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## STURT, CATHERINE ELLEN

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# EXPRESSED EMOTION IN PARENTS OF BEHAVIOURALLY DISTURBED LEARNING DISABLED CHILDREN

# by CATHERINE ELLEN STURT

A thesis submitted to the University of Plymouth in partial fulfilment of the degree of

#### DOCTOR OF CLINICAL PSYCHOLOGY.

Department of Psychology and Faculty of Human Sciences.

In collaboration with the Education Department of Avon County

Council.

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#### ABSTRACT

Title: Expressed Emotion in parents of behaviourally disturbed learning disabled children.

Author: Catherine Ellen Sturt

Expressed emotion (EE) represents a measure of the emotional quality of the relationship between a key caregiver and relative, where the latter is experiencing a psychiatric or medical condition, and with implications for the course of this condition. To the author's knowledge, despite the salience of behavioural disturbance for families with learning disabled children, no published study has specifically investigated the relationship between parental EE and child behavioural disturbance. The current study focused on a comparison of high and low EE households with regards to child behavioural disturbance, parental stress and coping, and service and respite care usage. Forty parents were interviewed with a modified Camberwell Family Interview. The results showed no significant difference between high and low EE groups with regards to child behavioural disturbance, parental coping as related to factors such as social support and familial resources, and service and respite care usage. High EE parents reported significantly higher levels of stress and significantly less use of support and advice outside the family system than low EE parents. The findings conflict with conclusions from EE research e.g. with learning disabled adolescents, dementia and non-learning disabled children, which have demonstrated a relationship between EE and behavioural disturbance, but concur with studies, mainly with regards to schizophrenia, which have found that level of EE is independent of behavioural disturbance. level of EE in the current study appears principally to reflect parental characteristics as opposed to child-related characteristics. The results suggest that a focus on parental psychological needs in relation to both the emotional quality of the parent-child relationship, and the care of the child more generally, might be more appropriate for both parents and children, as opposed to a traditional child-centric service delivery. Further research is required to elucidate the relationship between EE and behaviour, and there is value in exploring the relationship between EE and behaviour over time, within a longitudinal design. Indeed, the scope for further study of EE in the area of learning disability is tremendous, and the inherent modifiability of the EE construct renders it an appealing guide in terms of service development and outcome evaluation.

| CONTENTS             |  | Page |
|----------------------|--|------|
| Copyrigi             | ht Statement   | 1    |
| Title Page           |  | 2    |
| Abstract             |  | 3    |
| List of Contents     |  | 4    |
| List of Tables       |  | 7    |
| Acknowledgements     |  | 8    |
| Author's Declaration |  | 9    |
| List of a            | bbreviations   | 10   |
| СНАРТ                | ER 1: INTRODUCTION:                                    | 11   |
| 1.0.                 | Overview   | 11   |
| 1.1.                 | Part 1: Parents and their behaviourally disturbed      |      |
|                      | learning disabled children                             | 12   |
| 1.1.0.               | Overview   | 12   |
| 1.1.1.               | Methodological issues                                  | 13   |
| 1.1.2.               | Behavioural disturbance in learning disabled children  | 14   |
| 1.1.3.               | Vulnerability to behavioural disturbance               | 15   |
| 1.1.4.               | Socio-environmental factors and behavioural            |      |
|                      | disturbance  | 17   |
| 1.1.4.1.             | The operant model                                      | 18   |
| 1.1.4.2.             | Psychoanalytic models                                  | 20   |
| 1.1.4.3.             | Parent-child interaction                               | 21   |
| 1.1.4.4.             | Stimulation  | 23   |
| 1.1.4.5.             | Family factors   | 23   |
| 1.1.5.               | The parent-child relationship                          | 26   |
| 1.1.5.1.             | Stress in parents of learning disabled children        | 27   |
| 1.1.5.2.             | Stress and behavioural disturbance                     | 28   |
| 1.1.5.3.             | Coping   | 33   |
| 1.1.5.4.             | Parental acceptance and rejection                      | 35   |
| 1.1.6.               | Interventions  | 37   |
| 1.1.7.               | Conclusion to Part 1.                                  | 39   |
| 1.2.                 | Part 2: Expressed Emotion                              | 39   |
| 1.2.0.               | Expressed emotion (EE): An overview                    | 39   |
| 1.2.1.               | Cross-cultural and cross-diagnostic applications of EE | 43   |
| 1,2,2.               | EE and learning difficulties                           | 45   |
| 1.2.3.               | Validity of the concept of EE                          | 47   |
| 1.2.4.               | Characteristics of high and low EE relatives           | 50   |
| 1.2.5.               | Stability of EE over time                              | 55   |
| 126                  | Intervention studies                                   | 56   |

| CONTE    | NTS contd   | Page |
|----------|---|------|
| 1.2.7.   | Conclusions regarding EE research                 | 57   |
| 1.2.8.   | Outcome in the current study                      | 58   |
| 1.2.9.   | Rationale for the current study                   | 59   |
| 1.2.10.  | Aims of the current study                         | 60   |
| 1.2.11.  | Hypotheses  | 60   |
| 1.2.12.  | The predictive utility of EE in the current study | 61   |
| СНАРТ    | ER 2: METHOD:                                     | 62   |
| 2.1.     | Participants                                      | 62   |
| 2.1.1.   | Selection of the sample                           | 62   |
| 2.1.2.   | Exclusion criterion                               | 63   |
| 2.1.3.   | Characteristics of the study's ungrouped sample   | 64   |
| 2.2.     | Pilot study                                       | 65   |
| 2.3.     | Design  | 66   |
| 2.4.     | Measures  | 66   |
| 2.4.1.   | Expressed Emotion                                 | 66   |
| 2.4.1.1. | Modifications to the CFI                          | 68   |
| 2.4.1.2. | Author's EE reliability                           | 71   |
| 2.4.1.3. | EE inter-rater reliability                        | 71   |
| 2.4.2.   | Behavioural disturbance                           | 72   |
| 2.4.2.1. | Behavioural sub-categories                        | 74   |
| 2.4.3.   | Stress  | 75   |
| 2.4.4.   | Coping  | 76   |
| 2.4.5.   | Service utilization                               | 77   |
| 2.4.6.   | Children's level of intellectual functioning      | 78   |
| 2.4.7.   | Children's dependency needs                       | 80   |
| 2.5.     | Procedure   | 81   |
| 2.6.     | Ethical approval                                  | 82   |
| 2.7.     | Statistics  | 82   |
| СНАРТ    | ER 3: RESULTS:                                    | 83   |
| 3.1.     | Screening of data                                 | 83   |
| 3.2.     | Descriptive statistics                            | 84   |
| 3.3.     | EE components and HEE sub-groups                  | 86   |
| 3.4.     | Association between EE and demographic and        |      |
|          | selected child descriptor variables               | 87   |
| 3.5.     | Testing of the hypotheses and post hoc analyses   | 90   |
| 3.6.     | Predictive utility of EE                          | 100  |

| CONT | ENTS CONTD   | Page |
|------|--|------|
| CHAP | TER 4: DISCUSSION AND CONCLUSION:                        | 102  |
| 4.1. | Summary of the results                                   | 102  |
| 4.2. | Components of EE   | 104  |
| 4.3. | (Hypothesis 1): High EE parents will report greater      |      |
|      | frequency, management difficulty and severity of         |      |
|      | child behavioural disturbance than low EE parents        | 106  |
| 4.4. | (Hypothesis 2): High EE parents will report more         |      |
|      | stress than low EE parents                               | 112  |
| 4.5. | (Hypothesis 3): High EE parents will possess a more      |      |
|      | restricted repertoire of coping behaviours than          |      |
|      | low EE parents   | 117  |
| 4.6. | (Hypothesis 4): High EE parents will have more           |      |
|      | extensive face-to-face contacts with services pertaining | ing  |
|      | to the needs of their learning disabled children than    |      |
|      | low EE parents, and (post hoc hypothesis 5);             |      |
|      | High EE parents will make greater use of respite         |      |
|      | care than low EE parents                                 | 120  |
| 4.7. | Service implications                                     | 123  |
| 4.8. | Methodological issues and implications for               |      |
|      | future research  | 126  |
| 4.9. | Conclusion   | 129  |
| APPE | NDICES:  |      |
| 1.   | Letter to parents requesting permission for their        |      |
|      | child's behaviour to be assessed in the sampling         |      |
|      | phase, and permission for the author to contact          |      |
|      | the parents following the assessment                     | 131  |
| 2.   | Modified Camberwell Family Interview                     | 133  |
| 3.   | Author's EE reliability ratings                          | 139  |
| 4.   | Checklist of Challenging Behaviours with rating          |      |
|      | codes and behavioural categories                         | 142  |
| 5.   | Malaise Inventory  | 149  |
| 6.   | Coping Health Inventory for parents (CHIP) with          |      |
|      | reworded questions.                                      | 151  |
| 7.   | Service utilization checklist                            | 154  |
| 8.   | Bedfordshire Dependency Checklist                        | 156  |
| 9.   | Letter thanking and debriefing parents                   | 158  |
| 10.  | Letters of ethical approval for research                 | 159  |
| DEFE | DENCES   | 161  |

| LIST OF | TABLES   | Page |
|---------|--|------|
| 1.      | Mean and standard deviation from the mean for          |      |
|         | the key variables, and including respite care          |      |
|         | usage, for ungrouped and grouped data.                 | 85   |
| 2.      | Median, mean, and standard deviation for               |      |
|         | critical comments, positive comments and warmth.       | 86   |
| 3.      | Descriptive statistics for demographic and child       |      |
|         | descriptor variables: means, standard deviations from  |      |
|         | the mean, medians, modes and percentages for           |      |
|         | high and low EE groups.                                | 89   |
| 4.      | The percentage of children in high and low EE          |      |
|         | groups displaying: high and low levels of aggression,  |      |
|         | anti-social behaviour, destruction towards property,   |      |
|         | rituals and stereotypies and problems with compliance, |      |
|         | and the presence and absence of self-injury, withdrawa | I    |
|         | and night-time disturbance, with Chi and Phi values.   | 93   |
| 5.      | One-tailed independent t-test results with EE as       |      |
|         | the grouping variable.                                 | 97   |
| 6.      | The relationships between the variables included       |      |
|         | in the hypotheses, and in addition, critical           |      |
|         | comments, warmth and positive comments.                | 97   |
|         |  |      |

7.

8.

9.

The relationship between EE and the key variables

in the study and EE as the grouping variable.

Direct discriminant function analysis with key variables

98

99

101

in the study with the Eta statistic.

Stepwise regression summary.

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### **AUTHOR'S DECLARATION**

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this bound volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South West Region based in the United Bristol Healthcare Trust, and the research was conducted with the collaboration of the Educational Department of Avon County Council.

Signed CESCUSE

Date 23/9/93

#### LIST OF ABBREVIATIONS

BDC: Bedfordshire Dependency Checklist

CFI: Camberwell Family Interview

CHIP: Coping Health Inventory for Parents

EE: Expressed Emotion

HEE: High Expressed Emotion

LEE: Low Expressed Emotion

WHO: World Health Organization

#### CHAPTER 1: INTRODUCTION

#### 1.0. Overview

Expressed Emotion (EE) represents a standardized measure of the emotional quality of the relationship between key caregivers (usually parents), and individuals or patients experiencing psychiatric and/or medical conditions. Expressed Emotion is measured from the perspective of a key caregiver, and has been shown to have implications for the course of conditions. It is measured according to the extent to which caregivers express critical, hostile or overinvolved attitudes or feelings about the individual or patient, when discussing the latter's condition, and family life with an interviewer. Behavioural and psychophysiological concurrent validation of EE characteristics (see section 1.2.4.) lend support to the utility of the construct as an indicator of the emotional quality of a relationship, and not simply as an attitudinal measure.

The purpose of the current study is to establish whether EE, can usefully be applied to parents with behaviourally disturbed learning disabled children, by determining whether there is an association between parental EE and child behavioural disturbance, and in addition other factors such as parental stress and coping.

The INTRODUCTION in this paper is divided into two parts. Part 1. principally reviews the literature pertaining to socio-environmental factors associated with behavioural disturbance in learning disabled children, and in addition, factors of relevance to a consideration of the emotional quality of the parent-child relationship. Part 2., provides a comprehensive review of the EE literature and its current status, and the relevance of the construct for families with behaviourally disturbed learning disabled children.

Finally, any reference in this paper to learning difficulties or the learning disabled refers to the population of children who were formerly labelled mentally handicapped/retarded, and does not refer to specific learning difficulties such as dyslexia.

# 1.1. Part 1: Parents and their behaviourally disturbed learning disabled children

#### 1.1.0. Overview

The advent of community care emphasizes the home and family as the appropriate placement in terms of the upbringing of learning disabled children (Griffiths, 1988). This factor coupled with the ongoing dependency of learning disabled children on their social environment, highlights the need to consider the quality of the relationship between the children and key caregivers (usually the parents) if such children are to remain within a family setting.

Attention to behavioural disturbance in learning disabled children is especially relevant in terms of considering the quality of the parent-child relationship. The essential characteristic of behavioural disturbance is its interference with care and social interaction. Behavioural problems create a social world in which the learning disabled child cannot act effectively and in which the important parent-child relationship is potentially jeopardized. The dependency of these children suggests that the quality of this relationship, and to some extent the maintenance of behavioural problems, are likely to be influenced by parental attitudinal and response styles. This highlights the potential relevance of EE.

Much of the literature pertaining to children with learning difficulties and behavioural problems has focused on maternal adjustment. This bias is similarly reflected in this chapter. The author acknowledges, however, that carers other than the mother may occupy a primary position in a child's life, e.g. fathers, foster/adoptive parents and relatives such as grandparents and older siblings. The literature pertaining to the role and adjustment of these carers is, however, sparse. Some attention will be given to fathers and adoptive/foster parents in this chapter, however, since within the broad category of "other carers", these have received relatively more empirical consideration.

Part 1. considers general methodological issues in carrying out research with families with behaviourally disturbed learning disabled children; prevalence of behavioural disturbance in learning disabled children; vulnerability and socio-environmental factors of relevance in the development and maintenance of behavioural disturbance; parental stress and coping and parental acceptance and rejection, and finally, interventions.

#### 1.1.1. Methodological issues

Research with families with behaviourally disturbed learning disabled children is varied particularly in terms of the instruments employed, the inherent heterogeneity of the population studied, and in addition whether or not a comparison group is included. Such differences restrict opportunities for comparison with other studies. Furthermore, very little of the research has been effectively replicated.

Measurement of behavioural disturbance in learning disabled individuals is often unreliable. Shortcomings of many of the instruments, particularly in terms of comparisons with other studies, include differential weightings of categories of behavioural disturbance, the problem of rater subjectivity and in addition, a failure to reflect the salience of behavioural problems for caretakers (Clements, Bost, Dubois & Turpin, 1980; Holmes & Batt, 1980).

A recurring dilemma in research with families with behaviourally disturbed learning disabled children, and families with learning disabled children in general, is whether or not a comparison group is useful. Baumeister (1967, 1984) has been particularly vociferous on the subject, and argues that in order to gain an understanding of mental retardation one should study mental retardation, particularly in view of limited research resources and the overall lack of interpretative power gained from comparison groups.

Indeed, the sheer number of factors on which groups need to be effectively matched (but in fact rarely are), in order to make useful comparisons, supports Baumeister's reservations. Similarly, the risk of inadvertently pathologizing families with behaviourally disturbed learning disabled children in such comparisons, also lends support to the suggestion of focusing solely on these families. A control group is not included in the current study.

Methods of research vary across studies, but have largely consisted of cross-sectional, correlational designs, relying on self-report measures usually completed by the mother alone, and often unjustifiably generalized to the entire family system. This "static" methodology has been criticized by Wikler (1981, 1986) who advocates a life-cycle perspective. Indeed, longitudinal studies are largely absent from the literature. Finally, the growing emphasis on the bidirectional influences of parent-child behaviour (Bell & Harper, 1977; Sameroff, Seifer & Zax, 1982) recommends the combination of self-report and observation to increase the validity of findings (Stoneman & Brody, 1984).

1.1.2. Behavioural disturbance in learning disabled children Behavioural disturbance can be considered a serious secondary handicap for children who are already cognitively, emotionally, and often physically disabled, with implications for the development and quality of interpersonal relationships (Gath & Gumley, 1986; Webster, 1971).

Documented rates of behavioural disturbance in learning disabled children vary in the literature, and seem to depend largely on the instruments employed to measure behavioural disturbance and more specifically, the differential weightings given to the various types of behaviour (Maisto, Baumeister & Maisto, 1978). Additionally confusing, is the tendency for the terms behavioural disturbance and psychiatric disorder to be used interchangeably. Fraser, Leudar, Gray & Campbell (1986) have attempted clarification amidst the confusion, and have demonstrated that behavioural

disturbances are not, in general, expressions of psychiatric disturbances. Categories of behavioural disturbance include aggression towards others, self-injury, destruction towards property and stereotyped behaviours. Psychiatric disorders in contrast, include the affective disorders and psychoses. Clearly the two might coexist, but for the purpose of the current study, the focus is on behavioural disorders.

Notwithstanding the confusion surrounding the estimates for rates of behavioural disturbance in learning disabled children, it is estimated that between 20% (Stein & Susser, 1975) and 50% (Rutter, Tizard & Whitmore, 1970) have some degree of behavioural disturbance. Kaminer, Jedrysek & Soles (1984) found a 75% rate of behavioural disturbance in their sample of learning disabled children. Their stiff criteria for rating absence of behavioural disturbance e.g. if the child had no deviant behaviours, would appear, however, to explain the high rates they reported.

In attempting to understand rates of behavioural disturbance in learning disabled children it is relevant to consider the literature pertaining to the vulnerability of such children to behavioural disturbance, and moreover, socio-environmental factors associated with behavioural disturbance. The latter are of particular relevance to the current study. Although vulnerability and socio-environmental factors are considered separately, they are likely to be mutually influential to some extent. These factors are considered in the following two sections.

## 1.1.3. Vulnerability to behavioural disturbance

Various vulnerability markers have been suggested for subsequent behavioural problems. These include poor communication, with behavioural disturbance serving a socio-communicative function (Donnellan, Mirend, Mesaros & Fassbender, 1984; Durand & Carr, 1987; Iwata, Dorsey, Slifer, Bauman & Richman, 1982), and the increased likelihood of physical and sensory problems in the learning disabled e.g. cardiac problems and hearing deficits (Heller, Rafman, Zvagulis & Pless, 1985). Other support for vulnerability to behavioural disturbance comes from a neurological deficit model of behavioural disturbance. Hagberg, Hagberg, Lewerth & Lindberg (1981 a,b) found that 81% of children with severe learning difficulties and 43% of children with mild learning difficulties had additional neurological handicaps. Presence of epilepsy often represents the best example of neurological dysfunction in the learning disabled (Corbett, Harris & Robinson, 1975).

Vulnerability to behavioural disturbance has also been related to a child's diagnosis e.g. the deficits in social behaviour associated with autism (Donovan, 1988). Furthermore, behavioural abnormalities have been related to certain metabolic deficiencies such as phenylketonuria (Knox, 1972) and Lesch-Nyhan syndrome (Lesch & Nyhan, 1964; Nyhan, 1978). The latter manifests itself in self-injurious behaviours of an extreme nature. It has also been suggested that certain patterns of temperament e.g. non-adaptability and irregularity of biological functions, play a role in the genesis of behavioural disorders (Chess & Korn, 1970).

The finding that maladaptive behaviour is inversely proportional to the level of an individual's intellectual development has been replicated in numerous studies (e.g. Ando & Yoshimura, 1979; Eyman & Call, 1977; Quine, 1986). It is not clear, however, whether the findings reflect a true relationship, or whether they represent artefacts of the types of behavioural disturbance studied. A focus on self-injurious behaviour, for example, would immediately highlight elevated rates in more severely learning disabled children (Maisto et al., 1978). Furthermore, in the more mildly learning disabled, vulnerability to behavioural disturbance might be viewed as a consequence of interpersonal difficulties and poor acceptance by others (Beveridge & Conti-Ramsden, 1987), as opposed to severity

of disability.

Finally, although it is not traditionally considered a vulnerability factor, disruptions in early attachment feasibly predispose learning disabled children to maladaptive patterns of interaction in the form of behavioural problems. Bowlby (e.g. 1980) considers close emotional attachment an imperative for good adjustment throughout life.

Disruptions in attachment have been documented to be common in the parent-learning disabled infant relationship, for both mothers and fathers (Beckman, 1991; Stone & Chesney, 1978). Several authors (e.g. Blacher, 1984; Blacher & Meyers, 1983; Collins-Moore, 1984; Waechter, 1977) have suggested characteristics of learning disabled children which might impede the formation of attachment. These include: the child's appearance, e.g. facial disfigurement; negative responses to being handled, e.g. stiffening, hypotonicity or lack of responsiveness; medical fragility leading to frequent hospitalization and hence separation; an inability to maintain eye contact, and distressing behaviours such as seizures.

In addition to predisposing children to behavioural disturbance, such disruptions also feasibly have implications for the ongoing development of the emotional quality of the parent-child relationship, particularly since the emotional state of the parents, and notably the mother, is fragile in the early weeks and months after the birth (Featherstone, 1980; Olshansky, 1962; Solnit & Stark, 1961). This statement cannot be substantiated empirically, and longitudinal investigations would be required to quantify this issue.

1.1.4. Socio-environmental factors and behavioural disturbance
Expressed Emotion represents a socio-environmental factor which
has been shown to have implications for the course of various
psychiatric and medical conditions, and is typically considered in
terms of its provocative influence on these conditions. Hence, in

addition to the consideration of vulnerability markers, it is relevant to consider socio-environmental factors, and in particular parental factors, which have informed an understanding of both the development and the maintenance of behavioural disturbance in the learning disabled. It must be noted, that compared to non-learning disabled children, the literature is sparse with regards to the influence of parental and family characteristics on the adjustment of learning disabled children. The operant model (Skinner, 1974), which is considered below, has received the most empirical and applied attention.

1.1.4.1. The operant model From an operant perspective, behavioural problems are viewed as being lawfully related to environmental factors, and as being learned and shaped in the same ways as adaptive behaviours such as dressing skills. In very simple terms, problem behaviours are seen as being maintained by two types of reinforcement, namely positive and negative reinforcement. Positive reinforcement of maladaptive behaviours represents the contingent occurrence of rewarding consequences to the behaviours, such as social attention. Negative reinforcement represents the cessation of an unpleasant experience, for example an undesirable task, contingent on the occurrence of specific behaviours. Yule & Carr (1980) provide a comprehensive account of the application of operant principles.

Maladaptive behaviours are viewed as either having a function such as communication, and maintained by the above reinforcement processes, or as having developed inadvertently as a result of reinforcement processes. It is important to ascertain whether a behaviour has a function or not, in order to guide intervention. Communication, for example, represents a legitimate goal, but one that could be achieved in a more adaptive fashion than by head-banging, for example. More will be said about interventions

in section 1.1.6.

It is interesting to note, that whilst operant principles have been successfully applied to the understanding and management of behavioural disturbance in the learning disabled, there has been little attention to how parental factors such as psychological well-being, for example, might influence strategies for managing the behaviours. Section 1.1.5.2. considers the consistently documented association between parental (usually maternal) stress (the usual measure for psychological well-being) and behavioural disturbance in learning disabled children. The erratic, chaotic and indiscriminate parenting which has been demonstrated with psychologically distressed mothers of non-learning disabled children (e.g. Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Dumas & Wahler, 1986; Wahler & Dumas, 1989) has potential applicability with regards to mothers of learning disabled children. Moreover, a combination of maternal stress and child behavioural disturbance feasibly establishes a vicious cycle of maladaptive interactional patterns, providing ongoing intermittent/erratic positive and/or negative reinforcement of problem behaviours, depending on how the mother is feeling. Such intermittent reinforcement might, for example, involve ignoring the behaviours on one occasion, and then responding to them, albeit conflictually, on the next occasion. The oft noted emotional unavailability of psychologically distressed mothers (e.g. Cox, Puckering, Pound & Mills, 1987) would suggest, furthermore, that there would be little time for attention to and positive reinforcement of appropriate behaviours. It is relevant to note that intermittent reinforcement of behaviours has been shown to render behaviours more resistant to change or extinction (Koegel, Schreibman, Britten & Laitinen, 1979; Walker, 1984, p.52).

The association between stress and behavioural disturbance will be discussed at greater length in section 1.1.5.2.. It would appear, however, to have relevance for both the emotional quality of

the parent-child relationship, and in addition, the maintenance of problem behaviours. Furthermore, in considering the pathogenic role of high EE in the course of schizophrenia, it is relevant to note that an unpredictable response style, feasibly akin to the erratic, indiscriminate parenting associated with parental psychological distress, has been shown to be a feature of high EE relatives' response style with schizophrenic family members (MacCarthy, Hemsley, Schrank-Fernandez, Kuipers & Katz, 1986).

1.1.4.2. Psychoanalytic models Intrapsychic conflict is seen as the root of all problems in the psychoanalytic model (Freud, 1966). Psychopathology in the learning disabled, is viewed as primarily a deficit in ego functioning (e.g. Sternlicht, 1977). In simple terms, the ego represents the rational and realistic component of Freud's tripartite division of human personality. The other two components are the id, the impulsive component, and the superego, the moralistic The deficit in ego functioning is attributed to the component. cognitive impairments of the learning disabled, which limit reality testing, the anticipation of the consequences of behaviour, and the development of higher cognitive functions such as spoken language. The drive energy of the id is assumed to remain intact in the learning disabled and it is suggested that in attempting to face the demands of reality, the deficiencies in the ego give rise to primitive defence mechanisms (Robinson & Robinson, 1965). Furthermore, the abnormal development of the ego, abnormally affects development of the superego and its evaluative functions (Robinson & Robinson, 1965). Thus from a psychoanalytic perspective, the learning disabled child is highly susceptible to poor adjustment and behavioural disturbance.

Konarski & Cavalier (1982) have considered factors regarding the parent-learning disabled child relationship, which in addition to the intellectual and social deficits of the learning disabled, appear to be significant with regards to the subsequent development of a deficient ego in these individuals. These factors include early experience of parental rejection (Sternlicht & Deutsch, 1972), emotional negativity from others (Waisbren, 1980) the possibility of abuse and neglect (Frodi, 1981) and increased levels of parental stress (Friedrich & Friedrich, 1981). A history of negative social interactions and in addition, insights of the more mildly learning disabled into their deficits, feasibly heighten the use of immature defence mechanisms such as regression, perpetuating impulsive behaviours such as aggression, for example, (Sternlicht & Deutsch, 1972). Furthermore, of relevance to a history of disrupted interpersonal relations, self-injury, has been considered a manifestation of frustrated needs for contact with other individuals (Kebbon & Windahl, 1986).

The amount of psychic energy that is assumed to be required in maintaining the primitive defence mechanisms feasibly precludes the development of more mature defences and the general strengthening of the ego in the learning disabled (Konarski & Cavalier, 1982; Weiland & Rudnick, 1961). Clearly, however, since empirical support for psychoanalytic formulations is always difficult to find, the utility of a psychoanalytic perspective can only be speculated upon.

1.1.4.3. Parent-child interaction In terms of both eliciting and maintaining maladaptive behaviours, studies of interactions between parents of learning and non-learning disabled children have demonstrated a relationship between vague, inconsistent maternal communications and non-contingent maternal responsivity to their children's behaviour, and subsequent child behavioural disturbance (e.g. Breiner & Forehand, 1982; Field, 1977; Wahler & Dumas, 1989). Furthermore, in a thorough and rigorous investigation of maternal style of interaction with learning disabled children, Dunst &

Trivette (1986) reported an association between maternal non-contingent responsivity with developmentally delayed children, and poor maternal well-being, both emotional and physical. This association between maternal psychological well-being and interactional effectiveness has also been noted in research with non-learning disabled children (Bettes, 1988; Wahler & Dumas, 1989). Furthermore, the robust finding of an association between parental (usually maternal) stress and behavioural disturbance in learning disabled children suggests that reciprocally maladaptive interactional patterns are likely to persist.

Fathers of learning disabled children have been shown to elicit more negative child behaviours and to comply less with their children's initiations, as compared to mothers (McConachie & Mitchell, 1985). Interpretation of behavioural cues from learning disabled children has, however, generally been shown to require heightened response sensitivity on the part of the parent (Brooks-Gunn & Lewis, 1984; Hanzlik & Stevenson, 1986; Hodapp, 1988), and hence feasibly predisposes parent-child interactions to disruption.

