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Adult Sibling Expressed Emotion towards Individuals with Intellectual Disabilities: An investigation into the relationship between sibling influences and behavioural outcome.

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Thesis Abstract

This thesis looks at sibling expressed emotion (EE) towards brothers and sisters with intellectual disabilities (ID). The first paper discusses family influences on children's outcome with a focus on those of siblings, both in childhood and adulthood. In order to examine adult sibling relationships and their relation to outcome the construct of EE is considered, with a focus on its previous application to parents of individuals with ID and siblings of other clinical groups. The clinical importance of understanding these relationships is explored.

The second paper explores suggestions for future research made in the literature review, by application of the construct of EE to adult siblings of individuals with ID. Results suggest that sibling EE is related to a number of sibling characteristics and may predict some behavioural variance in individuals with ID. These findings warrant further investigation of EE with this population.

Literature Review:

A Review of Family Members' Influences on each other in Families where one Child has Intellectual Disabilities

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A Review of Family Members' Influences on each other in Families where one Child has Intellectual Disabilities

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Abstract

This paper reviews literature on family influences on outcomes for children with intellectual disabilities (ID). Parenting differences observed towards children with and without ID are explored and factors that may affect these differences are highlighted.

The focus on family influences is then extended to consider the influences of siblings on each other in childhood and through into adulthood. Impacts upon the emotional and behavioural adjustment of siblings to the presence of a child with ID are discussed, and the impacts upon the daily lives of these children are examined. In adulthood, the literature focuses more on the support typically developing siblings can offer to the sibling with ID, their roles and relationships. In order to examine these relationships further and to investigate their impact upon outcome for the adult with ID, the construct of Expressed Emotion (EE) is discussed. The application of EE to families of adults with ID and its use with adult siblings is also examined.

This article comments on methodology used in research in this area and makes suggestions for further research. Clinical implications of such research are outlined in terms of quality of life issues, consideration of the wider family and the inclusion of siblings in family interventions.

Introduction

Children's development is known to be influenced by a number of factors, both genetic and environmental in origin. Parenting is one environmental factor which has been widely investigated in terms of its effects upon outcome for the child. The characteristics of both the child and the parent are determinants of parent-child interactions and therefore the nature of these interactions may vary for different siblings within the same family. This has been illustrated, more specifically, in families where one child has intellectual disabilities (ID). Observations of parent-child interactions in these families have shown how the child with ID may receive different parenting to their siblings (e.g. Corter *et al.* 1992; Floyd & Phillipe, 1993).

In addition to the influences of parenting on child outcome, sibling influences have also been considered as one way of extending our understanding of the impact of the wider family on child outcome. However, in childhood, sibling influences have often been investigated in terms of the impact of having a brother or sister with ID on typically developing siblings in the family. In adulthood, sibling influences have been examined with more of a focus on the supportive nature of siblings for their brothers or sisters with ID.

In order to investigate the emotional climate of the relationship between siblings, where one has ID, consideration is made of the application of the construct of Expressed Emotion (EE). EE has been used not only to measure attitudes and feelings of one family member towards another, but EE status has also been found to relate to outcome.

Parenting Influences on Child Outcome

There has been much research with regards to the influence parenting behaviour has on the development of the child (e.g. see O'Connor, 2002, for a recent review) and this association has often been explored with reference to both genetic and environmental influences throughout the course of the parent-child relationship.

Initially, research followed a unidirectional approach focussing on parental behaviour directly affecting child outcome. For example, 'parenting style' has been one such way of conceptualising parents' behaviours towards their children. Darling & Steinberg (1993) have drawn on historical reviews of parenting style to present a model whereby it is conceptualised as a context that moderates the influence of specific parenting practices on the child. More specifically, it has been suggested that negative parenting interactions can predict negative outcomes for children in the family (e.g. Kendziora & O'Leary, 1993). In addition, the marital relationship has also been identified as having an impact upon the child's development, distress and the parent child relationship (Davies & Cummings, 1994; Howes & Markman, 1989). Research has also widened to encompass the concept of the parenting alliance and its impact on child outcomes. The parenting roles. Mothers' reports of disagreements with their

husbands about childcare have been found to correlate with child behaviour problems (Jouriles *et al.* 1991).

More recently, a bi-directional approach has been favoured which takes into account the role child characteristics play in influencing the parenting the child receives. For example, certain child characteristics which may place more burdens on a parent have been found to place a child at risk for abuse (Bugental & Shennum, 1984). In addition, it been found that unresponsive and inappropriate behaviours displayed by children have been related to high levels of coercive behaviour by parents (Frey *et al.* 1989). However, the child-parent interactions were found to be the same as interactions observed between the child and another adult (a non primary caregiver). The researchers suggested this to be an indication that the child's behaviour elicits a specific response rather than the parental response being representative of a general parenting style.

Parenting children with intellectual disabilities

This focus on parent-child interaction and child outcome in the general developmental literature has been applied in a number of studies examining families where one child has ID. This follows from research with families which suggests parent-child interactions, where the child has ID, may suffer both in quality and quantity (Stoneman *et al.* 1983).

Most research examining parent child relationships in these families has tended to focus on how parents interact differently with their children with ID as compared to parents of children who do not have disabilities (e.g. Floyd & Phillipe, 1993; Lardieri *et al.* 2000). These studies have highlighted there to be both similarities and differences in parent-child interactions with children who have ID and those who do not. Floyd & Phillipe (1993) observed interactions between parents and their child with ID (n=53) and in families where the child was typically developing (n=51). Even though children with ID were more likely to display higher levels of behavioural problems, parents of these children were not more likely to use increased levels of coercion or aversiveness. In fact, in these families it appears that persistent directiveness was necessary to help the child comply with a request (Floyd & Phillipe, 1993) and to engage in play (Tannock, 1988). In addition, mothers of children with ID were more likely to initiate interactions than parents of children without disabilities (Eheart, 1982) and were more likely to play with their child as a form of teaching (Floyd & Phillipe, 1993).

There are however, some very specific problems with these between family research designs. By comparing parent-child interactions where the child has ID with interactions in control families, these studies lack consideration that these families probably function in different ways to other more typical families. Research into other characteristics of families where a child has ID has found that the severity of the child's difficulties is related to the stress experienced by the parents (Smith *et al.* 2001) and that these families may also differ in terms of some very specific demands of caring for a child with very special needs (Beckman, 1983).

Another way of investigating whether parents treat children with ID differently to children without disabilities is to explore parent-child interactions within the same family. Even though there may be difficulties matching for variables such as age and gender within families, this type of design does allow for control of a great number of within family variables.

One such study by Corter *et al.* (1992) explored the consistency of parenting towards two children in the same family, where one had ID. In this study 31 mothers were observed interacting with their child with Down's syndrome (DS) (aged 18-117 months) and their other typically developing child (12-132 months) over two one hour sessions. Overall, mothers were found to be more directive and positive in their behaviours towards their child with DS than their other child, although mothers received more positive behaviours from the other child.

Differential parenting

It would seem then that parents of children with ID may parent these children differently to those who are typically developing and that these differences even occur within the same family. This is supportive of child characteristics being a determinant of parenting.

The study of differential parenting originated from investigations into the observation that children in the same family differ even though biological siblings share

a common familial environment and on average share 50% of their segregating genes (Daniels & Plomin, 1985). Comparison of adoptive and biological siblings (Daniels & Plomin, 1985) identified these differences as environmental in origin. Rowe & Plomin (1981) have described other differential sibling experiences aside from parental treatment, including sibling interactions and extra-familial network influences.

Differential parenting towards siblings within the same family has been observed in families where both children are typically developing (Brody et al. 1992a) and has been shown to be perceived by children of different ages. For example, children, adolescents and young adults have reported that they experienced different intra-familial environments than did their siblings in a wide variety of areas (Daniels et al. 1985; Kowal et al. 2002). In addition, and perhaps more surprising because of cultural and societal norms, parents have also perceived differences in their treatment of their children (Daniels & Plomin, 1985). In support of these perceived differences have been the findings of observational studies of parents interacting with their two children in naturalistic and semi-structured situations (Brody et al. 1987; Brody et al. 1992a). They have found that when parents are together with both siblings they direct higher rates of affectionate, responsive and controlling behaviour towards the younger sibling. Although these data suggest that it is normative for parents to direct more of their behaviour towards the younger, and so more needy child, difficulties with individual child adjustment and family relationships appear to be associated with higher levels of parental differential treatment (e.g. Brody et al. 1987; Dunn et al. 1990).

Dunn et al. (1990) conducted maternal interviews and observations of differential maternal and sibling behaviour in 67 sibling dyads (aged 4 and 7 years). Differential experiences were then related to the adjustment of the older sibling in terms of internalising (e.g. depression, social withdrawal and somatic complaints) and externalising (e.g. aggressiveness, delinquency and hyperactivity) behaviours. Younger siblings' adjustment was also measured when they reached the same age. Significance was only found in this study when comparing maternal self reports of differential parenting and of their child's adjustment. O'Connor (2002) warns against relying on single sources of information on two measures because of the inflated likelihood of finding associations. Therefore, utilising only one family member as a respondent in this study threatens the reliability and credibility of these findings. Keeping this in mind, differential maternal behaviour was found to be an important predictor of adjustment problems in the siblings. Older siblings showed more internalising problems in families in which mothers were less affectionate to the older than to the younger sibling. Also, greater maternal control towards the older than the younger sibling predicted both internalising and externalising behaviours. Differential maternal behaviour explained 34% of the variance of internalising behaviours and 27% of the variance of externalising behavioural problems, independent of the variance explained by family structure variables. Although these results only apply to the normal range of childhood behaviour problems, the authors suggest clinical levels of behavioural problems would also be predicted by differential maternal affection and control and that this may be an even stronger relationship.

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It has been suggested that paternal patterns of behaviour are similar to those found for mothers because the processes by which differential parental behaviour affects sibling relations does not appear to depend on parent gender. Brody *et al.* (1992b) found this to be the case when they conducted observations of father-child and mother-child interactions with both children (109 same sex dyads in order to control for gender effects) in the family. They noted that in terms of differential treatment of siblings, there were no significant differences between mothers and fathers.

A number of other studies have examined sibling relationship correlates of differential treatment, some by means of observational assessments. They are suggestive that differential affection and control (shown by the individual parent) are linked to more negativity in the sibling relationship e.g. sibling conflict and antagonism (Brody *et al.* 1987; Furman & Buhrmester, 1985) and they also relate to competition and controlling behaviours between siblings (Stocker *et al.* 1989). Equal parenting (by both parents) has the most positive correlates for the sibling relationship (McHale *et al.* 1995).

Some researchers have observed that it may be more difficult to parent each child in a family equally when under stress. Research in this field has been mixed, finding some links between parental stress and parental differential treatment of each child, using different indicators of stress, including marital conflict (Deal, 1996; McHale *et al.* 1995; Volling, 1997), and aspects of maternal personality that suggest psychopathology (Dunn & Plomin, 1986).

One way of exploring the impact of the presence of differential parenting in families for the sibling has been to explore children's understanding and their attributional processes about these differences. McHale & Pawletko (1992) conducted a between family study examining the differential parental treatment of siblings in two contexts, families with and without a child with ID. Sixty-two children were examined. 31 with a younger sibling with ID and 31 with a younger sibling who was typically developing. They demonstrated that although parental differential treatment was more likely to occur in families with a child with ID, it was associated with fewer negative effects on the quality of sibling relationship in these families. In fact, an increase in differential maternal discipline and love was related to more positive sibling behaviours in families with a child with ID. These findings were in contrast to the families with typically developing children, where children experiencing relatively more discipline than their siblings reported engaging in lower levels of positive behaviour with their sibling. The authors suggest that children with siblings who have ID may view their sibling's additional needs as legitimising differential parenting. Therefore, children are more likely to perceive differential parenting as justified when they view it as occurring in the service of meeting one of their sibling's unique needs.

Kowal & Kramer (1997) hypothesised that children who viewed parental differential treatment as justified would enjoy more positive sibling relationships than those who viewed it as unjustified. They interviewed 61 children aged 11-13 years separately about their parents' treatment of them and their sibling. Children did not

report differential parenting in two thirds of the instances they discussed. Three quarters of the children who did acknowledge that differential treatment was occurring did not find this to be 'unfair'. These children justified differential parental behaviours by identifying ways in which they and their siblings differed from one another, e.g. differences in age, personal attributes, needs and relationship with parents. Kowal & Kramer's (1997) study highlights the fact that it is not merely the presence of differential parenting that is important for children, but the significance that children place on these events. They also stressed the importance of other factors including birth order, developmental status and family roles as impacting upon children's perspectives of these complex family relationships.

Examination of this literature suggests that parenting in families where one child has ID will, at some level, be differential towards each child. This may be because parents are experiencing a greater degree of stress, making equal parenting more difficult, or as part of a normal process of allocating their resources differentially according to the needs of the child. Either way, children growing up in the same family experience shared and different environments.

The literature still does not fully address the direction of causality of the relationships hypothesised between differential parenting and child outcome. The completion of longitudinal research to explore causality questions (Brody *et al.* 1992b) is necessary and future research should take into account more subtle issues including siblings' relative developmental status, attributions and perceptions of these differences.

