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PARENTS OF YOUNG PERSONS WITH LEARNING DISABILITY: AN APPLICATION OF THE FAMILY ADAPTABILITY AND COHESION SCALE (FACES II)

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Introduction

A significant body of research has accumulated on the effects of having a learning disabled (LD) or long-term ill child living at home. Parenting styles (Saetermoe *et al.*, 1991), adaptation patterns (Crnic *et al.*, 1983), parental attitudes and expectations (Edwards-Beckett, 1991) have been examined. Current research acknowledges that relationships and influences between LD children and their families are reciprocal and families with chronically ill children have been reported to cope successfully (Kazak *et al.*, 1988). This represents a significant shift in the conceptualisation of the difficulties that families face when one of their members is learning disabled. A thorough review by Beresford (1994) draws attention to the characteristics of family life more likely to contribute to successful coping when a younger member is learning disabled.

In family life changes occur at the different stages of the life-cycle. Puberty and adulthood may have a de-stabilising effect on the family system (Morrison and Zetlin, 1988). The effects of the handicap on the young person's self-esteem and abilities as well as any parental inability to offer the emotional basis for the process of separation-individuation to take place can considerably delay the transition to the next stage (Shulman and Rubinroit, 1987; Floyd and Zmich, 1991). These difficulties can recur throughout the child's lifetime as developmental progress is not achieved at a typical pace.

Surveys have shown that acting out of threatening and aggressive behaviour peaks in the late teenage years and early 20s, and is more prominent in those with severe learning difficulty (Holland and Murphy, 1990). There may be substantial predisposing organic factors to this behaviour but the familial/environmental contribution can compound and maintain inappropriate behaviours (Murphy, 1994). Parents with LD children have been described as demonstrating conflict avoidance that can result in less conflict resolution, over-protectiveness in their interactions and rigidity (Margalit and Heiman, 1986). They are also more likely to see their children as demanding and unacceptable and to report more marital

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tension and health problems. The purpose of this study was to examine the functioning and mental health of parents of young LD adults who have behaviour disorders and or mental illness using the Family Adaptability and Cohesion Scale (FACES) and the Clinical Rating Scale(CRS). The hypothesis was that those parents would report more psychological symptoms and be clearly differentiated from a similar group without the challenging behaviours.

Challenging behaviour is defined as behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities (Emerson *et al.*, 1988).

Method

The sample consisted of 24 families with learning disabled children, either attending the Learning Disability Unit of a general hospital or known to the local educational authorities and the MENCAP (a parent organisation). The subjects were divided into two groups:

1) parents of 13 LD children with disruptive behaviour and/or mental illness of whom 7 had epilepsy (study group)
2) parents of 11 children without behavioural or mental health problems of whom only 2 had epilepsy (control group).

All the young persons were living at home and were attending special schools or other age appropriate day care facilities in the community. The learning disability ranged from mild to severe in both groups.

There were 2 reconstituted and 1 adoptive family in the study group and 2 single (divorcees) parents and 1 reconstituted family in the control group. In terms of ethnicity, there were 1 Indian and 1 Jamaican family in the study and 1 Italian family in the control group. All the other families were of white English/Irish origins. Parental (paternal) occupation was classified as Class II, III and VI (Office of Population & Surveys Guide, 1991). Parents in the study group were older (mean age: 53.6 years for fathers and 49.3 years for mothers) compared to the control (mean age: 47.8 years for fathers and 46.2 years for mothers). The age range for the two groups of young individuals was 15 to 25 years (mean age: 21.7 and 19 respectively), see TABLE I.

Consent was obtained and the interviews were performed at the family home once. Each spouse was requested to complete separate forms of the FACES and the GHQ. A meeting with the whole family, if possible, was held to obtain information for the Clinical Rating Scale. In order to examine the differences between the study and the control groups a two-way analysis of variance was performed for the dimensions of cohesion, adaptability and the GHQ, using the SPSS statistical package.

Instruments

- General Health Questionnaire (Goldberg and Williams, 1988). Consists of 28 questions grouped into somatic, anxiety, social dysfunction and depression subscales.

TABLE I
Summary of the Demographic Characteristics of the Study and Control Groups

	Study Group (n = 13)	Control Group (n = 11)
	range mean	range mean
Age		
Fathers	36-72 (53.6)	36-64 (47.8)
Mothers	41-66 (49.3)	38-61 (46.2)
Children	17-25 (21.7)	15-22 (19)
Sex (Young Persons)		
Male	7	3
Female	6	8
Epilepsy	7	2
Mental Illness	3	None
Ethnicity	1 Indian 1 Jamaican	1 Italian
Family Status	1 adoptive family 2 reconstituted families	2 single parents 1 reconstituted family