In considering the findings from interactional studies, it is relevant to note that a majority of the studies took place in analogue or clinic settings. This clearly leaves the reliability and generalizability of the findings open to debate.

The issues of non-contingent responsivity and vague, inconsistent communications, have relevance not only with regards to the development and maintenance of behavioural difficulties, but also feasibly, with regards to the attitudes and feelings of parents towards their learning disabled children. In the literature pertaining to parents of non-learning disabled children, parents have been found to experience more positive emotion if they are able to coordinate their interactions with their children, producing mutually satisfying behavioural outcomes (Goldberg, 1977). Furthermore, such

coordination of interactions has been shown to be an important feature of successful interpersonal relations, generally (Kelley, 1984).

1.1.4.4. Stimulation Associations between levels of stimulation available and behavioural disturbance have been demonstrated in a number of studies, particularly with regards to stereotypies, such as hand flapping, and self-injurious behaviours (e.g. Baumeister & Forehand, 1973; Berkson & Mason, 1963). Much of the literature pertaining to the relationship between levels of stimulation and behavioural disturbance has focused on the sterile environments of institutions (Berkson & Mason, 1963; Gardner & Cole, 1984). Furthermore, the improvement in behaviour following the provision of appropriate stimulation supports the evidence for this relationship (Porterfield, Blunden & Blewitt, 1980). With the advent of community care, and since most children reside with their families and attend school, the issue of levels of stimulation is less pertinent. General difficulties, however in establishing a mutually satisfying interaction with a cognitively and socially impaired child, feasibly heighten the possibility that the child will not be regularly engaged in social interaction and activities by the parents, increasing the prospects of an understimulating environment at home. The increased levels of stress in parents with learning disabled children in general, might feasibly compound the issue of diminished stimulation at home, since as was noted above, psychological distress has been associated with emotional unavailability in mothers of non-learning disabled children (e.g. Cox et al., 1987).

1.1.4.5. Family factors Nihira, Mink & Meyers (1983) and Mink, Blacher & Nihira (1988) have made a significant contribution to the understanding of the relationship between maladaptive behaviour and socio-emotional qualities of the family environment. They

challenged the inadvertent homogenization of learning disabled children and their families in the literature, and identified five distinctive clusters of family environment across the levels of disability: cohesive, harmonious; control-oriented, somewhat inharmonious; low disclosure, inharmonious; child-oriented, expressive; and disadvantaged, low morale. Of relevance to the consideration of behavioural disturbance, children in the controloriented, somewhat low harmonious families, where conflictual relations were a feature, demonstrated low adaptive behaviour and high maladaptive behaviour both at home and at school. This contrasted particularly with the child-oriented families which were characterized by affection and warmth towards the children, and in which the children demonstrated higher levels of adaptive behaviour. It is unclear from this taxonomy why different family styles emerge and how useful they are in terms of family and individual coping strategies. There is no doubt, however, that this approach marks a sophisticated and sensitive attempt to consider the influence of the familial social environment on learning disabled children's adjustment.

Additional family factors and their association with behavioural disturbance in learning disabled children have been considered by Gath (1986) and Gath & Gumley (1986). These authors noted no clear association between frequency of behavioural disorders and family socioeconomic status, no overall effect of maternal age at birth on behavioural disorders, and no effect of sibship size. Parental psychiatric disorder was, however, found to be associated with behavioural disorder, and furthermore, with maternal subjective perceptions of elevated degrees of behavioural disorder as compared to objective measures of disorder. Finally, child behavioural disturbance was found to be more common in less harmonious marriages, and to increase modestly in cases where both marital disharmony and parental psychiatric disorder were present.

Adding to these findings, Quine (1986) found an association between behavioural disturbance and single parent households. It is relevant to note that single marital status for mothers was found by Beckman (1983) to be the single demographic feature which best predicted maternal psychological distress.

To conclude this section on socio-environmental factors associated with behavioural disturbance, it must be noted, that despite the salience and intrusiveness of behavioural disturbance for families with learning disabled children (Carr, 1990), very few studies have considered more directly the influence of parental and family characteristics on the development and maintenance of behavioural disturbance. This dearth is particularly notable compared with the literature pertaining to families with behaviourally disturbed non-learning disabled children (Downey & Coyne, 1990; Goodyer, 1990; Lahey, Russo, Walker & Piacentini, 1989; Rutter & Quinton, 1984). Furthermore, as will be noted in section 1.1.5.2. the robust association between parental stress and behavioural disturbance in learning disabled children is usually interpreted in terms of the latter influencing the former, to a greater extent than the reverse (Quine, 1986). In addition, it has been suggested, that particularly with regards to the more severely learning disabled, family and psychosocial influences on behaviour are feasibly less relevant due to the multiplicity of other factors which increase vulnerability to behavioural disturbance, e.g. neurological deficits (Corbett, 1986).

A measure of EE provides a valuable tool for considering the relationship between parental attitudes and feelings towards their learning disabled children and the latters' behaviour, and the occurrence of child behavioural disturbance. These attitudes and feelings potentially have implications for the maintenance, and also possibly, the development of child behavioural disturbance. As will be shown in the Part 2. of this chapter, Dossetor's (1991) broad

survey of adolescent needs showed that parental criticism and emotional overinvolvement, as components of EE, were found to be related to behavioural problems in learning disabled adolescents. The purpose of the current study is to consider in greater depth the relationship between EE and behavioural disturbance in learning disabled children between the ages of 3-19 years. Clearly, however, without the benefits of a longitudinal design including in vivo observations of the parent-child dyad, the current study is limited in terms of drawing conclusions about the influence of parental EE on behaviour, and it is only possible to consider the association between the two.

Generally, however, in considering the influence of socioenvironmental factors on behavioural disturbance it must be noted,
that the current emphasis in the literature on the bidirectionality of
influence of both child and parent behaviours (Bell & Harper, 1977;
Kozloff, 1973) accentuates the need to consider the complex
interactions of parent-child responses. Indeed, from an ecological
perspective, the isolation of cause and effect relations is all but
impossible (Crnic, Friedrich & Greenberg, 1983). As will be shown
in Part 2. of this chapter, bidirectionality of influence has received
increasing consideration in EE research. A bidirectional emphasis
does not detract from the influential role of EE in the course of
psychiatric, non-psychiatric and medical conditions, it highlights,
however, the complexity of the relationship between EE and
outcome.

## 1.1.5. The parent-child relationship

Expressed Emotion represents a measure of the emotional quality of a significant relationship from the perspective of a key carer, and is a measure of the latter's attitudes and feelings towards an offspring or spouse. This section focuses on areas of research which appear to highlight the importance of considering the emotional quality of the parent-child relationship, where the child is both learning disabled and behaviourally disturbed. Very little research has considered the emotional quality of this relationship, and the quality mostly has to be inferred from the impact of the learning disabled child on parental well-being and family life generally. The areas considered are parental stress and coping, and parental acceptance and rejection of their learning disabled children. In addition to affecting the emotional quality of the parent-child relationship, these factors are also relevant with regards to the development and maintenance of behavioural problems, since they are likely to influence parental management and interactional styles.

1.1.5.1. Stress in parents of learning disabled children In order to provide a context for consideration of the relationship between parental stress and child behavioural disturbance, it is relevant to refer briefly to the literature pertaining to stress in families of learning disabled children in general.

Stress in parents of learning disabled children has received a vast amount of attention in the literature, particularly with regards to maternal adjustment. Definitions of stress are rarely explicit, but generally assume that it represents the consequence of demands which exceed psychological and physical resources (e.g. Antonovsky, 1979), producing concomitant deleterious psychological and psychosomatic changes. Stress usually represents the measure of psychological, in particular, and general well-being of parents in this population. The two standardized instruments which have been the most widely used in the measurement of stress in these families, are the Malaise Inventory (Rutter et al., 1970) and the Questionnaire on Resources and Stress (Holroyd, 1974).

The literature has shown that mothers and fathers of learning disabled children generally report stress, and in addition, report greater stress as compared to parents of non-learning disabled children (Beckman, 1983; Burden, 1980; Byrne & Cunningham, 1985; Chetwynd, 1985; Friedrich & Friedrich, 1981; Quine & Pahl, 1985; Rousey, Best & Blacher, 1992; Wilton & Renaut, 1986; Wishart, Bidder, & Gray, 1981). In addition, mothers of learning disabled children have been shown to report more stress than fathers (Beckman, 1991; Bristol, Gallagher & Schopler, 1988).

With regards to adoptive/foster parents, positive adjustment of these parents and successful placement of the child, have mostly been documented in the literature (Glidden, 1986; Glidden, Valliere & Herbert, 1988), and are possibly related to the process of choosing a learning disabled child (Glidden & Pursley, 1989). Nevertheless, stressors such as single status for women and child maladaptive behaviour, which have been identified as relevant in the adjustment of biological parents, have also been shown to be influential in the adjustment of adoptive/ foster parents (Stoneman & Crapps, 1988).

1.1.5.2. Stress and behavioural disturbance Most studies which have included a measure of child behavioural disturbance, have found an association with maternal stress, with behavioural disturbance often representing the best predictor of stress (e.g. Beckman, 1983; Bradshaw & Lawton, 1978; Byrne, Cunningham & Sloper, 1988; Chetwynd, 1985; Friedrich, Wilturner & Cohen, 1985; Quine & Pahl, 1985; Sloper, Knussen, Turner & Cunningham, 1991). The issue of maternal stress has been given the most attention in terms of the impact of behavioural disturbance on parental and family life.

Consideration of parental stress is relevant with regards to the emotional quality of the parent-child relationship. Dix (1991) has provided a stimulating and comprehensive review of the influence of parental emotion on parenting. Relevant issues considered, include substantial correlations in the literature between stress and negative emotions (Clark & Watson, 1988). Furthermore, Dix (1991) considers how stress (particularly maternal stress) has been

shown to be related to parenting deficits with regards to non-learning disabled children. Such deficits include harsh and erratic styles of discipline (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983), hypersensitivity to aversive stimuli (Lahey, Conger, Atkenson & Treiber, 1984) and indiscriminate parenting (Dumas & Wahler, 1986). The interaction between stress-related parenting styles and child behavioural disturbance is considered later in this section. Unfortunately, the evidence is meagre to be able to draw conclusions about the effects of stress on parenting and on the parent-child relationship, with regards to parents of behaviourally disturbed learning disabled children. It seems reasonable to assume, however, that similarities with parents of non-learning disabled children are likely to exist. Moreover, in the case of parents of learning disabled children, child-related stressors may produce more persistent stress and frustration reactions since the children's ability to learn adaptive behaviours is compromised by their intellectual impairments.

In considering the relationship between parental stress and behavioural disturbance, it must be borne in mind that the reliability of the measurement of behavioural disturbance is often questionable. In a substantial number of studies, the parent reporting their experience of stress also rates the child's behaviour (Sloper et al., 1991). The potential for subjective distortion is obvious. Validation of these ratings by objective raters is also questionable in its utility, given the oft found context-/situational-specificity of behaviour.

It is not always clear from studies whether particular types of behavioural disturbance are differentially associated with parental stress. Excitability, aggression and night-time disturbance have, however, emerged as particular stressors (Clements, Wing & Dunn, 1986; Margalit, Schulman & Stuchiner, 1989; Quine & Pahl, 1985;. Sloper et al., 1991). Examples of key studies which have demonstrated an association between child behavioural disturbance and parental stress are considered in more detail below.

In a significant and widely cited study, Quine & Pahl (1985) carried out a survey involving 200 children with learning difficulties. They found that the presence of behavioural problems (as measured by teachers and care assistants) was the best predictor of maternal stress, with more severe behavioural disturbance producing greater stress. Mothers' night-time disturbance and social isolation, adversity in the family and multiplicity of impairments in the child followed behavioural disturbance in order of importance.

Byrne et al. (1988) described learning disabled children with severe behavioural problems as having enduring effects on family life, restricting the children's activities, detrimentally affecting relationships with friends and family, and often having an association with maternal psychological distress, notably depression. This study is particularly significant since it highlights the multiplicity of consequences associated with behavioural disturbance, for both the child and family.

Sloper et al. (1991) similarly found an association between high levels of behavioural disturbance and high levels of maternal reported stress. They found in addition, that a positive attitude towards the child did not, in itself, remove the stressful effects of the behavioural problems. This finding clearly has implications for the emotional quality of the parent-child relationship. An ability to disassociate the behavioural problems from the child appeared to permit more positive feelings towards the child.

Sloper et al. (1991) make the valid point that low levels of behavioural problems cannot necessarily be considered a positive factor. Indeed, this seems to be an assumption made in many studies. Low levels of behavioural disturbance might for example, represent a form of learned helplessness on the child's part (Seligman, 1975). This is purely speculation, but it highlights a need for more multidimensional studies, in order to obtain a clearer understanding of the association between levels of child behavioural problems

reported, and parental and family characteristics.

Comparisons of maternal and paternal responses to child behavioural problems have generally demonstrated that fathers report less stress than mothers (Sloper et al., 1991). Margalit et al. (1989) found, however, that paternal stress was associated with internalizing disorders such as social isolation and anxiety, whereas maternal stress was associated with aggressive and disruptive behaviours.

The association between behavioural disturbance in learning disabled children and parental stress is often interpreted in terms of behavioural disturbance having a causal role in the development of parental stress (Quine, 1986). Interestingly, in research with families with non-learning disabled children, the converse is true, and responsibility for causality of child behavioural problems is placed with the parents (Rutter & Quinton, 1984). Quine (1986) concluded from her study that given the correlates of behavioural disorder e.g. poor communication skills and a high level of physical burden, it was unlikely that maternal stress was a sufficient explanation for the appearance of behavioural disorder. She suggests instead, that behavioural disorder may induce or maintain stress in carers which then has an influence on parenting competence and the quality of interaction with the child. This interaction would feasibly serve to perpetuate both maternal stress and child behavioural disturbance. Consistent with Quine's (1986) conclusions, but with greater emphasis on the bidirectionality of parental and child behaviours, Friedrich et al. (1985) speculated on the mutually reinforcing influence of maternal stress and child behaviour.

Consideration beyond speculation of how parental stress and child behavioural disturbance interact, has not to the author's knowledge received attention in the literature pertaining to learning disabled children and their families. In contrast, this issue has received attention with regards to behavioural disturbance in non-learning disabled children.

Consistent with cognitive theories of stress, which suggest that stress narrows attention (Baddeley, 1972), stressed, psychologically distressed mothers of non-learning disabled children have been shown to be disengaged and emotionally unavailable to their children (e.g. Cox et al., 1987). This appears to lead to high intensity demand behaviours on the child's part in order to attain the mother's attention (Cox et al., 1987). The interaction of these behaviours with the mother's diminished tolerance for aversive child stimuli e.g. noise (Frodi & Lamb, 1980; Weissman & Paykel, 1974) establishes a negatively escalating cycle of conflict between mother and child, with increased maternal stress and positive reinforcement, in the form of social attention, of maladaptive child behaviour. The finding that maternal psychopathology distorts perceptions of the severity of child behaviour for both learning and non-learning disabled children (Brody & Forehand, 1986; Gath & Gumley, 1986; Griest, Wells, & Forehand, 1979) would appear to compound the negativity of this interactional pattern.

These findings are feasibly applicable to children with learning difficulties, since parent-child interactional asymmetry is more likely to be present in the first place (see section 1.1.4.3.). In addition, these findings highlight the bidirectionality of child and parental behaviours (Bell & Harper, 1977; Friedrich et al., 1985).

This section has focused exclusively on the relationship between parental stress and child behavioural disturbance. This relationship is complex, however. Thus a focus on behavioural disturbance does not ignore the reality that parental responses to the behaviours will be influenced by the presence of other stressors, both related and unrelated to the behavioural disturbance. Such stressors might include the degree of caregiving demands made by the child (Beckman, 1983; Quine & Pahl, 1985), single status for mothers (Beckman, 1983), perceived and actual restrictions on social and leisure activities (Bradshaw & Lawton, 1978) or financial concerns

(Chetwynd, 1985). Similarly, any consideration of the association between child behavioural disturbance and parental stress is incomplete without attention to factors which facilitate coping. The availability of coping resources for the parent has been shown to moderate stress experienced. This moderation of stress will no doubt have implications for the parent-child relationship and for parental management of child behavioural disturbance.

1.1.5.3. Coping Two models of coping have principally informed recent research with families with learning disabled children. In brief, these models propose that the outcome of a stressful event is determined by the combination of an individual's appraisal of the event (Folkman, Schaefer & Lazarus, 1979) or the family's perception of the event (McCubbin & Patterson, 1983), and the availability of resources and coping strategies to facilitate adaptation, and to mediate the impact of the stress.

In considering effective coping resources, much attention has been paid to the quality of the marital relationship and to social support networks. With regards to marital adjustment, Friedrich (1979) found that the best overall predictor of a mother's coping behaviour was marital satisfaction. It has been assumed in some studies that the presence of a behaviourally disturbed learning disabled child will inevitably have a deleterious impact on the marital relationship. There is no conclusive evidence that this is so, however, and the evidence for marital disruption remains sparse and contradictory (Friedrich et al., 1985; Quine, 1986).

In general, the literature suggests that the marital relationship has potentially supportive functions particularly with regards to the mother's morale and sense of competence as a mother (Pedersen, 1981). Furthermore, this relationship has also been identified as an important resource for fathers (Gallagher, Cross & Scharfman, 1981; Sloper et al., 1991). In addition, mutual maternal and paternal

support has been shown to be reciprocally enhancing in terms of parenting competencies (Bristol & Gallagher, 1986).

Numerous studies have demonstrated that the effects of stress on parents with learning and non-learning disabled children, can be ameliorated by adequate social support systems (Crnic, Greenberg, Ragozin, Robinson & Basham, 1983; Dunst, Trivette & Cross, 1986; Levitt, Weber & Clark, 1986; Petersen, 1984; Stoneman & Crapps, 1988). These findings have been replicated in studies of mothers with behaviourally disturbed learning disabled children (Donovan, 1988; Friedrich et al., 1985). Quine (1986) reported, however, that although mothers whose children were behaviourally disturbed did not differ from control mothers in terms of frequency of social activities outside the home, they reported feeling more restricted than controls. This emphasizes the need to consider parental perceptions of their situation in making comparisons. Furthermore, Kazak & Marvin (1984) and Waisbren (1980) have challenged the assumption, that all social support is helpful. They demonstrated increased levels of stress in mothers of learning disabled children who have dense, cohesive social networks.

Additional factors which have been shown to assist coping include maternal perceived control (Friedrich et al., 1985; McKinney & Peterson, 1987), absence of life events (Sloper et al., 1991), maternal employment (Sloper et al., 1991) and access to respite facilities (Rimmerman, 1989; Upshur, 1982; Wikler, 1981).

The process of how different moderator variables influence adaptation largely remains a mystery. The inevitably interactive nature of such variables as social and spousal support with coping and stress responses, renders many of the conclusions circular. Furthermore, the cross-sectional and correlational nature of much of the research does not assist in the elucidation of underlying processes.

1.1.5.4.. Parental acceptance and rejection In terms of parental adaptation to their child, acceptance and rejection can be considered a continuum of adaptation. The acceptance/rejection literature has particular relevance for families with behaviourally disturbed learning disabled children, since positive parental feelings towards their learning disabled children have been shown to be related to positive child-related temperamental and behavioural attributes (Affleck, McGrade, McQueeney & Allen, 1982; Gunn & Berry, 1985; Holroyd & McArthur, 1976). Furthermore, of relevance to an application of EE, rejection represents a component of the hostility scale in particular, and the criticism scale more generally. These two scales represent key scales in the measurement of EE.

In considering the literature pertaining to parental acceptance and rejection of their learning disabled children, it must be borne in mind that measurement inadequacies, inappropriate control groups and conflicting results, limit the usefulness of much of this work.

Generally speaking, parents of learning disabled children have been shown to be more rejecting than parents of non-learning disabled children, particularly with regards to children with mild learning difficulties (Cook, 1963; Wetter, 1972). The term rejection seems to embrace a multitude of somewhat vaguely defined behaviours and attitudes towards the child, including hostility, criticism and unrealistic expectations.

Abusive/neglectful treatment and requests for out-of-home placement (Rousey, Blacher & Hanneman, 1990) are arguably the best indicators of poor acceptance or rejection of the child. In her review of child abuse, Frodi (1981) has provided evidence that learning disabled children are at risk of physical abuse (e.g. Martin, Beezley, Conway & Kempe, 1974). Furthermore, of relevance to behavioural disturbance in these children, Frodi (1981) highlighted child-related qualities such as hyperactivity, high pitched screaming (Nichamin, 1973), irritability and "failure to be loveable", as

disproportionately predisposing "deviant" children to abusive/neglectful treatment by their stressed parental caregivers. Such treatment has been considered to lead subsequently to further aversive behaviours on the part of these children (Bakan, 1971), establishing a vicious cycle of child behavioural disturbance and parental abuse.

With regards to out-of-home placement, a reliable predictor has been shown to be behavioural disturbance (Eyman, Borthwick, & Miller, 1981; Eyman, O'Connor, Tarjan & Justice, 1972; Tausig, 1985). The availability of respite care has been cited as the resource most frequently associated with preventing out-of-home placement (German & Maisto, 1982).

Interestingly, Peck & Stephens (1960) found, albeit in a small study (N=10), that fathers determined the pattern for family acceptance or rejection of the learning disabled child. This finding has been partly corroborated by evidence that maternal perceptions of paternal support are related to the acceptance of the child and to the quality of parenting in the home (Bristol & Gallagher, 1986).

In general terms, acceptance as the converse of rejection is less well defined than rejection, and it is not always clear whether acceptance refers to the child or to the disability, or how it might shape the quality of the relationship with the child (McConachie, 1986, p.52). Relating acceptance to child behavioural disturbance, Gath & Gumley (1986) reported a high degree of tolerance towards even serious behavioural problems. Many parents in their sample considered the behavioural problems to represent an integral part of the learning disability. This appears to be consistent with Sloper et al.'s (1991) findings, which demonstrated positive maternal feelings towards their children independent of the degree of behavioural disturbance, where the mother was able to disassociate the behaviour from the child. As will be seen in Part 2., attributions of relatives with regards to abnormal behaviour are related to the level of EE

rated (Brewin, MacCarthy, Duda & Vaughn, 1991).

From an ecological perspective, parental attitudes and behaviour towards their learning disabled children cannot be completely understood without consideration of both, societal values and the influence these will have on parental adjustment (Crnic, Friedrich & Greenberg, 1983) and, moreover, the consequences of stigmatization (Goffman, 1963). In addition, race (Vasquez, 1974) and religion (Canino & Reeve, 1980) also undoubtedly exert an influence on parental attitudes and behaviour. Although it is beyond the scope of this chapter to do justice to such factors, their influence is acknowledged nonetheless.

#### 1.1.6. Interventions

Consideration of parents and their learning disabled children is incomplete without a cursory inspection of the literature pertaining to interventions for behavioural disturbance. The involvement of parents as behaviour therapists has become increasingly popular with the aim of increasing parental knowledge and coping, and benefiting both parents and children (Baker, 1980). Training programmes usually include operant principles which involve increasing positive reinforcement for adaptive behaviours and suppressing maladaptive behaviours. The latter is usually achieved by time out from positive reinforcement or the forfeit of something desirable, contingent on the maladaptive behaviours (Burchard & Barrera, 1972).

Numerous evaluation studies have demonstrated that training programmes meet their specific goals, and that children with problem behaviours show adaptive behavioural changes (Baker, 1984; Breiner & Beck, 1984). Non-contingent parental responsivity in interactions with their children has also been shown to be amenable to change, with adaptive changes in both parental and child behaviours (Seifer, Clark & Sameroff, 1991). There has, however, been some concern in the literature, that parent training programmes can add to family

strain due to frustrations at goals not being met, and excessive and inappropriate demands on parents (Allen & Hudd, 1987; Benson & Turnbull, 1986; Gallagher, Beckman & Cross, 1983). Furthermore, indirectly supporting these concerns, Davis & Rushton (1991) demonstrated positive outcomes in maternal psychological well-being and child behaviour by employing individual counselling with the mothers, independent of systematic training of the learning disabled children. Other studies have, however, shown reductions in parental psychological distress as a result of training programmes (e.g. Baker, Landen & Kashima, 1991).

Effective replication of parent training programmes is stymied, however, by the failure of many evaluation projects to specify the precise contents of their training packages. Furthermore, a dearth of longitudinal studies restricts comments regarding the maintenance and generalization of skills obtained by parents. Still on a critical note, very few studies consider the systemic constraints within families e.g. marital disharmony, which might block the effectiveness of parent training. Indeed, O'Dell, O'Quinn, Alford, O'Briant, Bradlyn & Giebanhain's (1982) findings of a 40% to 50% dropout and failure rate in parent training, highlight the need to consider constraints within the family system.

Other treatment approaches to behavioural problems in learning disabled children include individual psychotherapy with the child, which has been shown to have some degree of success (e.g. Balbernie, 1985; Sinason, 1989), and self-regulation of behaviour (Browder & Shapiro, 1985). The application of family therapy largely remains virgin territory for families with learning disabled children, but is beginning to receive some attention (Berger & Foster, 1986). Indeed family systems theories feasibly have relevance for these families, where a child's behavioural disturbance might be perpetuated in order to mask more fundamental problems in the family (Minuchin, 1974; Palazzoli, Boscolo, Cecchin & Prata,

1978). Finally, whilst there is evidence that psychotropic medication may reduce stereotypies and aggression towards others and the self (Craft & Berry, 1987), there are few recent studies as to the use of such medication in learning disabled children and adolescents.

#### 1.1.7. Conclusion to Part 1.

The purpose of Part 1. has principally been to highlight parental factors which appear to be relevant with regards to the development and maintenance of behavioural disturbance in learning disabled children, e.g. operant factors and parental interactional styles, and furthermore, factors relevant with regards to the emotional quality of the parent-child relationship i.e. parental stress and coping, and acceptance/rejection of the child. Expressed Emotion (EE) has become one of the most widely used measures of the emotional quality of the relationship between key caregivers and their relatives (usually offspring) with implications for the course of a range of psychiatric and medical conditions. This makes it an exciting tool with which to explore the qualities of the parent-child relationship in the field of learning disabilities, and moreover, its association with behavioural disturbance. Part 2. of this chapter provides an overview of the EE research, and its potential relevance in families with behaviourally disturbed learning disabled children.

## 1.2. Part 2: Expressed Emotion

## 1.2.0. Expressed Emotion (EE): An overview

In considering the EE literature, it must be noted, that the vast majority of EE studies have been carried out with relatives of schizophrenic patients. This bias will be reflected in the literature reviewed below, and in the references to relatives and patients.

The concept of Expressed Emotion (EE) originated from the early work of Brown, Carstairs & Topping (1958). In a retrospective investigation, Brown et al. (1958) found that the best

predictor of clinical outcome for discharged male schizophrenics, was the emotional response of significant relatives to the patients' behaviour.

Three subsequent, prospective studies by Brown, Monck, Carstairs & Wing (1962), Brown, Birley & Wing (1972) and Vaughn & Leff (1976) confirmed the significant relationship between the emotional climate to which a schizophrenic returned following discharge, and the likelihood of subsequent relapse, particularly with regards to male patients. Moreover, these and future studies were able to eliminate measures of premorbid adjustment, severity of psychopathology on admission, or residual symptomatology after discharge, as explanations of the relationship between EE and relapse (Brown et al., 1972; Vaughn & Leff, 1976; Vaughn, Snyder, Jones, Freeman & Falloon, 1984).

The Camberwell Family Interview (CFI) was developed (Brown & Rutter, 1966; Rutter & Brown, 1966) and implemented in the Brown et al. 1972 study in order to investigate aspects of the emotional climate in families in a more standardized fashion. This interview was modified and abbreviated in the Vaughn & Leff study (1976). The CFI is rated on five scales: critical comments; hostility; emotional overinvolvement; warmth and positive remarks. The first four components have been found to relate to outcome in schizophrenia in a large number of studies. In contrast, the number of positive comments appears to bear no relationship to the course of schizophrenia or any other conditions.