Therefore, the ways in which parenting influences the child's outcome are well documented and have been applied to families of children with ID. The influence of other family members on child outcome, particularly siblings, is less well understood. However, previous research suggests that sibling interactions and their socialising influences are important factors in the child's non-shared environment impacting on the child's outcome (Vandell, 2000).

Influences of Siblings on Children

Sibling relationships

In general, sibling relationships have been found to be affected by a number of factors including the relationship between the parent and child (Volling & Belsky, 1992). Also, other family variables such as the gender of the siblings, the children's relative ages and their age spacing appear to be important in determining the quality of childhood sibling relationships. Furman & Buhrmester (1985) investigated perceptions of the sibling relationship by 198 sixth grade children, in order to validate a structured self-report questionnaire. Their findings reflected the wealth of literature that exists about the determinants of childhood sibling relationships. For example, greater warmth and closeness was found in same sex sibling dyads than in opposite sex dyads and this was magnified for close in age siblings. The authors hypothesised that similarities in age and gender may make the sibling relationship more reflective of a friendship. Widely spaced siblings were found to have complementary type relationships where there were more asymmetrical features such as nurturance and admiration than close in age sib-ships,

which were more reciprocal. However, interestingly, conflict was also found to be greatest in sibling dyads that were close in age. Newman (1996) has reviewed the literature on age spacing of siblings in families and suggests that conflict is greatest in these sib-ships because of their similarity in developmental status and so competition for family resources.

Siblings may acquire many social and cognitive skills central to their social development during their interactions with each other (Furman & Buhrmester, 1985) and it has been suggested that the impact each sibling has on the others' development is likely to be magnified when one has ID (Rossiter & Sharpe, 2001).

Siblings of children with intellectual disabilities

The majority of research studies investigating the impact of a sibling with ID have compared groups of siblings according to the nature of their sibling's disability, usually in terms of degree of ID (mild, moderate, severe or profound) or in terms of particular diagnoses (e.g. Down Syndrome or Autism). This group division of siblings with relation to the characteristics of their brothers and sisters appears to be an attempt to recognise the heterogeneity of individuals with ID. In addition, the majority of studies in this area take the stance of examining the impact of the sibling with ID on the typically developing sibling. Older research tends to focus solely on the negative impacts of having a brother or sister with ID on these siblings, although more recent literature appears to acknowledge some of the more positive effects such as the strength

of the relationship and positive impacts upon the siblings' acceptance of other individuals with disabilities and future career choices (e.g. Taunt & Hastings, 2002).

Rossiter & Sharpe (2001) carried out a meta-analysis to integrate 25 studies and 79 effect sizes regarding sibling relationships where one has ID. The majority of early literature was found to make the assumption that these siblings were disadvantaged because their parent's resources and attention were monopolised by the needier child. Early literature also suggested that sibling relationships suffered and that the typically developing sibling was isolated and burdened with extra care-taking responsibilities. Overall, they identified that there was a small negative effect for having a sibling with ID.

Children living with siblings who have ID have been identified as experiencing problems of their own (Evans *et al.* 2001). Parents reported a range of problems for these siblings including bullying at school, worries about not being able to give their sibling enough love and attention, difficult behaviour, eneuresis and a high level of referral to other services in the course of an evaluation of the effectiveness of a support group for school-aged siblings of children with ID and challenging behaviour. These findings directed the completion of a small survey (n=10) of parents with children between the ages of 8-12 years, examining sibling interaction and the sibling's social networks. Whilst the authors acknowledge that the number of participants limited the reliability and validity of this survey, the analysis was suggestive that at least half of these siblings required help with living with a child with ID and challenging behaviour.

Adjustment of siblings of children with intellectual disabilities

Coleby (1995) compared 41 school aged siblings of severely disabled children (ID and physical disabilities) to a comparison group, matched for age and a number of other demographics, to determine the effects of having a severely disabled sibling. The study identified that siblings had higher anxiety levels than controls and this was especially the case if they were a younger sibling. McHale & Gamble (1989) have also found that siblings of children with ID scored higher on measures of anxiety and depression and lower on measures of social acceptance and conduct. Female siblings of younger children in this study were also found to have lower self esteem then controls.

In contrast, Mates (1990) found that the siblings of 33 autistic children showed no adjustment problems and that, in fact, they had higher levels of self-concept than the general population. Although, it should be noted that there was no control group used in this study and that all participating families were enrolled in the TEACCH programme, designed to help families with a child with autism. Therefore, this level of support may have improved self-concept, academic achievement and behaviours and so may mean this was an unrepresentative sample (Mates, 1990). More recently, Kaminsky & Dewey (2001) investigated psychosocial adjustment of siblings of children with autism (n=30) compared with siblings of children with Downs syndrome (DS) (n= 30) and those who were typically developing (n=30). The siblings of children with autism were as well adjusted as siblings of children in the other two groups. Adolescent siblings of children

with ID have also been found to not differ to matched controls on measures of selfefficacy and competence (O'Kane *et al.* 2001).

Behavioural problems displayed by siblings of children with ID have been identified in a number of studies. Gath (1973) investigated 104 siblings of children with DS compared with unmatched controls. The siblings of children with DS were found to be twice as likely to be rated as having abnormal behaviour by their parents and teachers than controls. However, these results have been criticised on the basis that numerous siblings were drawn from the same family, therefore threatening the true independence of cases (Coleby, 1995). Coleby (1995) found that siblings of affected children were more likely to present with higher antisocial behaviour, especially if they were older than the affected sibling, and Cuskelly & Gunn (1993) found more conduct problems in the sisters of children with DS.

Child-related variables have been suggested to be one way of understanding these inconsistencies in the literature. For example, Dyson (1989) found that family variables such as age of the child with ID, birth spacing and family size were all moderators of adjustment. More specifically, there were more behavioural problems when the child with disability was older and when the age gap between the siblings was smaller. In addition, male siblings have been found by Hastings (2003) to be more at risk for adjustment problems. He hypothesised a number of reasons to explain this finding including consideration of the fact that boys may generally score more poorly on measures of adjustment and that brothers of children with autism may have a

neurological vulnerability (risk of autism phenotype for male first degree relatives). Hannah & Midlarsky (1999) also found there to be significant gender differences, with male siblings having more problems at school, and female siblings scoring higher on measures of internalising problem behaviours. However, no gender effects on sibling adjustment (Mates, 1990; Rodrigue *et al.* 1993; McHale *et al.* 1986), social adjustment and depression (Gold, 1993) and perceived competence (Rodrigue *et al.* 1993) have been found in other studies.

Family life

Siblings of children with ID have been identified as having greater household and caregiving responsibilities (Powell & Gallagher, 1993). Older siblings have been found to experience more externalising and internalising problems and these have been suggested to be the result of increased responsibilities at home exacerbating stress (Rodrigue *et al.* 1993).

There is still controversy over whether increased responsibility for non-affected siblings always has a negative effect on adjustment. For example, Mates (1990) found that increased responsibility on the child did not necessarily have a negative impact on achievement or behaviour at home or at school. Also, McHale & Gamble (1989) have found that siblings of children with ID take on more care-giving and household responsibilities but that this is not necessarily associated with psychological or emotional symptomatology requiring therapeutic input. A more recent review of the literature on responsibility and adjustment in siblings of children with ID (Damiani,

1999) concluded that in fact these siblings did not necessarily experience increased responsibilities and if they did it was not necessarily a risk factor for psychological wellbeing. Also, in studies that did include comparison groups, girls had more home and child-care responsibility than boys whether or not there was a child with ID in the home (Damiani, 1999).

Apart from the potential for increased responsibilities, siblings of children with ID have also been identified as having a number of other specific non-shared experiences. Bagenholm & Gillberg (1991) looked at the experiences of 60 siblings; 20 siblings of children with autism; 20 siblings of children with ID and 20 siblings of children with no disability. Children with siblings with autism were found to experience problems directly associated with the nature of autism such as lack of empathy and stereotyped behaviours and also described more problems with their siblings breaking things and disturbing them. Siblings of children with ID have also reported more experiences of their sibling displaying difficult and unusual behaviours and appearing to get upset for no reason (Roeyers & Mycke, 1995) than those with typically developing siblings.

Relationships

Nixon & Cummings (1999) examined how having a sibling with ID predicted a child's reactions to everyday stress of family-related conflicts. Siblings (30 of children with ID and 30 of typically developing children) responded to a series of scenarios depicting disputes involving other family members. Having a sibling with ID was found to predict

sensitisation to these everyday family stresses, including more emotional distress; more expected involvement, perceived threat and personal responsibility; more active coping strategies, and lower thresholds of conflict intensity for responding.

Siblings of children with ID have also been assumed to experience different quality sibling relationships. Siblings of children with ID have been found to show more hostility towards their sibling (McHale *et al.* 1986) and to be more embarrassed by them than those with non-affected siblings (Roeyers & Mycke, 1995). In addition Kaminsky & Dewey (2001) found that siblings of children with autism experienced less intimacy with and less nurturing by their sibling than those with siblings who were not affected or who had DS.

In contrast, children with siblings with ID have also been found to report more affection in their sibling relationships than those with non-affected siblings (Kaminsky & Dewey, 2001). Wilson *et al.* (1989) interviewed school aged siblings of children with severe ID and found consistently high levels of involvement, strong feelings of responsibility and an emphasis on positive aspects of family life. McHale *et al.* (1986) have attempted to explain these apparently opposing findings by suggesting that siblings of children with disabilities show a more wide-ranging set of responses to their relationship than do control siblings. Therefore, although some siblings adjust well, others can experience a significant amount of distress with regards to their affected sibling.

In addition to the impact upon family life and sibling relationships, peer relationships for children with siblings who have ID are also affected. Bagenholm & Gillberg (1991) found that 35% of their sample with autistic siblings reported feeling lonely, having few friends and preferring to stay home to keep their sibling company than go out. Interestingly, siblings in their other groups did not report loneliness. Coleby (1995) has also identified that siblings of children with ID experienced restricted contact with their friends and this was especially the case if they were close in age to the child with ID and if they had no other typically developing siblings. Hastings' (2003) study of 22 siblings (aged 6-16 years) of children with autism, identified that brothers of siblings with autism and also those younger than their sibling with autism were found to engage in fewer pro-social behaviours. However, Coleby (1995) commented upon some positive impact for relations with others, finding that siblings of children with ID demonstrated greater acceptance of other children with disabilities than did a comparison group, especially boys older than their sibling with ID.

Adult Sibling Relationships where one has Intellectual Disabilities

It would seem that growing up with a brother or sister with ID will have inherent in it some potential differences from growing up in a family with typically developing siblings, although these may not all be conceptualised as being negative. It also seems likely that developmental periods influence how siblings are affected, and how they relate to and cope with their siblings. Therefore, we may expect to see greater psychological adjustment in adulthood (Rossiter & Sharpe, 2001). This may be because in adulthood, greater cognitive and social development allows for siblings to re-

conceptualise their relationships better and may provide improved coping mechanisms for dealing with sibling and family stressors, and also because the impact of siblings with ID and the influence of the birth family diminish in adulthood (Rossiter & Sharpe, 2001).

Although the majority of literature on sibling relationships focuses on those in childhood there has been increasing interest in their patterns across the lifespan (Cicerelli, 1982). Studies of the interactions and affection between siblings in middle-age confirms that these relationships are as important as those experienced in childhood (Allan, 1977). Sibling interest in the activities of their brothers and sisters continues even with little contact (Allen, 1977; Cicerelli, 1982) and because of this the majority of adult sibling research has focussed on perceptions of sibling relationships (Stocker *et al.* 1997).

Sibling relationships typically operate best in adults when there is balanced reciprocity between the two and failure to reciprocate has the potential to disrupt this relationship (Avioli, 1989). In the case of sibling dyads where one has ID one might expect it may not be possible for these relationships to be truly reciprocal with a hypothesised negative resultant impact on the sibling relationship. In a study by Zetlin (1986) of adult sibling relationships (35 adults with mild ID and their siblings), a number of sibling relationship types were identified based on the affective quality of the relationships, frequency of contact and level of involvement. These ranged from those siblings who assumed almost surrogate parent roles (having almost daily contact and

oversight of daily events) through to siblings who maintained virtually no contact and had difficult relationships with their brother or sister with ID. Often these relationships were hierarchical rather than equally reciprocal with strong emotional dependency of the adult with ID on their typically developing sibling. However, the majority of this sample regarded reciprocity to be just as important in their sibling relationships and in many cases, although not able to manage an equivalent exchange, siblings with ID offered their assistance in areas they could manage such as babysitting for nieces and nephews. This highlights that even in these sibling relationships there is still an expectation that some offer is necessary for the care and support they receive from siblings. However, it is unclear how these findings would relate to siblings where one has a more severe ID.

Adult siblings play a central role in the lives of their brothers and sisters with ID, especially when they reside together in the family home (Egan & Walsh, 2001; Wyngaarden *et al.* 1996). It has been reported that siblings make up about a quarter of the members of informal support networks of adults with ID living with their parents (Krauss *et al.* 1992). Brothers and sisters of adults with ID can often act as parental surrogates and caretakers (Edmundson, 1985) and it is hypothesised that gradually the balance of responsibility shifts from parents to siblings, who then become the 'next generation' of care-givers (Goetting, 1986). Potential expectations that siblings will continue to provide family care in the future, without planning, can contribute to siblings feeling guilty, angry and confused as to their role, which can result in family conflict (Cleveland & Miller, 1977).

