	11	0	11	0.19	0.23	0.21	0.16	0.21
75	30	14	10	4	2	4	0.12	0.18	0.19	0.26	0.25
76	29	14	9	6	0	5	0.22	0.12	0.1	0.27	0.28
77	28	12	8	7	1	4	0.27	0.13	0.15	0.19	0.26
78	33	7	10	13	3	7	0.25	0.08	0.22	0.22	0.24

Table 11. Raw data from the QRS-F, GHQ-12 and WC-R (cont.)

Participant No.	Variable										
	1	2	3	4	5	6	7	8	9	10	11
79	24	2	6	10	6	0	0.24	0.05	0.25	0.19	0.26
80	32	11	9	6	6	7	0.16	0.19	0.18	0.2	0.27
81	32	11	7	12	2	5	0.26	0.13	0.08	0.34	0.19
82	10	4	1	5	0	.	0.22	0.22	0.21	0.2	0.15
83	46	16	10	14	6	0	0.16	0.24	0.09	0.35	0.16
84	29	10	7	10	2	4	0.19	0.33	0.08	0.12	0.27
85	33	16	5	11	1	10	0.19	0.2	0.07	0.16	0.38
86	44	15	11	14	4	2	0.19	0.16	0.1	0.31	0.24
87	35	10	9	10	6	10	0.19	0.25	0.25	0	0.32
88	32	8	10	11	3	1	0.1	0.31	0.25	0.13	0.21
89	20	7	8	4	1	0	0.25	0.12	0.23	0.13	0.26
90	36	14	9	9	4	12	0.22	0.2	0.23	0.05	0.3
91	24	6	7	9	2	3	0.31	0.12	0.24	0.18	0.15
92	21	6	6	6	3	0	0.26	0.13	0.16	0.19	0.27
93	39	16	11	12	0	3	0.23	0.22	0.21	0.11	0.24
94	21	1	7	8	5	1	0.24	0.05	0.29	0.26	0.16
95	39	12	11	9	6	6	0.25	0.1	0.1	0.33	0.22
96	36	13	7	12	4	7	0.17	0.22	0.2	0.22	0.2
97	34	11	11	10	2	0	0.14	0.12	0.15	0.27	0.32
98	29	7	7	10	5	1	0.17	0.09	0.17	0.29	0.28
99	39	12	8	13	6	0	0.26	0.13	0.33	0.11	0.18
100	39	11	11	12	4	0	0.24	0.1	0.23	0.15	0.28
101	33	9	8	10	6	0	0.14	0.24	0.19	0.05	0.39
102	31	7	8	11	5	0	0.31	0.01	0.05	0.45	0.17
103	41	15	10	13	3	2	0.25	0.16	0.18	0.18	0.22
104	39	15	10	12	2	4	0.18	0.13	0.19	0.19	0.31
105	24	11	6	4	3	2	0.37	0.02	0.21	0.11	0.29
106	19	2	8	4	5	0	0.28	0.21	0.23	0.29	0
107	48	20	10	12	6	7	0.25	0.15	0.22	0.09	0.3
108	22	2	6	9	5	0	0.21	0.13	0.14	0.25	0.27
109	32	12	9	11	0	10	0.17	0.2	0.24	0.17	0.23
110	34	17	10	6	1	10	0.24	0.21	0.18	0.21	0.16
111	46	18	11	12	5	6	0.23	0.31	0.2	0.2	0.07
112	26	8	7	9	2	2	0.16	0.14	0.28	0.19	0.23
113	40	15	11	12	2	11	0.25	0.29	0.23	0	0.23
114	21	7	7	6	1	0	0.25	0.13	0.13	0.33	0.16
115	32	15	4	7	6	10	0.22	0.18	0.3	0.11	0.19
116	42	17	10	9	6	6	0.25	0.13	0.14	0.19	0.29
117	38	13	11	12	2	8	0.13	0.23	0.19	0.19	0.26
118	32	10	10	10	2	0	0.22	0.17	0.18	0.18	0.26
119	19	9	5	3	2	2	0.28	0.08	0.17	0.3	0.18
120	34	9	11	13	1	5	0.16	0.25	0.13	0.04	0.42
121	7	1	3	3	0	0	.	.	.	.	.
122	35	14	8	8	5	.	0.27	0.12	0.2	0.03	0.38
123	31	8	6	11	6	2	0.16	0.11	0.26	0.26	0.22