The term "Expressed Emotion" was first used in the Brown et al. 1972 study. Expressed Emotion (EE) became an operationally defined construct, which is a measure of the extent to which relatives express critical, hostile or overinvolved attitudes about a patient when discussing the patient's illness and family life, with an interviewer. It is scored by trained raters who consider the content, and in addition, the vocal qualities of the relative's speech during the

standardized CFI. Expressed Emotion was developed to reflect aspects of ordinary family relationships/interactions, and the propensity for the relative interviewed to respond to the patient in a particular way at a time of crisis, with implications for the patient's condition over time. Interviews were usually carried out shortly after the schizophrenic patient had been hospitalized. In terms of degree of contribution to outcome, number of critical comments has consistently been found to be the most crucial determinant, followed by hostility, and then emotional overinvolvement. The reader may refer to the METHOD (chapter 2) in this document, for more descriptive details concerning the components of EE.

In measuring EE, two assumptions are made. Firstly, that the relative's account of relationships in the home is reliable and valid, independent of in vivo observations of the relationship, and secondly, that the attitude shown by the relative towards the patient during the interview is representative of the enduring quality of their relationship over time (Vaughn & Leff, 1976). These two assumptions are considered further in sections 1.2.3. and 1.2.5., respectively.

The 1980's and 1990's have produced a flourish of research applying the EE construct. Kavanagh (1992) has calculated that to date, of the 26 studies investigating EE and schizophrenic relapse internationally, the median relapse over 9-12 months is 21% for patients returning to low EE homes and 48% for patients returning to high EE homes. Kavanagh asserts on the basis of this evidence, that EE represents a phenomenon as valuable clinically as medication (30% relapse with neuroleptics and 65% on placebo; Davis, 1975).

Not all studies, however, have confirmed a relationship between EE and relapse. MacMillan, Gold, Crow, Johnson & Johnstone (1986) and Parker & Johnston (1987) have highlighted the confounding of EE status and duration of untreated schizophrenic illness, with regards to relapse, and consider the latter to be more

predictive of relapse than EE. These authors' findings are not confirmed by Nuechterlein, Snyder, Dawson, Rappe, Gitlin & Fogelson (1986).

Two factors have emerged which appear to exert a protective influence on schizophrenic patients in high EE households, namely, less than 35 hours of face-to-face contact with the high EE relative, and compliance with neuroleptic medication (Brown et al., 1972; Vaughn & Leff, 1976). Furthermore, these two factors have been shown to have an additive effect, reducing high EE patients' relapse rates to those of low EE patients (Vaughn & Leff, 1976).

The usefulness of these two protective factors has been challenged by contradictory findings (MacMillan et al., 1986; Nuechterlein et al., 1986). Certainly, with regards to contact, duration of contact with a relative is not necessarily indicative of the degree of exposure to negative interactions. Nevertheless, consideration of why 50% or more of schizophrenics do not relapse in high EE households, above and beyond methodological flaws in the studies, can only further an understanding of EE and relapse.

Interestingly, Falloon & McGill (1985) demonstrated that relapse rates in patients from low EE families doubled when contact was low (9% to 20%). This highlights the relevance of warmth and feasibly, positive comments in low EE households. Consideration of these two components is often neglected due to their poor predictive utility. In the early studies, however, Brown et al. (1972) and Vaughn & Leff (1976) noted the moderating impact of warmth on concurrent criticism.

The EE construct has thus become an operationally defined entity, the validity of which is derived from its ability to predict the likelihood of relapse to a greater extent than characteristics such as behavioural disturbance. The development of EE marked a shift in emphasis in research from the study of families' role in the aetiology of schizophrenia (Bateson, Jackson, Hayley and Weakland, 1956) to

the study of family factors in the course of the illness. The construct has, however, been criticized for blaming families (Hatfield, Spaniol & Zipple, 1987). Key developments in EE research and their relevance for the current study will be considered below.

# 1.2.1. Cross-cultural and cross-diagnostic applications of EE

Cross-cultural comparisons of the predictive utility of EE, in terms of relapse in schizophrenia, support the robustness of the construct. Inevitably, cultural variations have emerged, and Jenkins & Karno (1992) have suggested that an understanding of the relationship between EE and relapse can only be obtained by considering these cultural variations.

High EE is much more common in Western cultures than in developing countries, with correspondingly higher rates of relapse in the West. This provides additional support for EE since global incidence of schizophrenia is more or less uniform. The East-West distinction is highlighted by Wig, Menon, Bedi, Ghosh, Kuipers, Leff, Korten, Day, Sartorious, Ernberg & Jablensky's (1987) studies in rural and urban Chandigarh (India) where only 23% of relatives were rated as high EE. The Los Angeles study (Vaughn et al., 1984) in contrast, produced the highest number of high EE relatives - 67%, as compared to the 58% and 50% in the British studies (Brown et al., 1972; Vaughn & Leff, 1976, respectively). Mexican-American relatives fall below the British and American rates for high EE, with 41% of relatives so categorized (Karno, Jenkins, de la Selva, Santana, Telles, Lopez & Mintz, 1987).

In addition to an interest in the trans-cultural relevance of EE, there has been a burgeoning of research within patient populations other than schizophrenia. The EE index has demonstrated significant predictive power in determining the prognosis in a number of other conditions. These have included unipolar depressive disorders (Hooley, Orley & Teasdale, 1986;

Hooley & Teasdale, 1989; Vaughn & Leff, 1976), recent onset mania (Miklowitz, Goldstein, Nuechterlein, Snyder & Doane, 1986; Miklowitz, Goldstein, Nuechterlein, Snyder & Mintz, 1988) and coronary heart disease (Priebe, Kuppers & Sinning, 1992. See Kuipers, 1992, p.434). Level of EE has also been found to be predictive of treatment compliance in both anorexia nervosa (Szmukler, Eisler, Russell & Dare, 1985) and obesity (Fischmann-Havstad & Marston, 1984; Flanagan & Wagner, 1991). Level of EE was not found to have predictive value, however, in glycaemic control for diabetic adolescents (Stevenson, Sensky & Petty, 1991).

The relevance of level of EE to a variety of conditions has been demonstrated, without necessarily reference to outcome in these conditions. These conditions include dementia (Bledin, MacCarthy, Kuipers & Woods, 1990; Gilhooly & Whittick, 1989; Orford, O'Reilly & Goonatilleke, 1987), diabetes (Sensky, Stevenson, Magrill & Petty, 1991), learning difficulties (Dossetor, 1991; Greedharry, 1987) and childhood psychopathology (Doane, West, Goldstein, Rodnick & Jones, 1981; Hibbs, Hamburger, Lenane, Rapoport, Kruesi, Keysor & Goldstein, 1991; Schwartz, Dorer, Beardslee, Lavori & Keller, 1990). A wealth of other studies are currently at different stages of completion, in the areas of intractable childhood epilepsy, irritable bowel syndrome, childhood autism and Parkinson's disease. No published study to date has investigated the role of EE in families with behaviourally disturbed children with learning difficulties.

Although rarely discussed at any length, behavioural disturbance or behavioural change is common to most of the conditions in which EE has been applied. Furthermore, a positive association between EE and behavioural disturbance has been found (e.g. Bledin et al., 1990; Dossetor, 1991; Hibbs et al., 1991; MacMillan et al., 1986; Schwartz et al., 1990). In contrast to these findings, however, Brown et al. (1972) and Vaughn & Leff (1976)

have found EE to be independent of measures of behavioural disturbance. Whilst it is not clear why EE and behavioural disturbance are associated with one another, the trend in EE research is to consider the bidirectionality of influence of carers' and relatives' behaviour. Since level of EE has also been shown to be independent of behavioural disturbance, investigative efforts have focused in addition, on differences between high and low EE relatives e.g. attributional style (Brewin et al., 1991). These issues are considered in greater detail in section 1.2.4. below.

The interest of researchers in EE and a variety of conditions emphasizes the recognition of EE as a potentially relevant risk indicator or marker variable which has value beyond schizophrenia. Diagnostically relevant modifications to the CFI and variations in cutoff points render comparisons between studies dubious, however, and associations between EE and outcome potentially spurious. Furthermore, such modifications are rarely made explicit.

Nevertheless, a compelling feature of the EE construct is its robustness in its relationship to outcome across diagnostic categories. It must be noted, however, that it has not been shown how EE relates to the course of most conditions studied. Furthermore, there is always the risk that research can be justified purely on the basis that EE is being investigated. Indeed, Jenkins & Karno (1992), have criticized the repetitiousness of EE research, without sufficient attention being paid to clarification of the theoretical underpinnings of the construct. These authors criticize the fact that theoretical elucidation of the construct of EE lags far behind clinical and research interest in the construct.

# 1.2.2. EE and learning difficulties

In his pilot study of parental EE towards learning disabled adult offspring, Greedharry (1987) found an absence of hostility in his sample of 10 parents. Criticism was low, and moreover the degree of

warmth expressed towards the learning disabled individuals was moderate. Greedharry's small sample clearly limits the conclusions that can be drawn. Furthermore, an absence of information regarding characteristics of both parents and offspring, and regarding relevant modifications to the interview, block effective replication. The study has initiated, however, a timely consideration of the value of EE in non-psychiatric and non-medical populations.

Dossetor's (1991) study represents the study with greatest relevance for the present investigation. Dossetor examined EE in 92 families with learning disabled adolescents, as part of a broader survey of the dependency needs of learning disabled adolescents. High EE was rated in 35% of the parents, with 25% of high EE parents so rated on their criticism and hostility, and 75% so rated on their expressed emotional overinvolvement. High EE significantly related to the following aspects of the comprehensive interview administered: informal practical support; insecure style of short term care usage; the parents' GHQ scores; quality of the marriage; the presence of psychiatric disorder in the adolescent; the presence of moderate or severe behavioural disturbance; an interviewer's global rating of the parents' expressed dissatisfaction towards services; the parents' declared difficulty in bringing up the adolescent and the parents' ratings of recent difficulties.

With regards to sub-groups of high EE, Dossetor found that criticalness was related to hyperactivity in the adolescents, and emotional overinvolvement to difficulties regarding the adolescents' emotional independence.

High EE was not found to be related to general behavioural disturbance in the adolescents. When Dossetor reduced the cutoff for critical comments to 3, however, a significant relationship between criticalness and behaviour emerged. Dossetor concluded that a cutoff of 3 tapped with greater sensitivity, the association between criticism and behavioural disturbance.

Investigation of EE in the Dossetor study was one part of a comprehensive survey. The overwhelming number of issues superficially addressed in the study makes it difficult, however, to make anything more than general comments about the value of EE. It is the aim in the current study to consider in greater depth the value of EE in families with behaviourally disturbed learning disabled children. Despite the broadness, and to some extent, superficiality of the Dossetor study, and his attention to EE, Dossetor has clearly highlighted the importance of considering the emotional quality of the relationship with primary caregivers when assessing the problems faced by adolescents with developmental disabilities. In addition, his study has indicated the potential value of EE as an index of need in families in which the ongoing care of a learning disabled offspring is uncertain.

## 1.2.3. Validity of the concept of EE

Level of EE has variously been criticized as representing little more than a "snapshot" of a relative's attitude towards the patient, with little relevance to ongoing in vivo interactions in the home. Furthermore, the fact that in the schizophrenic studies EE is usually assessed at a crisis point in the patient's illness, i.e. around admission into hospital, might feasibly produce spuriously high levels of EE. The presence of low EE relatives in samples challenges this criticism, as does the reliable and consistent predictive utility of EE. The absence of interactional correlates to EE is, however, conspicuous in most EE studies, and certainly with regards to conditions other than schizophrenia. Some of the most noteworthy attempts to remedy this dearth of interactional studies are considered below.

Doane et al. (1981) developed an interpersonal analogue of the EE construct which measures the Affective Style of relatives. Affective Style is assessed according to the presence of benign and harsh criticisms, neutral intrusive statements and supportive statements. This measure was employed in a study carried out by Valone, Norton, Goldstein & Doane (1983) with disturbed but non-psychotic adolescents and their families. It was found that individual parents who had been rated as high EE made significantly more criticisms when involved in face-to-face interactions with their offspring than did low EE parents. This study clearly provides behavioural validation of the EE construct. The study's replicability with offspring with established diagnoses of schizophrenia was demonstrated by Miklowitz, Goldstein, Falloon & Doane (1984). In their study, high EE critical parents were clearly distinguisable from high EE emotionally overinvolved parents since the former were more critical and the latter more neutrally intrusive.

Miklowitz et al.'s (1984) study demonstrates that there seems to be a tendency not only for high EE parents to behave in different ways as compared to low EE parents, but also for parents within the high EE group to behave somewhat differently according to whether they are critical or emotionally overinvolved. This clearly raises the question of whether valuable information is lost in terms of the utility of EE when it is employed as a unitary construct i.e. high EE or low EE, as opposed to a compound construct, acknowledging the different impact of criticism and emotional overinvolvement. Indeed, the relationship between criticism and emotional overinvolvement has been shown to be weak, i.e. 0.30 for fathers, and -0.03 for mothers (Vaughn et al., 1984). Hostility is rarely rated independent of criticism.

The potentially reactive influence of the interview setting cannot be ignored in these observational studies. Of interest in the Valone et al. (1983) study, however, was the finding that the presence of one low EE parent exerted a buffering influence on the negative Affective Style of the other high EE parent. This contradicts Vaughn & Leff's (1976) classification of households as

high EE if only one relative was so rated.

Despite the optimism that has been shown regarding the behavioural validation of the EE construct, it must be remembered that EE and Affective Style tap different aspects of relationships, since EE is an attitudinal measure, and Affective Style reflects interactional behaviour. Moreover, very few attempts have been made to relate interactional style to outcome at follow-up.

In addition to attempts to validate EE with behavioural and interactional evidence, some success has been demonstrated in the domain of psychophysiology. Increased frequencies of spontaneous fluctuations of skin conductance have been demonstrated among schizophrenics in the presence of high EE relatives (Sturgeon, Kuipers, Berkowitz, Turpin & Leff, 1981; Sturgeon, Turpin, Kuipers, Berkowitz & Leff, 1984; Tarrier, Vaughn, Lader & Leff, 1979), with no apparent differences between critical and emotionally overinvolved relatives (Tarrier et al., 1979). Furthermore, Sturgeon et al. (1984) demonstrated a remarkable 83% correct classification of patients into high EE or low EE groups based purely on their spontaneous fluctuation rates.

The relevance of differential spontaneous fluctuations is questionable, however, since in an intervention study which produced a reduction in EE (Leff & Vaughn, 1985, pp.207-208), spontaneous fluctuations did not correspondingly decrease. Nevertheless, evidence of this elevated autonomic arousal in schizophrenics in high EE households is consistent with the vulnerability-stress model of schizophrenia (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977). This model predicts the occurrence of psychotic episodes in individuals vulnerable to schizophrenia if they are exposed to stressful environments, and appears to be the best explanation for the relationship between EE and relapse. Consideration of high EE as a stressor within a vulnerability-stress framework feasibly has relevance for levels of behavioural disturbance in learning disabled

children, who, as was shown in section 1.1.3. in Part 1., are vulnerable to behavioural disturbance.

## 1.2.4. Characteristics of high and low EE relatives

In attempting to understand the relationship between EE and outcome, it became clear in the various longitudinal studies that patients could not be distinguished on measures of premorbid adjustment, severity of psychopathology on admission or residual symptomatology after discharge (Brown et al., 1972; Miklowitz, Goldstein & Falloon, 1983; Vaughn & Leff, 1976; Vaughn et al., 1984). It was therefore concluded that the explanations for the differences in EE must lie with the relatives, and their perceptions of patients' behaviour, their coping skills and their interactional styles, and the expression of these characteristics during the time between the patients' discharge and relapse.

Brewin et al. (1991) found that critical and/or hostile relatives were more likely to attribute patient behaviours to factors personal to and controllable by the patient than to the schizophrenic illness. Attributing behaviours to the illness appeared to be a characteristic of low EE relatives. This concurs with Vaughn (1977) who found that two-thirds of critical comments were related to longstanding attributes of the patient, with no attempt to distinguish between pre- and post-illness behaviour. These findings emphasize the importance of educating relatives about schizophrenia or the condition in question, and how it is likely to manifest itself in the patient. Furthermore, the issue of attribution feasibly has relevance in terms of differential parental tolerance of behavioural disturbance in learning disabled children. Greater tolerance has been shown to be associated with parents considering the behaviour an integral part of the learning disability (Gath & Gumley, 1986).

Equally valuable was the finding by MacCarthy, Hemsley, Schrank-Fernandez, Kuipers & Katz (1986) that highly critical relatives appear to provide an unpredictable home environment for schizophrenics. It was suggested by these authors, that this unpredictability creates a cognitively confusing environment. This confusion heightens the risk of relapse through its interaction with the cognitive deficits which are thought to develop in schizophrenia e.g. an inability to filter out redundant information (Hemsley & Zawada, 1976). The learning disabled population can be considered akin to schizophrenics with regards to their information processing deficits, although clearly the aetiology and nature of these deficits are different. Similarly, the reader will recall that vague, noncontingent parental interactions have been shown to be related to behavioural disturbance in learning disabled children (e.g. Breiner & Forehand, 1982).

In attempting to distinguish between high and low EE relatives, a dearth of direct attention to differential coping strategies is conspicuous in the literature. It seems reasonable to suggest that this dearth is the product of an assumption that a categorization of low EE is synonymous with adaptive coping, and high EE with maladaptive coping. As will be seen below, it is misguided to ignore the potentially deleterious influence of low EE. In addition, there is the risk in EE research that suppression of emotion becomes an unspoken goal for high EE families without due attention to more constructive expressions of feelings (Hatfield et al., 1987). The current study investigates parental coping strategies and their relationship with EE.

Kuipers & Bebbington (1988) have proposed that level of EE and relatives' coping efficacy interact to determine the stability of EE. Furthermore, Bledin, Kuipers, MacCarthy & Woods (1987. See Kuipers & Bebbington, 1988, p.906) have provided evidence that high EE is associated with ineffective coping responses in carers of elderly demented people. Such strategies include avoidance and overeating as opposed to more effective strategies such as problem-

solving.

Birchwood & Smith (1987) and Birchwood & Cochrane (1990) have been critical of the limited nature of EE, and have focused on quantifying families' coping behaviours and coping styles. They have argued that coping styles evolve with the progression of schizophrenia from an acute to a chronic state. Lower rates of high EE in first admission schizophrenics' families compared to more chronic cases, support this assertion (Leff & Brown, 1977). Unfortunately, their work, whilst usefully broadening the consideration of family factors in schizophrenia, has not investigated the relationship between coping strategies and EE.

Finally, also of relevance to coping, Greenley (1986) demonstrated an association between level of EE and attempts to control the behaviour of the person with schizophrenia by anxious and fearful family members, particularly when the patient's behaviours were not attributed to the illness. The issue of control as a characteristic of high EE relatives is supported by Hooley & Hahlweg (1983; see Hooley, 1985, p.134) in their study with spousal caregivers of depressed patients. Indeed, control is certainly consistent with the nature of criticism, which can be seen as an attempt to alter another's personality and/or behaviour.

Attempts to distinguish between high and low EE relatives in terms of personality have not yielded significant differences (Parker & Johnston, 1988). In contrast, there is evidence to suggest that high EE relatives experience greater levels of psychopathology as compared to low EE relatives. It is interesting, that despite a growing consensus that high EE represents a non-specific stressor for both patients and relatives (Hubschmid & Zemp, 1989), minimal attention has been paid to the psychological well-being of relatives.

Studies which have investigated the role of EE in families with both disturbed and normal children have highlighted, however, the interaction between EE and parental psychopathology (Hibbs et

al., 1991; Schwartz et al., 1990). Indeed, Hibbs et al. (1991) have suggested that parental psychopathology might be considered an effective substitute for EE in determining risks for child psychopathology. These studies challenge the notion that EE is a measure of ordinary family interactions (Brown et al., 1962; 1972). Attention to parental psychological well-being, notably stress, is a feature of the current study.

Other differences between high and low EE relatives have been highlighted in the interactional studies. Hubschmid & Zemp (1989) described high EE relationships as rigid and conflict prone. In low EE relationships, low EE relatives, in contrast, appeared to be more responsive to the patients' behaviour, more emotionally positive and less rigid. These authors concluded that high EE interactions represented a source of stress for both patients and relatives. Strachan, Leff, Goldstein, Doane & Burtt (1986) found that high EE relatives expressed more negatively emotional statements in face-toface contact with patients. Furthermore, high EE relative and patient dyads were more mutually antagonistic, with evidence of escalating tension. Low EE interactions in contrast, were calmer, more positive and more supportive. These findings suggest that low EE relatives are not on the whole neutral, but potentially more supportive. The finding that low EE patients experience more life events than high EE relatives prior to relapse (Leff & Vaughn, 1980), suggests, however, that the emotional support often attributed to low EE households, might not suffice.

A finding that high EE relatives talk more and have a more immediate response style than low EE relatives (Bertrando, Bressi, Clerici, Cunteri & Cazzullo, 1989) has direct relevance to learning disabled children and their cognitive abilities to assimilate communications from their parents. At present, however, there is minimal evidence to support cross-diagnostic generalization of these findings beyond schizophrenia.

The issue of whether low EE really is protective and supportive has recently begun to receive attention. Concern has been expressed that a low EE household might reflect emotional underinvolvement on the relative's part, lack of stimulation for the patient, low expectations of functioning, and an inappropriate tolerance of provocative behaviours. Thus a patient's overall level of functioning is potentially compromised, including motivation for selfimprovement (Hatfield et al., 1987; Kanter, Lamb & Loeper, 1987). Indeed, there has been a notable neglect in the EE literature of attention to quality of life issues for patients, which include level of stimulation in the home. The aforementioned concerns highlight the risk of low EE families' needs being neglected, based on the misplaced assumption that low EE is synonymous with positive effects for relatives and patients. Furthermore, the association between lack of stimulation and behavioural disturbance in the learning disabled (Baumeister & Forehand, 1973; Berkson & Mason, 1963) highlights the relevance of considering qualitative features of low EE households in the current study.

Finally, whilst it is valuable to distinguish between high and low EE relatives, EE research in general has been criticized for its unidirectional emphasis, i.e. the effect that a relative has on the target patient's condition. Suggestion of a two-way relationship determining level of EE has attracted some attention in the literature. Miklowitz et al. (1983) reported that although they found little relationship between familial EE and acute symptoms, consistent with Brown et al. (1972), they did find a strong association between emotional overinvolvement and withdrawn behaviour in the patients during adolescence. Furthermore, Brown et al. (1972) found that improvement in patients' behaviour led to a decrease in EE in relatives. Hogarty, Anderson, Reiss, Kornblith, Greenwald, Javna & Madonia (1986) stated that it was just as reasonable to infer that a reduction in EE was due to a patient's improvement as it was to infer

that lowering familial EE improved a patient's outcome.

Studies with children have been particularly informative with regards to the bidirectional influence of parental and child behaviour in high and low EE interactions. Cook, Strachan, Goldstein & Miklowitz (1989) used sequence analysis to explore interactions of high EE and low EE parent-child dyads in a sample of disturbed adolescents. They found that adolescents in high EE dyads had an oppositional style of responding, contributing to a negatively escalating cycle in the interaction. Low EE parent-child dyads influenced each other less, and there was greater affective stability in the adolescents.

## 1.2.5. Stability of EE over time

The issue of stability of EE over time clearly has theoretical significance for EE in terms of assumptions regarding ongoing familial interactions. As was noted earlier, EE is typically measured around the time of the patient's admission, and therefore may be intensified by the acuteness of the patient's illness at that time.

Brown et al. (1972) noted a decrease from 30% to 14% in the number of relatives making 7 or more critical comments nine months after the initial interview. Brown et al. (1972) concluded that EE does not reflect a continuous state of criticalness or overinvolvement, but rather the proclivity to assume these attitudes at times of stress. Other studies have supported Brown et al.'s findings and demonstrated that if relatives are retested on the CFI 6-12 months after discharge, 50% or more of the people who were initially rated as high EE subsequently obtain a low EE rating (Dulz & Hand, 1986; Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts & Freeman, 1988). In contrast to these findings, Leff, Kuipers, Berkowitz, Eberlein-Fries & Sturgeon (1982) and Hogarty et al. (1986) demonstrated in their intervention studies stability in high EE over time in a significant number of relatives in their

untreated groups.

Thus, there appears to be evidence that EE can represent both a state and a trait. Indeed, the research appears to highlight three EE groups (Kuipers & Bebbington ,1988), namely, a stable low EE group, a fluctuating EE group which may change over time, and a stable high EE group. In addition, there is some evidence to suggest that criticism is more unstable than emotional overinvolvement (Brown et al., 1972). More research is required to clarify the issue of EE stability, however, since many studies, including the current study, employ EE as a measure of the emotional quality of a relationship, independent of specific crises e.g. admission to hospital. Measuring EE in this way feasibly represents a more reliable indicator of the emotional quality of the relationship since the measurement is not influenced by relatives' reactions to a crisis. The long-term stability of EE measured in this way remains to be determined.

#### 1.2.6. Intervention studies

The consistent predictive value of EE has stimulated research into its causal role. In order to demonstrate a causal relationship, it is necessary for EE to be manipulated and its effects on illness outcome assessed. This has been done in a series of intervention studies with patients and/or relatives from high EE groups, with clinical and theoretical significance for EE (e.g. Falloon, Boyd, McGill, Razani, Moss & Gilderman, 1982;. Hogarty et al., 1986; Leff et al., 1982). Such studies have employed high EE as a baseline index of familial stress and ineffective coping. Reduction in EE has not always been the focus in the outcome of these studies, but relapse rates have been shown to decrease dramatically in intervention groups, and to be largely maintained at follow-up with a corresponding decrease in EE where this has been measured (Leff et al., 1982).

The ingredients of the intervention packages are largely

vague, and the methodological limitations, which are a hazard in social research, restrict effective replications. Family interventions including education and problem-solving, and social skills training for the patient, appear, however, to be important components (Falloon et al., 1982; Hogarty et al., 1986; Smith & Birchwood, 1987).

Whatever the criticisms of EE might be, and the doubts regarding its relevance in such interventions (Lam, 1991), there is no doubt, that EE research has been instrumental in developing social intervention research. Given the utility of EE in other disorders, the development of intervention packages relevant for such conditions would appear to be the next stage in the intervention research. Hogarty et al. (1986) have queried, however, whether social interventions do anything more than delay relapse. As is always the need but rarely the case, longer follow-up periods are required.

# 1.2.7. Conclusions regarding EE research

Similar to many reviews of the EE literature, it is necessary to conclude that it is still not entirely clear what EE actually is. As Koenigsberg & Handley (1986) so aptly state: "Expressed Emotion is a concept which has been legitimized by its predictive validity: its meaning and construct validity remain to be established". Nevertheless, EE does appear to tap attitudes, feelings, responses and difficulties common to the care of many disabling conditions. Compelling features of EE include its inherent modifiability, and in addition, its robustness cross-culturally and cross-diagnostically. These features render EE an exciting tool with which to apply to families with behaviourally disturbed learning disabled children.

A theoretical basis for EE is not altogether clear, however, (Jenkins & Karno, 1992), although Lam (1991) has highlighted theoretical models with which EE and the intervention studies are consistent, e.g. attribution and coping theories. Moreover, whilst

the oft criticized dichotomization of EE (Hatfield et al., 1987) does appear to have validity for research purposes, for clinical purposes, a continuum of EE would appear to provide more information regarding the idiosyncrasies of relationships.

Finally, the training that is required to rate EE and to administer the CFI restricts the accessibility of EE for clinical and research purposes. Attempts have been made to address this issue, with abbreviated assessments e.g. Magaña, Goldstein, Karno, Miklowitz, Jenkins & Falloon's (1986) Five Minute Speech Sample, and in addition, by using untrained raters (Hooley & Richters, 1991). The predictive utility of EE appears to be compromised by these shortcuts, although general correspondence with EE ratings from the uncut CFI, and from trained raters, is satisfactory.

## 1.2.8. Outcome in the current study

Before concluding the INTRODUCTION, it is relevant to note, that the current study differs from the original format of EE studies, in that EE is not measured at a time of crisis, nor is it used to predict outcome in a longitudinal design. An outcome of a sort was, however, measured in the frequency of service contacts families had, had pertaining to the needs of their learning disabled children. There is very little literature concerning the use of services by families with learning disabled children (Ineichen, 1986). Factors such as local variations in the availability of services and families' awareness of available services, complicate assessments of actual service usage. Notwithstanding this, there is evidence to suggest that use of respite services for example, represents an indicator of subjective difficulties of carers (usually mothers) of learning disabled children and adults (e.g. Grant & McGrath, 1990). Furthermore, it is feasible to suggest that use of services might reflect parental need in terms of the general management of the child. It was therefore considered likely that high EE as an indicator of poor psychological well-being (Hibbs

et al., 1991) and poor coping (Bledin et al., 1987) would be associated with greater use of services as compared to low EE (see hypothesis 4 below).