There is evidence to suggest that adult siblings of individuals with ID continue to be emotionally and instrumentally involved with their brother or sister throughout the life span. Cleveland & Miller (1977) surveyed 90 adult siblings (aged over 25 years) of 72 institutionalised adults with ID, focussing on whether their life commitments had been influenced by the presence of their sibling. Most of these siblings reported positive perceptions of growing up with their severely or profoundly disabled sibling and that their subsequent career, marriage and family decisions had not been affected by their sibling. Within the minority of siblings who did report that their adult life commitments had been influenced various patterns were observed. Firstly, female adult siblings had a close relationship with their sibling during childhood and this continued into adulthood and they reported more instances of taking jobs within the caring professions. Secondly, male adult siblings were found to have had limited contact with their sibling whilst growing up and reported lacking information about their sibling's disability and fearing having children with ID of their own. Therefore, it is important to note the impacts of growing up with a sibling with ID are not necessarily always negative.

A number of studies in the 1990s looked at the roles of siblings in families where brothers or sisters had ID (Griffiths & Unger, 1994; Seltzer *et al.* 1991; Wyngaarden *et al.* 1996). Griffiths & Unger (1994) studied 41 pairs of parents and siblings of adult family members with ID who were living with one or both of their parents. They found that almost half (44%) of the siblings were willing to assume care-giving responsibilities in the future but that parents were actually often reluctant for them to do this. Parents

who did consider their children as possible future caregivers tended to look more towards daughters. This is in agreement with the majority of research that suggests female, rather than male, siblings are more likely to assume the care-giving role and are often more likely to be chosen by parents for this responsibility (e.g. Coward & Dwyer, 1990). The demands of adult children with ID and the quality of family communication were predictive of sibling's willingness to help with the provision of future care. The more physical problems experienced by the adult child with ID the less parents wished to pass the care-taking responsibility on to their other children.

Seltzer *et al.* (1991) examined the relationships between adults with ID and their siblings and in turn the effects of these relationships on the well-being of their ageing mothers (aged over 55 years). The analyses were based on data collected in a longitudinal study of 461 families who provided care for their adult child with ID within the home. Two types of sibling involvement were investigated: instrumental (care-giving and companionship) and affective (positive affect and emotion) support. Overall, it was found that it was the norm for siblings in these families to provide affective support (80%), but they were less likely to help with self-care and daily tasks (20%; instrumental support). Once again, this study found an imbalance in the exchange of affective support they get back. How much the sibling was involved with the adult with ID depended on the family environment, so that more involved siblings tended to be part of families that were more expressive and cohesive, more oriented towards achievement and independence and more likely to participate in recreational activities.

Again, the sibling identified as being the 'most involved' with the adult with ID was most likely to be a sister than a brother and more likely to be the same gender as the adult with ID. Sibling involvement was a predictor of maternal well-being, with mothers whose other children were involved with their sibling feeling less burdened than those whose other children were uninvolved.

Wyngaarden *et al.* (1996) extended the above study using the 140 siblings from these families and identified that 36% of these siblings planned to co-reside and 64% to live apart from their sibling with ID in the future. The main factors that differentiated these two groups were firstly, gender, sisters of sisters with ID being more likely to plan to co-reside than any other dyad. Secondly, level of ID differentiated the two groups, with less severe ID predicting co-residence. Thirdly, the greater the number of activities the siblings participated in together the greater the prediction that they would co-reside. Finally, the mothers of siblings planning to co-reside had poorer health and so were more vulnerable.

Factors found to promote emotional involvement between siblings, where one has ID have been found to include proximity of the sibling, gender of the sibling and behavioural problems in the adult with ID (Greenberg *et al.* 1999). More specifically, the closer the sibling lives, if the sibling is a sister as opposed to a brother and the less behavioural problems displayed by the adult with ID, the more emotionally involved the siblings.

More recently, a study investigating the differences and similarities between 78 brothers and 167 sisters (aged 21-59 years old) of adults with ID (with respect to the instrumental and affective aspects of the sibling relationship) found that sisters scored higher than brothers in care-giving and companionship and positive affect aspects of the sibling relationship (Orsmond & Seltzer, 2000). Brothers' sibling relationships were conditioned by the gender of their sibling; brothers of brothers with ID had a more favourable emotional response than did brothers of sisters. Two-wave longitudinal data showed that sibling involvement and closeness increased over time, but was dependent upon changes in their mother's health.

Egan & Walsh (2001) explored the sources of stress for 39 adult siblings of Irish men and women with ID. Siblings who were primary caregivers were older and earned less income than their counterparts in a second group who lived in the parental home and who had an especially close bond with their brother or sister with ID. Perceived social support, as well as their siblings' level of independence, was significantly related to stress. Neither levels of stress nor the presence of a plan for their relative's future distinguished the two groups of siblings.

Rimmerman & Raif (2001) have compared two groups of siblings (76 with and 69 without a brother or sister with ID) in terms of their levels of involvement and role perceptions. Siblings of adults with ID were found to have more frequent contact than siblings of other typically developing individuals. However, as predicted and supported by previous research, the relationship between siblings where one had ID was less

reciprocal in terms of affective and instrumental assistance than between two nonaffected siblings.

Within-family studies of parenting children in the same family, where one has ID, have highlighted how child and parental characteristics determine parenting with a resultant impact on the adjustment of both children. In addition, siblings with ID have been shown to impact on adjustment of the typically developing child in a number of ways. In adulthood, siblings are important members of social and supportive networks for individuals with ID and each have been found to impact on the other and the mothers' well-being. Taken together, these lines of research underline the importance of non-shared environmental influences for these siblings, specifically the experience of having a brother or sister with disability (Anderson *et al.* 1994).

Expressed Emotion

One psychosocial measure of attitudes and feelings towards a relative which has been widely used in research is the construct of Expressed Emotion (EE). This measure has often been related to patient outcomes and has been suggested to be a way in which unshared variance in the family may be assessed (Daley *et al.* 2003; Hirshfield *et al.* 1997; Plomin, 1994).

EE is a measure of emotional climate and relationships which has been used extensively in the mental health literature. It is a concept that has been reviewed at length (Hooley, 1985; Wearden *et al.* 2000) and which has been most widely used in prospective studies to predict outcome in schizophrenia.

Initially, Brown *et al.* (1958) conducted a number of studies in the UK, looking at the influence of environmental factors, such as the family, on relapse rates of patients with schizophrenia. They found that health status was associated with which living group these patients returned to. More specifically, patients were more likely to relapse with a close relative e.g. parent or spouse, than with a more distant relative or in a hostel. This effect also appeared to be dependent on the amount of contact between the relative and the patient.

Brown *et al.* (1962) conducted a follow-up prospective study to identify the exact variables of these living situations that contributed to patient outcome. EE was assessed in the key female relative (usually a wife or mother) for each patient (128 males aged 20-49). They found that patients returning to homes rated as high in emotional involvement were more likely to relapse over the one-year follow-up period than those returning to live with relatives who had been rated as having low levels of emotional involvement. It highlighted the association between relative's emotional attitudes and the deterioration of the patient's illness. In addition, it showed the apparent independence of severity of the patient's disturbance, and finally, the seemingly protective effect of social distance from the involved relative. Nearly all the important themes to arise out of subsequent studies related to EE are to be found in this first study.

Brown and colleagues developed the Camberwell Family Interview (CFI) as a measure of EE. The CFI is a semi-structured interview which is still widely used today.

It evaluates family members for Criticism, Hostility, Emotional Over-Involvement (EOI) and lack of warmth in their relationship with the relative. Individuals with any of these characteristics receive a rating of high EE compared with low EE for asymptomatic individuals. Unfortunately, the CFI can take up to 5 hours to administer with a similar amount of time to score (Mueser *et al.* 1992) and so in more recent studies the Five Minute Speech Sample (FMSS) is often used as a more cost effective alternative, which is a measure of Criticism and EOI (Magana *et al.* 1986). The FMSS requires the relative to talk about the patient for 5 minutes whilst being audio-taped. EE is rated on the basis of the particular statements made in the speech sample and takes into account factors such as tone of voice.

Whilst conducting a replication study, Vaughan & Leff (1976) used a depressed comparison group and found that Criticism was significantly associated with relapse in this depressed group (when they adopted a threshold of two critical comments rather than six). This suggested that EE was not unique to schizophrenia and that it could be usefully applied to relatives of patients with other psychiatric problems and medical conditions. Subsequent studies have investigated EE in the relatives of adults with depression (Hooley *et al.* 1986; Miklowitz *et al.* 1988), anxiety disorders (Tarrier *et al.* 1999) and eating disorders (Blair *et al.* 1995; Szmukler *et al.* 1985). Also, it has been examined in relatives of children with psychiatric (Asarnow *et al.* 1993; Hibbs *et al.* 1991), medical (Hermanns *et al.* 1989) and behavioural problems (Hibbs *et al.* 1991).
The multitude of studies examining EE in various populations is indicative of this being an important family variable related to patient outcome, however it leaves the question of whether EE exerts a general effect through some common pathway in all these disorders or whether it operates on different mechanisms in different disorders (Wearden *et al.* 2000).

Factors determining expressed emotion

EE status appears to reflect a style of interaction between relative and patient. Relatives who score high on Criticism tend to make more critical comments during their interactions with patients and those who are high EOI tend to be more intrusive (Miklowitz *et al.* 1984; Strachan *et al.* 1986). High EE relatives tend to be poor at communication with their affected relative, in that they talk more and listen less effectively (Kuipers *et al.* 1983). Simoneau *et al.* (1998) found that family members with high levels of EE were more likely to engage in negative interactions and to use negative communication strategies than family members with low EE. The patients themselves have also been found to engage in patterns of reciprocal negative non-verbal and verbal interactions when interacting with high EE family members (Simoneau *et al.* 1998).

However, it still is unclear as to what factors determine levels of EE. One way researchers have tried to understand this has been to consider whether it represents a response to certain circumstances or persons (state) or a trait-like characteristic that is relatively more stable. The original researchers believed that EE reflected some

enduring trait of the relatives. Schreiber *et al.* (1995) compared the ratings of EE responses from 17 parents towards one child with a diagnosis of schizophrenia and another without this diagnosis, using a modified version of the CFI. The data suggested that the variables of EOI and warmth were state related, with more EOI shown towards the child with schizophrenia and more warmth towards the sibling. They found no significant differences in critical comments expressed towards either group. However, this study could not establish whether the differences in response patterns preceded or post-dated the onset of the illness in the child with schizophrenia. Despite the study's methodological limitations, the authors suggest that these findings were consistent with high Criticism reflecting a parental trait and EOI resulting from the care of a sick relative.

Hooley & Richters (1995) describe what they believe to be a complex circular relationship between EE and relapse with patients' behaviour leading to changes in relatives' EE, and relatives' EE in turn affecting the course of the patient's illness. Similarly, Birchwood & Smith (1987) present a feedback or adjustment model, where a family's coping efficacy and coping style will develop over time. Other studies have supported this notion of the characteristics of high EE arising from an interaction between the attributes of the relative and of the patient (e.g. Dosseter *et al.* 1994).

How is expressed emotion related to outcome?

It has been hypothesised that relapse or outcome may be mediated via physiological arousal. This hypothesis suggests that living in an adverse home environment

characterised by high EE would result in an accumulation of psychosocial stress and this has been supported by psycho-physiological studies. Tarrier *et al.* (1978) measured electrodermal and cardiovascular activity in a group of patients with schizophrenia living with relatives. The patients were studied interacting with their relatives and high levels of skin conductance were found in patients who lived with their high EE relatives. Excessive arousal in these patients was suggested to contribute to subsequent relapse. These findings have also been replicated in the child literature (e.g. Hibbs *et al.* 1991).

If having a high EE relative is considered to be an environmental stressor, EE can be conceptualised within a vulnerability stress model of schizophrenia. However intervention studies (e.g. Leff *et al.* 1982) appear to be at odds with the notion that physiological arousal is a mediator for high EE in families. They have illustrated that changes in EE are not associated with concomitant changes in psycho-physiological ratings of patients. Therefore, the benefits for patients from changes in relatives' EE do not appear to work solely through changes in level of arousal.

Attributional models

Attributional processes have more recently been suggested to play a part in how EE in caregivers is related to relapse. Attribution theory (Weiner, 1986) states that people seek to explain the events they observe or happen to them, in order to gain a sense of control. The theory suggests people may explain the behaviour of others in terms of causes that 'reside within' the person (internal attribution) or in terms of environmental causes (external attribution).