**APPENDIX 10**

**Summary of Results Sent to Schools**

## STUDY OF PARENTS' MANAGEMENT OF PARENTING STRESS

### SUMMARY OF MAIN RESEARCH FINDINGS

In the autumn and winter 1999 school terms parents of children with severe learning disabilities (SLD) were invited to take part in a large-scale research project investigating parents' experiences of parenting stress and the coping strategies used to manage such stress. The research aimed to add to the growing body of literature on stress, parents' coping strategies and the relationship between use of individual coping strategies and parental well-being.

Six Special Schools across the county of Derbyshire took part in the project. Pupils took questionnaire packs home to their parents. Completed returns were received from 123 eligible respondents (overall response rate 40 %). Whilst returns were received from parents from a variety of backgrounds, participants were predominantly white (86.2 %), female (91.9 %) and married (74.0 %). The main findings are summarised below.

#### *1. Levels of Parenting Stress and Psychological Distress Experienced by Parents*

In this study parenting stress was measured using the QRS-F. Scores on this questionnaire range from 0 to 52. Parents' mean QRS-F total score was 30.05 (SD = 9.31), indicating that, on average, parents reported high levels of parenting stress. The results are comparable to American research findings with regard to parents of children with SLD (Rousey, Best & Blacher, 1992). By way of comparison, Dyson (1996) found that the mean score for parents of non-disabled children was 3.5 (SD = 4.5).

In this study psychological distress was measured using the GHQ-12. Scores on this questionnaire range from 0 to 12. A score of three or higher indicates distress at the level of psychiatric caseness. Parents' mean GHQ-12 total score was 3.61 (SD = 3.68). Almost half of the parents who completed the GHQ-12 (49.59 %) scored above the threshold for caseness, indicating that they experienced psychological distress at clinically significant levels, warranting professional assistance.

#### *2. The Relationship Between Coping Strategies and Parental Well-being*

Correlational analyses were performed to examine the association between use of individual coping strategies, as measured by the WC-R, and the two measures of well-being.

Coping strategies found to be associated with **lower** levels of stress and distress:

Practical Coping	(e.g. "I make a plan of action and follow it", use of problem-solving, use of professional support e.g. counselling)
Seeking Emotional Social Support	(e.g. "I talk to someone about how I am feeling", use of support from friends and family, informal sources)

Coping strategies found to be associated with **higher** levels of stress and distress:

Wishful Thinking (e.g. “I hope a miracle will happen”, avoidance of the source of stress, pretending it is not there, avoiding thinking about it)

Passive Acceptance (e.g. “I accept it, since nothing can be done, no action taken to remedy the problem)

In this study, passive acceptance accounted for the largest proportion of parents’ coping efforts – a coping strategy associated with increased parenting stress and increased psychological distress. Practical coping strategies, including use of professional support, were employed less often. Thirty-five percent of parents indicated that they did not use professional help of any kind to manage stressful parenting situations.

### *3. Other Coping Strategies Used by Parents to Manage Parenting Stress*

- Maintain a positive attitude, get on with life
- Use of distraction (e.g. engagement in other activity)
- Make time for self
- Relaxation
- Exercise
- Catharsis (e.g. crying, releasing pent-up anger)
- Take one day at a time
- Reappraise or rethink the situation (e.g. think of how much worse it could be)
- Use of religious belief / faith

### **Clinical Implications**

The results indicate that parents in the sample experienced high levels of parenting stress and psychological stress. The results also suggest that certain ways of coping with stressful parenting situations are more effective than others: a finding that has been replicated in previous large-scale research studies with related populations. Thirdly, the results show that the coping strategy accounting for the largest proportion of parents’ coping efforts was passive acceptance, a strategy found to be associated with lower levels of well-being.