It was considered dubious to obtain retrospective accounts of service input purely related to behavioural disturbance, due to the multiplicity of needs (physical, behavioural etc.) with which learning disabled children often present (Fraser & Rao, 1991) and which would undoubtedly complicate a simple self-report assessment of such service usage. Thus, although arguably more limited, it was considered more reliable to tap general need within the families in terms of general service usage. To this end, a comprehensive checklist of services was compiled (see METHOD 2.4.5.).

## 1.2.9. Rationale for the current study

Whilst there is evidence to suggest that socio-environmental factors such as inappropriate reinforcement of behaviour and parental interactional styles can contribute to the development of behavioural disturbance in learning disabled children, there has been little consideration of the emotional quality of the parent-child relationship and its association with child behaviour. The robust association between parental stress and rejection and behavioural disturbance in learning disabled children highlights the potential fragility of the emotional quality of the parent-child relationship for parents and their behaviourally disturbed learning disabled children. Expressed Emotion has come to represent a valuable tool for measuring the emotional quality of significant relationships, with demonstrated congruence with actual interactional patterns, and of relevance to a range of psychiatric, non-psychiatric and medical conditions. A current emphasis on community care and placement of the child with their family supports the importance of considering the emotional quality of the parent-child relationship, and its association with child behavioural disturbance. The relationship between parents

(usually mothers) and their behaviourally disturbed learning disabled children appears to be potentially prone to disruption, feasibly leading to an escalation of parental stress and child behavioural disturbance and possibly ultimately, to the breakdown of care of the child (Eyman et al., 1972; Frodi, 1981).

## 1.2.10. Aims of the current study

- To explore the value of the EE concept for families with behaviourally disturbed learning disabled children;
- 2) To determine whether high EE is a risk indicator for child behavioural disturbance, and stress, poor coping and high service usage amongst parents who have a learning disabled child;
- frequency, management difficulty and severity of child behavioural disturbance, with a post-hoc comparison regarding types of behavioural disturbance; parental stress and coping; service input, with a post hoc comparison of respite care usage; family demographic characteristics and the children's level of intellectual functioning and physical dependency;
- 4) Contingent on whether the EE concept is discovered to be a marker variable in this population, to make suggestions regarding support and skill training relevant to such families, in contrast to the traditional emphasis on the individual child referred.

# 1.2.11. Hypotheses

An association between EE and behavioural disturbance (Bledin et al., 1990; Hibbs et al., 1991) including learning disabled adolescents' behaviour (Dossetor, 1991), and an association between negative parental attitudes and behaviour and behavioural disturbance in

learning disabled children (Frodi, 1981), support the hypothesis:

 High EE parents will report greater frequency, management difficulty and severity of child behavioural disturbance than low EE parents;

An association between EE and psychological well-being (Bledin et al., 1990; Hibbs et al., 1991) supports the hypothesis:

High EE parents will report more stress than low EE parents;

An association between EE and coping (Bledin et al., 1987) supports the hypothesis:

 High EE parents will possess a more restricted repertoire of coping behaviours than low EE parents;

Since high EE has been identified as an indicator of both poor coping and poor psychological well-being it was hypothesized that:

4) High EE parents will have more extensive face-to-face contacts with services pertaining to the needs of their learning disabled children, than low EE parents;

Evidence of an association between respite care usage and subjective difficulties of carers of the learning disabled (Grant & McGrath, 1990), supports a post hoc hypothesis that:

 High EE parents will make greater use of respite care than low EE parents.

# 1.2.12. The Predictive utility of EE in the current study.

It was considered valuable to compare the predictive utility of EE with other variables such as reported stress and child behavioural disturbance. Post hoc analyses examining EE as a predictor were therefore included where statistically significant relationships between EE and other variables were identified.

#### CHAPTER 2: METHOD

#### 2.1 Participants

#### 2.1.1. Selection of the sample

Parents of school age children (3-19 years) from three schools for children with learning difficulties received a letter (see APPENDIX 1) from the author requesting permission for their child's behaviour to be assessed by his/her teacher, and for the author to make contact with the family by letter or telephone following the assessment. All letters were sent to parents via the school to preserve the anonymity of families who might decline to participate in the research. A total of 96 parents gave permission both for their child's behaviour to be assessed by the teacher and for the author to contact them following the assessment.

The teachers were requested to assess the children's behaviour generally, on the basis of their knowledge of the children's behaviour both at school and at home over the previous three Teachers assessed the children's behaviour using the months Checklist of Challenging Behaviours (Harris, Humphreys & Thomson, 1989. Unpublished) (see below in section 2.4.2.) (see APPENDIX 4). Knowledge of the children's behaviour at home was derived both from daily diaries which the schools require the parents to complete and to send to the school on a daily basis, and in addition, from parental contact with the schools. Assessment of the children's behaviour over the preceding three months provided a period of time long enough to allow patterns of behaviour to be seen, but short enough to reduce the likelihood of distortion in the teachers' retrospective accounts. The headteachers and teachers were thanked by the author in person, following the completion of the assessments.

Following the assessment, the 96 children were categorized as mild, moderate or severely behaviourally disturbed according to whether teachers assigned a predominance of 1s and 2s (mild), 3s (moderate) or 4s and 5s (severe) to the items listed in the Checklist

of Challenging Behaviours. The division of behavioural disturbance into the above categories of severity was considered by the author to be the most meaningful way of ensuring a spread of behavioural disturbance in the study's sample. There was no attempt to match the children in any way across the categories.

A quota sampling technique was employed in the current study. A sample of 40 children from the three categories of behavioural disturbance was randomly selected for inclusion in the present investigation, with 13 children in the mild and severe categories, and 14 in the moderate category, which represented the largest category overall.

One mildly and one severely behaviourally disturbed child were randomly selected from those not included in the study in order to pilot the assessment procedure outlined below. Data from these two families are not included in the statistical analyses carried out.

The parents of the 42 children were contacted by telephone. The parent who spent the most time with the child was invited to participate in the study. All 42 parents contacted were willing to participate. One father and four foster mothers were included in the main study. The remainder of the sample consisted of biological mothers.

#### 2.1.2. Exclusion criterion

Children categorized as profoundly and multiply learning disabled by their school were not included. Such children were excluded due to the multiplicity of their dependency needs and generally poor physical health when compared to other children with learning difficulties. It was considered likely that this group's extensive needs would exert a confounding influence on the variables under investigation, as would the recognized low level of arousal of such disabled children and their subsequent poor receptivity to environmental stimuli (Mulliken, 1983).

## 2.1.3. Characteristics of the study's ungrouped sample

The study included 21 female and 19 male children. The range of children's ages was between 3 and 19 (mean 10.22; sd. 4.46). Age of the parents ranged between 23 and 56 (mean 38.75; sd. 7.07). The number of siblings in the families ranged between 1 and 6 (mean 1.78; sd. 1.08), with a total of three "only" children in the sample. The size of the nuclear families ranged between 2 and 9 members (mean 4.43; sd. 1.34). The ordinal position of the learning disabled child in the family was calculated using three code points:

- 1 if the child was the oldest;
- 2 if the child came between the oldest and the youngest child,
   irrespective of the total number of children in the family, and,
- 3 if the child was the youngest, again regardless of family size.

The range of ordinal positions was 1 to 3 and the modal position was the youngest (3).

The number of single mothers in the sample was nine. Twenty-nine of the families were intact. Two of the mothers in the sample had divorced since the birth of their handicapped child and had either remarried or were living with a new partner. Four foster families were included. One of the foster mothers was single. There were 13 working mothers in the sample and 28 of the male partners were currently in employment. None of the single mothers nor the only father were employed. There were 12 households in the sample in which no-one was employed.

Two of the families in the sample were of Afro-Caribbean origin. The remainder were white European. Socioeconomic status was assessed using Goldthorpe & Hope's (1974) 36-category collapsed version of their scale for grading occupations of the person contributing the main source of income in the household. The median categorical rating was 17.50.

Twenty-five children in the sample had undifferentiated mental retardation; five had Down's syndrome; two were categorized

as autistic (mothers' reports of professional diagnosis); two had Rubinstein-Taybi syndrome; three had microcephaly; one had muscular dystrophy; one had myoclonic estatic epilepsy accompanied by progressive mental retardation following measles, and one had an unlabelled chromosomal abnormality. Six of the children in the undifferentiated category had accompanying cerebral palsy. Ten or 25% of the children in the sample were reported by their parents to have epileptic seizures of varying severity. A comparison between high EE (HEE) and low EE (LEE) groups in terms of children's diagnoses was not considered feasible due to small numbers in all categories apart from undifferentiated mental retardation.

The intellectual level of functioning of each child was assessed using the World Health Organization's (WHO) categories for mental retardation (1980) (see section 2.4.6. below). Mild learning difficulties were rated as 1, moderate difficulties as 2, and severe as 3. The modal level of learning disability was moderate (2).

The physical dependency needs of the children were measured using the Bedfordshire Dependency Checklist (Conduit, 1982) which measures an approximate care time for the child, in terms of physical needs, in minutes per day (see below in section 2.4.7.) (see APPENDIX 8). The mean daily care time for physical needs obtained on this checklist was 41.5 minutes (sd. 34.7).

#### 2.2. Pilot study

Two preliminary interviews were carried out, including parents' completion of the selected self-report measures (see below in section 2.4.). The purpose of these two interviews was primarily to provide the author with an opportunity to evaluate the effectiveness of a modified Camberwell Family Interview (CFI) in terms of eliciting attitudes and feelings regarding the child, in a low-key informal manner. Minor modifications were made to the interview used in the main study as a result of this pilot study. Otherwise, in spite of the

brevity of this pilot investigation, the modified CFI (see APPENDIX

2) was considered a viable tool with which to elicit EE status in the population under investigation.

## 2.3 Design

A between-subjects design was used, comparing emergent HEE and LEE groups on the demographic and key variables in the study at one time only. The key variables are as follows: child behavioural disturbance, parental stress, parental coping and service usage. A comparison between groups regarding respite care usage was carried out on a post hoc basis, as was a comparison between groups in terms of types of child behavioural disturbance. Children in HEE and LEE households were also compared with regards to their level of intellectual functioning and their dependency needs. Further information regarding the key variables and the latter two child-related variables can be found in section 2.4. below.

The predictive utility of EE was assessed post hoc within a regression design.

#### 2.4. Measures

## 2.4.1. Expressed Emotion

Expressed Emotion was assessed using an abbreviated and modified version of the standardized, semi-structured Camberwell Family Interview (CFI) (Vaughn & Leff, 1976) (see APPENDIX 2). The interview allows the flexible use of standard questions and probes, and encourages an interviewer to listen to information as it emerges. The interviews each took approximately one hour to administer and were audiotaped for subsequent rating. There are five unipolar scales on the CFI (Leff & Vaughn, 1985, ch.3):

 Critical comments indicating unambiguous resentment, disapproval or dislike of particular behaviours, or of the personality of the person to whom it refers. Criticisms may be evident in the content of the comment alone, but they are principally evident in the pitch, speed and inflection imparted to the statement, by the person making it;

- Hostility expressed towards the person rather than the behaviour, in the form of a generalized criticism or a frankly rejecting remark;
- 3) Emotional overinvolvement (EOI), indicated by several forms of reported behaviour, including exaggerated emotional response in the past, unusually self-sacrificing behaviour and extremely overprotective behaviour. It is assumed that a degree of overconcern is not unusual, particularly in response to serious illness or disability in the family this scale refers to an excess;
- Warmth based on sympathy, affection and empathy, evident in the tone of voice and spontaneity of the remarks,
- 5) Positive remarks, indicated by expressions of praise, approval or appreciation of the behaviour or personality of the person to whom it refers. Positive remarks are defined primarily by their content, although tone may be used to clarify the content.

Critical comments and positive remarks consist of frequency counts of all such comments occurring during the interview. Hostility (rated as 1,2 or 3), emotional overinvolvement (rated 0-5) and warmth (rated 0-5) are measured on global scales which involve an overall judgement about the degree to which the emotion was shown, taking into account the interview as a whole.

In the present study all five scales were rated. In addition, the Vaughn & Leff (1976) criteria for HEE were used, so that parents were classified as HEE if they: a) made 6 or more critical comments in the interview, and/or, b) displayed a hostile attitude towards the child i.e. a rating of 1 for generalized criticism alone, or

2 for rejection alone, or 3 for both generalized criticism and rejection, and/or c) showed marked emotional overinvolvement, i.e. a rating of 3 or above. Otherwise, parents were rated as LEE.

The emotional overinvolvement (EOI) scale represents the scale which is potentially most influenced by both the type of relationship considered, i.e. parent and child versus husband and wife, and in addition, the condition under investigation. current study, the original indicators of EOI (Vaughn & Leff, 1976) were found to be applicable to parents of learning disabled children. Marked EOI (i.e. 3 or above) was rated according to the criteria outlined on the previous page, and in addition, where there was evidence from the parents' reports that level of care or supervision was disproportionate to the level of the child's independence. Thus, by way of example, if the parent reported that the child was capable of attending to his/her own washing and dressing needs but still had them done for them by the parent, this might be rated for infantilization, depending on the context in which the reported assistance occurred. Clearly, however, comparisons with other populations with regards to emotional overinvolvement are limited. This reflects a general concern with the rating of EOI in EE research.

2.4.1.1. Modifications to the CFI were made to render it relevant for families of children with learning difficulties and behavioural problems. Modifications were kept to a minimum in order to preserve the validity of the interview insofar as it was possible. In making modifications to the CFI, this study is consistent with other studies applying EE to conditions other than schizophrenia. Since the modifications made were minimal, the author does not provide data concerning the reliability and validity of the modified interview. Effective verification of the reliability and validity of the interview is beyond the scope of the current study.

Vaughn & Leff's (1976) abbreviation of the original CFI (Brown et al., 1972) demonstrated that certain sections of the interview required greater priority than others. The three sections of the interview which concern Psychiatric History, Irritability and Quarrelling and Clinical Symptoms in the three month pre-admission period, accounted for 67% of the total number of critical comments in a sample of 15 interviews carried out during Brown et al.'s (1972) study. These three sections were therefore given priority in the current study but included relevant modifications. The eight sections included in the modified CFI are described below.

Prior to beginning the main interview, questions were asked relating to the demographic characteristics of the families and to issues such as when the parents found out that their child was learning disabled and the degree of intellectual and social functioning of the child (Section 1). The aim of this section was primarily to enhance rapport between the author and the parents, in order to facilitate a more reliable expression of feelings and attitudes on the parents' part. Information pertaining to demographic characteristics was also gathered for use in subsequent descriptive and inferential statistics.

The first section on Psychiatric History in the three month pre-admission period was replaced by a section on how the child had been in the previous three months with specific reference to their behaviour (Section 2). The section on Family Time Budget (Section 3) was administered with minimal modifications to the CFI. Relevant additions included the use of respite care and the child's degree of self-care skills.

The Irritability and Quarrelling section was abbreviated and focused principally on the two CFI sub-sections concerning occasions of and triggers to irritability in the child, and in addition reasons for the parent "nagging and grumbling" at the child (Section

4). Irritability with other family members was only superficially investigated, the main emphasis being on the parent-child dyad.

The second section on Psychiatric History or Clinical Symptoms in the CFI was replaced by a section on the child's behavioural history (Section 5). This included the majority of the areas of psychopathology covered in the original CFI section on Psychiatric History (Brown et al., 1972; Vaughn & Leff, 1976). The section on Household tasks was included only when it was relevant in terms of the child's abilities (Section 6). Questions pertaining to the relationship between the parent and the child (Section 7) were administered with minimal modifications to the CFI. Questions addressing the impact of the child on the parent and family's life, and the most disturbing aspect of the child's difficulties, were administered according to the wording in the CFI (Section 8). This last section also included a question regarding parents' perceptions of their child's future.

The sections on the Marital Relationship, Money Matters, Clinical Symptoms specific to schizophrenia and Medication were omitted. Furthermore, these sections have been found to contribute only minimally to final EE status.

The CFI was designed to elicit two types of information, objective and subjective information. The rating scales in the CFI, which can be used to obtain relatively objective information regarding the offspring or spouse's behaviour and symptoms etc., were omitted in the current study. This represents an acceptable use of the CFI and is suggested as an option in the training course.

The current study focused on the elicitation of parental subjective attitudes towards, and feelings about their children. Standard CFI probes were therefore employed e.g. regarding legitimacy of behaviours, reactions to the behaviours, and frequency and severity of behaviours, but with the intention of eliciting attitudes and feelings rather than accounts of frequency etc.

The author adhered to the interviewing techniques stipulated in the administration of the CFI (Leff & Vaughn, 1985, ch.2). Such techniques include avoiding leading questions, and limiting probes such as "How do you feel about that?", which arguably "milk" a relative for HEE, to a total of three or four for the entire interview. In addition, flexibility of questioning and coverage of topics is encouraged, in order to facilitate establishing a low-key, informal interview. Flexibility is also required to adapt to idiosyncratic response styles amongst individuals in order to elicit genuine attitudes and feelings.

In summary, the author made relevant modifications to the CFI, with the primary intention of delivering a flexible, semi-structured interview which allowed the parents to talk about their attitudes towards, and feelings about their children. The emphasis was on flexibility, within the broad framework of the CFI, but with adherence to recommended interviewing techniques, and standardized post-interview rating techniques.

- 2.4.1.2. Author's EE reliability In order to qualify as an EE rater the author undertook a training course of 10 days (with Christine Vaughn). The author achieved satisfactory reliability with trained criterion raters on mastertapes previously rated from earlier EE studies. The author's reliability was assessed by Vaughn using the Phi coefficient and the Pearson Product Moment and Spearman Rank-Order correlations. The author's reliability for overall EE status and for the five component scales is as follows: overall EE 1.00; Critical Comments 0.88; Emotional Overinvolvement 1.00; Hostility 0.85; Warmth 0.94 and Positive Comments 0.94. (see APPENDIX 3).
- 2.4.1.3 EE inter-rater reliability A random sample of 12 interviews were re-rated by three independent raters, two of whom had achieved reliability on an EE training course. The third rater was untrained

but was given copies of the instructions which the author herself had been given on the training course, in order to rate the interviews on the five separate scales. The latter rater was also provided with three practice tapes. The use of untrained raters has proved to be reliable (Hooley & Richters, 1991). The independent raters were all blind to data pertaining to parental and child characteristics and to the study's hypotheses. The Phi coefficient and Pearson Product Moment and Spearman Rank-Order correlations were employed to assess inter-rater reliability. The reliability for overall EE and for the five EE scales is as follows: overall EE 0.84; Critical Comments 0.86; Emotional Overinvolvement 0.84; Hostility 0.82; Warmth 0.66; Positive Comments 0.75.

### 2.4.2 Behavioural disturbance

The children's behavioural disturbance was assessed using the recently developed Checklist of Challenging Behaviours which was devised for a research project at the Norah Fry research centre in Bristol (Harris, et al., 1989. Unpublished) (see APPENDIX 4).

The Checklist assesses behavioural disturbance in learning disabled individuals of all ages, in terms of frequency of occurrence, management difficulty and severity, over the previous three months. These three aspects of behavioural disturbance are rated on a five point scale. Severity is assessed only with regards to aggression to others and self-injury.

Very few valid and reliable instruments exist for the assessment of behavioural disturbance in people with learning difficulties. The appeal of the Checklist is its provision of objective definitions for each rating scale. "Moderate injury" on the severity scale for example, is defined as: "caused moderate tissue damage to other person (e.g. bites/hits or kicks breaking the skin or resulting in bruising). First aid but not medical attention needed". Moreover, "often" on the frequency scale is defined as "more than 4 times in the

past month". These definitions feasibly reduce distortion produced by subjectivity and retrospective recall.

Harris et al. (1989) have demonstrated satisfactory reliability with the Checklist. Overall inter-rater reliability (same interviewer, same disabled person but different informant) on the three scales was calculated to be 76%; between interviewer reliability (same informant but different interviewers) was calculated to be 84% on the three scales, and test-retest reliability was 82%. In addition, the Checklist appears to have high content validity and there is evidence to support its construct validity. No firm evidence has yet been obtained to support or reject its concurrent validity. This is a reflection both of the dearth of reliable means of assessing behavioural disturbance in the learning disabled population, and also of the difficulty in obtaining reliable professional records of behavioural disturbance. No further normative data is currently available to report.

In the current study, the three scales of the Checklist, namely Frequency, Management Difficulty and Severity, were found to be strongly related to one another. The strength of the relationships between these scales was found to range between r=.79; p<.001, and r=.93; p<.001. In order to avoid the problem of multicollinearity in subsequent analyses, it was decided to create a single measure of behavioural disturbance based on the cumulative scores on the three scales.

Severity scores are rated only for aggressive and self-injurious behaviours. Their inclusion in the cumulative score was justified, however, on the basis that the cumulative ratings for these items, obtained from Frequency, Management Difficulty and Severity scores, are satisfactorily related (r = .65, p< .001) to cumulative ratings for items in the rest of the Checklist based on scores of Frequency and Management Difficulty. It was therefore considered unlikely that the inclusion of severity would distort a composite score of behavioural disturbance. To validate this statement further,

no notable differences were revealed when severity was either included or excluded from a composite measure of behavioural disturbance in all relevant analyses in Chapter 3 (RESULTS). Severity was therefore retained, in order to provide a more complete measure of behavioural disturbance.

In the sample selection phase, teachers assessed the children using the Checklist. The reliability of the relationship between 15 randomly selected teachers' ratings and the corresponding 15 parental ratings was r= .62 p<.01. This was considered satisfactory given that the teachers were rating the children's behaviour generally, and some degree of contextual variation in behaviour would be expected between school and home. Verification of parents' subjective reports of behavioural disturbance was considered important in the light of evidence that parental perceptions of children's behaviour can be distorted as a result of parental psychological distress (Brody & Forehand, 1986).

2.4.2.1. Behavioural sub-categories Post hoc, it was considered worthwhile to examine the relationship between EE and the different types of behavioural disturbance included in the Checklist, in order to avoid losing valuable information by focusing solely on a composite measure of behavioural disturbance. To this end, the author collapsed behaviours into categories based on their similarity in type and not on any specific theoretical model.

Eight different types of behavioural disturbance were derived from the Checklist: aggression; self-injurious behaviour; destruction towards property; anti-social behaviour; rituals and stereotypies; problems with compliance; social withdrawal and night-time disturbance. Similar to overall behavioural disturbance, correlations of above 0.80 between the scales of frequency, management difficulty and severity in the case of aggression and self-injury (calculated together), and between frequency and management difficulty for the remaining categories, recommended the use of cumulative scores for the categories. The reader may refer to the copy of the Checklist in APPENDIX 4 to see how specific behaviours have been categorized with number coding. Self-injurious behaviour, social withdrawal and night-time disturbance represent single items in the Checklist, but it was considered appropriate to maintain them as separate categories.

The presence of three categories based on single items, and the varying sizes of the other categories suggested the benefits of converting all the categories into dichotomous variables. To this end, scores in the three single item categories were coded as 0 if the behaviour was absent and 1 if it was present. The medians for each of the five remaining categories were obtained, and scores were coded as 0 if they fell below the median and 1 if they were above the median. A score of 0 denoted low rates of the specific behaviour, and 1, high rates of the behaviour.

An independent rater was provided with the above eight categories and a copy of the Checklist, and requested to assign behaviours to one of the categories. The agreement between the author and the independent rater was 100%.

#### 2.4.3. Stress

Parental stress was assessed using the Malaise Inventory (Rutter et al., 1970) (see APPENDIX 5) which is self-administered and well standardized from wide usage. The Malaise Inventory has had particularly wide usage in research concerning the impact that a child with learning difficulties has on parental psychological well-being. The Inventory is based on the Cornell Medical Index and has met adequate standards of validity and reliability in a number of studies (Bradshaw & Lawton, 1978; Hirst & Bradshaw, 1983; Rutter et al., 1970; Tew & Lawrence, 1975). The Inventory consists of 24 questions about physical or emotional states which have an important psychological component. Each question requires a yes/no response.

The total number of questions answered affirmatively is taken as the malaise score. Rutter et al. (1970) suggested that scores of greater than 5 or 6 can be considered as outside the normal range and as evidence of stress.

### 2.4.4 Coping

Parental coping was assessed using the Coping Health Inventory for Parents (CHIP) (McCubbin, McCubbin, Nevin & Cauble, 1979) (see APPENDIX 6). This self-administered inventory comprises a Likerttype scale with 45 items, and identifies three separate coping patterns: I: "Maintaining family integration, cooperation and an optimistic definition of the situation"; II: "Maintaining social support, self-esteem and psychological stability", and III: "Understanding the (medical) situation through communication with other parents and consultation with (medical) staff". The latter pattern also measures the parent's development of knowledge about difficulties with their child through reading. The Inventory was developed in order to assess parents' perceptions of their response to the management of family life when they have a child member who is seriously and/or chronically ill. It was hypothesized in the development of the instrument that families possessing a larger repertoire of coping behaviours would manage the situation of the chronically ill child more effectively.

The Inventory has been satisfactorily validated against criterion measures of improvements in the child's health, and dimensions of the family environment, amongst parents of children with cystic fibrosis (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983). Furthermore, reliabilities of 0.79, 0.79 and 0.71, respectively, for the above three coping patterns, were obtained when Cronbach's alpha was computed for the items on each coping pattern. Normative data from the McCubbin et al. (1983) study is as follows: means of 40 (sd. 15), 28 (sd. 12) and 15 (sd. 7) were

obtained for mothers, and means of 36 (sd. 20), 25 (sd. 15) and 12 (sd.8) for fathers, for the three coping patterns, respectively.

Researchers using the Inventory with parents of a learning disabled child (e.g. Flynt & Wood, 1989) have made minor modifications to the third coping pattern addressing the educational as opposed to the medical situation. Minor modifications were made in the current study in order to address understanding difficulties in the management of the child and consultation with relevant professionals. Cronbach's alpha was computed for the items in this coping pattern for all parents in the sample, in order to assess the reliability of these modifications. A reliability coefficient of 0.80 was produced. Therefore, the modifications can be considered satisfactorily reliable. Minor modifications were also made in the first coping pattern in order to render wording relevant for learning disabled children as opposed to medically ill children. Cronbach's alpha was similarly computed for items in this pattern for all parents in the sample, producing a reliability coefficient of 0.82. Modifications to this coping pattern can also therefore be considered reliable. The reworded questions for these two coping patterns can be found in APPENDIX 6.

### 2.4.5. Service utilization

Service utilization pertaining to the needs of the learning disabled children, was assessed using a comprehensive list of services compiled by the author (see APPENDIX 7) and guided by that used in the Dossetor (1991) study. The parents were required to record the number of face-to-face contacts with each of the services over the previous three months. A three month period was selected in order to provide consistency with both the CFI period and the behavioural checklist employed. Three months were considered long enough for established patterns of service usage to emerge, but short enough to allow satisfactorily accurate retrospective recall.

In subsequent statistical analyses the items on the list pertaining to the use of toy libraries and voluntary agencies (excluding those listed for respite care) were omitted, since factors such as the children's age, and knowledge about and accessibility to the services emerged as possible confounding influences. In addition, use of playgroups during the holiday was also omitted, since the timing of interviews meant that the rating of service contacts for some parents was inflated by this item, whilst for other parents there was no overlap with the school holiday period in their ratings. Finally, items pertaining to occupational therapy, speech therapy and physiotherapy were not rated by parents, unless such professional input took place in the family home. Organization of such therapeutic input at school feasibly confounded parental requests and need, and school staff recommendations.

The face validity of the list was confirmed by the fact that only one parent out of the 40 in the main study added a service not included. Test-retest reliability was established by asking one in four of the parents to complete the list on a second occasion 10 days after they had first completed it. Only eight of the parents returned the second checklist. The reliability obtained, however, was 93% (Spearman's r = .93, p < .001). Despite the small numbers, this indicates that the recording of service contacts in this way by parents represents an adequately reliable means of assessing service usage.