From an attributional perspective, the way that family members perceive the patient's behaviour is central to the household's emotional climate. Research by Brewin et al. (1991) and Barrowclough et al. (1994) has found that the type of attributions made by relatives of patients with schizophrenia is a powerful predictor of emotional attitudes. For example, relatives who were rated as critical or hostile made more attributions to factors personal to and controllable by the patient. Relatives rated high on EOI made attributions similar to low EE relatives (uncontrollable attributions for the patient's behaviour). Similar work by Lopez et al. (1999) identified that high EE, particularly Criticism, and relatives' perceptions of controllability were predictive of relapse and symptomatology within a nine month follow-up period. Such findings led these researchers to conclude that any predictive significance of EE is due to its association with key causal beliefs of relatives and that these account for relapse possibly through relatives' attempts to limit or control difficult situations. These patterns of attribution have been identified in numerous studies with relatives of patients with depression (Hooley & Licht, 1997; Hooley & Campbell, 2002), children with behavioural problems (Bolton et al. 2003) and older adults with Alzheimer's disease (Tarrier et al. 2002). An intervention study by Brewin (1994), which assessed EE as well as attributonal style, identified that reductions in hostility in relatives of patients with schizophrenia were related to shifts towards more universal and uncontrollable attributions.

However, a criticism of some of this research (e.g. Brewin *et al.* 1991) is that it has typically used the CFI which is lengthy and can elicit multiple attributions.

Therefore, it measures general attributional style of relatives for negative events rather than their responses to specific situations. Such interviews do not directly solicit beliefs so it is impossible to determine whether each relative's causal belief profile in terms of quantity, content and type of attribution is equally representative of their 'true' causal belief structure (Barrowclough *et al.* 1994).

Expressed emotion and intellectual disabilities

The concept of EE has also been applied to the parents of children with ID in a very small number of studies. In these studies, instead of relating EE to relapse rates, associations between EE and patient variables including problem behaviours, cognitive functioning and activities of daily living, and also between EE and caregiver variables such as burden and stress, have been examined.

There are hypothesised to be a number of impacts on family carers of individuals with ID related to this potentially lifelong task, for example stress, burden of care and heightened emotions such as grief. There has been much research into how parents cope with this stress of raising children with ID (Frey *et al.* 1989; Smith *et al.* 2001). Family stress models applied to families where one has a LD (McCubbin & Patterson, 1983) have emphasised the importance of other family members and their relationships together for adequate coping. Research has also supported these ideas finding that spousal and grandparental support can reduce parental stress (Floyd *et al.* 1998; Hastings, 1997).

The first study to examine EE in these families (Greedharry, 1987) assessed EE, using the CFI, in a very small sample of 10 parents and family carers of adults (aged 16-50 years old) with ID. Overall, two of the relatives were rated as high EE (EOI) and there were only low levels of Criticism and no Hostility assessed in these carers. Greedharry suggested that high EOI was a feature of these relationships as these relatives and dependants had a high number of hours of face-to-face contact with each other over the week (approximately 40 hours). Contrary to the belief that caring for a dependant over a long period of time may be a stressful task, Greedharry suggested that the low levels of EE found in this group of relatives suggested they had been able to adjust to their relatives' ID for a significant number of years and had therefore become more accepting of the situation. It is hypothesised that relatives of individuals with ID may be able to do this more successfully and therefore be less critical because a diagnosis of ID is more stable in presentation over a period of time than is schizophrenia where there can often be marked windows of improved functioning (Wearden *et al.* 2000).

Secondly, EE was investigated in the parental primary carers of adolescents with ID using the CFI (Dosseter *et al.* 1994). The mothers of 92 adolescents (14-19 years old) were interviewed and it was hypothesised that high EE of the carer towards the adolescent with ID would be associated with difficulties in the adolescent and the carer and would also be reflected in family functioning and home environment. This more comprehensive study found that high maternal EE was associated with parenting difficulties. High EOI mothers also had a poorer quality of marriage, less social support

and a more insecure style of respite care usage than mothers who were not high EOI towards their children. The children of these mothers also had more severe ID and they displayed more behavioural problems in public. In contrast, highly critical mothers had children who displayed a pattern of more general behaviour disturbance and psychiatric disorder (in particular symptoms of high activity and agitation) and had less severe ID.

In order to understand these findings Dosseter *et al.* (1994) suggest a number of hypotheses. Their first suggestion depicts high EE as an end-state in emotionality, where EOI and Criticism are both ways of coping with this emotionality. Secondly, they suggest high EE is a result of living with the difficult behaviours exhibited by the adolescent with ID. Therefore, behaviour difficulties may cause parents to be more critical and a greater degree of disability may prolong attachment on the part of the carer. Finally, they suggest that both hypotheses may exist side by side in a model where qualities of the carer and dependant serve to perpetuate qualities in the other, a model suggested by other researchers in this field (e.g. Birchwood & Smith, 1987).

More recently, Beck *et al.* (2003) have used the FMSS to explore EE in 33 parents of children with ID (aged 4-14 years). Comparisons of parent's EE towards two of their children (one with ID and the other without) identified that mothers with high EE towards their child with ID had children with more behaviour problems. Analysis also indicated that mothers were more negative towards their child with disability for all domains of the FMSS (except dissatisfaction) regardless of gender of the children. Rates of high EE towards the child with ID were found to be lower when compared to

EE found for other clinical samples of children (e.g. OCD, behavioural problems) but higher than for mothers of normal controls from studies with comparable methodologies. The authors noted that this could be explained by a sample bias whereby the sample of children with ID contained 18 who had DS. Previous research has indicated that mothers of children with DS are more stressed than mothers of controls but less stressed than mothers of children with other disabilities (e.g. Stores *et al.* 1998).

Expressed emotion applied to other respondents

The majority of research using the EE construct has measured EE in relatives of patients with various diagnoses. The most common relatives assessed are the parent, spouse or child of the patient. Subsequently, EE has also been applied to other 'important others' including psychiatric care staff (Ball *et al.* 1992; Moore *et al.* 1992), GPs (Cohen & Wamboldt, 2000) and teachers (Daley *et al.* 2003).

These studies have highlighted how EE is related to similar processes in professionals. For example Cohen & Wamboldt, (2000) used the FMSS to estimate the prevalence of relationship difficulties between 20 parents of children with chronic asthma and their general practitioners (GPs). They found 40% of GPs displayed high EE towards parents of children with chronic asthma. High EE seemed to affect the quality of care provided by these professionals and the outcome for the clients. In addition, Daley *et al.* (2003) have used the FMSS to assess EE in 21 teachers towards disruptive and non-disruptive boys in their class. Although these speech samples did not relate any EOI, they were characterised by the presence of critical comments and a lack

of positive comments. High EE in these cases was associated with the child's behavioural difficulties (usually conduct problems rather than hyperactivity).

Few studies have examined the link between EE of other family members and psychopathology (Asarnow *et al.* 1993). Previous research investigating EE in parents of children with internalising and externalising problems seems to suggest that EE measures behaviour and attitudes that play an important role in the course of psychological adjustment. More specifically it has been suggested that criticism and negativity may be indicative of more pervasive problems within the family system that are maintained in the interactions between family members (Bullock *et al.* 2002).

Bullock *et al.* (2002) have widened the application of EE to investigate adult sibling EE in relation to younger brothers' problem behaviours. In this study the authors conceptualised sibling EE as indicative of a systemic family process. Working from a systemic perspective this team of researchers have regarded EE as measured in a fellow relative as indicative of the affective climate of the entire family system. They assessed 73 older siblings in early adulthood with the Five Minute Speech Sample (FMSS) using a longitudinal design. Sibling critical EE was significantly associated with younger brothers' current and subsequent behaviour problems (including antisocial conduct, substance misuse and arrests). Siblings of younger brothers with behaviour problems were also more likely to be critical, and to report negative relationships with these brothers than were siblings of well-adjusted brothers. Sibling critical EE also predicted brother's maladjustment 1-2 years later, even when parental discipline and sibling

conflict were controlled for. The authors refer to attributional research to suggest that sibling disapproval of their younger brothers reflects a belief that these brothers are responsible for and able to control their antisocial behaviour, which may in turn affect the brothers' ongoing psycho-social adjustment. The authors suggest that this dynamic is likely to be occurring in these adult sibling relationships. These results accentuate the need to assess the EE of all family members and understand the function of sibling process and course in various disorders, in this case, externalising disorders. These results show the importance and relevance of sibling contribution to the family climate and behavioural problems as well as parents.

Future Directions for Research

The bi-directional determinants of parenting have been well documented. However, the influences of siblings on other children in the family, related to outcome for each child are less well understood.

In the case of families caring for adult children with ID, the family, including the siblings, have been found to be very important members of that individual's social and supportive network. In these families, it seems likely, following from previous research, that the attitudes and feelings of these 'important others' towards the individual with ID could well be related to and impact upon adjustment of the adult with ID.

Consideration of the literature using EE as a measure of emotional climate has illustrated that this construct can be usefully applied to the relatives of individuals with

ID (Greedharry, 1987; Dosseter *et al.* 1994) and the adult siblings of those with behavioural problems (Bullock *et al.* 2002). In fact, just as parental EE is clearly related to outcome it seems that siblings' attitudes also present a unique vantage point on individual and family affect and attitudes which may impact on adjustment of the identified patient (Bullock *et al.* 2002).

Application of EE to the siblings of adults with ID would also add something over and above previous studies of the relationships between these siblings. Research examining these relationships has mainly focussed on the types of support offered, the buffering effects for parent caregivers of sibling involvement and siblings' perceptions of their caregiving roles in the future. Examination of the emotional climate of these relationships and their impact on sibling outcome, therefore, seems to be an extension of this research which recognises the importance of these relationships, now and in the future.

<u>Clinical Implications</u>

Research on the emotional relationships of adult siblings where one has ID is important clinically. In providing services for adults with ID it is important that clinicians recognise the importance of siblings and pay attention to the family system as a whole, rather than just the parents (Pruchno *et al.* 1996). In this way, consideration of the siblings and their relationships may have positive implications for the quality of life for the adult with ID, their parents and other family members.

In addition, services involved in care-planning for the future should consider the roles and relationships of the siblings in the family and involve them as much as is possible early on in the planning process.

Investigation of EE in siblings of adults with ID may also highlight the influences of affective relationships on outcome for the adult with ID. If this were the case it would underline the importance of broadening the focus of family interventions to include the 'important others' (Seltzer *et al.* 1991).

Conclusions

Environmental influences such as parenting have been linked to outcome for children. Such environmental influences are also hypothesised to exist between other family members, including siblings. Furthering our knowledge in the area of adult sibling relationships and their relationship to outcome is important clinically to inform interventions and support families in their care of adults with ID. Interventions that modify the elements of EE can have an impact on behavioural and emotional outcomes. This is important for the treatment of behavioural problems given that siblings' attitudes and feelings towards their brother or sister with ID may be a factor in the development and/or maintenance of these behavioural problems.

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Empirical Paper:

An Investigation into the Relationship Between Sibling Expressed Emotion and Behavioural Problems in Adults with Intellectual Disability

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An Investigation into the Relationship Between Sibling Expressed Emotion and Behavioural Problems in Adults with Intellectual Disability

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Running Head: Sibling expressed emotion

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Abstract

Background: Expressed emotion (EE) is a measure of emotional climate between a patient and their relative. It has been shown to be predictive of patient outcome and has been applied to the parents of individuals with intellectual disabilities (ID). This study examined the relationship between sibling EE and behavioural outcome for adults with ID. Method: 30 siblings of 23 adults with ID were assessed for EE status towards their brother or sister with ID using the Five Minute Speech Sample (FMSS). High and low EE siblings were compared on measures relating to a number of variables, including sibling psychopathology, sibling relationship, magnitude of differential parenting and behavioural problems of the adult with ID. The predictive nature of sibling EE on behavioural outcome was examined. **Results:** Of the 30 siblings examined 11 (37%) were assessed as high EE. High EE siblings were found to be more anxious, to have perceived maternal differential parenting to have been more 'unfair' and to report more conflict in their sibling relationship than low EE siblings. High EE siblings were also more likely to have lethargic brothers or sisters with ID. Level of adaptive behaviour was found to be the most important predictor of behavioural problems, with sibling EE contributing to very little of the variance. However, sibling EE was found to be a better predictor of the behavioural problem of lethargy. Conclusions: The results support further investigation of EE in siblings of adults with ID. In addition, they highlight the importance of considering siblings as part of a broader family focus when delivering clinical interventions.

Introduction

Expressed Emotion (EE) is an unique construct which measures the attitudes and feelings people express about a relative and reflects some key aspects of interpersonal relationships and the quality of the emotional climate within the home. It is a concept that has been reviewed at length (Hooley, 1985; Wearden *et al.* 2000) and which has been most widely used in prospective studies to predict outcome in schizophrenia.

EE was originally identified as an important environmental factor which played a part in determining relapse rates of patients with schizophrenia (Brown *et al.* 1958). More specifically, patients were more likely to relapse when returning to live with a close relative than with a more distant relative or in a hostel.

Follow-up prospective studies identified the exact variables of these living situations that contributed to patient outcome so that patients returning to homes rated as high in emotional involvement were more likely to relapse over the one-year follow-up period than those returning to live with relatives who had been rated as having low levels of emotional involvement (e.g. Brown *et al.* 1962). They highlighted the association between relatives' emotional attitudes and the deterioration of the patient's illness, the independence of severity of the patient's disturbance and that outcome was related to the social distance from the involved relative (e.g. Brown *et al.* 1972).