The results, therefore, suggest that parents may benefit from the opportunity to learn effective ways of coping with the demands of caring for a child with SLD. Coping skills training could form part of a comprehensive programme offered to parents. Further, the results suggest that professionals need to actively encourage parents to use their services and ensure that these are relevant and accessible.

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**APPENDIX 11**

**Parents' Responses to the Optional Open-ended Coping Item**

Responses to Ways of Coping (Revised) – WC-R Optional Open-ended Question  
“I try something entirely different from any of the above.”

1. Participant 1 (mother)

“I get on with life, being negative will not change things, the same situation will always be there.”

2. Participant 4 (mother)

“I try to be positive about situations and look at ways to make things better instead of just complaining.”

3. Participant 5 (mother)

“I have taken a degree course in order to keep my mind off the problems”.

4. Participant 7 (mother)

“Aromatherapy or luxury facials – I feel I could take on the world and I feel so relaxed and calm. Unfortunately I can only have one every four weeks due to finances.”

5. Participant 8 (mother)

“Look forward to respite care!!! Time to spend quality time with the rest of the family. I also try to spend time alone with my husband. Time to ourselves.”

6. Participant 12 (mother)

“When children younger could never make/plan further than one day at a time – due to medical problems of one child. Took things one day at a time. Blinkers on to “jobs”. Unable to complete or start. Had to acknowledge fact I wasn’t “Superwoman” and it didn’t mean I wasn’t a good mum, because I could no longer care for one child (I did have two others who needed a “mum” too). Proven by the fact that older child now has professional 24 hour package of care. I managed for 11 years. Accept – Everyone has bad days. Parents of “normal” children have bad days. You can too – it doesn’t mean you’ve failed.”

7. Participant 23 (mother)

“Cry”.

8. Participant 29 (mother)

“I get on with as normal family life which our son takes in his stride and make most of each time as it is now because I feel I could destroy the good in “now” if I spoil it worrying over the future or berating the past. Our son is great in spite of his difficulties.”

9. Participant 37 (mother)

“My faith in God keeps me going.”

10. Participant 59 (mother)

“I value my special needs children’s way of being more and more and get angrier and angrier with the society outside!!”.

11. Participant 61 (mother)

“Take each day / situation day by day”.

12. Participant 65 (mother)

“I work full time!”

13. Participant 71 (mother)

“I try to keep going with a smile on my face for the rest of my family and children. My children find it hard to see their sister this way.”

14. Participant 85 (mother)

“When my son was about four I had professional counselling for a year or two which was extremely valuable – helped me come to terms with my feelings. Would have been even more valuable earlier.”

15. Participant 94 (mother)

“I enjoy going for a long walk with the dog as even if it is only for half an hour to be in fresh air is very relaxing.”

16. Participant 97 (mother)

“I make sure to make time for myself. I keep horses and enjoy my special time with them - exercise and relaxation together.

17. Participant 100 (father)

1. Counselling by B.A.C. Counsellor helped.
2. Other informal support networks helps.
3. Routine, interspersed with mini-adventures that are manageable helps.
4. The occasional (selfish) distraction helps
5. The quality of the relationship and trust that exists between family members is the real strength that keeps us all going.
6. Self-awareness, including allowing myself to be genuinely challenged by others, helps me to see things from other viewpoints. It also keeps a sense of balance and stops things from getting too distorted.”

18. Participant 105 (father)

“Understanding, love and cuddles works wonders for our sanity.”

19. Participant 106 (mother)

“I just get on with life. I accepted my son’s decision from the beginning.”