### 2.4.6. Children's level of intellectual functioning

The children's level of intellectual functioning was categorized, using categories 2, 3 and 4 of the World Health Organization ICD9 (1980) classification of mental retardation, i.e. excluding profound mental retardation. These categories were rated as 3, 2 and 1, respectively, in the current study (see section 2.1.3.).

- "Individuals who may respond to skill training in the use of legs, hands and jaws". (Intellectual Impairment Number 10: profound mental retardation, IQ < 20).</li>
- "Individuals who can profit from systematic habit training".
   (Intellectual Impairment Number 11: severe mental retardation. IQ 20-34).
- 3) "Individuals who can learn simple communication, elementary health and safety habits, and simple manual skills, but do not progress in functional reading or arithmetic". (Intellectual Impairment Number 12: moderate retardation. IQ 35-49).
- 4) "Individuals who can acquire practical skills and functional reading and arithmetic abilities with special education, and who can be guided towards social conformity". (Intellectual Impairment Number 13: mild mental retardation. IQ 50-70).

Assessment of the children's level of intellectual functioning was made by the author on the basis of information extracted from the CFI. An independent rater assessed a randomly selected 15 of the children based on synopses of this information provided by the author, e.g. "X has no speech. Communication is made with a limited repertoire of Makaton signs. No progress has been made with regards to reading etc. at school. Gross motor coordination is good, but finer coordination is poor. X is very sociable". Inter-rater agreement was found to be 73%. When assessed using the Kappa statistic, the agreement was 53% after correcting for chance.

Since an association between degree of intellectual disability and degree of dependency needs is acknowledged in the literature (e.g. Carr, 1985; Mink et al., 1988) such a comparison was considered relevant in the current study, in order to further validate the method for rating level of intellectual functioning. The association between children's level of intellectual functioning and their level of physical dependency was assessed by converting scores

on the Bedfordshire Dependency Checklist (see below in section 2.4.7.) into discontinuous data. Scores in the lower 25% were coded as 1, scores in the middle 50% as 2, and scores in the top 25% as 3. A significant association was found between level of intellectual disability and level of dependency needs using Chi-square (Chi-square (2) = 19.48, p<.001), although the association was only moderately strong (Cramer's V= .49 p<.001). The strongest association between level of intellectual functioning and dependency was found for the mildly learning disabled children, of whom, 100% were rated as low in dependency (i.e. scores in the lower 25%). Thus, the ratings for intellectual disability can be considered moderately reliable in this study.

The primary reason for rating the children's intellectual functioning was to permit future comparisons with other studies. The author defends her decision not to assess intellectual functioning more rigorously, since assessments of intellectual functioning become notoriously more unreliable with increasing severity of learning disability. The author acknowledges the crude nature of this assessment and the limited use of such data. Categorization of the children does, however, provide an indication of the spread of intellectual impairment in the sample.

### 2.4.7. Children's dependency needs

Dependency needs of the children were assessed using the Bedfordshire Dependency Checklist (BDC) (Conduit, 1982) (see APPENDIX 8). The score obtained on the Checklist represents the "dependency" in minutes per day. An inter-rater reliability score of 0.92 has been reported with the dependency sub-sections which comprise the first section of the Checklist. In addition, both the predictive and concurrent validity of the measure have been established in four hospital wards (Conduit, 1982).

#### 2.5. Procedure

All parents who took part in the main study gave their consent verbally via the telephone. Prior to this telephone contact, parents had given written consent for the author to make contact with them following the assessments of the children at school (see APPENDIX 1). The telephone contact was unpressured for the parents, and allowed parents to ask questions. Parents were informed during this telephone contact that they would be able to withdraw their consent at any time prior to or during the procedure. The author offered her telephone number to the parents. All parents who participated were enthusiastic to assist in research concerning families in a similar position to themselves.

Parents who agreed to participate in the main study were visited in their homes, at their choice, by the author, on one occasion only. Parents were required to complete all of the self-report measures outlined above. This was followed by the interview which was audiotaped for subsequent rating with the permission of the parents. Parents were informed that the author wished to audiotape the interview prior to the agreement to participate in the research. Length of the interviews varied between approximately 30 minutes and one hour and 15 minutes. At the end of the interview the author ascertained from parents whether any unmet needs had emerged during the interview, and moreover, if they were satisfied regarding knowledge of existing services. None of the parents who participated in the study made any requests for further information regarding services.

Parents who had participated were contacted once all the data had been collected to thank them for their participation, and to tell them once again briefly about the research (see APPENDIX 9).

### 2.6 Ethical Approval

The author obtained ethical approval from the two healthcare trusts in which the research was carried out (see APPENDIX 10). In addition, consent to carry out the research was obtained from the Education Department of the local County Council.

#### 2.7 Statistics

Data was analysed using the computerized statistical package SPSS/PC+ version 4.0.1..

The independent t-test, Mann-Whitney U, and Chi-square, with the Phi and Cramer's V coefficients were used where appropriate, in order to compare groups for the different demographic variables, including the children's level of intellectual functioning and dependency needs. The Phi and Cramer's V coefficients were used to assess the strength of association between discontinuous demographic variables and level of EE. One-tailed independent t-tests were used to test the a priori hypotheses with EE as the grouping variable. A Mann-Whitney U was employed to compare HEE and LEE groups with regards to the use of respite Chi-square with Phi coefficients were used post hoc, to investigate the association between behavioural categories and EE, and the strength of association, respectively. Univariate group comparisons were followed by a direct discriminant function analysis in order to determine the best discrimination between HEE and LEE parents. The relationships between key variables in the study, namely, behavioural disturbance, stress, coping, and service usage, and in addition, respite care usage, critical and positive comments and warmth, were assessed with the Pearson Product Moment and Spearman Rank-Order correlations. The strength of the relationship between EE and key variables was assessed using the Eta statistic. Finally, a stepwise multiple regression was used on a post hoc basis to evaluate the predictive utility of EE.

#### CHAPTER 3: RESULTS

### 3.1. Screening of data

The statistical analyses described below include all 40 cases, there were no missing data in the key variables, nor were any cases deleted.

Prior to any statistical analyses, the key variables under investigation were examined through various SPSS/PC+ programmes in order to assess the fit between their distributions and the assumptions of univariate and multivariate normality.

Normality of distribution was assessed for each of the variables. Transformations of variables were kept to a minimum to avoid ambiguity in the interpretation of results, and were only applied where skewing and kurtosis were marked. These deviations from normality were inspected using histograms and stem and leaf plots. Square root transformations were carried out on the Malaise Inventory (measuring stress) and the BDC.

Since pairwise comparisons between variables for both grouped and ungrouped data would have been a time-consuming task in testing for linearity and homoscedasticity, statistics on skewness and kurtosis were used to screen for pairs which were likely to depart from both these assumptions. As was described above, the appropriate transformations were carried out where necessary.

Finally, variables were examined for univariate and multivariate outliers using boxplots and Mahalanobis' distance with p<.001, respectively. No multivariate outliers were identified in any of the relevant analyses. Univariate outliers were checked for both grouped and ungrouped data. Very few outliers overall were identified and any occurring in grouped data were also evident in the ungrouped data. Since the occurrence of outliers was rare, with two representing the greatest number of outliers in any variable, the outliers were dealt with by changing their score to one unit greater

or smaller than the next most extreme score in the distribution for ungrouped data (Tabachnick & Fidell, 1989, p.70).

Additional data-screening strategies specific to statistical analyses employed, are described where relevant in this chapter.

### 3.2. Descriptive statistics

Table 1. below displays the mean and standard deviation from the mean for the key variables in the study, i.e. behavioural disturbance, stress, coping and service usage, and in addition, respite care usage, for ungrouped and grouped data.

With regards to parental stress, as measured by the Malaise Inventory, since this variable was subjected to a square root transformation, reference will be made to the untransformed means and the medians, the latter offering a more reliable measure of central tendency in these circumstances. The ungrouped mean (5.95) and median (5.00) lie above and at, respectively, the cutoff of 5 to 6 suggested by Rutter et al. (1970), as evidence of stress. The grouped means and medians place HEE parents above this cutoff (mean 8.11 and median 7) and LEE parents below the cutoff (mean 4.35 and median 4).

With regards to the three coping patterns, the means obtained for ungrouped data in the current study closely approximate those obtained for the normative data (40, 28, 15 for the three patterns, respectively) with mothers of children with cystic fibrosis (McCubbin et al., 1983). Moreover, the means for grouped data show that HEE parents consistently fall beneath these normative means for all three coping patterns, whereas LEE parents' means are equal to or above the normative means. Since 39 out of the current sample of 40 are mothers (principally biological, but also foster) it seems appropriate to compare ungrouped and grouped means obtained with maternal normative data. The reader may refer to section 2.4.4 in Chapter 2 for norms for fathers.

| Variable    |       | Mean  |        | Standard<br>deviation |        |
|-------------|-------|-------|--------|-----------------------|--------|
| Behaviour:  | Total | 78.42 |        | 51.09                 |        |
|             | HEE   | 90,71 |        | 69.46                 |        |
|             | LEE   | 69.35 |        | 30.25                 |        |
| Stress:     | Total | 5.95  | (2.31) | 4.06                  | (0.80) |
|             | HEE   | 8.11  | (2.74) | 4.57                  | (0.80) |
|             | LEE   | 4.35  | (1.99) | 2.79                  | (0.65) |
| Coping I:   | Total | 38.55 |        | 9.39                  |        |
|             | HEE   | 35.71 |        | 10.21                 |        |
|             | LEE   | 40.65 |        | 8.35                  |        |
| Coping II:  | Total | 28.42 |        | 10.78                 |        |
|             | HEE   | 25.12 |        | 10.71                 |        |
|             | LEE   | 30.87 |        | 10.40                 |        |
| Coping III: | Total | 16.42 |        | 5.40                  |        |
|             | HEE   | 13.82 |        | 5.78                  |        |
|             | LEE   | 18.35 |        | 4,28                  |        |
| Services:   | Total | 14.27 |        | 9.99                  |        |
|             | HEE   | 11.76 |        | 10.71                 |        |
|             | LEE   | 16.13 |        | 9.21                  |        |
| Respite:    | Total | 4.45  |        | 6.81                  |        |
|             | HEE   | 4.70  |        | 7.31                  |        |
|             | LEE   | 4.26  |        | 6.58                  |        |

Table 1. Mean and standard deviation from the mean for the key variables, and including respite care usage, for ungrouped and grouped data. (Bracketed values) provide the mean and standard deviation from the mean for the transformed variable.

Normative data is not available for comparison with regards to behavioural disturbance, since a composite measure of disturbance is employed in the current study. Data with regards to service utilization and respite care were obtained from a checklist devised for the current study, and hence normative data is also not available.

### 3.3 EE components and HEE sub-groups

Summary statistics for critical comments, positive comments and warmth are displayed in Table 2. below. These statistics are not provided for hostility, since 80% of the entire sample did not express hostility. Nor are these statistics provided for emotional overinvolvement (EOI), since only three individuals in the sample received a rating of marked EOI, i.e. 3 or above. Scores below 3 are not considered useful in terms of level of EE. In contrast, whilst the cutoff for critical comments is usually set at 6, this has been manipulated, in some studies, in rating EE (e.g. Vaughn & Leff, 1976). Therefore it is useful to consider the difference between HEE and LEE groups with regards to descriptive statistics.

| Variable  |       | M    | ( <b>x</b> ) | sd   |
|-----------|-------|------|--------------|------|
| Critical: | Total | 4.00 | 4.80         | 3.92 |
|           | HEE   | 7.00 | 7.65         | 4.33 |
|           | LEE   | 3.00 | 2.70         | 1.64 |
| Positive: | Total | 3.00 | 3.42         | 2.37 |
|           | HEE   | 2.00 | 3.53         | 2.43 |
|           | LEE   | 3.00 | 3.35         | 2.39 |
| Warmth:   | Total | 3.00 | 3.12         | 0.82 |
|           | HEE   | 3.00 | 3.26         | 0.75 |
|           | LEE   | 3,00 | 2.94         | 0.89 |

Table 2. Median (M), mean (x), and standard deviation (sd) for critical comments, positive comments and warmth.

Sub-groups of HEE were considered too limited in size to enable meaningful conclusions to be drawn from comparisons. Of the 17 parents rated as HEE (42.5% out of the 40 parents), eight were so rated on the basis of both 6 or more critical comments and the presence of hostility (47%), six on the basis of 6 or more critical comments (35%), and three on the basis of EOI alone (18%). Out of the 47% of HEE parents who expressed criticism and hostility, 62.5% expressed hostility in the form of generalized criticism, and 37.5% in the form of both generalized criticism and rejecting remarks.

It was considered valuable to compare HEE and LEE parents for warmth and positive comments. To this end, a Mann-Whitney U was carried out to compare HEE and LEE parents on the amount of warmth directed towards their children during the interview. No significant difference was found (U = 150.0, p>.20; two-tailed). Similarly, no significant difference was found when the number of positive comments HEE and LEE parents had made during the interview was compared (t (38) = .24, p>.80; two-tailed).

### 3.4 Association between EE and demographic and selected child descriptor variables

Table 3. below displays relevant descriptive statistics for demographic and child descriptor variables for HEE and LEE parents. The reader may refer to section 2.1.3. for descriptive statistics for ungrouped data.

Demographic characteristics The ages of parents and children in the HEE and LEE groups were compared with independent t-tests. No significant differences were found between the two groups for either mothers' or children's ages (t (38) = 1.83, p>.075; two-tailed, and t (38) = 1.55, p>.10; two-tailed, respectively).

A series of Chi-squares was carried out to evaluate the degree of association between relevant demographic variables and level of EE. A Phi coefficient was included to demonstrate the

strength of the association in 2 x 2 tables, and Cramer's V for 2 x 3 tables.

There was no significant association between gender of the children and level of parental EE (Chi-square (1) = .35, p>.50) and the association was weak (Phi = .09, p>.50). Similarly, there was no significant association between whether a parent was employed or not, and level of EE (Chi-square (1) = .85, p>.30; Phi = .15, p>.30). The results indicate overall low levels of outside employment amongst HEE and LEE parents. A child's ordinal position in the family was not associated with parental EE (Chi-square (1) = .27, p>.80; Cramer's V = .08, p>.80).

In contrast to the above findings, a significant association was found between whether a parent was married or not and level of EE (Chi-square (1) = 5.91; p< .02; Phi = .38, p<.02). Of the single mothers in the sample, 77.8% received a HEE rating.

The socioeconomic status of the HEE and LEE groups was compared with a Mann-Whitney U test, yielding no significant difference (U= 164.5, p>.40; two-tailed). Similarly, size of family and the number of siblings were compared for the two groups. No significant differences were found (t (38) = .77, p>.40; two-tailed, and t (35) = .95, p>.30; two-tailed, respectively).

Child descriptor variables No association was found between level of a child's intellectual functioning and parental EE (Chi-square (2) = .63, p>.70; Cramer's V = .12, p>.70).

Level of physical dependency of the children was compared for HEE and LEE groups and also demonstrated no significant difference between the two groups (t (38) = 1.12, p>.20; two-tailed). Visual inspection of the medians for the two groups (see Table.3.) demonstrates higher dependency in the LEE group as compared to the HEE group (33 and 23, respectively). This variable had been

subjected to a square root transformation, and therefore, the median was considered a more reliable measure of central tendency.

| Variable         |                         | HEE           | LEE           |  |
|------------------|-------------------------|---------------|---------------|--|
| Demographic va   | ariables:               |               |               |  |
| Mother's age:    | mean (sd.)              | 41.07 (6.58)  | 37.04 (6.15)  |  |
| Child's age:     | mean (sd.)              | 11.43 (4.25)  | 9.30 (4.67)   |  |
| Child's gender:  | female                  | 47.1%         | 56.5%         |  |
|                  | male                    | 52.9%         | 43.5%         |  |
| Parent employe   | d: yes                  | 17.6%         | 30.4%         |  |
|                  | по                      | 82.4%         | 69.6%         |  |
| Ordinal position | n: mode                 | 3.00          | 3.00          |  |
| Marital status:  | yes                     | 58.8%         | 91.3%         |  |
|                  | no                      | 41.2%         | 8.7%          |  |
| Socioeconomic    | status: median          | 15.00.        | 19.00         |  |
| Family size:     | mean (sd.)              | 4.71 (1.20)   | 4.56 (1.20)   |  |
| Siblings:        | mean (sd.)              | 2.00 (1.04)   | 1.65 (1.11)   |  |
| Child descripto  | r variables:            |               |               |  |
| Child's IQ:      | mode                    | 2.00          | 2.00          |  |
| % of:            | mild                    | 17.6%         | 13.0%         |  |
|                  | moderate                | 58.8%         | 52.2%         |  |
|                  | severe                  | 23.5%         | 34.8%         |  |
| Dependency:      | mean (sd.)              | 37.23 (38.51) | 44.74 (32.03) |  |
|                  | median                  | 23,00         | 33.00         |  |
| Square root trai | nsformation: mean (sd.) | 5.29 (3.16)   | 6.26 (2.41)   |  |
|                  |                         |               |               |  |

Table 3. Descriptive statistics for demographic and child descriptor variables: means, standard deviations from the mean (sd.), medians, modes and percentages for HEE and LEE groups.

### 3.5. Testing of the hypotheses and post hoc analyses

The univariate and unidirectional nature of the four a priori hypotheses recommended the use of one-tailed independent t-tests to compare HEE and LEE groups. In order, however, to avoid an inflated Type I error rate due to multiple univariate testing, a stringent level of alpha (level of significance) was determined prior to the analyses. A Bonferroni type adjustment (see Tabachnick & Fiddell, 1989, p.399) was made to the level of alpha whereby each of the analyses in the four a priori hypotheses (i.e. excluding the post hoc hypothesis 5 regarding respite care, and other post hoc univariate analyses) was assigned a level of alpha prior to the analysis, so that the alpha for the set of six dependent variables in the analyses (behavioural disturbance, stress, three coping patterns and service usage) did not exceed 0.05. All six were assigned the same alpha level according to the following computation: alpha = 1 -(1 - alpha 1) (1 - alpha 2)....(1 - alpha x) etc.. The level of alpha was set at 0.0083 for each of the six dependent variables.

Table 5. below displays the results for these analyses. Tables 6. and 7. display the relationships between the variables examined in the hypotheses, and the relationship between the key variables in the study (excluding respite care usage) and EE, respectively. All correlations in Table 6. are one-tailed.

# Hypothesis 1: HEE parents will report greater frequency, management difficulty and severity of child behavioural disturbance than LEE parents

No significant difference was found between HEE and LEE parents in terms of a composite measure of the frequency, management difficulty and severity of behavioural disturbance reported for their children (t (38) = 1.32, p>.09; one-tailed). Heterogeneity of variance was, however, revealed by means of the F test (F = 5.27, p<.001). (The F test is provided by SPSS/PC+ when a t-test is

calculated). The t' value based on a separate variance estimate was therefore considered to represent a more reliable comparison of HEE and LEE groups. A finding of no significant difference between the two groups was maintained when the t' value was calculated for this separate variance estimate (t(20.51) = 1.19, p > .10; one-tailed).

substantial standard deviations behavioural disturbance obtained for both groups, particularly with regards to HEE parents, indicate some overlap between the two groups. Therefore, consistent with previous studies (e.g. Vaughn & Leff, 1976) which have attempted to discriminate between EE groups by manipulating the cutoff division for HEE and LEE in terms of critical comments, the cutoff was manipulated in the current study. An initial reduction to 5 critical comments produced no change in the result, neither did a reduction to 4 comments. Further reduction was not feasible due to the restricted sample size. Raising the cutoff for critical comments to 8 and then 10 comments, similarly produced no difference between the HEE and LEE groups in terms of behavioural disturbance. After 10 critical comments, the size of the HEE group was too small to allow further useful elevation of the cutoff. A cutoff of 6 critical comments was therefore retained. These attempts to manipulate the cutoff testify to the robustness of the finding of no significant difference between HEE and LEE groups, in the current sample, with regards to child behavioural disturbance.

An inspection of the relationship between the number of critical comments and behavioural disturbance in Table 6. below shows, however, that the number of critical comments is moderately, positively related to behavioural disturbance (r = .41, p<.01). Critical comments represent the main component of HEE both in this study, and in previous research, and therefore it was considered relevant to quantify this relationship further.

Since stress is also moderately associated with both critical comments and behavioural disturbance (r=.33 n.s., and r=.40, p<.01,

respectively) it was considered valuable to assess the strength of the relationship between critical comments and behavioural disturbance, partialling out the effects of stress. The relationship between critical comments and behavioural disturbance was weakened but remained significant, by controlling for stress (r=.32, p<.05), as was the relationship between stress and behavioural disturbance when the number of critical comments was partialled out (r=.30, p<.05).

Thus, the relationship between critical comments and behavioural disturbance is partly explained by the level of stress reported. This association between the number of critical comments and behavioural disturbance, although moderate in strength, questions, however, the validity of using a dichotomized EE index to differentiate between HEE and LEE groups regarding this variable.

Rehavioural subcategories A post hoc attempt was made to quantify further, levels of behavioural disturbance in the two groups. A series of Chi-squares was carried out in order to determine if specific types of behavioural disturbance were associated with level of parental EE. Eight different categories of behaviour were extracted from the Checklist of Challenging Behaviours: aggression; self-injurious behaviour; anti-social behaviour; destruction towards property; rituals and stereotypies; social withdrawal; problems with compliance and night-time disturbance (see section 2.4.3. in the METHOD for a description of how these categories were obtained).

Table 4. below shows the percentage of children in HEE and LEE households displaying high and low levels of aggression, antisocial behaviour, destruction towards property, rituals and stereotypies and problems with compliance, and in addition the presence or absence of self-injurious behaviour, social withdrawal and night-time disturbance.

The results from the Chi-squares are consistent with the result obtained for overall behavioural disturbance, and indicate no

significant association between level of parental EE and types of child behavioural disturbance. Phi coefficients obtained for each of the categories are similarly non-significant, and demonstrate a weak relationship between all the categories and level of EE.

| Behaviour     |         | HEE   | LEE   | Chi    | Phi  |
|---------------|---------|-------|-------|--------|------|
|               |         |       |       | (df 1) |      |
| Aggression:   | high    | 58.8% | 43.5% | 0.92   | 0.15 |
|               | low     | 41.2% | 56.5% |        |      |
| Anti-social:  | high    | 47.1% | 43.5% | 0.05   | 0.04 |
|               | low     | 52.9% | 56.5% |        |      |
| Destruction:  | high    | 52.9% | 26.1% | 3,01   | 0.27 |
|               | low     | 47.1% | 73.9% |        |      |
| Rituals and   |         |       |       |        |      |
| stereotypies: | high    | 41.2% | 43.5% | 0.02   | 0.02 |
|               | low     | 58.8% | 56.5% |        |      |
| Compliance    |         |       |       |        |      |
| problems:     | high    | 52.9% | 43.5% | 0.35   | 0.09 |
|               | low     | 47.1% | 56.5% |        |      |
| Self-injury:  | present | 58.8% | 56.5% | 0.02   | 0.02 |
|               | absent  | 41.2% | 43.5% |        |      |
| Withdrawal:   | present | 23.5% | 47.8% | 2.46   | 0.25 |
|               | absent  | 76.5% | 52.2% |        |      |
| Night-time    |         |       |       |        |      |
| disturbance:  | present | 47.1% | 65.2% | 1.32   | 0.18 |
|               | absent  | 52.9% | 34.8% |        |      |
|               |         |       |       |        |      |

Table 4. The percentage of children in HEE and LEE groups displaying: high and low levels of aggression, anti-social behaviour, destruction towards property, rituals and stereotypies and problems with compliance, and the presence and absence of self-injury, withdrawal and night-time disturbance, with Chi and Phi values.

# Hypothesis 2: HEE parents will report more stress than LEE parents

HEE and LEE parents' scores on the Malaise Inventory were compared. The result demonstrated that consistent with the hypothesis, HEE parents report more stress than LEE parents (t (38) = 3.31, p< .001; one-tailed). Table 7. shows that the relationship between EE and stress is moderately strong (Eta = .47, p<.01).

Table 6. below shows that stress is moderately and significantly positively related to behavioural disturbance (r = .40, p < .01). Furthermore, it is moderately and significantly negatively related to Coping Pattern I (r = -.41, p < .01), but only weakly and non-significantly, negatively related to Coping Patterns II. and III. (r = -.21, n.s., and r = -.15, n.s., respectively). Stress is weakly/moderately, positively related to service usage (r = .30, n.s.).

# Hypothesis 3: HEE parents will possess a more restricted repertoire of coping behaviours than LEE parents.

HEE and LEE parents' scores were compared for the three different types of coping pattern. All three coping patterns were found to have moderate/high relationships with one another (for I. and II. r= .69, p< .001; for II. and III. r= .56, p< .001; and for I. and III. r= .63, p< .001). Moreover, as has already been noted, Coping Pattern I. is moderately, significantly, negatively related to stress (r= -.41, p< .01). The relationships between these coping patterns and other variables in the study are otherwise uniformly weak.

# Coping Pattern I: Maintaining Family Integration, Cooperation and an Optimistic Definition of the Situation

HEE and LEE parents were not found to differ significantly on this coping pattern, with both HEE and LEE parents appearing to make similar use of coping strategies which centre around intra-familial

resources and maintaining a positive outlook (t (38) = -1.68, p > .04; one-tailed).

Coping Pattern II: Maintaining Social Support, Self-Esteem and Psychological Stability

Similar to the findings for Coping Pattern I. HEE and LEE parents were not found to differ significantly on this coping pattern. HEE and LEE parents appear to make similar use of coping strategies which involve efforts to develop relationships with others, engaging in activities which enhance feelings of individual identity and self-worth, and in addition, behaviours to manage psychological tensions and pressures (t (38) = -1.71, p> .04; one-tailed).

Coping Pattern III: Understanding Difficulties in the Management of the Child Through Communication with Other Parents and Consultation with Relevant Professionals

HEE and LEE parents were found to differ significantly on this coping pattern. HEE parents appear to make less use of support from other parents and relevant professionals than LEE parents, and in addition, fewer attempts to acquire knowledge and understanding of the difficulties they are experiencing in the management of their children (t (38) = -2.85, p< .003; one-tailed). Table 7. shows that the relationship between EE and this coping pattern is moderately strong (Eta = .42, p<.01).

Hypothesis 4: HEE parents will have more extensive face-to-face contacts with services pertaining to the needs of their learning disabled children than LEE parents

HEE and LEE parents were compared to determine if there was a significant difference in the number of contacts they had, had with services in the previous 3 months including respite care usage. No significant difference was found between the two groups (t (38) =

-1.38, p > .08; one-tailed). Visual inspection of the means obtained for the two groups (see Table 1.) demonstrates that in further contradiction of this hypothesis, the mean amount of service input for LEE parents is greater (16.13) than that for HEE parents (11.76).

Table 6. shows that parents' overall service usage is weakly related to most key variables in the study, with the exception of behavioural disturbance, with which it is moderately and significantly, positively related (r = .45, p < .01), and stress with which it is weakly/moderately but non-significantly, positively related (r = .30, n.s.). Of relevance, is the observation that stress is also significantly and positively related to behavioural disturbance (r=. 40, p<. 01). The moderate, significant, positive relationship between behavioural disturbance and service usage was maintained, although weakened, when stress was partialled out (r=.38, p< .05).

### Hypothesis 5: HEE parents will make greater use of respite care than LEE parents

On a post hoc basis, it was considered of value to compare HEE and LEE parents on the amount of respite care used in the previous three months. These figures were extracted from the list of services for each parent, and HEE and LEE parents were compared. Since 50% of the sample did not make use of respite care at all, the use of the Mann-Whitney U was considered the most suitable statistic for a group comparison. The result obtained revealed no significant difference between HEE and LEE parents in terms of their use of respite care (U = 194, p>.45; one-tailed).