Relatives' EE status appears to reflect a style of interaction with the patient. Relatives who score high on Criticism tend to make more critical comments during their

interactions with patients and those who are highly emotionally over-involved (EOI) tend to be more intrusive (Miklowitz *et al.* 1984; Strachan *et al.* 1986). High EE relatives tend to be poor at communication with their affected relative, in that they talk more and listen less effectively (Kuipers *et al.* 1983).

However, the basis of EE in relatives remains an unresolved issue. The original researchers believed that EE reflected some enduring trait of the relatives, but more recently researchers have begun to question whether it represents a certain response to a certain set of circumstances or person. Schreiber *et al.* (1995) have suggested that high Criticism reflects a parental trait and that EOI probably results from the care of a sick relative, whose needs evoke a response of EOI. However, Hooley & Richters (1995) describe what they believe to be a complex circular relationship between EE and relapse with patients' behaviour leading to changes in relatives' EE, and relatives' EE in turn affecting the course of the patient's illness. Similarly, Birchwood & Smith (1987) present a feedback or adjustment model, where a family's coping efficacy and coping style will develop over time. Therefore the characteristics of high EE arise from an interaction between the attributes of the relative and of the patient.

Much of the earlier research has employed the Camberwell Family Interview (CFI) as a measure of EE (e.g. Chambless & Steketee, 1999; Hubschmid & Zemp, 1989). It evaluates family members for Criticism, Hostility, Emotional Overinvolvement (EOI) and lack of warmth in their relationship with the identified relative. Individuals meeting any of these characteristics receive a rating of high EE compared

with low EE for asymptomatic individuals. Unfortunately, the CFI can take up to 5 hours to administer with a similar amount of time to score it (Mueser *et al.* 1992) and so in more recent studies the Five Minute Speech Sample (FMSS) is often used as a more cost effective alternative, which is a measure of Criticism and EOI (Magana *et al.* 1986). The FMSS requires the identified relative to talk about the individual for five minutes, whilst being audio-taped. EE is rated on the basis of the particular statements made in the speech sample and takes into account factors such as tone of voice. When using the FMSS with families it has been found to underestimate the score of the CFI in 20-30% of the samples, so that a high EE score on the FMSS implies a high EE score on the CFI, but that a low EE relative is not necessarily low on the CFI (Van Humbeeck *et al.* 2002).

Following on from the original research examining families of individuals with schizophrenia, subsequent studies have investigated EE in the relatives of adults with depression (Hooley *et al.* 1986; Miklowitz *et al.* 1988), anxiety disorders (Tarrier *et al.* 1999) and eating disorders (Blair *et al.* 1995; Szmukler *et al.* 1985). Also, it has been examined in relatives of children with psychiatric (Asarnow *et al.* 1993; Hibbs *et al.* 1991), medical (Hermanns *et al.* 1989; Schobinger *et al.* 1992) and behavioural problems (Hibbs *et al.* 1991).

The majority of research using the EE construct has measured EE in relatives of patients with various diagnoses. The most commonly assessed relatives have been the parent, spouse or child of the patient. However, EE has also been applied to other types

of 'important others' including psychiatric care staff (Ball *et al.* 1992; Moore & Kuipers, 1992), GPs (Cohen & Wamboldt, 2000) and teachers (Daley *et al.* 2003).

In the field of Intellectual Disabilities (ID), there have been two published studies to date that have applied the construct of EE to the parents of individuals with ID (Dosseter *et al.* 1994; Greedharry, 1987). The first assessed EE, using the CFI, in a very small sample of 10 parents and family carers of adults (aged 16-50 years old) with ID (Greedharry, 1987). Overall, there were only low levels of Criticism and no Hostility assessed in these carers, with only two rated as high EE (EOI). Greedharry suggested that high EOI was a feature of these relationships with relatives and dependants having high rates of contact with each other over the week (approximately 40 hours). Although caring for someone over a long period of time is often understood to be a stressful task, living with the relative for so many years may mean carers are able to adjust and become more accepting of the situation (Greedharry, 1987). It is also hypothesised that relatives of individuals with ID may be able to do this more successfully and therefore be less critical because a diagnosis of ID is more stable in presentation over a period of time than it is with patients with a diagnosis of schizophrenia, where there can often be marked windows of improved functioning (Wearden *et al.* 2000).

Secondly the mothers of 92 adolescents (14-19 years old) were interviewed using the CFI (Dosseter *et al.* 1994). It was hypothesised that parents with high EE towards the adolescent with ID would be associated with adolescent and parent difficulties and would also be reflected in family functioning and home environment. High maternal EE

was associated with parenting difficulties. High EOI mothers reported a poorer quality marriage, less social support and a more insecure style of respite care usage than mothers who were not high EOI. The children of these mothers also had more severe ID and they displayed more behavioural problems in public. In contrast, mothers who were highly critical had children who displayed a pattern of more general behaviour disturbance and psychiatric disorder (in particular symptoms of high activity and agitation) and had less severe ID.

Dosseter *et al.* (1994) suggested that high EE could be thought of as an end-state in emotionality, so that both EOI and Criticism could be ways of coping with this. Secondly, they suggested high EE could be a result of living with the individual with difficult behaviours. Therefore, behaviour difficulties may cause parents to be more critical and a greater degree of disability may prolong attachment on the part of the carer. A final suggestion was that both hypotheses could exist side by side in a model where both qualities of the carer and child serve to perpetuate qualities in each other as has been found in other childhood problems (e.g. Patterson, 1982).

It is widely recognised that children growing up in the same family experience different environments (Plomin *et al.* 2001). These non-shared experiences can cover a number of factors including differential parenting towards siblings. In families where one child has ID, parents have been shown to exhibit different parenting styles towards this child as compared to the typically developing child (e.g. Corter *et al.* 1992; Floyd & Phillipe, 1993; McHale & Pawletko, 1992). Overall these studies have identified that

parents are more likely to initiate interactions with their child with ID, and to be more dominating and directive in these interactions.

These differences reflect the findings of more general parenting literature where observational studies have found that when parents are together with both siblings they direct higher rates of affectionate, responsive and controlling behaviour towards the younger sibling (e.g. Brody *et al.* 1987; Brody *et al.* 1992). Although these studies suggest that it is normative for parents to direct more of their behaviour towards the younger, and needier child, difficulties with individual child adjustment and family relationships appear to be associated with higher levels of differential parenting (Feinberg & Hetherington, 2001; Stoneman, 2001).

EE has recently been applied to a within family study of parents of children with and without ID (Beck *et al.* 2003) where it was suggested that EE could be a way of assessing this unshared variance in the family (Daley *et al.* 2003; Hirshfield *et al.* 1997).

Beck *et al.* (2003) employed the FMSS to explore EE in 33 parents towards two of their children, one with ID (aged 4-14 years) and the other without. Data from this study suggested that mothers with high EE towards their child with an ID were more likely to have children with behaviour problems. Analysis of differential maternal parenting, through comparisons of EE towards their two children showed that mothers were more negative towards their child with disability for all domains of the FMSS (except dissatisfaction) regardless of the gender of the children. Rates of high EE
towards the child with an ID were found to be lower when compared to EE for other clinical samples of children (e.g. OCD, behavioural problems) but higher than in mothers of controls from studies with comparable methodologies. However, the authors note that this could be because of a possible sample bias, whereby the sample contained 18 children with a diagnosis of Down's syndrome (DS). Previous research has indicated that mothers of children with DS are more stressed than mothers of controls but less stressed than mothers of children with other disabilities (e.g. Stores *et al.* 1998).

Therefore, EE may be a useful way of measuring emotional climate within families of individuals with ID and relatives' EE may impact upon outcome for these family members with ID. However, few studies have examined the link between the EE of family members, other than parents and spouses, with psychopathology (Asarnow *et al.* 1993) although interactions with siblings have been suggested to be important influences on outcome (Vandell, 2000). The assessment of EE in siblings and its relation to outcome for the individual with ID may seem a natural progression for investigation.

This study focuses on the relationships of adult siblings where one has ID because of the identification of the importance of siblings in the social and supportive networks of adults with ID. For example, Krauss *et al.* (1992) examined the social support networks of adults with ID (n=418, average age 33.6 years) who resided in the family home. The average size of social support networks was 7.1 people and on average almost three quarters of the network members were relatives (usually parents

and siblings). Adults' perceptions of sibling relationships are likely to guide and influence patterns of interaction and are important to assess because sibling relationships are often maintained at a distance in adulthood (Stocker *et al.* 1997).

Literature searches have revealed only one paper to date investigating sibling EE. This was not in the field of ID but an investigation of adult sibling EE in relation to younger brother's problem behaviours (Bullock *et al.* 2002). In this study the authors conceptualised sibling EE as indicative of a systemic family process. Seventy-three older siblings were assessed in early adulthood with the FMSS using a longitudinal design. Sibling critical EE was significantly associated with younger brothers' current and subsequent behaviour problems (including antisocial conduct, substance misuse and arrests). Siblings of younger brothers with behaviour problems were also more likely to be critical, and to report negative relationships with these brothers than were siblings of well-adjusted brothers. Sibling critical EE also predicted brother's maladjustment 1-2 years later, even when parental discipline and sibling conflict were controlled for. The authors refer to attributional research and suggest that sibling disapproval of their younger brothers reflects a belief that these brothers are responsible for and able to control their antisocial behaviour, which may in turn affect the brother's ongoing psycho-social adjustment. This study (Bullock et al. 2002) accentuates the need to assess the EE of other family members to understand the function of sibling process and course in various disorders, in this case, externalising disorders. These results show the importance and relevance of sibling, as well as parent, contribution to the family climate and siblings' behavioural problems.

There is a scarcity of literature addressing EE in family members of adults with ID and an absence of literature regarding sibling EE and behavioural problems in adults with ID. Rossiter & Sharpe (2001) have suggested that there should be more studies which assess the adult siblings of individuals with ID and their relationships together. In addition the use of multiple respondents in family research has been promoted in order to protect against the increased likelihood of finding associations when only one family member completes measures about themselves and the identified patient (O'Connor, 2002).

Following on from the literature it would seem likely that similar processes could be expected to be occurring in the relationships between siblings and their brothers or sisters with an ID, as has been shown in studies of other relatives and professionals with various clinical groups.

Therefore, in the present study it was hypothesised that:

- 1. The brothers and sisters with ID of high EE siblings would have higher levels of behavioural problems than those of low EE siblings.
- 2. The variables relating to sibling psychopathology, perceptions of differential parenting and sibling relationships and satisfaction with the family would significantly differ for high and low (EE) siblings.

3. Sibling EE would predict behavioural problems in the sibling with ID when other variables including sibling relationship, differential parenting, family satisfaction and psychopathology were controlled for.

<u>Method</u>

Participants

Participants were 30 siblings of 23 adults with ID (in 19 families 1 sibling took part, in 4 other families 2 siblings were participants and in 1 family 3 siblings took part). Participants comprised 70% sisters and 30% brothers. The average age of the participants was 35 years (SD 11.66) ranging from 20 - 56 years. In terms of birth order, 40% of siblings were second-born in the family and 37% were first-born, the rest being later-born. Nearly half (47%) of the sample had face to face contact with their brother or sister with an ID weekly and 20% had contact daily. The rest of the sample had contact that ranged between twice a month to less than once a month (33%). A large proportion of siblings (70%) lived in the same town as their brother or sister with an ID. One sibling lived out of the UK, in Denmark.

In terms of the sibling with ID, 50% were male and 50% were female. The average age of these siblings was 34 years (SD 9.79) ranging from 22 years to 57 years. Diagnostic descriptions of these siblings included: ID acquired pre-natally or at birth (35%), Down's Syndrome (DS) (39%) and other diagnoses (26%), as described by the parents.

Measures

Measures were employed to assess the following factors:

Emotional Climate

Emotional climate was measured using the Five Minute Speech Sample (FMSS; Magana *et al.* 1986). The FMSS was developed from the Camberwell Family Interview (CFI; Brown & Rutter 1966; Vaughan & Leff, 1976) and provides a brief measure of EE. During the FMSS a relative is requested to speak for 5 minutes about what kind of person their sibling is, the relationship they have with their sibling, and how the two of them get along together, with no questions or interruptions from the researcher.

EE is rated by the coder for:

- Initial statement (IS) the first statement the sibling makes about their brother or sister with an ID (coded either positive, neutral or negative);
- 2. Criticism (CC) critical comments made by the sibling about their brother or sister with an ID (coded as a frequency count);
- Positive remarks (PR) positive statements about the brother or sister (coded as a frequency count);
- Relationship (REL) evidence that the sibling spends time with their brother or sister and enjoys it (coded either positive, neutral or negative);
- Dissatisfaction (DIS) describes a brother or sister's unfavourable behaviours, characteristics, or personality traits, which are not enough to meet the Criticism criteria (coded as either present or absent);

6. Emotional Over Involvement (EOI) - broken down into specific components: Self-sacrificing behaviour/overprotective behaviour (SS), Emotional display (scored when the sibling cries or is unable to speak) (ED), Excessive detail (scored when a large amount of information is given about their siblings' distant past) (EXD), and Statement of attitude (scored when the sibling expresses very strong feelings of love for their brother or sister or a willingness to do anything for them in the future) (SOA).