20. Participant 107 (mother)

“Ask: “Is there anything or anyone who can help with the problem in a way that is acceptable to me?”. If “yes” I try and get help. If “no” I just carry on and try to deal with or accept the problem”.

21. Participant 115 (mother)

“I feel that as our son has matured things have become easier. You just have to get on with it, there’s people much worse off in life.”

22. Participant 118 (mother)

“When problems with (CHILD’S NAME) are at their worst my partner and I take turns so that we do not get over stressed and this helps till it passes.”

23. Participant 120 (mother)

“I do puzzles a lot and write poetry”.

**APPENDIX 12**

**Inter-rater Reliability of Content Analysis Coding**

Inter-rater reliability of content analysis coding

The results of the inter-rater reliability check of content analysis coding are presented in Table 12. It can be seen from Table 12 that agreement between the two raters was very high, with Cohen's kappa ranging from .623 (substantial agreement) to 1 (perfect agreement) (Dewey, 1995). Agreement on non-occurrence of the response category in participants' responses was higher than agreement on occurrence. Percentage agreement on non-occurrence ranged from 90.5 % (code 3) to 100 %, whereas percentage agreement on occurrence ranged from 50 % (code 3) to 100 %. It can be seen, therefore, that code 3, "Make time for self", was the least reliable category, although the value of Cohen's kappa still indicates substantial agreement nevertheless (Dewey, 1985).

Table 12. Results of inter-rater reliability check of content analysis coding

Response Category Code <sup>a</sup>	Agreement on Occurrence <sup>b</sup>		Agreement on Non-occurrence <sup>c</sup>		Cohen's kappa
1	7/7	(100 %)	16/16	(100 %)	1.000
2	4/4	(100 %)	19/19	(100 %)	1.000
3	2/4	(50 %)	19/21	(90.5 %)	.623
4	3/3	(100 %)	20/20	(100 %)	1.000
5	2/2	(100 %)	21/21	(100 %)	1.000
6	2/2	(100 %)	21/21	(100 %)	1.000
7	2/2	(100 %)	21/21	(100 %)	1.000
8	3/5	(60 %)	18/20	(90 %)	.701
9	3/3	(100 %)	20/20	(100 %)	1.000
10	3/3	(100 %)	20/20	(100 %)	1.000
11	2/2	(100 %)	21/21	(100 %)	1.000
12	3/4	(75 %)	19/20	(95 %)	.832

*N* = 23

<sup>a</sup> Please refer to Table 9 for definition of response category codes.

<sup>b</sup> Refers to agreement between raters that response category is present in participants' responses.

<sup>c</sup> Refers to agreement between raters that response category is absent from participants' responses.

**APPENDIX 13**

**Results of Post-hoc Correlational Analyses**

## Results of post-hoc correlational analyses

Findings from multivariate studies comparing mothers' and fathers' coping (e.g. Sloper *et al.*, 1991; Sloper & Turner, 1993) suggest that the relationship between use of certain coping strategies and parental well-being is less pronounced for fathers than mothers. Associations between use of individual coping strategies and parental well-being found in the present study may, therefore, have been weakened by the pooling of responses from fathers and mothers. Post-hoc correlational analyses of mothers' responses were, therefore, conducted to check for this.

To aid comparison, the results of the post-hoc correlational analyses of mothers' responses are presented with those of the entire sample in Table 13. It can be seen from Table 13 that the associations found were not affected significantly by the pooling of fathers' and mothers' responses.

Table 13. Spearman's rho correlations between WC-R relative coping scores and measures of well-being for the whole sample and mothers only (in parentheses).