The relationship between use of respite care and other key variables in the study is uniformly weak, with the obvious exception of overall service usage (r=.59, p<.001).

| Variable            | t' value | (dfs)  |  |
|---------------------|----------|--------|--|
| Behaviour           | 1.19     | (20.5) |  |
| Stress              | 3.31**   | (38)   |  |
| Coping Pattern I.   | -1.68    | (38)   |  |
| Coping Pattern II.  | -1.71    | (38)   |  |
| Coping Pattern III. | -2.85*   | (38)   |  |
| Services            | -1.38    | (38)   |  |
|                     |          |        |  |

<sup>\*</sup> p < 0.01 \*\* p<0.001

Table 5. One-tailed independent t' test results and degrees of freedom (dfs) with EE as the grouping variable.

| Variable                 | 1      | 2      | 3     | 4     | 5      | 6       | 7     | 8    | 9     | 10   |
|--------------------------|--------|--------|-------|-------|--------|---------|-------|------|-------|------|
| 1. Crit.                 | 1.00   |        |       |       |        |         |       |      |       |      |
| 2. Warmth†               | -0.24  | 1.00   |       |       |        |         |       |      |       |      |
| 3. Pos.                  | 0.15   | 0.39*  | 1.00  |       |        |         |       |      |       |      |
| 4. Behaviour             | 0.41   | -0.17  | -0.23 | 1.00  |        |         |       |      |       |      |
| 5. Stress                | 0.33   | -0.24  | -0.14 | 0.40* | 1,00   |         |       |      |       |      |
| 6. Cop.I.                | -0.11  | 0.04   | 0.28  | -0.18 | -0.41* | 1.00    |       |      |       |      |
| 7. Cop.II.               | -0.12  | 0.10   | 0.07  | -0.29 | -0.21  | 0.69‡   | 1.00  |      |       |      |
| 8. Cop.III.              | -0.26  | -0.05  | 0.16  | 0.07  | -0.15  | 0.63‡   | 0.56‡ | 1.00 |       |      |
| 9. Services              | -0.001 | -0.09  | -0.22 | 0.45* | 0.30   | 0.002   | -0.01 | 0.24 | 1.00  |      |
| 10. Respite <sup>†</sup> | 0.21   | -0.08  | -0.01 | 0.28  | 0.24   | -0.17   | -0.08 | 0.07 | 0.59‡ | 1.00 |
| * n < 0.01               | t.     | n<0.00 |       | +     | Snearr | nan'a D |       |      |       |      |

<sup>\*</sup> p < 0.01 ₹ p<0.001 T Spearman's R

Table 6. The relationships between the variables included in the hypotheses, and, in addition, critical comments (Crit.), warmth and positive comments (Pos.).

| Variable            | Eta   |  |
|---------------------|-------|--|
| Behaviour           | 0.21  |  |
| Stress              | 0.47* |  |
| Coping Pattern I.   | 0.26  |  |
| Coping Pattern II.  | 0.27  |  |
| Coping Pattern III. | 0.42* |  |
| Services            | 0.22  |  |

<sup>\*</sup> p < 0.01

Table 7. The relationship between EE and the key variables in the study with the Eta statistic.

It was considered valuable to extend beyond statistical inference and attempt to predict membership of the HEE and LEE groups from the set of key variables in the study, namely, behavioural disturbance, stress, coping (Patterns I., II. and III.) and total service usage in the previous three months.

To this end, a direct discriminant function analysis was carried out in order to determine a discriminant function which maximizes the separation of the two groups, and a classification function which reliably predicts group membership in EE. No attempt was made to establish the validity of the discriminant function obtained, by cross-validating the classification coefficients, thus limiting the possibility of generalizing the findings to populations other than the study's sample. The multivariate statistic Box's M confirmed homogeneity of variance-covariance matrices.

Table 8. below shows a significant Chi-square (Chi-square (6) = 24.54, p < .001), which confirms the reliability of the discriminant function. Thus although the two groups were not found to differ significantly except with regards to stress and Coping Pattern III., the significant Chi-Square, and the high classification accuracy

indicate that all six variables in combination contribute to a reliable discriminant function which maximizes the separation of the two groups. This suggests the existence of underlying and intercorrelated characteristics related to this set of predictors, which distinguish between the two groups. The loading matrix of correlations between predictor variables and the discriminant function in Table 8., suggests that the discriminant function primarily measures parental stress, in particular, and in addition, the third coping pattern which involves understanding difficulties in the management of the child through communication with other parents and consultation with relevant professionals. This is consistent with the results from the one-tailed independent t-tests, and suggests that these two variables are the best predictors of level of EE in the current study. The overall accuracy of the classification of cases appears to be adequate for the purposes of the current research.

| Predictor<br>Variables | Wilks'<br>Lambda | Univariate<br>F (1, 38) | Standardized<br>Coefficient | Correlation<br>with<br>Discriminant |
|------------------------|------------------|-------------------------|-----------------------------|-------------------------------------|
|                        |                  |                         |                             |                                     |
| Behaviour              | 0.96             | 1.74                    | 0.46                        | 0.21                                |
| Stress                 | 0.78*            | 10.92*                  | 0.96                        | 0.53                                |
| Coping I.              | 0.93             | 2.84                    | 0.60                        | -0.27                               |
| Coping II.             | 0.93             | 2,92                    | -0.11                       | -0.27                               |
| Coping III.            | 0.82*            | 8.12*                   | -0.77                       | -0.46                               |
| Services               | 0.95             | 1.91                    | -0.76                       | -0.22                               |
| Chi-Square             | 24.54‡           |                         |                             |                                     |
| Canonical R            | 0.71             |                         |                             |                                     |
| Eigenvalue             | 1.02             |                         |                             |                                     |

Cases correctly classified: HEE - 82.4%; LEE - 78.3%; Overall: 80.00%.

Table 8. Direct discriminant function analysis with key variables in the study and EE as the grouping variable.

### 3.6 Predictive utility of EE

The value of EE has traditionally been linked to its predictive utility in terms of outcomes of conditions or compliance with treatments. No attempt was made in the current study to relate level of EE to a specific outcome measured at some point in the future. It was, however, considered relevant to address the issue of the contribution EE makes to the prediction of key variables in the study. The two variables with which EE was found to have a significant relationship at the univariate level were entered as dependent variables into stepwise multiple regression analyses. These variables are stress and Coping Pattern III. Level of EE was included as a dummy variable in these analyses and compared with variables which were also significantly associated with the two dependent variables. stress as the dependent variable, Coping Pattern I. and behavioural disturbance were entered along with EE as the independent variables. With Coping Pattern III. as the dependent variable, Coping Patterns I. and II. were entered along with EE as the independent variables. The results of these analyses are displayed in Table 9. below.

Examination of residuals scatterplots for each of the multiple regressions carried out provided a test of the assumptions of normality, linearity and homoscedasticity between predicted dependent variable scores and errors of prediction. A visual inspection of these scatterplots demonstrated evidence of departures from these assumptions. These departures were not considered marked enough to merit transformation of any of the variables. The independence of the errors of prediction from one another was confirmed with the Durbin-Watson statistic.

The author acknowledges the controversial nature of stepwise regression, with entrance to the prediction equation being based solely on statistical criteria. Furthermore, since no attempt has been made to cross-validate the regression coefficients, and since the overall sample size is small, generalization of the findings is limited.

| Variable    | R    | R2   | Adjusted | R2     | F      | df   | р       |
|-------------|------|------|----------|--------|--------|------|---------|
|             |      |      | R2       | change | change |      |         |
| Analysis 1: |      |      |          |        |        |      |         |
| EE          | 0.47 | 0.22 | 0.20     | 0.22   | 10.92  | 1,38 | < 0.01  |
| Behaviour   | 0.56 | 0.32 | 0.28     | 0.10   | 5.11   | 2,37 | < 0.05  |
| Analysis 2: |      |      |          |        |        |      |         |
| Coping I.   | 0.63 | 0.40 | 0.38     | 0.40   | 25.20  | 1,38 | < 0.001 |
| EE          | 0.68 | 0.47 | 0.44     | 0.07   | 4.78   | 2,37 | < 0.05  |
|             |      |      |          |        |        |      |         |

Table 9. Stepwise regression summary. Analysis 1 entered stress as the dependent variable, and analysis 2 entered Coping Pattern III.

In the first analysis, EE appears to be the best predictor of stress, albeit weak/moderate, since EE explains a significant 22% of the variance in reported stress. Behavioural disturbance entered next into the equation, adding a significant 10% explained variance in stress. Coping Pattern I. in contrast, was not able to add significantly to the prediction of stress, and failed to enter the predictive equation, despite the fact that the former's relationship with stress is moderately significantly positive (r = .41, p<.01). In the second analysis, EE followed Coping Pattern I. in a predictive equation for Coping Pattern III., with the latter explaining a significant 40% of the variance in Coping Pattern III., and EE adding a significant 7% to the explained variance. In this analysis, although the relationship between Coping Pattern III. and Coping Pattern III. is significantly positive (r = .56, p<.001), the former does not make a significant contribution to the prediction of Coping Pattern III.

### CHAPTER 4: DISCUSSION AND CONCLUSION

### 4.1. Summary of the results

The results from this study demonstrate that parents of behaviourally disturbed learning disabled children can be distinguished using the EE dichotomization of high and low EE. Out of the current sample, 42.5% parents were rated as high EE. This figure is consistent with the percentage of high EE categorizations in other studies, where high EE has been shown to range between 35% and 77% of samples.

To briefly summarize the findings, group differences in terms of level of EE were not found to be associated with any of the demographic variables, such as the age of the mother and child, the child's position in the family and the socioeconomic status of the family. The only demographic variable found to be significantly associated with EE was parental marital status, with 77.8% of the single mothers in the sample receiving a high EE rating. The child-related variables of intellectual functioning and dependency needs were similarly not found to differ for high and low EE groups.

With regards to the main hypotheses and related post hoc analyses, partial confirmation of the hypotheses can be found in the results obtained. These findings will be discussed in greater detail below. Briefly, however, high EE parents were found to differ significantly from low EE parents in terms of reporting higher levels of stress, and in addition, in terms of making less use of support and advice outside the family system (Coping Pattern III.). In addition, EE was shown to be the best predictor of stress. discriminant function analysis showed that information regarding stress and Coping Pattern III. provides the best discrimination between high and low EE groups in the current study. On the basis of the discriminant function obtained from all the key variables combined, namely, behavioural disturbance, stress, Coping Patterns I., II. and III. and total service usage, 82.4% of high EE parents and 78.3% of low EE parents were accurately classified.

In contrast to the above significant findings, no significant difference was found between high and low EE parents in terms of a composite measure of frequency, management difficulty and severity of behavioural disturbance, and types of child behavioural disturbance reported. Similarly, high and low EE parents did not appear to differ in terms of maintaining family integration, cooperation and an optimistic definition of the situation (Coping Pattern I.), and, in terms of maintaining social support, self-esteem and psychological stability (Coping Pattern II.). Finally, there were no apparent differences between high and low EE parents in terms of the amount of contact they had, had with services in the previous three months, including use of respite care.

Despite these non-significant findings, the contribution of all the key variables combined to the formation of a reliable discriminant function, with high classification accuracy (see above), indicates the existence of underlying and intercorrelated characteristics related to this set of variables, which distinguish between high and low EE parents. This suggests the value of further investigation of how these variables, combined and intercorrelated, discriminate between the two groups, and what they reflect in combination which produces this discrimination.

This chapter firstly considers the current study's findings with regards to components of EE (section 4.2.). This is followed by a discussion of possible explanations for and the implications of the results obtained with regards to the study's hypotheses (sections 4.3 to 4.6., inclusive). Implications for service provision are then considered (section 4.7.), followed by a critique of the study's methodology and suggestions for future research (section 4.8.). Finally, an overall conclusion to the study is provided (section 4.9.).

### 4.2. Components of EE

Of the 17 (42.5% of the sample) high EE parents in the current study, 47% (20% of the sample) were so rated according to both the frequency of critical comments and evidence of hostility expressed with regards to their children during the interview. A further 35% (15% of the sample) were rated as high EE based on the frequency of critical comments alone, and 18% (7.5% of the sample) were so rated based on the degree of emotional overinvolvement. The predominance of criticism as a component of high EE is consistent with most other EE research (e.g. Brown et al., 1972).

The current sample (N = 40) was notably smaller than that included in the Dossetor (1991) study (N = 92), and this possibly accounts for the slightly higher percentage of high EE parents. Dossetor rated 35% of his sample as high EE (N=32). Furthermore, emotional overinvolvement (N=24) represents the most significant component of the high EE group (75%) in his study. Criticism and hostility (N=8) comprised 25% of his high EE group, although only 1 parent in this sub-group expressed criticism and hostility.

The lower percentage of emotionally overinvolved parents in the current study in comparison to the Dossetor study, can feasibly be attributed to the presence of younger children in the current sample. This is likely to have reduced opportunities for parental expression of excessive and inappropriate overinvolvement due to the more limited numbers of older children, as compared to Dossetor's sample. The average age of the children in the current study was 10. In contrast, the average age in the Dossetor study was 16. The "independence-dependence struggle" between parents and teenagers, characteristic of the adolescent years, has been shown to apply to learning disabled children and their parents (Zetlin & Turner, 1985). It is feasible that features of this "struggle" were revealed in Dossetor's interviews with the parents, and were rated as emotionally overinvolved due to the age of the children.

The virtual absence of hostility in Dossetor's sample contrasts with the finding in the current study where 47% of the high EE parents expressed both criticism and hostility about their children, with 62.5% of this 47% expressing hostility in the form of generalized criticism, and 37.5% expressing hostility in the form of both generalized criticism and rejecting remarks. The current study also differs from the results in the Greedharry (1987) study where an absence of hostility was also noted. Differences in the degree of hostility found in the three studies are possibly also explained to some extent by the different age ranges of learning disabled family members. The current study provides the youngest sample. It is possible that increasing adaptation to a learning disabled offspring over time, brings with it a reduction in hostile feelings. Age ranges for children within the critical/hostility sub-group in the current study, were between 6 and 17, with 50% (i.e. four) of the children aged below 13.

The current study also differs from the Dossetor (1991) study in that a cutoff of 5 critical comments was initially employed in the latter. The current study conformed to the traditional cutoff of 6 critical comments (Vaughn & Leff, 1976). Further consideration will be given to the issue of cutoff variations, in section 4.3. below.

Of interest in the current study was the finding that there was no significant difference between high and low EE parents with regards to the amount of warmth and number of positive comments expressed about their children. With regards to warmth, moderate amounts of warmth were found for both high and low EE parents. This is consistent with Greedharry's (1987) finding. A finding of moderate warmth clearly has relevance with regards to the emotional quality of the relationship between high EE parents and their children. Frequency of positive comments was found to be low for both groups, however, with a mean of 3.53 positive comments for high EE parents and 3.35 for low EE parents. Positive comments

have, however, been found to represent a somewhat redundant scale in EE studies. In contrast, the buffering influence of warmth against concurrent criticism has been noted in the literature (Brown et al., 1972; Vaughn & Leff., 1976), and is feasibly relevant in the current study, where no difference was found between high and low EE groups in terms of children's behavioural disturbance.

4.3. (Hypothesis 1): High EE parents will report greater frequency, management difficulty and severity of child behavioural disturbance than low EE parents.

The results demonstrate no significant difference between high and low EE groups with regards to both a composite measure of frequency, management difficulty and severity of behavioural disturbance, and the types of behavioural disturbance manifested by In addition, the relationship between EE and their children. behaviour is weak (Eta = .21). These findings contrast with the observed association between high EE and behavioural disturbance in the EE literature (Bledin et al., 1990; Dossetor, 1991; Hibbs et al., 1991; MacMillan et al., 1986; Schwartz et al., 1990). The results are, however, consistent with Brown et al's (1972) and Vaughn & Leff's (1976) findings that level of EE is independent of degree of behavioural disturbance. It must be noted, however, that in the latter studies, high EE was related to a deterioration in the condition of the schizophrenic family members at nine months follow-up. Thus, a longitudinal design might further elucidate the relationship between EE and behaviour in the current population. In terms of the current design, there are various possibilities as to why children in high EE households were not found to be more behaviourally disturbed than children in low EE households.

Prior to considering these possibilities, it must be noted that although no statistically significant difference was found between the two groups in terms of behavioural disturbance, the mean degree of disturbance for children in high EE households (90.71) was greater than that obtained for children in low EE households (69.35). The "age-old" methodological explanation for a non-significant difference is the use of an inadequately sized sample. This is clearly a possibility in the current study. Furthermore, it is possible that the high and low EE children's behaviour is similarly influenced by other factors and/or relationships at home or at school. On the basis of the data obtained with the key parental caregiver, however, possible reasons for a non-significant difference are considered below.

Comparisons of behavioural disturbance between sub-groups of high EE was not considered feasible due to the restricted size of the sub-groups. Dossetor (1991) was, however, able to compare the behaviour of children of critical parents and children of emotionally overinvolved parents, and found that the former were more likely to display difficulties related to hyperactivity, whilst the latter had problems pertaining to emotional independence. It is feasible that the single high EE rating in the current study concealed relevant differences in behaviour between sub-groups of high EE.

With regards to a comparison between high and low EE groups, manipulations of the cutoff for critical comments to as low as 4 and to as high as 10, were attempted in the current study, but failed to yield a significant difference between high and low EE groups for child behaviour. Such manipulations of cutoffs for critical comments are consistent with other EE studies (Fischmann-Havstad & Marston, 1984; Vaughn & Leff, 1976). Cutoffs below 4 and above 10 were not considered feasible due to the sample size. Dossetor (1991) reduced the cutoff for criticism from 5 to 3 comments and found a highly significant association between high EE criticalness and behavioural disturbance in learning disabled adolescents. Therefore, despite restrictions in the manipulations of the cutoffs in the current study, it is feasible that learning disabled children with behavioural problems are sensitive to low levels of

criticism similar to individuals with depression (Vaughn & Leff, 1976) or obesity-related problems (Fischmann-Havstad & Marston, 1984).

An alternative explanation for the non-significant difference between groups in terms of child behavioural disturbance, is that the EE dichotomization might simply not be appropriate in terms of differentiating between degree and type of behavioural disturbance for children in high and low EE households. Although there was no difference between high and low EE groups in terms of behavioural disturbance in the current study, a moderately strong relationship was found between the latter and a frequency count of the number of critical comments (r = .41, p< .01). This finding is consistent with the observed relationship between daughters' critical comments and behavioural difficulties of dementing parents in the Bledin et al. (1990) study. Furthermore, with regards to the current study, the moderate relationship between critical comments and behavioural disturbance was maintained to some extent, although weakened, when parental reported stress was held constant (r = .32, p< .05). It is beyond the scope of the current study to do more than report associations between variables, and hence it is not possible to determine the direction of influence in terms of critical comments and behavioural disturbance. A bidirectional influence of parent and child behaviours is the most reasonable explanation, and is consistent with trends both in EE research (Cook et al., 1989), and in the literature pertaining to parents and children in general (Bell & Harper, 1977).

A further possible explanation for the lack of differences in behavioural disturbance for the two groups is the lack of responsivity of learning disabled children to emotional expression in others. The extent to which emotions are salient, discriminable and meaningful to learning disabled children has received some attention in the literature (Hobson, 1986; Sigman, Kasari, Kwon & Yirimiya, 1992).

Generally, however, there is only meagre evidence to suggest that the learning disabled are impaired in their recognition of emotion (Gray, Fraser & Leudar, 1983). Furthermore, where impairments have been found, they generally pertain to the responsivity of autistic children (Hobson, 1986; Sigman et al., 1992). Since only two of the children in the current study's sample had received a diagnosis of autism, these findings are not of relevance to the current results.

The finding of no significant difference between the two groups in terms of child behavioural disturbance is, however, consistent with the literature which suggests that learning disabled children are vulnerable to behavioural disturbance, albeit in different ways. It is feasible that behavioural disturbance in learning disabled children is not significantly influenced by emotional negativity from another, but persists all the same due to vulnerability factors e.g. neurological deficits (Hagberg et al., 1981a,b) and poor communication skills (Donnellan et al., 1984). Thus high EE parents might actually respond to behavioural disturbance with criticism and hostility, for example, but with minimal, if any, additional influence on the child's behaviour. This explanation contrasts with the vulnerability-stress models (Nuechterlein & Dawson, 1984; Zubin & Spring, 1977) which have been employed to explain the relationship between schizophrenia and relapse, and in addition the relationship between EE and relapse. Even if this explanation is valid, however, the emotional quality of the relationship between high EE parents and their children is still potentially at risk, particularly if high EE parents perceive greater levels of behavioural disturbance than low EE parents, for similar levels of behavioural disturbance. This is considered in further detail below (4.4). Moreover, although no significant difference was found between high and low EE groups in terms of child behavioural disturbance, this does not rule out the possibility that other aspects of high EE children's repertoire of functioning e.g. social functioning, might be deleteriously influenced

by critical (in particular), hostile and emotionally overinvolved parental attitudes, feelings and possibly, behaviours. Further study is required to address these issues.

It is feasible to suggest that high EE parents might suppress the expression of negative emotions in in vivo interactions with their learning disabled children, preventing the differential escalation of behavioural disturbance for children in high EE households as compared to those in low EE households (Hubschmid & Zemp, 1989; Strachan et al., 1986). Indeed, the similarity in the degree of warmth expressed about their children by high and low EE parents might be a more legitimate indicator of actual interactional patterns than are the two most commonly found components of high EE in the current study, namely criticism and hostility. Alternatively, this warmth might be an adequate buffer against verbal expressions of criticism and hostility from the parents (Brown et al., 1972).

If suppression of feelings by high EE parents explained the lack of statistical difference between high and low EE groups in terms of levels of behavioural disturbance, this would have implications for the psychological well-being of high EE parents, and for the development of stress-related psychosomatic illnesses. If these parents are not expressing their feelings, albeit in a negative way, towards their children, there is the risk that they are internalizing any frustrations they might be feeling. It might also have implications for the quality of the high EE parent's relationships with other members in the family, namely the marital partner and other children. There has been no attempt in the current study to directly assess the quality of the marital relationship, nor to consider the emotional adjustment of siblings of the learning disabled children.

Clearly, it is not feasible to do more than speculate about the interactional correlates of EE in the current study. Based on previous studies, it does seem reasonable to assume, however, that the critical, hostile and emotionally overinvolved attitudes and

feelings expressed by high EE parents in the interview, are congruent, at least to some degree, with actual face-to-face interactions between the parents and children (Doane et al., 1981; Miklowitz et al., 1984; Strachan et al., 1986; Valone et al., 1983).

Finally, it might be speculated that an additional reason why no significant difference was found between high and low EE groups in the current study, with regards to child behavioural disturbance, was because both high and low EE response styles elicit and maintain problem behaviours, but in different ways. Thus problem behaviours might be elicited and maintained as a result of the provocative qualities of principally criticism and hostility, in high EE households, and due to lack of stimulation in low EE households. Lack of stimulation has been shown to be associated with behavioural disturbance in the learning disabled (Baumeister & Forehand, 1973; Berkson & Mason, 1963), and furthermore, has been forwarded as a potentially deleterious influence in low EE households (Hatfield et al., 1987; Kanter et al., 1987). Differential ways in which high and low EE parents might manage problem behaviours are considered in the next section.

To conclude this section, the emergence of high and low EE parents in the current study does not appear to be related to child behavioural disturbance. This suggests that consistent with other researchers' conclusions, high and low EE principally reflect differences in the parents (Brewin et al., 1991; Brown et al., 1972; Vaughn & Leff, 1976). These differences are possibly associated with differences in the psychological well-being of these parents, their differential perceptions of their children's behaviour and/or their interactional styles. These issues are discussed in more detail in the next section (4.4.).

Further research is required to maximize the sensitivity of exploration of the relationship between parental EE and behavioural disturbance in learning disabled children. This might include further correlational analyses of the relationship between critical comments and behaviour, and in addition, the division of high and low EE groups into sub-groups, either with regards to components of EE, or numbers of critical comments. Moreover, as was suggested earlier, an investigation of the relationship between EE and behaviour within a longitudinal design might further elucidate this relationship. Finally, there would appear to be value in exploring how high and low parental EE might contribute differentially to behavioural problems.

# 4.4. (Hypothesis 2): High EE parents will report more stress than low EE parents.

The hypothesis that high EE parents would report more stress than low EE parents, was confirmed by the results. This finding is consistent with other EE studies which have demonstrated an association between EE and psychological well-being (Bledin et al., 1990; Dossetor, 1991; Hibbs et al., 1991; Schwartz et al., 1990). The relationship between EE and stress in the current study is moderately strong (Eta = .47, p<.01).

In the current study, the median level of stress reported by high EE parents (7) comes above the cutoff of 5 or 6 suggested by Rutter et al. (1970) as evidence of stress. The median level of low EE parents' stress (4) falls below this cutoff. Furthermore, although it was not part of the main hypotheses, EE was found to be the best predictor of stress, albeit a weak/moderate predictor, particularly in comparison to behavioural disturbance, and hence appears to some extent to be a risk indicator for parental stress. These findings suggest consistency with the conclusion that a high EE response style is stressful for relatives (Hubschmid & Zemp, 1989). Furthermore, it potentially challenges the notion that EE reflects normal family interactions. In challenging this notion, the current study is consistent with studies which have applied EE to families with

psychiatrically disturbed non-learning disabled children (Hibbs et al., 1991; Schwartz et al., 1990). Clearly, it cannot be deduced from these findings that a high EE response style causes stress, any more than it can be deduced that stress causes a high EE response style. That EE is related to stress provides, however, a guideline to moderating stress since high EE is inherently modifiable.

Consistent with other studies (Byrne et al., 1988; Friedrich et al., 1985; Quine, 1986), stress was found to be related to child behavioural disturbance albeit only moderately (r= .40, p< .01). As has been noted above, however, no significant differences were found between high and low EE groups in terms of child behavioural disturbance. This latter finding is surprising in view of the differential levels of reported stress for high and low EE parents, since the literature pertaining to non-learning disabled children suggests that stressed mothers can both elicit or perpetuate maladaptive behaviours in non-learning disabled children due to their lack of responsivity (Cox et al., 1987; Wahler & Dumas, 1989) and moreover, their decreased tolerance for aversive child-related stimuli, such as noise (Lahey et al., 1984). Both of these parental reactions potentially provide inadvertent positive reinforcement of child behavioural disturbance and may contribute to a negatively escalating cycle of parental stress and child behavioural disturbance. Evidence of higher levels of criticism in the stressed high EE parents is particularly consistent with the reduced tolerance found in stressed mothers for aversive child-related behaviours.

Once again, these findings seem to support the suggestion that the occurrence of behavioural disturbance in the learning disabled children in the sample is relatively independent of social factors such as parental EE and parental psychological well-being. In addition, however, to indications that high EE parents have critical (in particular) and hostile feelings towards their children, the fact that they are also more stressed and therefore, to some extent,

less likely to be responsive to their children's needs, raises concerns about the emotional quality of the relationship between these parents and their children, and the implications in the longer term for both the parents and children.

Thus whilst the learning disabled children in the sample largely do not appear to be differentially influenced with regards to their behaviour, whether their parent is high EE or low EE, the high EE and low EE parents do differ in terms of their psychological wellbeing. It is feasible of course, that the stress reported by high EE parents is related to a greater extent to factors which were not measured in the current study, such as financial concerns (Chetwynd, 1985) or marital conflict (Friedrich, 1979), as compared to child behavioural disturbance. Furthermore, it was found that 77.8% of the nine single mothers in the study received a high EE rating. Beckman (1983) found that single marital status was the best predictor of maternal psychological distress. Alternatively, since EE proved a better predictor of stress than child behaviour, the stress might be related to documented distinguishing characteristics of high and low EE relatives, with regards to their perceptions of and ways of responding to abnormal behaviours. With regards to parents of learning disabled children, Gath & Gumley (1986) found, for example, that psychologically distressed mothers perceived greater behavioural disturbance in their Down's Syndrome children than was objectively rated. Similar to the current study, their results showed no significant difference in behavioural disturbance between children whose mothers were distressed and those whose mothers were not.

With regards to perceptions of behavioural disturbance and EE, Brewin et al. (1991) found that critical and hostile high EE relatives attributed abnormal behaviours in schizophrenic patients to controllable aspects of the latters' personality. Thus although the children's behaviour in the current study, does not appear to differ significantly between the two groups, parental tolerance for similar

behaviours might differ, as might their expectations of the children's ability to regulate their behaviours. Gath & Gumley (1986) reported a high degree of tolerance towards even the most serious objectively rated behavioural problems, where mothers considered the problems an integral part of the learning disability. This response is consistent with a low EE attributional style with regards to the behaviour of schizophrenic patients (Brewin et al., 1991). Expectations of the child's ability to control their behaviours would be consistent with a high EE attributional style. Furthermore, the greater criticism expressed by high EE parents is in itself indicative of intolerance of the behaviours. It would be of value to carry out content analyses of the interviews in the current study to determine whether differential attributional styles exist for high and low EE parents.