- Family Adaptability and Cohesion Evaluation Scales (FACES II, Olson *et al.*, 1989). This is a 30 item family version self-administered questionnaire which assesses the family environment on the dimensions of cohesion (degree to which family members are separated or connected to their family) and adaptability (the ability of a family system to change in response to situational and developmental stress). On the cohesion dimension families need a balance between too much (enmeshed system) or too little closeness (disengaged system). On the adaptability dimension, between too much (chaotic system) or too little (rigid system) change.
- Clinical Rating Scale (CRS-R, Olson and Volker, 1993). This is a semi-structured interview designed to elicit information on family functioning by obtaining an 'outsider's' perspective. The therapist/researcher rates the family on the dimensions of the family cohesion, communication and adaptability. The family is asked to describe a typical week, how they handle daily routines, decision-making and conflict-solving strategies.

The FACES II and the CRS generate 16 categories of family types. More details about these two instruments can be obtained from the author.

Results

There was no difference in paternal and maternal ratings on cohesion but the study group scored more on the dysfunctional domains on this dimension. On adaptability, there was a significant group event [$F(1,44) = 6.874$, $p = .012$]. More mothers reported psychiatric symptoms according to the GHQ (with a

TABLE II

GHQ* and FACES (Cohesion and Adaptability)† Scores by Sex (m/f) and Group (Study/Control)

Study Group						Control Group					
Fathers			Mothers			Fathers			Mothers		
GHQ	Coh	Ada	GHQ	Coh	Ada	GHQ	Coh	Ada	GHQ	Coh	Ada
28	6	5	5	7	7	0	0	0	11	4	5
6	5	6	7	6	5	10	5	4	11	7	5
11	2	2	22	2	2	14	5	5	0	0	0
9	5	6	12	6	7	7	4	3	8	2	2
8	5	6	20	6	5	3	4	6	5	4	4
5	7	7	12	7	8	9	6	4	12	8	6
0	0	0	19	5	6	6	3	4	6	8	4
8	5	4	18	5	5	2	8	7	11	7	7
5	6	6	6	5	6	9	4	5	14	2	3
10	6	5	16	8	7	0	5	2	10	4	2
5	5	6	9	5	6	0	0	0	21	5	4
9	5	4	14	6	4						
11	5	4	14	4	6						

* A cut-off point of 6 indicated caseness for the GHQ

† The table shows the location of the total cohesion and adaptability scores on the 1-8 score for each dimension. In order to obtain the **family type** the 1-8 cohesion and adaptability scores are added and divided by 2.

TABLE III

CRS Scores† by Group (Study/Control)

Study Group		Control Group	
Cohesion	Adaptability	Cohesion	Adaptability
6	7	4	7
6	4	7	5
4	7	4	4
5	7	4	7
5	4	6	5
6	4	6	5
7	2	6	5
4	7	6	6
5	5	5	5
6	5	6	5
6	2	4	7
3	4		
4	5		

† The table shows the location of the total cohesion and adaptability scores on the 1-8 score for each dimension. In order to obtain the **family type** the 1-8 cohesion and adaptability scores are added and divided by 2.

TABLE IV
Family Subtypes (FACES II) by Group from the Parents' (Fathers' and Mothers') and the Observer's Perspective

Fathers	Mothers	Observer
Families of Behaviourally Disturbed Children		
Balanced: 8 Mid-range: 3 Extreme: 1	Balanced: 12 Mid-range: 0 Extreme: 1	Balanced: 8 Midrange: 5 Extreme: 0
Families of Non-Behaviourally Disturbed Children		
Balanced: 4 Mid-range: 5 Extreme: 0	Balanced: 4 Mid-range: 5 Extreme: 2	Balanced: 10 Midrange: 1 Extreme: 0

cut-off of 5/6) [F(1,44) = 6.397, p = .015]. (TABLE II shows the scores on GHQ, adaptability and cohesion). The Clinical Rating Scale showed no significant differences in the overall functioning, although a trend towards more rigid or disengaged patterns of interaction was evident in the study, compared to the control group (TABLE III).

TABLE IV shows the family subtypes for both groups of families from the parents' (mothers' and fathers') and the observer's perspective.

Discussion

The relationship between challenging behaviour and organic or environmental factors is a complex one. The results highlight a serious problem in family research with LD dependants where stress is not clearly defined and can be associated with numerous variants such as marital relationship prior to the birth of the handicapped child, socio-economic status, available resources and interactions among the family members. The younger age of the LD persons, the lack of disturbed behaviour and availability or use of social support can reduce stress.