WC-R Subscale relative score	GHQ-12 total score		QRS-F total score	
1. Practical Coping	-.199*	(-.159*) <sup>a</sup>	-.193*	(-.185*) <sup>a</sup>
2. Wishful Thinking	.391**	(.352**) <sup>a</sup>	.351**	(.318**) <sup>a</sup>
3. Stoicism	-.019	(.045)	-.091	(-.069)
4. Seeking Emotional Social Support	-.284**	(-.335**) <sup>a</sup>	-.292**	(-.311**) <sup>a</sup>
5. Passive Acceptance	.185*	(.210*)	.237**	(.264**)

*N* = 122 (whole sample) *N* = 112 (mothers only)

\*  $p < .05$ ; \*\*  $p < .01$ .

<sup>a</sup> One-tailed test, all other tests were two-tailed.



**APPENDIX 14**

**Supplementary Data Analyses**

Supplementary Data Analyses  
(Requested by External Examiner, Dr Chris Hatton)

Table 14. Spearman’s rho correlations between the four QRS-F factors and the five WC-R relative coping scores and GHQ-12 total scores.

QRS-F Factor	WC-R Subscale relative coping score					GHQ-12 total
	Practical Coping	Wishful Thinking	Stoicism	Social Support	Passive Accept.	
Factor 1	-.189*	.397**	-.130	-.303**	.226*	.650**
Factor 2	-.250**	.250**	-.081	-.114	.177	.351**
Factor 3	-.192*	.294**	-.079	-.182*	.115	.369**
Factor 4	.035	.021	.105	-.187*	.138	.036

*N* = 122 (QRS-F/WC-R correlations) *N* = 121 (QRS-F/GHQ-12 correlations)

\* *p* < .05; \*\* *p* < .01. (two-tailed)

**Key:**

QRS-F Factor 1 = Parent and Family Problems

QRS-F Factor 2 = Pessimism

QRS-F Factor 3 = Child Characteristics

QRS-F Factor 4 = Physical Incapacity

The correlations displayed in Table 14 provide additional information with regard to parents’ use of WC-R coping strategies. It can be seen from Table 14 that use of practical coping to manage stressful parenting situations, a strategy found in the current study to be adaptive, is negatively associated with factors one to three of the QRS-F. These negative correlations suggest that parents are less likely to use practical coping strategies when experiencing problems within the family, when feeling pessimistic about their child with SLD and when perceiving their child with SLD as having behavioural and attitudinal difficulties. Moreover, the positive correlations between use of wishful thinking and QRS-F factors one to three suggest that at such times parents are more likely to use this coping strategy, a strategy found in the current study to be associated with lower levels of parental well-being.

Further, the positive correlation between use of passive acceptance and QRS-F factor one suggests that parents are also more likely to passively accept stressful parenting situations when experiencing problems within the family, a coping strategy also found to be negatively associated with parental well-being in the current study.

It can be seen from Table 14 that parents' use of emotional social support, a strategy found in the current study to be positively associated with well-being, is negatively associated with QRS-F factors one, three and four. These negative correlations indicate that parents are less likely to seek emotional social support to manage stressful parenting situations when experiencing other problems within the family, when perceiving their disabled child as having undesirable characteristics and when caring for a physically disabled child.

The correlations between QRS-F factors and WC-R relative coping scores displayed in Table 14 therefore suggest that stressors, such as undesirable child characteristics, child physical incapacity and family problems, may deplete parental coping resources and lead parents to employ coping strategies associated with more negative outcomes. Parents facing these stressors may perhaps be more likely to appraise stressful parenting situations as unchangeable and subsequently adopt less favourable emotion-focused coping strategies, such as wishful thinking and passive acceptance.

The correlations between the four QRS-F factors and the GHQ-12 total scores indicate that, as may be expected, parent and family problems, pessimism and undesirable child characteristics contribute to parents' overall levels of psychological distress. However, it can be seen from Table 14 that physical incapacity of the child, whilst contributing to parenting stress, as measured by the QRS-F, does not appear to contribute to parents' levels of psychological distress in general as measured by the GHQ-12. These correlations therefore further demonstrate that the QRS-F and GHQ-12, whilst positively correlated, served as two conceptually distinct measures of outcome in the current study.

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