Greenley (1986) noted that high EE relatives attempted to exert more control over the behaviour of their schizophrenic family member. Furthermore these high EE relatives usually presented as anxious and fearful about their offspring's condition, and similar to Brewin et al.'s (1991) findings, did not attribute the behaviours to the schizophrenia, but to the person. An association between high EE and control was also found by Hooley & Hahlweg (1983) with regards to spouses of depressed patients. The issue of control is relevant with regards to parental interactions with learning disabled children in general, and represents a notable feature of such interactions (Marfo, 1990). Furthermore, Nihira et al.'s (1983) and Mink et al.'s (1988) taxonomy of lifestyles of families with learning disabled children demonstrated a relationship between controloriented families in which low harmony and conflictual relations were also features, and child maladaptive behaviour. Such a family climate might account to some extent for child behavioural disturbance in high EE households. Given the documented vulnerability of some learning disabled children to behavioural problems, expectations on the parents' part that they can control their children's behaviour or that the children themselves can control their own behaviour, without the parents changing the social and/or environmental contingencies, are feasibly inappropriate, and moreover frustration- and stress-inducing for the parents.

Further research is clearly required to determine whether documented characteristics of high and low EE relatives' response styles with schizophrenic patients generalize to parents of behaviourally disturbed learning disabled children. Such studies might feasibly highlight a need to educate high EE parents in particular, about the functions of behavioural problems for some learning disabled children, e.g. socio-communicative functions (Donnellan et al., 1984; Durand & Carr, 1987), in order to facilitate constructive parental responses to the behaviours. Education about schizophrenia has become a standard ingredient of intervention programmes with high EE relatives of schizophrenic patients and has been welcomed by relatives (Smith & Birchwood, 1987).

Finally, with regards to higher levels of reported stress in high EE parents, Dunst & Trivette (1986) found an association between a non-contingent interactional style and decreased wellbeing, both emotional and physical, in mothers of learning disabled children. Furthermore, indiscriminate and inconsistent parenting have been found to be associated with psychological distress in mothers with non-learning disabled children (e.g. Wahler & Dumas, 1989). Linking with the EE literature, MacCarthy et al. (1986) found that critical high EE relatives were more likely to respond unpredictably to schizophrenic patients' behaviours, creating a cognitively more confusing environment. It is possible, therefore, that non-contingent, inconsistent, and the feasibly similar high EE unpredictable response style, are more consistently features of stressed and critical high EE parents of learning disabled children than of low EE parents. This would possibly lead to both greater levels of stress in the high EE parents due to the lack of a mutually

satisfying interaction with their child (Goldberg, 1977; Kelley, 1984) and, moreover, the development of reciprocally maladapative interactional patterns since parental non-contingent, vague and inconsistent interactional styles have been associated with behavioural disturbance in learning and non-learning disabled children (e.g. Breiner & Forehand, 1982; Field, 1977; Wahler & Dumas, 1989).

It would be of value to compare high and low EE parents in terms of their management of child behavioural problems. Within an operant framework for example (see section 1.1.4.1.), children's behaviour in high EE households might persist due to inadvertent, intermittent positive and/or negative reinforcement of problem behaviours. This would be consistent with an inconsistent or unpredictable style of parenting. Low EE parents might not reinforce negative behaviours in these ways, but behaviours might persist due to the lack of positive reinforcement of adaptive behaviours. To remind the reader, low EE parents in the current study were not found to be more positive than high EE parents, i.e. in terms of warmth and positive comments. On the basis of the data obtained, they were only less negative.

4.5. (Hypothesis 3): High EE parents will possess a more restricted repertoire of coping behaviours than low EE parents.

In part confirmation of hypothesis 3, high EE parents were found to make less use of support and advice outside the family system (Coping Pattern III.) as compared to low EE parents. With regards to family focused coping strategies (Coping Pattern I.) and maintenance of their own social support system, self-esteem and psychological stability (Coping Pattern II.), high and low EE parents were not found to differ significantly. There does appear, however, to be a trend for low EE parents to make greater use of the latter two coping patterns as compared to high EE parents.

The findings in the current study suggest that a rating of high or low EE does not necessarily indicate differential availability or use of coping resources e.g. with regards to the family and social support. Moreover, these findings support the possibility that increased levels of stress in high EE parents might well be related to documented characteristics of high EE relatives' perceptions of and responses to abnormal behaviour, as opposed to differential availability of coping resources. Different high and low EE response styles can, however, in themselves be considered indicators of coping strategies.

The findings that high EE parents make less use of support and advice outside the family system and are also more stressed, are feasibly consistent with the conclusions of Kazak & Marvin (1984) and Waisbren (1980). These authors reported increased levels of stress in mothers of learning disabled children who have dense, cohesive social networks, without the benefits of outside advice and opinions. The relationships between stress and Coping Patterns I. and II. (which include parental ratings of familial and social support resources, respectively) are, however, negative, and moderate and weak (r= -.41, p<.01, and r= -.21, n.s., respectively), and it is not possible to comment on the degree of cohesiveness or the size of familial and social networks for parents in the current study, and the relationship between these factors and parental stress.

The finding that high EE parents make less use of support and advice outside the family system might also suggest that if documented characteristics of high EE response styles do apply to parents with learning disabled children, such parents will be more likely to persist in maladaptive response styles and negative attitudes and feelings, without the benefit of external sources of challenge to these response and attitudinal styles. Such external sources might include other parents, professionals and relevant literature.

It is interesting to note that although high and low EE

parents differ significantly with regards to reported stress, they do not differ with regards to Coping Patterns I. and II., aspects of which include parental optimism, self-esteem and psychological stability. More indepth investigations would be required to enable comment on the relationship between these intra-individual coping resources and parental reported stress, which is associated with both high EE and child behavioural disturbance in the current study. Such parental resources, might for example, act as buffers against the deleterious impact of parental high EE on the child, specifically with regards to behavioural disturbance, and might feasibly offer an additional explanation for the lack of significant difference between high and low EE groups in terms of child behaviour. Since these intra-individual resources only represent aspects of the two coping patterns, it is not clear how high and low EE parents might have differed regarding their use of the specific resources/strategies.

The non-significant difference between high and low EE parents with regards to Coping Pattern I., which focuses principally on intra-familial resources, seems to suggest that a rating of high EE, and parental stress, associated both with a high EE rating and with child behavioural disturbance, do not detrimentally affect the family unit (Flynt & Wood, 1989), including the parents' relationships with their partners, and with other children in the family. With regards to the marital relationship, this important relationship has, been shown to have direct implications for the quality of parenting and interactions with the learning disabled child (Bristol & Gallagher, 1986). Thus a non-significant difference between high and low EE parents for this coping pattern, in which marital support and cooperation are features, might also explain the lack of a significant difference between the groups in terms of child behavioural disturbance. It must be noted, however, that 77.8% of the nine single parents in the study were rated as high EE, furthermore, the items in this coping pattern which pertain to the marital relationship

only represent an aspect of this pattern, and it is not clear how high and low EE parents might specifically differ in terms of marital support. In contrast to these suggestions, however, Dossetor (1991) found that high EE was associated with poor marital quality.

High and low EE parents also do not differ with regards to Coping Pattern II. Use of social support represents a focus of this This result is to some extent consistent with that of pattern. Anderson, Hogarty, Bayer & Needleman (1984) who did not find a relationship between overall ratings of parental EE and size and quality of social support networks. Thus it seems that there is no obvious relationship between intra-parental variables which relate to the emotional quality of the parent- child relationship, and relationships with external social networks. Alternatively, the impact of simply having a learning disabled child in the family, irrespective of the presence or degree of behavioural disturbance, might produce generally similar enduring effects on social support networks which distinguishable simply by differential EE Comparisons between families with learning and non-learning disabled children have produced equivocal findings with regards to social support networks (e.g. Kazak & Marvin, 1984; Quine, 1986). There is substantial evidence to suggest, however, that families with learning disabled children are socially isolated (Gayton, 1975), particularly with regards to families of older children (Suelzle & Keenan, 1981), and that a handicapped child may adversely affect relationships with family and friends (McAndrew, 1976).

4.6. (Hypothesis 4): High EE parents will have more extensive face-to-face contacts with services pertaining to the needs of their learning disabled children than low EE parents, and (post hoc Hypothesis 5): High EE parents will make greater use of respite care than low EE parents.

In contradiction of these hypotheses, there were no significant

differences between high and low EE parents in terms of service usage, including respite care. This is consistent with the Dossetor (1991) and Gilhooly and Whittick (1989) studies which also found no association between EE and service input. Indeed, low EE parents in the current study appear to use more services (mean usage 16.13) than do high EE parents (mean usage 11.76), although this does not reach statistical significance. It might be feasible to suggest that the needs of low EE parents are reflected in their degree of service usage, but that this is not the case with regards to the more stressed high EE parents. Indeed, it has been noted that use of services by families with learning disabled children is not always consistent with need (McAlister, Butler & Lei, 1973; Waisbren, 1980).

There are several explanations as to why a non-significant difference was found between high and low EE parents. A lack of awareness of services, for example, would be consistent with the finding in the previous section (4.5.) that high EE parents make less use of support and advice outside the family system, and therefore might not know that specific services exist either from other parents, from professionals, or from their own reading. On the other hand, high EE parents might have had frustrating experiences with services in the past due to their greater needs, and subsequently relied more on their families and friends for support as opposed to professional services. This might explain why high EE parents did not differ in terms of intra-familial support systems and use of social support.

The lack of a statistically significant difference between high and low EE groups in terms of overall service usage, might also reflect high EE parents' dissatisfaction at a traditional child-centric service delivery. This may have disillusioned high EE parents who appear to be in need of more individual psychological support, and also support in relation to the quality of their relationship with their child, and possibly more generally, regarding the care of their child.

Of interest in the Dossetor (1991) study was the difference

between critical and emotionally overinvolved parents. The latter were shown to have more service contacts than the former. Furthermore, although Dossetor similarly found no significant relationship between service contacts and EE rating, high EE was shown to be related to dissatisfaction with services. concluded that the more critical nature of critical high EE parents deterred service input. This feasibly would serve to fuel further dissatisfaction for high EE parents. Wahler (1980) similarly noted the relationship between negative interactions with social agencies and negative parent-child interactions. Since criticism is the most consistent feature of high EE parents in the current study, Dossetor's findings are feasibly applicable. Dossetor's findings thus might explain, why high EE parents do not overall have greater service input, despite their apparent needs for support due to both higher levels of stress, and an apparent poor tolerance of child behavioural disturbance, as evidenced by greater criticism, in particular.

Service usage was most strongly related to behavioural disturbance in the current study and this moderate and significantly positive relationship (r= .45, p< .01) was maintained to some extent, although weakened, when parental stress was partialled out (r= .38, p< .05). Although the relationships between all these variables are only moderately strong, the results provide an interesting contrast to other studies which have shown that parental psychological distress may significantly distort perceptions of degree of behavioural disturbance with regards to learning and non-learning disabled children (e.g. Gath & Gumley, 1986) and determine patterns of parental referrals to services, irrespective of objective ratings of low levels of child deviancy (Brody & Forehand, 1986).

With regards to respite care, the findings in the current study are consistent with Dossetor's results, and demonstrate no significant difference between high and low EE parents in terms of respite care usage. Dossetor found no association between respite care and high EE, but he found an association between high EE and irregular use of respite care. Since the emotional quality of the relationship between high EE parents and their children is potentially at greater risk of disruption, irrespective, it appears, of the degree of child behavioural disturbance, it is reasonable to suggest that the care of some of these children at home is less certain in the long-term. Furthermore, behavioural disturbance represents a reliable predictor of out-of-home placement (Eyman et al., 1981; Eyman et al., 1972), and use of respite care has been cited as the resource most frequently associated with preventing out-of-home placement (German & Maisto, 1982). Thus it appears that services might not always identify those families in most need of support, and moreover, potentially at most risk in terms of breakdown of care of the child.

Limitations in the current study preclude further interpretation of the data related to service usage. Unlike the Dossetor study, for example, measures of parental perceptions of, and attitudes towards services were not included. Such measures might have clarified the unanticipated finding that high and low EE parents do not differ in terms of service usage generally, and in terms of respite care, more specifically. The next section considers implications for services from the findings in the current study.

# 4.7. Service implications

The findings in the current study with regards to high EE parents, indicate that interventions with families with behaviourally disturbed learning disabled children should focus initially on parental attitudes towards and feelings about their children, and parental psychological well-being, as opposed to immediately addressing the difficulties with which the children present. Indeed, a "child-centric" emphasis has characterized many of the evaluated intervention studies (e.g. Guralnick & Bricker, 1987; Shearer & Shearer, 1972), with little attention to the way in which parental characteristics and adjustment

might impinge upon the child's adaptation and moreover, upon the generalization and maintenance of the principles of intervention programmes. Furthermore, it has been shown that intervention programmes, far from facilitating parental coping, can actually increase subjective burdens and parental stress, and disrupt the parent child-relationship due to frustrations at goals not being met and excessive and inappropriate demands on parents (Allen & Hudd, 1987; Benson & Turnbull, 1986; Gallagher, Beckman & Cross, 1983).

Child-focused intervention programmes which have attempted to teach parents skills to reduce their learning disabled children's behavioural problems have generally reported greater success, and maintenance of skills as compared to interventions aimed at facilitating general skill teaching in parents (Baker, Heifetz & Murphy, 1980). This can feasibly be attributed to the salience and intrusiveness of child behavioural problems in family life. This highlights the need to consider parental psychological well-being in order to maximize successes in reducing a recurring stressor in these families.

Davis & Rushton (1991) have provided a timely contrast to traditional intervention studies. They focused on a supportive counselling framework for use with mothers, excluding systematic child training. The emphasis in the counselling was on a partnership between mothers and professionals. They documented positive outcomes in terms of the mothers' psychological well-being, child developmental gains, and a reduction in behavioural difficulties. The authors attributed the gains to the establishment of a respectful relationship between counsellors and mothers, which provided the circumstances and support for increases in maternal self-esteem. The improvements in maternal self-esteem and psychological well-being feasibly facilitated positive adjustment on the children's part without direct training regarding child-related problems.

Such an individual approach is feasibly relevant for high EE parents in the current study. Whether there is an association between high EE and dissatisfaction with services (Dossetor, 1991) remains to be replicated, but the establishment of a respectful relationship with a professional would undoubtedly be of value. Furthermore, change in the level of EE would represent an indicator of outcome, in terms of both the emotional quality of the parent-child relationship, and in addition parental psychological well-being.

The value of education has already been discussed in section 4.4. of this chapter. Additional components of intervention packages which have proved efficacious with regards to families with schizophrenic relatives, are feasibly of value with regards to parents, and particularly high EE parents of behaviourally disturbed learning disabled children. These include problem-solving for the parents and social skills training for more mildly/moderately learning disabled children (Falloon et al., 1982; Hogarty et al., 1986).

It is too easy to focus on high EE parents and to neglect the needs of low EE parents, by assuming that low EE is synonymous with positive and supportive qualities in the parent-child relationship. Indeed a neglect of attention to low EE families has been a criticism of EE research in the past (Hatfield et al., 1987; Kanter et al., 1987). It is relevant to note in the current study that low EE parents were not significantly warmer in their expressed attitudes and feelings towards their learning disabled children, as compared to high EE parents. The combination of low warmth and high criticism has been documented in early EE research (Vaughn & Leff, 1976) and therefore a finding of moderate warmth for high EE parents, in the current study, is positive in terms of a high EE rating. Indeed, a combination of high criticism and moderate warmth feasibly represents a high degree of caring amongst some high EE parents towards their children, and a reflection of wanting the best for their children. Moderate warmth in low EE parents in the absence of criticism and hostility might, however, reflect emotional underinvolvement, or even a sense of parents not being bothered to criticize their children - a form of carer burnout.

Concerns regarding low EE households have considered lack of stimulation to be a possible feature (this has also been considered in relation to child behaviour in section 4.3.), with little encouragement of psychiatrically disturbed family members to improve themselves (Hatfield et al., 1987; Kanter et al., 1987). Related to this, it is of interest to note in the current study, that whilst no significant difference was found between children in high and low EE households, with regards to level of physical dependency, the median care time for children in low EE households is greater than that for children in high EE homes (33 and 23, respectively). Indeed, mild but measurable levels of stress, of the kind which a learning disabled child might experience in a high EE household, have been shown to produce improvements in learning disabled individuals' performance on cognitive tasks (Nucci & Reiss, 1987). These issues require further investigation.

The issues are therefore complex, as to whether high EE in this population is maladaptive or a form of caring, and as to whether low EE might represent in some cases lack of emotional involvement. Ascertainment of the true situation in any family is a test of the assessment skills of professionals involved, and feasibly requires both an assessment of EE, and observation of interactions between parents and their children in as naturalistic a setting as possible.

# 4.8. Methodological issues and implications for future research

The current study differs from much of the EE research in that EE is not measured at a specific crisis point for the families. This difference might feasibly have produced misclassifications, with an underestimate of the percentage of high EE parents in the sample. Alternatively, the ratings obtained in the current study might reflect

a more valid indication of the actual emotional quality of parentchild relationships, since they were not obtained at a time of stress and crisis in the family. Similarly, in contrast to traditional EE research, no assessment was made regarding the amount of face-toface contact between the children and their parents. The ages of the children suggested that this was irrelevant.

Weaknesses in the current study limit, however, conclusions that can be drawn. Such weaknesses include the fact that the author interviewed all 40 parents, and in addition, rated all 40 interviews, with full awareness of the study's hypotheses. An element of bias and distortion is inevitable in such circumstances despite satisfactory inter-rater reliability ratings. Other limitations of the study include the focus on one parent only. From this point of view, the current study is far from ecologically sound, since the adjustment of a child will depend on a range of relationships s/he has both within and outside the family, e.g. at school. Furthermore, since it has been demonstrated that a low EE parent can exert a buffering influence on a high EE parent (Valone et al., 1983), it is feasible that misclassifications occurred. Thus parents rated as high EE from their interview, might behave more like low EE parents in actual in vivo interactions with their learning disabled children, due to the moderating influence of the second parent who consistently demonstrates low EE response styles, e.g. calmer, more positive and supportive (Strachan et al., 1986). Indeed, this might well be an additional explanation for the non-significant difference between high and low EE groups in terms of child behavioural disturbance.

Further limitations of the study include the lack of reliability and validity data with regards to the modified CFI. Thus although the modifications were kept to a minimum to preserve the validity of the CFI, and although the author followed the guidelines with regards to the administration of the interview, further use of the modified interview is desirable to verify its reliability and validity.

A restricted range of variables was measured in the current study both in terms of parent- and child-related characteristics. No direct assessment was made, for example, of factors such as life events or financial concerns, the latter being common to these families (Chetwynd, 1985). Such factors might have been associated with high EE, stress and/or coping. Other relevant child-related characteristics might have included level of social functioning.

Additional flaws in the methodology include the lack of a control comparison group. This is defended, however, on the basis that it was considered of greater value to expand the sample size for the population under investigation. Thus whilst generalizations from the current study might be restricted, effort and resources were not squandered by the inclusion of an ill-matched control group. Such poor matchings are feasible due to the heterogeneity of physical and intellectual features in the learning disabled (Baumeister, 1967, 1984).

The current study represents an exploratory endeavour, however, and in achieving an initial aim of distinguishing between families in terms of EE, has opened the door for future research with families with learning disabled children to mirror the developments in EE research with schizophrenia in particular. Fruitful avenues for further study include the interactional and behavioural management correlates of parental EE in this population, and whether high and low EE parents can be distinguished with regards to their attributional styles. Furthermore, that a rating of high EE, brings with it the identification of interactional components which feasibly contribute to parental stress and to negative feelings about the child, highlights the inherent modifiability of EE. This is also relevant with regards to low EE parents, some of whom might be experiencing a form of burnout. The inherent modifiability of EE components might serve as a guidance to effective and constructive service delivery for these parents. Further research with regards to EE and behavioural

disturbance was considered at the end of section 4.3., and recommended the consideration of the utility of EE on a continuum for example, by correlational analyses of criticism and behaviour. A longitudinal design was also considered valuable for future studies, as was consideration of how high and low EE might contribute differentially to behavioural disturbance.

Finally, in terms of the accessibility of EE, brief EE assessments such as Magaña et al.'s Five Minute Speech Sample (1986) might have applicability to parents with behaviourally disturbed learning disabled children. Such assessments feasibly facilitate the implementation of longitudinal studies to explore the predictive utility of EE in this population, and its stability over time.

### 4.9. Conclusion

The current study, like many other studies, leaves more questions unanswered than answered. The study represented an exploration of the utility of EE as an indicator of the emotional quality of the relationship between parents and their behaviourally disturbed learning disabled children. The results showed that high EE represents to some extent an indicator and indeed predictor, of stress, and that EE distinguishes between parents in terms of use of support and advice outside the family system. The finding of nonsignificant differences between high and low EE groups in terms of child behavioural disturbance, most demographic characteristics, other child-related characteristics, other patterns of coping and finally, service and respite care usage, appears to suggest that the high and low EE distinction principally reflects characteristics of the parents. This is consistent with other EE research. In addition to high EE parents' greater reported stress and diminished use of support and advice outside the family, it was suggested that these parents might also differ with regards to their perceptions of their children's behaviour, and their attributional and interactional styles.

Identification of characteristics of high and low EE parents and their respective parenting styles, and the relationship of these features with child behaviour, require further research.

The emphasis on community care for the learning disabled renders consideration of the emotional quality of the parent-child relationship ever more important, in terms of both the parents' and children's needs. The purpose of the current study was not in any way to pin a pejorative label of high EE and therefore "bad" on parents, but to consider whether a tool which has had considerable value in areas of social psychiatry has relevance for this population. The results suggest that it does, both as a risk indicator of parental stress, and moreover as an indicator that high EE parents make less use of support and advice outside the family system, as compared to low EE parents. This might suggest that services are feasibly not identifying individuals in most need of information about support and actual support e.g. with regards to parental psychological well-being, and constructive challenges to potentially maladaptive response and attitudinal styles. The utility of brief measures of EE (Magaña et al., 1986) as screening devices in terms of families' needs, remains to be explored.

The scope is tremendous for further application of EE to families with behaviourally disturbed learning disabled children, moving beyond static cross-sectional designs to capture dynamic features of the emotional quality of the parent-child relationship and its interaction with other relevant systems for both parent and child. It is potentially a loss to furthering the understanding of the parent-child relationship, and moreover parental and child adjustment, if research is stymied by criticisms that EE blames families.

### APPENDIX 1

Letter to parents requesting permission for their children's behaviour to be assessed in the sampling phase, and permission for the author to contact the parents following the assessment.

Dear parent

# Children with Learning Difficulties and Problem Behaviour

I am carrying out research into the effects of having a learning disabled child with behavioural difficulties in the family.

In order to begin this research I would first of all require permission from parents of all children at your school, whether or not they have behaviour problems, to allow their child's behaviour to be noted by their teacher. This assessment would be brief, and would not require individual testing of the child in any way. It would simply involve teachers indicating whether or not a child has any behavioural problems and if so, which type (e.g. self-injury), how often the behaviour occurs, and how easy or difficult it is to manage. Each assessment should not take more than 5-10 minutes. Any information will be used for research only, and absolute confidentiality concerning the identity of individual children will be assured.

If you give your permission for your child to be assessed, it may be useful for me to contact you by letter and/or telephone to find out more information.

\*Please indicate your preference by writing a tick in the relevant box.

| Name of ChildAge of Child  |
|--|
| 1. I have read the above letter, and give permission for my child's behaviour to be assessed by his/her teacher.                                   |
| 2. I have read the above letter, and do not give permission for my child's behaviour to be assessed by his/her teacher.                            |
| 3. I have no objections to being contacted by the researcher by letter and/or telephone, following the assessment.                                 |
| 4. I do not wish to be contacted by the researcher by letter and/or telephone, following the assessment.   |
| Thank you for sparing the time to read this. I am looking forward to hearing from you. Please return this note to school in the envelope provided. |
| Yours faithfully,  |
|  |

Catherine Sturt, M.A., BSc

### APPENDIX 2

A modified and abbreviated Camberwell Family Interview (CFI) for families with behaviourally disturbed learning disabled children.

Consistent with the original CFI the interview is semi-structured in nature. Flexibility is permitted in terms of order of questions and sections (if necessary) and in wording of questions (if necessary) in order to allow as natural an interaction as possible to take place with parents. Questions are omitted if the relevant information is offered spontaneously by parents to avoid overestimation of positive or negative attitudes and feelings. Questions are not numbered, in order to permit a more flexible delivery of the interview.

For the sake of space, the interviewer is required in all sections subsequent to Section 2 to refer back to Section 2 for relevant probes.

# Section 1: Demographic and Background Information

(The purpose of this section of the interview is to obtain general information regarding demographic characteristics of the family and in addition to establish rapport between interviewer and parent prior to the main body of the interview).

- If I could start by asking who lives in the household and their ages.
- Are you and/or your husband working? (If yes): What do you do?
- When did you first realise that there was something different about your child (named)?

(Obtain general information concerning early diagnosis of the child, contacts with services early on and currently).

- Can you give me some idea of the level of functioning of your child (named) e.g. socially, intellectually, physically?.
- What's his/her speech like?

### Section 2: Previous 3 months

- Can you tell me how things have been in the past three months with your child (named)? (If the parent has difficulty in thinking about a three month period anchor them in time with significant calendar events, e.g. beginning around Easter or the Whitsun holiday).

(Focus on concrete examples of behavioural problems and parental responses to the behaviour)

### Probes

- What happened?
- Where did this happen?
- How severe was the behaviour?
- How often would this happen?
- What did you do?
- Can you tell me more?
- Can you give an example of when this last happened?

# Additional useful probes

- How did/do you cope?
- Do you think your child (named) could do more to

control this behaviour?

- What was your reaction?

(Questions such as "how did it (the behaviour) make you feel?" should be kept to minimum, but are useful occasionally if the parent is unforthcoming about feelings and attitudes. This is relevant for subsequent sections).

# Section 3: Family Time Budget.

(If aspects of the daily routine e.g. dressing or going to bed, prove a source of problems and have not already been addressed in Section 2, use probes recommended in Section 2 to explore what happens and parental responses).

- Can you give me some idea of how your child (named) spends his/her day? What's a typical weekday?
- What time does s/he get up?
- What happens next? (e.g. Breakfast).
- In terms of dressing and washing what usually happens?
- How much do you have to do for your child (named)?

(Where the child is dependent on the parent for dressing and washing)

- Do you think your child (named) could do more for him/herself?
- What time does your child (named) go to school?
- When does s/he return?
- How does s/he spend their time after school?
- Can s/he occupy him/herself?
- What time does s/he go to bed.
- What's a typical weekend?

- Would you be with your child (named) over the weekend?
- (Where relevant) Do you and your husband get much time alone together?
- (If not already mentioned) Do you make use of respite care?
- (Where relevant) How often?
- Do you think it's good for your child (named) to get away?
- How is it for you?

## Section 4: Irritability

# Child's irritability

- Sometimes when children with learning difficulties have problems in communicating it can make it difficult for them to express their needs. One of the ways this can show itself is in irritability. I wonder if that's the case with your child (named)?

(Probes employed in Section 2 are applicable in this section where a behaviour has not already been addressed).

### Where relevant:

- How does your child (named) get on with other members of the family?
- Who is s/he most likely to be irritable with?

## Parental irritability

- Are there things that you would nag and grumble about with your child (named)?
- What sort of things?
- What would you say?
- How often would this happen?

(If a parent reports that there is nothing in particular that they nag or grumble about, it is appropriate to probe with the following question):

- Is there anything that makes you cross?

# Section 5: Behavioural History

(If any of the behaviours have already been addressed in detail in earlier sections, the interviewer should proceed with the next question to avoid "milking" for negative attitudes and feelings. If a behaviour has not been addressed earlier, the probes detailed in Section 2 of the interview are applicable in this section).

- I have a list of different symptoms and behaviours that I would like to ask you about. Some of these we have touched on already, but if we can just go through the list:
- What is your child's (named) sleep like?
- What about appetite?
- What is his/her physical health like?
- Is s/he on any medication?
- What about level of activity? From overactive to underactive, how would you describe your child (named)?
- How about level of sociability? Is s/he a sociable child or is s/he likely to withdraw?
- Does s/he have any particular fears or anxieties?
- Is s/he aggressive/violent towards other people?
- What about aggression to him/herself?
- Is s/he destructive towards property?
- What is his/her mood like?
- Does s/he have any particular obsessions?
- Does anything have to be done in just a certain way?