Information from these dimensions of the FMSS can then be used to derive a high, borderline or low EE score using the Manual for Coding Expressed Emotion (Magana et al. 1986). In this study, sibling speech samples coded as borderline EOI or Criticism were included in the high EE category for the purposes of analysis because of the small number of siblings rated as high EE based on the original coding rubric. The only exception to this was with speech samples rated as borderline solely on the basis of 5 or more positive comments (excessive praise). In these cases, these speech samples were left as low EE. This decision was made on the basis of research by MCarty & Weisz (2002) who suggested that for children without schizophrenia the EOI dimension of the FMSS may be somewhat inappropriate as a risk factor for outcome. They suggested that some levels of EOI were probably appropriate for children who were still dependent on their parents for support. Leff & Vaughan (1987) had also stated in their original work that the criteria for assessing EE may need to be modified for use with different clinical populations. Therefore, it was felt that with this group of relatives of individuals who, although adult, were still dependent on familial support, a similar decision was made to drop this condition for a borderline EE rating.

In this study the FMSS was administered to siblings over the telephone, although this measure is usually given face to face. However a previous study has administered the FMSS over the telephone (Beck *et al.* 2003) and found reliability to be excellent with 100% agreement when compared to face to face administration.

In their review of EE assessment instruments, Van Humbeeck *et al.* (2002) report internal consistency of >0.80 and test-retest reliability r=0.64.

Adaptive Behaviour

The Vineland Adaptive Behaviour Measure (VABS; Sparrow *et al.* 1984) was employed in this study to assess the adaptive level and thus severity of disability of the adult with ID.

The VABS is a semi-structured interview comprising 297 items which allow for the evaluation of 4 sub-domains: communication; socialization; daily living skills and motor skills. Each item in each of the domains is scored as being always present, sometimes present or never present / no opportunity / don't know. The survey form is intended for use with caregivers of individuals from birth to 18 years and 11 months, or with an adult with ID. Scores can be used to determine age equivalents or an adaptive level (low, average or high). The VABS possesses good psychometric properties and has been standardised on a large sample of individuals with and without disabilities.

In this study, only the sub-domains of communication, socialisation and daily living skills were administered because the motor skills sub-domain can only be applied to children. The VABS is normally administered face to face, however, in this study it was administered over the telephone with the parent of the adult with ID. A previous study employing this technique (Beck *et al.* 2003) found there to be good agreement between telephone and face to face administration (r=.78).

Problem Behaviours

In order to identify any specific problem behaviours the Aberrant Behaviour Checklist (ABC; Aman *et al.* 1985a) was administered to the parent of the adult with ID as part of a postal questionnaire pack. The ABC consists of five subscales: irritability (IRRI); lethargy / social withdrawal (LETH); stereotypic behaviour (STER); hyperactivity / non-compliance (HYPE) and excessive speech (EXCE). Each item within the subscales is scored on a 4 point likert scale ranging from 'not at all a problem' to the 'problem is severe'.

Internal consistency for the five sub-scales of the ABC have been shown to be good; Irritability (α =.92); Lethargy (α =.91); Stereotypy (α =.90); Hyperactivity (α =.94) and Excessive Speech (α =.86) (Aman *et al.* 1985b). In this sample alpha coefficients indicated comparable internal consistency for the five scales; Irritability (α =.92), Lethargy (α =.86), Stereotypy (α =.90), Hyperactivity (α =.93) and Excessive Speech (α =.88).

Sibling Anxiety and Depression

The Hospital Anxiety and Depression Scale (HADS; Snaith & Zigmond, 1994) was used to assess levels of sibling psychopathology. The HADS is a self-report measure of psychopathology which was completed by the sibling as part of a postal questionnaire pack.

The HADS comprises 14 items to which the respondent underlines their reply to a statement which comes closest to how they feel. There are four replies to each statement and each is marked between 0-3. Responses can be used to determine an anxiety and depression score for each respondent which falls into either normal, mild, moderate or severe levels. The test's authors recommend that for anxiety and depression scales, raw scores of between 8-10 identify mild cases, 11-15 moderate cases and 16 or above, severe cases (Snaith & Zigmond, 1994). More recently Crawford *et al.* (2001) have used a large non-clinical sample (N=1792) to generate normative data in order to supplement the existing cut-off scores. Although this study was undertaken purely to provide supplementary information, its findings generated suggestions for new clinical cut-offs; so that a score of 10-11 was found to be a more appropriate cut-off (only classifying as cases those who were previously categorised as moderate or severe).

Reliabilities of the sub-scales of anxiety and depression in Crawford *et al.* (2001) were found to be good (α =.82, α =.77, respectively). Internal consistency for the Anxiety and Depression sub-scales of the HADS for this sample were also good (α =.84 and α =.77 respectively).

Family Satisfaction

This was assessed using the Family Satisfaction Questionnaire (FSQ; Olsen *et al.* 1982). This is a 14 item measure of family cohesion and adaptability which was completed by the sibling as part of the postal questionnaire pack. Respondents are asked to rate how satisfied they are with various issues related to family cohesion and adaptability on a five point likert scale ranging from dissatisfied through to extremely satisfied. Summing the 14 items gives a cohesion score, adaptability score and a total score.

The statistical properties of this test include a test-retest reliability score of r=0.75 and good internal consistency (α =0.92). Internal consistency of the scales of cohesion and adaptability in this sample were good (α =.81 and α =.86 respectively).

Perceptions of Differential Parenting

The Sibling Inventory of Differential Experience (SIDE; Daniels & Plomin, 1985) is a 73 item measure which asks one sibling to compare his or her experiences to those of another sibling in various domains. In order to assess the magnitude of sibling perceived differential parenting the Control and Affection scales of the SIDE were completed by the sibling as part of the postal questionnaire pack. The Control scale includes four items measuring parental strictness, punishment, blame and discipline. The Affection scale consists of five items relating to parental pride, favouritism, interest, enjoyment and sensitivity. Siblings responded to these 9 items about their mother and then about their father.

The 9 items on the differential parental treatment subscale load onto two factors; maternal and paternal control and maternal and paternal affection. Each item is rated on a five point likert scale which is summed for both maternal and paternal scores separately. A score of 3 is scored when equal parenting is perceived by the sibling towards them and their brother or sister with ID. A number of previous studies have used the differential treatment subscale of the SIDE as a stand alone scale of differential parenting (e.g. Kowal & Kramer, 1997; Kowal *et al.* 2002)

Previous studies using the SIDE have reported adequate internal consistency and test-retest reliability (Daniels & Plomin, 1985). Internal consistency for the Control and Affection scales in this sample were α =.90 and α =.81 respectively.

Following Kowal & Kramer (1997) and Kowal *et al.* (2002) siblings' perceptions of the fairness of parental preferential treatment were assessed by requesting siblings to rate the fairness of each of the Control and Affection items on the SIDE. Siblings' responses were coded as 1 (fair) or 2 (unfair).

Cronbach's alpha for these judgements of differential parental affection was good (α =.82). However, siblings' judgements of differential parental control on the SIDE was poor (α =.55). Inspection of the items indicated that removal of item 9 "Our mother has disciplined us" would improve the internal consistency of this scale and so this was removed (resulting in α =.62).

In this study, only maternal differential control and affection data were used in analysis, because a significant number of paternal data were missing.

Sibling Relationship

This was assessed by use of the Adult Sibling Relationship Questionnaire (ASRQ; Stocker et al. 1997). This questionnaire assesses the qualitative features of sibling relationships in adulthood and was completed by the sibling as part of the postal questionnaire pack. The ASRQ was developed from the Sibling Relationship Questionnaire (Furman & Buhrmester, 1985) which relates to childhood sibling relationships. The ASRO consists of 81 items spread over 14 scales which are combined to form 3 higher order factors; warmth, rivalry and conflict. For all ASRQ items (except rivalry items) respondents rate how characteristic each item is of themselves and of their sibling using 5 point likert scales, ranging from hardly at all (1) to extremely much (5). Rivalry items are also rated on a 5 point likert scale (1= respondent is usually favoured, 2= respondent is sometimes favoured, 3= neither respondent nor sibling is favoured, 4= sibling is sometimes favoured and 5= sibling is usually favoured). These items are recoded as absolute discrepancy scores (0 = neither sibling is favoured, 1 = parentssometimes favour one sibling over the others and 2= parents usually favour one child over the other).

Scale and factor scores have shown high levels of internal consistency, test-retest reliability and low correlations with measures of socially desirable responding (Stocker

et al. 1997). Internal consistency for the three scales of warmth, rivalry and conflict in the current sample were good (α =.96; α =.83 and α =.85 respectively).

Procedure

Siblings were identified as part of a wider family approach to examining EE within family members of adults with ID. Therefore, two researchers were involved in collecting data from both parents and siblings. This strategy was felt to be superior to researchers taking responsibility for either sibling data or parent data because it provided a more consistent approach for families. The parental data as related to parental EE is presented in another paper (see Lloyd, 2003).

The initial part of this family study involved postage of invitation letters and consent forms to families identified by four Social Services departments and two Social Services run daycentres, based in East and West Dorset. The researchers had already met with these services to clarify inclusion criteria (the individual with ID was over 18 and living with their parents) after which they agreed to take part in this study. Finally, a small number of parents were identified to take part through parent support groups in the Dorset area. In total 206 invitation letters were requested by the various interested groups and Social Services teams for postage to identified families.

Invitation letters comprised information about the study, a telephone contact number for further information and a consent form to complete and return if they wished to take part. Once parents had consented to participate in the research they took part in a

telephone interview (in which they completed the VABS and the FMSS) and completed a number of questionnaires by hand (the ABC plus a number of other measures) as part of a postal questionnaire pack. A more detailed description of this procedure for parents' participation is detailed in the paper relating directly to EE in parents caring for adults with ID (Lloyd, 2003).

Sibling participants for this study were identified through parents during the telephone interview. Parents either requested to be sent an invitation letter to pass onto their other child or they provided their contact details for invitation letters to be posted. In total 53 invitation letters were posted to siblings. As before, the invitation letter comprised information about the research, what participation would entail and a telephone contact number for further information, allowing siblings to make an informed decision to participate. Siblings who wished to take part completed the consent form and returned it in the freepost envelope, outlining a time of the day and week that would be convenient for the researcher to contact them. Researchers endeavoured to call participants at this requested time slot to complete the telephone interview during which the FMSS was administered and demographic data collected. Following completion of the telephone interview, the questionnaire packs (comprising the ASRQ, FSQ, SIDE and the HADS) were posted to participants along with an instruction sheet, which on completion they returned in the freepost envelope.

Researchers made telephone calls to prompt participants who had not returned their questionnaire packs within a 3 week period because of the often poor response rate to questionnaire based studies.

Results

Analysis Strategy

Data analysis comprised three stages; i) comparison of high and low EE siblings on measures of psychopathology, differential parenting, sibling relationship, family satisfaction and characteristics of their brother or sister with ID; ii) development of a continuous scale of EE; iii) investigation of whether sibling EE is a predictor of outcome for brothers or sisters with ID.

In order to meet the first aim of the analysis the data set was split into high and low EE groups using the guidelines set out earlier. Missing data were replaced with a mean for each item, calculated for the high and low EE groups. Total scores were calculated for each factor within each measure. Outliers were identified by the use of box plots and replaced with the mean total (calculated again for both high and low EE groups, excluding the outliers).

Kolmorgorov-Smirnoff tests were conducted to test the parametric status of the data. All of the variables were found to be parametric (Z>.68, p<.745) except for both scales relating to judgements of fairness of differential parenting relating to control and affection, which were non-parametric (Z=1.99, p<.01; Z=1.95, p<.01).

Reliability of the FMSS

Reliability was examined using Cohen's kappa for ratings of high and low EE, IS, REL, DIS, SS, ED and EXD. In addition, the continuous variables of CC, PR and SOA were examined using intra-class correlations. The reliability data are presented in Table 1. Reliability testing was conducted on a random sample of 10 speech samples and three types of reliability were examined for EE.

Insert Table 1 here

Code-recode reliability

To examine code-recode reliability of the FMSS, 10 speech samples were identified. The tapes were rated twice by the researchers within a 1 month period between the two ratings. Using kappa, EE, IS, REL, DIS, SS, ED, and EXD showed good reliability. Intra class correlations for both PR, CC and SOA showed a good association between code and re-code.

Inter-rater reliability

Inter-rater reliability was examined using the same 10 speech samples. Using kappa the same components showed good reliability, with the exception of ED which demonstrated poor reliability. Using intra-class correlations CC, PR and SOA showed a good association between the two researchers.

Test-retest reliability

Using the same 10 respondents, FMSS's were collected and rated on two separate occasions 1 month apart. Test-retest reliability using kappa was good for all components of the FMSS except for IS and REL which were poor. Intra-class correlations showed good associations between 1st and 2nd testing for the components of CC and SOA, however there was a poor correlation for PR. Previous studies have found good levels of test re-test reliability, and specifically using the FMSS with parents of children with LD (Beck et al, 2002). Following from this, it may be that test re-test reliability for this sample was poor on some components of the FMSS because of the small sample size.

Description of the Data

Sibling Expressed Emotion Towards their Brother or Sister with ID

Of the total of 30 siblings interviewed 11 (37%) showed high EE towards their sibling with ID. Only one critical comment was recorded in the whole sample, although 6 siblings did display dissatisfaction. The characteristics of the two groups of siblings (high EE versus low EE) were examined and any significant differences explored.