FACES demonstrated differences in adaptability but not cohesion between the clinic and non-clinic groups. On the dimensions of cohesion, the parents in the study and the control groups expressed similar perceptions of the degree to which family members are connected to each other and that perception appears to be independent of the presence or absence of challenging behaviour or mental illness in the offspring. This may on the one hand reflect the difficulty of the families with the more severely affected children in being flexible or in changing over time, and on the other, may represent an important source of discrepancy between individuals i.e. spouses. For example, Margalit *et al.* (1989) suggest that mothers prefer to stick to a certain routine so that they can accomplish a number of tasks during the day. It is important to notice that the majority of families in both groups appear to be well within the

balanced/reasonably functioning range. The difference between paternal and maternal ratings in the GHQ (that is mothers showed higher rates of minor psychiatric morbidity) suggests the operation of distinct variables for mothers and fathers in coping with an LD member in the family. It is possible that mothers, the primary carers in all but one of the families participating in the study, carry most of the burden of looking after their disabled child, and consequently are more likely to express dissatisfaction with their lives or depression about their circumstances and the future.

This study suggests that families in treatment are different from those who have not had contact with mental health services. Their patterns of functioning are more rigid and their mothers are predisposed to increased rates of psychiatric disorders. This is the first UK report using FACES. It is a valid and reliable research instrument (Olson *et al.*, 1989) and easy to administer. However, it may have a role not only in research but also in the routine evaluation, treatment and monitoring of interventions in families with difficulties.

Summary

This study investigated the family environment and the parental mental health among families of learning disabled (LD) young persons living at home. A sample of 13 families whose children were treated for behavioural disorders and/or mental illness was compared to 11 families in the community with learning disabilities alone. The instruments used were the Family Adaptability and Cohesion Evaluation Scales (FACES II-30), the Clinical Rating Scale, and the General Health Questionnaire (GHQ-28). The results indicated that despite a greater difficulty in changing (adaptability) in the families of the dependant young persons with behavioural problems and increased psychological disturbance reported by mothers in both groups, the family types were well within the range of normal variation. The merit of using FACES is discussed.

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References

Beresford, B. A. (1994). Resources and Strategies: How Parents Cope with the Care of a Disabled Child. *Journal of Child Psychology and Psychiatry*, 35, 171-209.

Crnic, K. A., Friedrich, W. N. and Greenberg, M. T. (1983). Adaptation of families with mentally retarded children: a model of stress, coping and family ecology. *American Journal of Mental Deficiency*, 88, 125-138.

Edwards-Beckett, J. (1991). Caregiver attributions of success or failure of their mentally retarded dependent. *Journal of Pediatric Nursing*, 6, 121-126.

Emerson, E., Cummings, R., Barrett, S., Hughes, H., McCool, C. and Toogood, A. (1988). Challenging behaviour and community services: who are the people who challenge services? *Mental Handicap*, 16, 16-19.

Floyd, F. J. and Zmich, D. E. (1991). Marriage and the parenting partnership: Perceptions and interactions of parents with mentally retarded and typically developing children. *Child Development*, 62, 1434-1448.

Goldberg, D. and Williams, P. (1988). *A user's guide to the General Health Questionnaire*. Windsor: NFER-Nelson Publishing Company, UK.

Holland, T. and Murphy, G. (1990). Behavioural and psychiatric disorder in adults with mild learning difficulties. *International Review of Psychiatry*, 2, 117-136.

Kazak, A. E., Reber, M. and Snitzer, L. (1988). Childhood Chronic Disease and Family Functioning: A Study of Phenylketonuria. *Pediatrics*, 81, 224-230.

Margalit, M. and Heiman, T. (1986). Family climate and anxiety in families with learning disabled boys. *Journal of the American Academy of Child Psychiatry*, 25, 841-846.

Margalit, M., Shulman, S. and Stuchiner, N. (1989). Behavior disorders and mental retardation. *Research in Developmental Disabilities*, 10, 315 326.

Morrison, G. M. and Zetlin, A. (1988). Perceptions of communication, cohesion and adaptability in families of adolescents with and without learning handicaps. *Journal of Abnormal Child Psychology*, 16, 675-685.

Murphy, G. (1994). Understanding Challenging Behaviour. In: Emerson, E., McGill, P. and Mansell, J. (Eds.). *Severe Learning Disabilities and Challenging Behaviours: designing high quality services*. London: Chapman and Hall Publications.

Olson, D. H., Russell, C. and Sprenkle, D. (1989). *Circumplex Model of Family Systems VIII: Family Assessment and Intervention. Circumplex Model: Systemic Assessment and Treatment of Families*, 7-49. Haworth Press, U.S.A.

Olson, D. H. and Volker, T. (1993). Problem families and the Circumplex model: observational assessment using the Clinical Rating Scale (CRS). *Journal of Marital and Family Therapy*, 19, 159-175.

Saetermoe, C. L., Widaman, K. F. and Borthwick-Duffy, S. (1991). Validation of the parenting style survey for parents of children with mental retardation. *Mental Retardation*, 29,149-157.

Shulman, S. and Rubinroit, C. I. (1987). The second individuation process in handicapped adolescents. *Journal of Adolescence*, 10, 373-384.