### Section 6: Household Tasks

(This section is included where it is appropriate in terms of the chronological age of the child and in terms of mobility and coordination).

- How much does your child (named) help around the house?
- What does s/he do?
- Do you think s/he could do more to help?

(Where appropriate, probes in Section 2 are applicable if a problem emerges which has not already been addressed).

### Section 7: Parent and Child.

- Can you tell me about how you and your child (named) get along?
- Do you find him/her a friendly child?
- Is s/he easy to get on with?
- Can you get close to him/her?
- In what ways would you like him/her to be different?
- Are there things that would get on your nerves?
- Do you feel any different towards your child (named) when s/he is behaving in these ways?
- How affectionate is s/he?
- Would you like him/her to be more affectionate?

### Section 8: Conclusion

- What difference has your child's (named) difficulties made to you and the family?
- From your point of view, what has been the most disturbing aspect of your child's (named) difficulties?
- How do you see your child's (named) future e.g. where s/he will live, occupation and relationships?

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Reliability

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Mother of Jimmy

Mother of Howard

Guardian of Darby

Father of James J.

Mother of Julie P.

Father of Julie P.

Father of Howard

Mother of Oscar

Wife of Sidney

Father of Gregory

Mother of Alec

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# APPENDIX 3 CONTD



MRC Social and Community Psychiatry Unstitute of Psychiatry
De Crespigny Park, London SE5 8AF

telephone 071-703 5411 ext 3540

answerphone 071-708 5670

lax 071-703 0458

9 April 1992

Catherine Sturt 5 Stoneyfields Easton in Gordano Bristol BS20 OLT

Dear Catherine,

Greetings! And thank you for your final EE ratings and the return of the CFI cassette tapes. In response I'm pleased to enclose a variety of materials: rating notes for the final three interviews; a summary sheet of all your EE scores vs the criterion scores for all 13 reliability interviews; the inter-rater reliability calculations for the key EE scales; a group photo (to remind you of your unforgettable Friern experience!) and, finally, a cheque for £100.

Re the cheque: I'm sorry about the delay in returning this money to you, but even after your most recent correspondence it was quite difficult to determine whether £100 or £200 had been paid by you in December 1991. The cheque for £100 mentioned in your letter of 10.12.91 was deposited by me on 13.12.91, but no other record of payment by you had been noted. In looking at my bank statements, however, a further £100 was paid in directly on 17.12.91 in a bank to bank transaction; no name was indicated. I can only assume this money came from you since I can't account for payment by anyone else! Anyway, you'll be relieved to have the matter cleared up.

The EE inter-rater reliability news is all good! Congratulations! Your final ratings were fine, and the calculations produced the best overall results of any returned to date by trainees on your course:

Critical Comments - 0.88 (n=12)

Positive Remarks - 0.94

EOI - 1.00

Warmth - 0.94

Hostility - 0.85

Overall EE - 1.00

The Critical Comments result would have been lower had I included all 13 interviews (if you recall, I said that I would drop one early interview as a 'training' interview), but I suspect it would still be above the desirable 0.80 threshold — if you're curious you can redo the calculation for n=13! Otherwise there are no particular weaknesses. It certainly won't be necessary to listen to additional tapes. Nevertheless I do recommend establishing links with someone else who could act as a co-rater — enabling you to guard against possible rating 'drift'.

I have not forgotten the promise to send you and Gillian a list of researchers studying EE in relatives of children! This will follow shortly I hope...I've been a bit swamped by other work and correspondence in the weeks since the course.

Meanwhile I hope that all goes well with life and work. Do keep in touch and let me know if I can be of further help...

Warm regards,

Chint

Christine Vaughn, Ph.D.

Encls.

### SECTION II - CHECKLIST OF CHALLENGING BEHAVIOURS

This section is concerned with the more problematic or challenging aspects of this person's behaviour. To give a balanced view there will be an opportunity at the end of the section to say something about his or her more positive characteristics.

Has this person exhibited any of the following behaviours during the past month?

|   | Aggressive behaviours                               |    | Enter Appropriate Numbers             |          |   |  |
|---|---|----|---------------------------------------|----------|---|--|
|   |   | Ň  | F                                     | MD       | S |  |
| í | Pinching people?                                    |    |                                       |          |   |  |
| 2 | Biting people?                                      |    |                                       |          |   |  |
| 3 | Scratching people?                                  |    |                                       |          |   |  |
| 4 | Hitting out at people?<br>(ie punching or slapping) |    |                                       |          |   |  |
| 5 | Grabbing, squeezing, pushing or pulling people?     |    |                                       |          |   |  |
| 6 | Kicking people?                                     |    |                                       |          |   |  |
| 7 | Headbutting people?                                 |    |                                       |          |   |  |
| 8 | Pulling people's hair?                              |    |                                       |          |   |  |
| 9 | Choking or throttling people?                       |    |                                       |          |   |  |
|   |   |    |                                       |          |   |  |
|   | Key to rating scales                                |    |                                       |          |   |  |
|   | F Francisco MD Me                                   | NO | · · · · · · · · · · · · · · · · · · · | Causaltu |   |  |

Aggressive behaviours

Enter Appropriate Numbers

|     | Aggressive benaviours   | Enter Appropriate Numbers |    |   |  |  |  |  |
|-----|---|---------------------------|----|---|--|--|--|--|
|     |   | F                         | MD | s |  |  |  |  |
| 10  | Using objects as weapons against people (eg knife or other hand held object)?   |                           |    |   |  |  |  |  |
| ш   | Throwing things at people?  |                           |    |   |  |  |  |  |
| 1.7 | Tearing other people's clothes?   |                           |    |   |  |  |  |  |
| 13  | Making unwanted sexual contact?   |                           |    |   |  |  |  |  |
| 14  | Injuring self (eg head banging, eye poking/gouging, biting or scratching self)? |                           |    |   |  |  |  |  |
|     | ÷   |                           |    |   |  |  |  |  |
|     | Does this person exhibit any other type of aggressive behaviour?                |                           |    |   |  |  |  |  |
|     | Yes 1 No 2  |                           |    |   |  |  |  |  |
|     | If yes, please describe:  |                           |    |   |  |  |  |  |
|     |   |                           |    |   |  |  |  |  |
|     |   |                           |    |   |  |  |  |  |
|     |   |                           |    |   |  |  |  |  |
|     |   |                           |    |   |  |  |  |  |

# Other challenging behaviours (Note: these behaviours are not rated for severity)

|  | Enter Appropriate<br>Numbers |    |  |  |
|--|------------------------------|----|--|--|
|  | F                            | MD |  |  |
| 15 Damaging clothes, furniture or other objects?   |                              |    |  |  |
| 16 Smashing windows?   |                              |    |  |  |
| 17 Slamming doors?   |                              |    |  |  |
| 13 Shouting and swearing at people?  |                              |    |  |  |
| 19 Making loud noises (eg banging, screeching, screaming)?   |                              |    |  |  |
| Zo Threatening to hurt others (either verbally or non-verbally)?   |                              |    |  |  |
| ZI Taking food or drink from others?   |                              |    |  |  |
| 22 Eating inappropriate things (eg rubbish, faeces, dangerous objects)?  |                              |    |  |  |
| 23 Displaying ritualistic or repetitive behaviour<br>(eg closing/opening doors, rearranging furniture,<br>hoarding rubbish etc)? |                              |    |  |  |
| Z4 Engaging in stereotyped behaviour (eg bodyrocking, finger tapping, hand waving etc)?  |                              | ~  |  |  |

|   | Numbers      |   |
|---|--------------|---|
|   | F MD         | į |
| 25 Showing withdrawn behaviour (ie difficult to reach or contact)?                    |              |   |
| Z6 Spitting at people?  |              |   |
| <b>S</b>  |              |   |
| 2.7 Deliberately soiling, wetting or vomiting?  |              |   |
| 28 Smearing or flicking faeces (or anal probing)?                                     |              |   |
| 29 Exposing his or her body inappropriately (eg stripping or masturbating in public)? | <u> </u>     |   |
| 30 Refusing to do things (eg to eat or to move)?                                      |              |   |
| 31 Absconding or trying to abscond from facility?                                     |              |   |
| 32 Causing night time disturbance?  |              |   |
| Does this person exhibit any other type of challenging                                | g behaviour? |   |
| Yes 1 No 2  |              |   |
| If yes, please describe:  |              |   |

#### APPENDIX 4 CONTD

# RATING CODE FOR THE CHECKLIST OF CHALLENGING BEHAVIOURS (Harris et al., 1989).

# FREQUENCY (F)

How often has this behaviour occurred?

1 = never: this behaviour has not occurred during the

past 3 months.

2 = rarely: has occurred during the past 3 months.

3 = occasionally: 1 - 4 times in past month.

4 = often: more than 4 times in the past month.

5 = very often: daily or more often.

## MANAGEMENT DIFFICULTY (MD)

How difficult do you find it to manage this situation?

1 = no problem: I can usually manage this situation without

any difficulty at all.

2 = slight problem: I can manage this situation quite easily

although it does cause me some difficulty.

3 = moderate problem: I find this situation quite difficult to

manage, but I feel confident that I can.

4 = considerable problem: I find it very difficult to manage this

situation on my own.

5 = extreme problem: I simply cannot manage this situation

without help.

## SEVERITY (S)

What were the most serious injuries caused by this behaviour during the past 3 months?

1 = no injury: did not appear to cause pain or tissue damage to other person.

2 = minor injury: caused superficial scratching or reddening of the other person's skin (e.g. light slaps/hits, gentle pushes, hair pulling without force). First aid or medical attention was not needed.

3 = moderate injury: caused moderate tissue damage to other person (e.g. bites/hits/kicks breaking the skin or resulting in bruising). First aid but not medical attention needed.

4 = serious injury: caused serious tissue damage (e.g. cuts/wounds requiring stitching). Medical attention essential.

5 = very serious injury: caused very serious tissue damage (e.g.
bones broken, deep lacerations/ wounds).

Hospitalization and/or certified absence
from work necessary.

# APPENDIX 4 CONTD.: BEHAVIOURAL SUB-CATEGORIES

The numbers below correspond to the numbers marked on the copy of the Checklist of Challenging Behaviour in this Appendix.

| Aggression                   | 1 to 13 (inclusive), and 18, 20 |
|------------------------------|---------------------------------|
| Self-injurious behaviour     | 14                              |
| Destruction towards property | 15, 16, 17                      |
| Anti-social behaviour        | 19, 21, 22, 26, 27, 28, 29,     |
| Rituals and stereotypies     | 23, 24                          |
| Social withdrawal            | 25                              |
| Problems with compliance     | 30, 31                          |
| Night-time disturbance       | 32                              |

# APPENDIX 5

# MALAISE INVENTORY (M. Rutter)

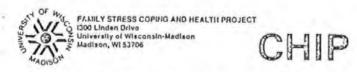
These are some questions about your health.

You do not have to answer them, so please tell me if you do not wish to answer them.

# Please circle the correct answer.

| 1  | Do you often have backache?                 | Yes | No |
|----|---|-----|----|
| 2  | Do you feel tired most of the time?         | Yes | No |
| 3  | Do you feel miserable or depressed?         | Yes | No |
| 4  | Do you often have bad headaches?            | Yes | No |
| 5  | Do you often get worried about things?      | Yes | No |
| 6  | Do you usually have difficulty in falling   |     |    |
|    | asleep or staying asleep?                   | Yes | No |
| 7  | Do you usually wake unnecessarily early     |     |    |
|    | in the morning?                             | Yes | No |
| 8  | Do you wear yourself out worrying about     |     |    |
|    | your health?                                | Yes | No |
| 9  | Do you often get into a violent rage?       | Yes | No |
| 10 | Do people often annoy and irritate you?     | Yes | No |
| 11 | Have you at times had a twitching of the    |     |    |
|    | face, head, or shoulders?                   | Yes | No |
| 12 | Do you often suddenly become scared for     |     |    |
|    | no good reason?                             | Yes | No |
| 13 | Are you scared to be alone when there are   |     |    |
|    | no friends near you?                        | Yes | No |
| 14 | Are you easily upset or irritated?          | Yes | No |
| 15 | Are you frightened of going out alone or of |     |    |
|    | meeting people?                             | Yes | No |
| 16 | Are you constantly keyed up and jittery?    | Yes | No |

| 17 | Do you suffer from indigestion?                 | Yes | No |
|----|---|-----|----|
| 18 | Do you often suffer from an upset stomach?      | Yes | No |
| 19 | Is your appetite poor?                          | Yes | No |
| 20 | Does every little thing get on your nerves      |     |    |
|    | and wear you out?                               | Yes | No |
| 21 | Does your heart often race like mad?            | Yes | No |
| 22 | Do you often have bad pains behind your eyes?   | Yes | No |
| 23 | Are you troubled with rheumatism or fibrositis? | Yes | No |
| 24 | Have you ever had a pervous breakdown?          | Vac | No |



FORM D 1983 U.H. McCubbin

# COPING-HEALTH INVENTORY FOR PARENTS

# Family Health Program

Hamilton I. McCubbin Marilyn A. McCubbin Robert S. Nevin Elizabeth Cauble

#### PURPOSE

CHIP — The Coping-Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which call for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

#### DIRECTIONS

- . To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- · For each coping behavior you used, please record how helpful it was.

HOW HELPFUL was this COPING BEHAVIOR to you and/or your family: Circle ONE number.

- 3 = Extremely Helpful
- 2 = Moderately Helpful
- 1 = Minimally Helpful
- 0 = Not Helpful
- For each Coping Behavior you did Not use please record your "Reason."

Please RECORD this by Checking @ one of the reasons:

|        | Chose n  | ot to use  | it Not     | Possible          |          |       |                |                 |
|--------|----------|------------|------------|-------------------|----------|-------|----------------|-----------------|
|        |          |            | or         |                   |          |       |                |                 |
| PLEASE | BEGIN: P | lease read | and record | your decision for | EACH and | EVERY | Coping Behavio | or listed below |
| сомриз | TER CODE | :S: 1      | 10 000     | a 610 aaa         | FAMID (  | 0000  |                |                 |
|        |          |            |            |                   |          |       |                |                 |

|     |  | Extremely Helplur | Moderately Helpful | Minimally Helpful | Not Helpful | // 1            | not cop<br>his way<br>ecause: |    | r Comp      | outer |
|-----|--|-------------------|--------------------|-------------------|-------------|-----------------|-------------------------------|----|-------------|-------|
| CC  | DPING BEHAVIORS  | Extren            | Morter             | Minin             | Not H       | Chose<br>Nai To | Not<br>Possible               | F  | Usa On<br>S | M     |
| 1   | Trying to maintain family stability  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 2   | and appreciated  | 3                 | 2                  | Ť                 | 0           | 0               | D                             | 00 | 0           |       |
| 4   | Trusting my spouse (or farmer spouse) to help support me and my child(ren) Sleeping  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  | 0           |       |
| 5   | Talking with the medical stall linurses, social worker, etc.) when we visit the nintlical center   | 3                 | 2                  | 1                 | 0           | 00              |                               | 0  |             | 0     |
| 6   | Believing that my child(ren) will get better   | 3                 | 2                  | 3                 | 0           |                 |                               | 0  | 0           |       |
| 7   | Working, outside employment  | 3                 | 2                  | 1                 | 0           | 100             |                               |    | Ó           |       |
| 8   | Showing that I am strong   | 3                 | 2                  | 1                 | 0           |                 |                               | 0  | ~           |       |
| 9   | Purchasing gifts for myself and/or other family members  | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           | 0     |
| 10  | Talking with other individuals/parents in my same situation  | 3                 | 2                  | 1                 | 0           |                 | 0                             | -  |             | 0     |
| 11  | Taking good care of all the medical equipment at home  | 3                 | 2.                 | ı                 | 0           |                 |                               | 0  | ~           |       |
| 12  | Euting   | 3                 | 2                  | Α.                | 0           |                 |                               | _  | 0           |       |
| 13  | Gratting other members of the family to help with chores and tasks at home   | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 14  | Gatting away by myself   | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| 15  | Talking with the Doctor about my concerns about my child(ren) with the medical condition.  | 3                 | 2                  | 1                 | 0           |                 |                               |    |             | 0     |
| 16  | Believing that the medical centur/hospital has my family's best interest in mind   | 3                 | 2                  | 1                 | 0           |                 | 0                             | 0  |             |       |
| 17  | Building close relationships with people   | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| 18  | Believing in God   | 3                 | 2                  | 1                 | 0           |                 |                               | 0  | 5           |       |
| 19  | Develop myself as a person   | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| 20  | Talking with other parents in the same type of situation and learning about their experiences  | 3                 | 2                  | t                 | 0           |                 |                               | 0  |             | O     |
| 21  | Doing things together as a family (involving all members of the family)  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 22  | Investing time and energy in my job  | 3                 | 2                  | 1                 | 0           |                 |                               | _  | 0           |       |
| 23  | Bolieving that my child is getting the best medical care possible.   | 3                 | 2                  | 1                 | 0           | . 0             | 0 .                           | 0  | ~           |       |
| 24  | Entertaining friends in our home   | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           | 0     |
| 25  | Reading about how other persons in my situation handle things  | 3                 | 2                  | 1                 | 0           |                 | 0,                            | 0  |             | 0     |
| 26  | Doing things with family relatives   | 3                 | 2                  | 1                 | 0           | 0.              |                               | 0  | 0           |       |
| 27  | Becoming more self reliant and independent   | 3                 | 2                  | 1                 | 0           | 0               | ö                             | 0  |             | _     |
| 28  | Telling myself that I have many things I should be thankful for<br>Concentrating on hobbies fart, music, jogging, etc.)  | 3                 | 2                  | Ŷ                 | 0           |                 | 0                             |    | 0           |       |
| 30  | Explaining our family situation to friends and neighbors so they will understand us  | 3                 | 2                  | - 2               | 0           |                 |                               | -  |             | 0     |
| 31  | Contract the contract of the c | 3                 | 2                  | i                 | 0           | 0               | .0                            | 0  |             |       |
| 32  | Kceping myself in shape and well groomed   | 3                 | 2                  | 1                 | 0           |                 | Q                             |    | 0           |       |
|     | Involvement in social activities (parties, etc.) with friends  | 3                 | 2                  | . 1               | 0           |                 |                               | C  | 0           |       |
|     | Going out with my spouse on a regular basis  | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| - " | Buing sure prescribed medical treatments for child(ren) are carried out at home on a daily basis   | 3                 | 2                  | 1                 | 0           |                 |                               |    |             | 0     |
| 36  | Building a closer relationship with my spouse  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 37  | Allowing myself to get angry   | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| 38  | Investing myself in my child(ren)  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 39  | Talking to someone (not professional counselor/doctor) about how I feel  | 3                 | 2                  | 1                 | 0           |                 |                               |    | 0           |       |
| 40  | Reading more about the medical problem which concerns me   | 3                 | 2                  | 1                 | 0           |                 |                               |    |             | 0     |
| 41  |  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             |       |
| 42  | Being able to get away from the home care tasks and responsibilities for some relief   | 3                 | 2                  | 1.                | a           |                 | □                             |    | 0           |       |
| 43  | regular basis"   | 3                 | 2                  | f                 | 0           |                 |                               | 0  |             |       |
| 44  |  | 3                 | 2                  | 1                 | 0           |                 | ב                             | 0  |             |       |
| 45  | Daing things with my children  | 3                 | 2                  | 1                 | 0           |                 |                               | 0  |             | -     |

LEASE Check all 45 items to be sore-you have either circled a number or checked a box for each one. This is important.

152

FAM OO

#### APPENDIX 6. CONTD

# MODIFICATIONS TO THE COPING HEALTH INVENTORY FOR PARENTS (McCubbin et al., 1979).

- 5. Talking with teachers when I visit the school.
- Believing that the current difficulties I am experiencing with my child will improve.
- Taking good care of any equipment to assist my child, e.g. special chair, or behavioural diary or charts.
- 15. Talking to the teachers or other professionals about my concerns about my child with learning difficulties.
- Believing that the school and other services have my family's best interests in mind.
- Believing that my child is getting the best education and training possible.
- Encouraging my child with learning difficulties to be more independent.
- 35. Being sure that any recommendations for my child are carried out at home on a regular basis.
- 40. Reading more about the difficulties which concern me.
- 43. Seeking regular assistance with my child.

#### APPENDIX 7

Which of the following professionals and agencies have you had contact with in the past three months?

Please record the number of face to face contacts below.

# Professional/Agency

- 1. School
  - 2. G.P.
  - 3. Respite care,
  - 4. Play groups during holidays.
  - 5. Sitting service.
- 6. Occupational therapist.
- 7. Physiotherapist.
- Speech therapist.
  - 9. Psychologist.
- 10. Community Mental Handicap Nurse.
- 11. Health visitor.
- 12. Social Worker.
- 13. Psychiatrist.
- 14. Toy Library.
- 15. Paediatrician.
  - 16. Senior Clinical Medical Officer.
  - 17. Hospital Casualty Department.

- 18. Other hospital specialities.
- 19. Dentist.
  - 20. Voluntary organizations e.g. Mencap.

Please state if you have had contact with any services other than those listed above.

If you have had contact with other services, please state the frequency of face to face contact over the past three months.

# APPENDIX 8

| NAME  | DEPENDENCY (DAYS)                       |               |                 |
|---|---|---------------|-----------------|
| WARD or ADDRESS   | INTERVIEWERS NAME AN                    | ND JOB        |                 |
|   |   |               |                 |
|   |   |               |                 |
|   | INFORMANT'S NAME                        |               |                 |
|   |   |               |                 |
| DATE OF BIRTH   | DATE ASSESSED                           |               |                 |
| CAUSE OF MENTAL HANDICAP (IF KNOWN)   |   | 0.            |                 |
| USING THE CHECK LIST  |   |               | 1.0             |
| Under each heading ring one number only in the "Day" column.                        |   |               |                 |
| Where there is a night score as well (white numbers), ring one night n              | umber if this is required. There are a  | o Clinical so | ores for nights |
| When you have ringed numbers under ever heading, add them for each days only.       | h page and put the total at the top in  | he *Depende   | eny" box, usin  |
| The numbers are care time in minutes. If in doubt think about how m                 | uch care the resident needs as a result | of the handic | sap.            |
| BASIC C   | ARE                                     |               |                 |
| MOBILITY  |   |               |                 |
| Cause of any walking difficulty (eg. blind, partially sighted, spastic, p           | aralysed, quadraplegic).                |               |                 |
| /min  |   |               |                 |
|   |   |               | 1               |
|   | -                                       | Day           | Night           |
| Unable to walk at all (wheelchair needs pushing, 2 staff to lift etc).              |   | 30            | 5               |
| Support needed for walking, and needs lifting for toilet or bath.                   |   | 23            | 4               |
| Wheels own chair OR uses walking frame OR crawls, bottom-shuffle                    | es etc.                                 | 11            | 3               |
| Walks alone but has frequent falls <u>OR</u> needs support of chairs etc. <u>OF</u> | R needs to be led even inside ward      | 7             | 2               |
| through lack of understanding.  | S Income to the creat make water        |               |                 |
| Walks unaided inside ward, but not outside or up stairs.                            |   | 3             | 1               |
| Walks unaided anywhere.   |   | 0             | 0               |
|   | . L                                     |               |                 |
| FEEDING   |   |               |                 |
| Needs to be spoon-fed, and is difficult to feed.                                    |   | (36           | 3               |
| Needs to be spoon-fed and given drinks  |   | 28            | 2               |
| Can drink and finger-feed, but uneasily.  | 1                                       | 16            | Í.              |
| Can feed using spoon, but uneasily.   |   | 10            | 0               |
| Can use cuttery appropriately, but needs some help or prompting.                    | +                                       | 6             | 0               |
| Needs only minimal supervision during meals.  | -                                       | 2             | 0               |
| Needs no help or supervision during meals.  | -                                       | 0             | 0               |
|   |   | w .           |                 |

# WASHING & BATHING (including teeth)

|  | Day  | Night |
|--|------|-------|
| Needs extra baths (3 or more a week).  | 8    | 4     |
| Does not wash self at all OR needs to be showered nearly every day.  | 5    | 3     |
| Is usually washed and dried, but can make some contribution given time (eg. dry self).                       | 2    | 1     |
| Can wash and dry self without help, but inadequately unless reminded.  | 0    | 0     |
| Washes, baths and dries self without help or reminder.   | 0    | 0     |
| DRESSING (including hair care).  |      |       |
| Cannot dress self at all, and resists being dressed or undressed (including stiffness or rigidity of limbs). | 38   | 4     |
| Cannot dress self at all, but assists passively.   | : 34 | 3     |
| Cannot dress self, but assists actively during dressing or undressing.                                       | 16   | 3     |
| Dresses self but needs continuel propelling or supervision (eg. clothes inside out, buttons undone).         | 10   | 2     |
| Can dress self, but needs help with buttons, faces.  | 6    | 2     |
| Can dress self without supervision, but needs help to select clean and appropriate clothes.                  | 2    | 1     |
| Dresses self, and selects clean and appropriate clothes.   | 0    | 0     |

# TOILETING

| Does not toilet self, wets or soils more than once a day even if taken regularly ("regularly" = 3-5 times a day). | 15 | 10 |
|---|----|----|
| Does not toilet self, wet or soiled about once a day even if taken regularly.                                     | 10 | 9  |
| Not usually wet or soiled if taken, but occasional accidents.   | 7  | 7  |
| Toilets self, but occasional accidents.   | 3  | 6  |
| Takes self, hardly ever or never incontinent  | 0  | 0  |
|   |    | -  |

APPENDIX 9

Farleigh Hospital, Flax Bourton, Bristol, BS19 3QZ.

2nd April 1993

Dear XXX,

I am writing to thank you once again for participating in my research. I have now completed my research. In total I interviewed forty parents of learning disabled children with varying degrees of behavioural disturbance. The aim of my study was to investigate how the parent -child relationship is affected by the child's behaviour disturbance, be it minor or severe, and to determine how different parents fare both in terms of their stress levels, and coping strategies that they might use.

In many ways, parents of children with learning difficulties are the true experts and I have certainly learned a great deal from meeting and talking with you. I hope that through my research I can convey how different parents have adapted to the needs and demands of their learning disabled children. I hope ultimately, that this knowledge will contribute to guiding professional intervention when it is required.

Thank you once again for telling me about X and your relationship with him/her, and how you cope when things are less than easy.

Yours sincerely,

C.E. STURT.

#### APPENDIX 10

# U B H T

10 Marlborough Street Bristol BS1 3NU Fax (0272) 290666 ext 220 Tel (0272) 290666 ext 220

Our ref

Your ref

11 December 1991

Miss C E Sturt 31 Church Road Easton in Gordano Avon BS20 ONB

Dear Miss Sturt

E.2247. "Bepresed Emotion" families of behaviourally disturbed children with learning difficulties

I am pleased to advise you that at its meeting held on 5 December 1991, the Ethics Research Committee gave approval to the above project under consent category B. Some members of the Committee were anxious that the length of the interview would be too invasive and felt it would be preferable to offer the families two 11/2, hour interviews.

The Committee requires to be advised of the starting and finishing dates of projects and would welcome a report on completion of the study.

<u>Data Protection Act 1984</u>. If the project involves computerising data on patients and/or volunteers, it is essential that you contact the Data Protection Co-ordinator, Mr J F Gray at the above address (ext 243) before you begin.

Should you wish to submit further ethical applications, the next meeting will be held on 31 January 1992, the closing date for receipt of applications being 10 January.

Yours sincerely

Mrs S C Hillier

Secretary to the Ethics Research Committee

N H S

The United Bristol Healthcare NHS Trust

### APPENDIX 10 CONTD

## BRISTOL AND DISTRICT HEALTH AUTHORITY

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February 6, 1992

REF: JF/JD

Ms. C E Sturt 31 Church Road Easton-in-Gordano BRISTOL BS20 0NB

Dear Ms Sturt

PROJECT NO.91/68

EXPRESSED EMOTION IN FAMILIES BEHAVIOURALLY DISTURBED CHILDREN WITH

LEARNING DIFFICULTIES

Further to my letter dated January 28, 1992 I am pleased to inform you that the Ethics committee formally ratified your project at their meeting held on January 28, 1992.

Yours sincerely,

JANET FULLFORTH

SECRETARY TO THE ETHICS COMMITTEE

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