Independent t-tests were conducted to examine the differences in ages of siblings in the high and low EE groups. Differences in ages of siblings in the high EE (M=37, SD=10.5) and low EE (M=34, SD= 12.5) groups were found to be non-significant (t=.625, df=28, two-tailed p=.54). Comparisons between siblings with high and low EE towards their brother or sister with ID were also conducted for categorical variables, first by inspection of the differences in frequencies (see Table 2) and secondly by the use of Mann Whitney Utests to assess the significance of these differences.

Insert Table 2 here

Using a Mann-Whitney U-Test, no significant differences were found between the gender composition of the high and low EE groups (U=94, two-tailed p=.57). High and low EE siblings were also found to be comparable in socioeconomic status (U=91, two-tailed p=.54) and also how much contact they had with their sibling with ID (U=103.5, two-tailed p=.96). However, high and low EE siblings were found to significantly differ in the distance they lived apart from their sibling with ID (U=66.5, two-tailed p=.04). Siblings who were rated as high EE towards their sibling with ID lived significantly closer to this brother or sister than low EE siblings.

Furthermore, the characteristics of the brothers and sisters (with ID) of siblings in the high and low EE groups were explored. There were no significant differences in the ages of brothers and sisters with ID between the high (M=35.8, SD=10.2) and low (M=33.9, SD=9.0) EE groups (t=.523, df=28, two-tailed p=.61).

There were also no significant differences in the gender composition of brothers and sisters with ID of siblings in the two EE groups (U=97, two-tailed p=.71) or for diagnosis (U=78.5, two-tailed p=.23).

Finally, in order to assess any differences between high and low siblings in terms of their brother or sisters' adaptive level, an ANOVA was conducted based on the parametric nature of the VABS scores. No significant differences were found between the high EE (M=247.82, SD=76.21) and low EE (M=226, SD=105.13) groups for adaptive level of the sibling with ID (F<1; p=.55).

Differences in Behavioural Problems in the Three Diagnostic Groups

The diagnoses of the 23 siblings with ID were assigned to three separate diagnostic groups, DS (39%), other diagnoses (26%) and ID acquired pre-natally or at birth (35%). The data were visually inspected (see Figure 1) and no apparent differences were evident between the levels of behavioural problems for the three groups. The small number of participants in each group precluded formal analysis.

Insert Figure 1 here

Exploring Differences Between High and Low Groups on

Sibling Well-being and Relationship Measures

A series of multi-variate analyses of variance (MANOVA) were performed to test whether there were any significant differences between siblings who were high or low EE in terms of a number of variables relating to them and their sibling with ID. The dependent variables were problem behaviours of the individual with ID (ABC), psychopathology of the sibling respondent (HADS), perceptions of the magnitude of differential parenting (SIDE), sibling relationship (ASRQ) and family satisfaction (FSQ).

EE and Behaviour Problems in the Sibling with ID

A MANOVA was conducted to examine the differences between high and low sibling EE on problem behaviours of the sibling with ID. The dependent variables were the 5 subscales of the ABC and the independent variable was EE (high or low). A non-significant multivariate difference (F<1; p=.73) existed between the two groups (see Figure 2).

Insert Figure 2 here

Because of the small sample size, effect sizes (d) were calculated to explore significance of differences, irrespective of the size of the sample. A moderate effect size (d = -.50) was found for the subscale of lethargy for the two groups. This suggests siblings who show low EE, are more likely to have brothers and sisters with higher levels of lethargy.

EE and Sibling Anxiety and Depression

A MANOVA was conducted to examine the differences in sibling psychopathology between high and low EE siblings. A non-significant multivariate difference $(F_{2,27}=1.475; p=.25)$ was found overall (see Figure 3).

Insert Figure 3 here

However, on inspection of the univariate statistics the anxiety scale of the HADS was marginally significant ($F_{1, 28}=2.89$; p=.10). Therefore an effect size was calculated and was found to be high (d =.71). This indicates that those siblings who are high EE are also more anxious.

EE and Perceived Magnitude of Differential Parenting

The influences of high and low sibling EE on sibling's perceptions of the magnitude of differential parenting by their mother towards them and their sibling with ID was investigated by the use of a MANOVA. A significant multivariate difference ($F_{4, 25}$ = 4; p=.012) was found overall (see Figure 4).

Insert Figure 4 here

Further exploration of the univariate statistics found that only sibling's judgements of the fairness of differential maternal control was significant between the high and low EE groups ($F_{1, 28}$ = 16.77, p < .01). These findings indicate that those

siblings who had high EE towards their sibling with ID also judged the levels of maternal differential control to be more unfair than siblings who showed low EE.

The data for measures of judgements of fairness of maternal differential treatment had originally been found to be non-parametric. Therefore, in order to check that this had not affected the reliability of the MANOVA a non-parametric analysis was conducted. The Kruskal Wallis test revealed the same results.

EE and Sibling Relationship

A MANOVA was conducted to examine the differences between perceptions of sibling relationship for high and low EE siblings and there was a marginally significant multivariate difference ($F_{3, 26}=2.39$; p=.09) (see Figure 5).

Insert Figure 5 here

Further investigation of the univariate statistics found that for the relationship factor of rivalry differences between the two groups were significant ($F_{1,28}$ =4.77; p=.04). If siblings were high EE towards their brother or sister with ID, they were less likely to report rivalry in this relationship.

The differences in the relationship factor of conflict for high and low EE groups were found to be approaching significance (F_{1, 28}=3.81; p=.06). Therefore an effect size was calculated for this factor and found to be high (d=.87). Therefore if siblings were

high EE they were more likely to report conflict in their relationship with their sibling with ID.

EE and Family Satisfaction

No multivariate differences were found for siblings in the high and low EE groups on the measure of family satisfaction (F<1; p=.90) (see Figure 6).

Insert Figure 6 here

Data Reduction

In order to be able to use EE as a predictor variable in a regression model it was necessary to construct a way of representing high or low EE on a continuous scale with more variance than the usual binary code would allow. However, the size of the sample meant that there was not enough power to conduct a factor analysis. Therefore, a continuous measure of EE was developed in line with Beck (2002) whereby a number of variables (Initial statement, relationship, dissatisfaction, positive comments and criticisms) were allocated a binary code of 1 or 0 according to the criteria outlined in Table 3. In Beck (2002) this new continuous variable was found to have good factor structure and was applied to a series of speech samples from mothers of individuals with ID. In this way, siblings were rated between 0-5 for EE, with 0 representing the lowest EE rating and 5 the highest.

Insert Table 3 here

Does Sibling EE towards a Brother or Sister with ID Predict Levels of Behavioural Problems in this Individual?

The extent to which sibling EE explains variance in the behaviour problems of the sibling with ID (independent of this sibling's level of adaptive behaviour and the sibling relationship, magnitude of differential parenting and sibling psychopathology) was explored using a hierachical linear multiple regression analysis.

The order predictor variables were entered into the model was determined by theory (e.g. adaptive behaviour is known to be associated with levels of behavioural problems) and also led by previous statistical analyses.

In a hierachical linear multiple regression model (see Table 4), level of adaptive behaviour was entered first and explained a significant proportion (53%) of the variance (F_{3,26}=9.87, p<.001, r²=.53) of behavioural problems. In the next step of the model, measures of anxiety, differential parenting and relationship variables of conflict and rivalry were entered and explained an additional 10% of the variance over and above adaptive behaviour, although this was not a significant increment (F_{7,19}=.75, p=.63, r^2 =.10). In the last step of the model, EE was entered (in its continuous form). However, this did not explain a significant amount (2%) of further variance in behavioural problems (F_{1,18}=.94, p=.35, r²=.02).

Insert Table 4 here

The beta value indicates that a lower adaptive level is predictive of a higher score for behavioural problems in individuals with ID.

In addition, a series of further hierachical linear multiple regressions were conducted to examine the extent to which the same predictor variables explained variance in the specific elements of behavioural problems (5 subscales of the ABC) of the sibling with ID. Analyses revealed that sibling EE was not a significant predictor of specific behavioural problems. However, sibling EE was marginally significant as a predictor of lethargy.

The same predictors were used in this model to investigate variance in the behavioural problem of lethargy (see Table 5). As before, level of adaptive behaviour was entered first and explained a significant proportion (77%) of the variance (F_{3,26}=29.63, p<.001, r^{2} =.77) of behavioural problems. In the next step of the model, measures of anxiety, differential parenting and relationship variables of conflict and rivalry were entered and explained an additional 5% of the variance over and above adaptive behaviour, although this was not a significant increment (F_{7,19}=.72, p=.65, r^{2} =.05). Entry of EE (in its continuous form) again only explained a small amount (3%) of further variance in lethargy, although it was noted that this was marginally significant (F_{1,18}=3.45, p=.08, r^{2} =.03).

Insert Table 5 here

Therefore, this model would suggest that high sibling EE, towards a brother or sister with ID, predicts lower lethargy in this individual with ID.

Analyses of Data using only one Sibling Respondent per Family

Because participants were 30 siblings of 23 adults with ID, it was thought prudent to remove siblings to leave a sample of 23 (1 sibling per adult with ID) to test if the inclusion of multiple siblings from families had biased the data in any way.

The sibling closest in age to the adult with ID was chosen for inclusion, and identical data analysis was conducted. Similar results were found at each stage of data analysis, suggesting that inclusion of the multiple siblings from the same families did not affect the representativeness of this sample.

Discussion

This study found that high EE siblings were more likely to have brothers or sisters with ID who had lower levels of lethargy than those of low EE siblings. There were no differences between high and low EE siblings on a number of demographic details including age and gender (of both respondent sibling and sibling with ID), socioeconomic status or amount of contact. Although, high EE siblings were found to live significantly closer to their brother or sister with ID than low EE siblings did. High EE siblings were also found to be more anxious than low EE siblings, to judge differential maternal control to be more unfair and to report lower levels of rivalry and more conflict in relationships with their brothers or sisters with ID. Finally, adaptive behaviour was

found to be the best predictor of variance in behavioural problems of the brother or sister with ID rather than EE.

Investigation of how the high and low EE groups of siblings differed in terms of characteristics of their sibling with ID found that siblings with high EE were more likely to have a sibling who had a low score on the subscale of lethargy (ABC). At first, this result appears to contradict this study's hypotheses that high EE would be associated with higher behavioural problems. However, on inspection of the items which comprise this scale it becomes apparent that they relate to a certain lack of responses and activity in the individual with ID rather than outwardly directed behaviours. For example it includes factors such as unresponsivity, preferring to be alone and isolating, lack of communication and inactivity. It could be that higher lethargy in the sibling with ID causes siblings to be more neutral about their relationship (and hence rated as low EE) because there are less occasions for interactions to occur.

Overall, the lack of association between siblings EE status and their brothers' and sisters' behavioural problems may be understood in relation to this specific client group. More specifically, it may be that siblings are able to remain uncritical of behavioural problems, possibly through attributional processes. In line with previous research (e.g. Barrowclough *et al.* 1994; Brewin *et al.* 1991), siblings of adults with ID may be able to attribute many behavioural problems to the diagnosis of ID rather than their siblings as individuals. On the other hand, it could be argued that in this sample there were quite low levels of behavioural problems suggesting that these results may

not be truly representative for families where there are more severe behavioural problems and where we may find higher estimates of EE in siblings.

Using regressional analyses, the adaptive level of the individual with ID explained the largest amount of variance in their total behavioural problems. This can probably be understood in the context of the large area of research that exists about behavioural problems at least in part being related to a lack of communication skills. Therefore, if the adult with ID has a high adaptive level it is likely that they will exhibit fewer behavioural problems. When the individual subscales of behavioural problems were entered as criterion variables, high EE (in its continuous form) was found to predict lower lethargy with marginal significance. However, it is important to remember that the small sample size in this study limits the conclusions we can make based on the results of the regressional analyses.

Investigation of the differences in respondent siblings' characteristics between those in high and low EE groups were found to exist for anxiety, perceptions of the fairness of maternal differential control and sibling relationship variables of conflict and rivalry.

When sibling psychopathology was investigated in the high and low sibling EE groups, siblings who were high EE towards their brother or sister with ID were also found to be more anxious. This is reflective of the literature which has indicated that family members who are rated as high EE towards their relative have been found to be

more at risk for psychological ill health (Dossetor *et al.* 1994) and psychiatric illness (Hibbs *et al.* 1991). In these studies it has been suggested that increased psychopathology is related to coping difficulties experienced whilst caring for the patient. However, in this sample it is more difficult to make any assumptions about the reasons for increased levels of anxiety in siblings who are high EE, except to say that the presence of both could be indicative of their own or their sibling's characteristics.

Significantly more siblings who were high EE perceived differential maternal control to have been 'unfair' throughout childhood. Interestingly, these findings are supportive of the work by Kowal & Kramer (1997) who suggested that the mere presence of differential parenting towards siblings does not necessarily impact negatively on sibling relationships. Instead, what seems to be important is the more subtle question of whether these differences were perceived to be fair or unfair.

In support of the literature, more sibling conflict was perceived in sibling relationships where siblings were rated as high EE towards their sister or brother with ID than for siblings rated as low EE. This makes sense if we conceptualise EE as a measure of the emotional climate in the relationship. However, the fact that that less rivalry was found in high EE siblings is contradictory and less well understood.

Sampling Difficulties

The sample size of 30 in this study was small, but reflects the difficulties experienced in identifying adult siblings to take part in such studies. These difficulties have been

previously noted by other researchers (e.g. Hastings, 2003) who have commented that the lack of statistical power in sibling research is an important issue because sample sizes are typically small. Because of this it was necessary to use multiple siblings from a small number of families. Although, not ideal the inclusion of these siblings was not found in this study to threaten the validity of these results.

Another consideration, are the potential biases in this study through selection processes for inclusion. Siblings were identified through parents, who in turn had been identified by Social Services. Potentially, Social Services may have chosen not to approach families who were experiencing current difficulties. In addition, out of the families approached, this study only surveyed those who chose to take part. Therefore it may be fair to hypothesise that although this was a clinical sample, the data may not fully represent the full range of families served by services and a random selection of siblings of adult children with ID would have possibly provided a more diverse sample.

Measures

The FMSS procedure was used with 30 adult siblings. A proportion of the siblings did report finding it difficult to talk about their brother or sister for the required 5 minutes. Also, they found the structure of such a task particularly difficult e.g. the lack of response from the researcher during administration and being audiotaped. The basis of the FMSS is that it assumes the relative has a degree of regular contact with the client. In this study, siblings did not have as much contact perhaps as has been the case in previous research, with the majority of contact being on a weekly basis rather than daily, with one sibling respondent actually living abroad. Because of this, siblings found it more difficult to fill 5 minutes than parents did. These observations warrant further investigation of EE in siblings.

Secondly, with regards to the FMSS, it could be the case that siblings rated as high EE according to critical factors may be different to those categorised as high EE using EOI factors. This follows from previous research whereby for some clinical groups (e.g. those who were highly dependent because of developmental status) high EOI in relatives was found not to be related to poor outcome (Wamboldt *et al.* 2000). This could be viewed as being applicable in the case of siblings of adults with ID, where the nurturant aspects of these relationships may only reflect the developmental status of each sibling, rather than restrictive EOI. If this were the case, siblings allocated to high EE because of EOI factors may be better placed in the low EE group. However, exploration of these suggestions using this sample was impossible because of the small sample and the inequity of group size if these changes to group allocation were made.

In addition, some research has promoted the use of a more balanced approach when studying families of individuals with ID (e.g. Hannah & Midlarsky, 1999) where the importance of framing questions regarding the impact on siblings in a more positive way has been highlighted. It would seem important that future research using the construct of EE with family members should keep an open mind to some of the positive impacts high EE relatives may have on outcome for the patient as well as some of the risks it may pose.

In this study, those siblings who were coded borderline EE, were in fact included in the high EE group of siblings, because of the low numbers of siblings who met the full criteria for high EE (according to the FMSS manual). The low levels of EE in this sample could be understood with reference to Greedharry's (1987) investigation of EE in parents of those with ID. In this paper, it suggests that parents may have adjusted to their situation over a long period of time. This suggestion is applicable to the case of adult siblings who may have had a number of years to adjust to the situation and who in adulthood may be able to utilise greater cognitive and social development to reconceptualise their relationships better. Therefore, the impact of siblings with ID and the influence of the birth family diminish somewhat in adulthood (Rossiter & Sharpe, 2001).

Although it is important to use siblings' perceptions to assess their relationships, especially when the siblings no longer live together and hence have less contact, it may also have been useful to utilise observational data (Stocker *et al.* 1997) to provide a complete picture. Observations of sibling interaction may have offered more objective data on the nature and process of these sibling relationships. However, the use of observational data was beyond the scope of this study, given the difficulties finding siblings to take part in telephone interviews.

The strengths of the study include the use of independent data sources, i.e. the use of parents' data to assess behavioural problems and adaptive level in the child with

ID, and the sibling respondent to provide data on measures relating to themselves. This is a more robust form of data collection which has been advocated by previous literature within the fields of parenting and EE (e.g. O'Connor, 2002).

Future Directions for Research and Clinical Implications

Rossiter & Sharpe (2001) have highlighted the importance of conducting more research to extend our understanding of adult sibling relationships, where one has ID, and the environmental influences these siblings have on each other. They advocate studies that specifically employ observational data to collaborate with sibling and parent reports (Rossiter & Sharpe, 2001). This type of research could be useful to investigate whether sibling EE is reflected in their interactions with their siblings with ID, as has been found between other family members and adults with mental health problems (e.g. Miklowitz *et al.* 1984; Simoneau *et al.* 1998; Strachan *et al.* 1986). In this way, researchers could investigate the ways in which interactions vary as a function of sibling EE and other sibling variables.

Possible limitations of this study taken alongside some of the good effect sizes identified, are suggestive of the need for further investigation of sibling EE towards adults with ID, using samples including more 'at risk' families.

The finding that significantly more high EE siblings perceived differential maternal control in childhood to be unfair than did low EE siblings, has a number of clinical implications. Services working with families of children with ID should be

aware of the long-term implications of children's attributions of differential parenting. Therefore, alongside support groups for siblings of children with ID, clinicians could also support and educate parents about providing clear explanations to typically developing children about the reasons behind preferential treatment and help these children explore and maybe modify their perceptions of what constitutes fair and unfair treatment (Kowal *et al.* 2002).

The findings that high EE siblings are more anxious and perceive their relationships with their brothers or sisters with ID to be more conflictual in addition to the fact that siblings are often one of the most important members of the adult with ID's social network has a number of clinical implications. Firstly, it indicates that sibling relationships should be considered during assessment of individuals with ID, so that the family system is considered as a whole (Pruchno *et al.* 1996). Secondly, the application of interventions designed to decrease critical attitudes regarding the client have been found to improve outcome (e.g. Leff *et al.* 1982). Therefore, in the field of ID, similar interventions may have subsequent positive effects, and these interventions would benefit from a broader family focus including adult siblings (Seltzer *et al.* 1991).

Conclusion

This study has extended our knowledge of the construct of EE as applied to siblings of adults with ID. The limitations and merits of this study should be taken alongside previous research to determine where future research efforts in this area should be directed and also which methodological considerations may improve our understanding of these complex and long-lasting relationships. Such research is important to support families caring for an adult with ID and more specifically to include adult siblings in these family approaches.

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Table 1:

Reliability of EE components using the FMSS (N=10)

Measures	Code-recode	Inter-rater	Test-retest
	К	К	ĸ
High or Low EE	100%	100%	100%
Initial Statement	1.0*	.78*	18
Relationship	1.0 *	.80*	.20
Dissatisfaction	100%	100%	100%
Self Sacrificing	100%	100%	100%
Emotional Display	100%	100%	100%
Excessive Detail	100%	11	100%
	ICC	ICC	ICC
Criticisms	100%	100%	100%
Positive Remarks	.97*	.97*	.37
Statements of Attitude	100%	100%	100%

Note

* = p< .01

 $\kappa =$ Cohen's kappa

ICC = intra-class correlation coefficients

Table 2:

Comparisons between siblings with High versus Low expressed emotion towards their brother or sister with ID.

Sibling Variables	High EE N=11 Frequency (%)	Low EE N=19 Frequency (%)	
Gender			
Female	7 (64)	14 (74)	
Male	4 (36)	5 (26)	
Socioeconomic Status			
Managerial and technical	4 (36)	8 (42)	
Skilled (non-manual)	2(18)	6 (32)	
Skilled (manual)	5 (46)	4 (21)	
Semi-skilled	-	1 (5)	
How far the two siblings			
live apart			
Same town/city	10 (91)	11 (58)	
Between 50-100 miles	1 (9)	1 (5)	
Between 100-200 miles	-	2 (11)	
Between 200-500 miles	-	4 (21)	
over 500 miles	-	1 (5)	
How much contact between			
the two siblings			
Daily	1 (9)	5 (26)	
Weekly	7 (64)	7 (36)	
Twice a month	2 (18)	2(11)	
Once a month	-	2(11)	
Less than once a month	1 (9)	3 (16)	

Table3:

New Scoring System for Continuous EE Variable.

EE Factor	FMSS Coding		Numerical Code
Initial Statement	Positive		0
	Neutral		0
	Negative		1
Relationship	Positive		0
	Neutral		0
	Negative		1
Dissatisfaction	Present		1
	Absent		0
Criticisms	Number	0	0
		1 or more	1
Positive Comments	Number	0	1
		1 or more	0

Table 4:

Hierachical multiple regression of predictors of behavioural problems of the sibling with ID.

Steps		B	Beta	р
Step 1	Adaptive Behaviour	38	56	.10
	Socialisation	.01	.03	.92
	Daily Living Skills	14	22	.45
	Communication			
Sten 2	Sibling Anxiety	-1 12	- 19	24
Step 2	Differential Maternal Control	-6.79	12	.21
	Differential Maternal Affection	-0.79	22	.12
	Independent of Differential Maternal	2.15	02	.02
	Control	2.70	.02	.71
	Judgements of Differential Maternal	-62.69	11	.52
	Affection	,		
	Sibling Conflict	.03	.02	.92
	Sibling Rivalry	24	05	.75
Step 3	EE	-4.35	16	.35

Table 5:

Hierachical multiple regression of predictors of lethargy in the sibling with ID.

Steps		В	Beta	р
Step 1	Adaptive Behaviour	23	87	<.01
	Socialisation	02	10	.59
	Daily Living Skills Communication	.02	.09	.66
Step 2	Sibling Anxiety	23	11	.35
-	Differential Maternal Control	-1.47	13	.27
	Differential Maternal Affection	-1.86	09	.46
	Judgements of Differential Maternal Control	2.14	.05	72
	Judgements of Differential Maternal Affection	3.91	.02	.88
	Sibling Conflict	04	06	.65
	Sibling Rivalry	.21	.12	.30
Step 3	EE	-2.04	20	.08

Figure 1:

Comparison of the means of behavioural problems (as measured by the Aberrant Behaviour Checklist) of siblings with intellectual disabilities according to diagnostic group.



Note: IRRI = Irritability LETH = Lethargy STER = Stereotypy HYPE = Hyperactivity EXCE = Excessive speech

Figure 2:

Comparisons of the means of the 5 subscales of the Aberrant Behaviour Checklist between high and low EE sibling groups.



Note: IRRI = Irritability LETH = Lethargy STER = Stereotypy HYPE = Hyperactivity EXCE = Excessive speech

Figure 3:

Comparisons of the means of the 2 subscales of the Hospital Anxiety and Depression Scale between high and low EE sibling groups.



Figure 4:

Comparisons of the means of the 2 subscales of the Sibling Inventory of Differential Experience (and judgements about their fairness) between high and low EE sibling groups.



Note: JU Control = Judgements of differential control JU Affec = Judgements of differential affection

Figure 5:

Comparisons of the means of the 3 subscales of the Adult Sibling Relationship Questionnaire between high and low EE sibling groups.



Figure 6:

Comparisons of the means of the 2 subscales of the Family Satisfaction Questionnaire between high and low EE sibling groups.



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	Ethical Approval Sibling Inventory of Differential Experience (SIDE) Adult Sibling Relationship Questionnaire (ASRQ) Flowchart depicting Recruitment Procedure Invitation Letter Instruction sheet (accompanied the questionnaire pack) Instructions to Authors (Journal of Intellectual Disability Research)

Appendix I

Ethical Approval



University of Southampton

Department of Psychology University of Southampton Highfield Southampton SO17 1BJ United Kingdom

Telephone +44 (0)23 8059 5000 Fax +44 (0)23 8059 4597 Email

10 September 2002

Lindsey Rouse Flat 1, Carlton Mount 2 Cranborne Road Bournemouth BH2 5BR

Dear Lindsey,

<u>Re:</u> <u>An investigation into the relationship between sibling expressed emotion and challenging behaviour in adults with a learning disability</u>

The above titled application - which was recently submitted to the departmental ethics committee, has now been given approval.

Should you require any further information, please do not hesitate in contacting me on 023 8059 3995. Please quote reference CLIN/2002/28

Yours sincerely,

KMhucas

Kathryn Lucas Ethical Secretary

cc. Janet Turner

Appendix II

Sibling Inventory of Differential Experience (SIDE)

- This questionnaire relates to your parents interactions with you and your sibling with a learning disability.
- Circle the numbers that fit with the right statement for your MOTHER on this page (and your FATHER on the next page).
- If your parents were divorced or one of them died answer the questions for the parent with whom you lived with for the longest period of time.
- In the end column please indicate whether you felt these interactions with you and your sibling were fair or unfair.

	Our mother was much more this way towards my sibling than me	Our mother was a bit more this way towards my sibling than me	Our mother was the same towards my sibling and me	Our mother was a bit more this way towards me than my sibling	Our mother was much more this way towards me than my sibling	Was this fair or unfair? (Please circle)
Has been strict with us	1	2	3	4	5	Fair / Unfair
Has been proud of the things we have done	1	2	3	4	5	Fair / Unfair
Has enjoyed doing things with us	1	2	3	4	5	Fair / Unfair
Has been sensitive to what we think and feel	1	2	3	4	5	Fair / Unfair
Has punished us for our misbehaviour	1	2	3	4	5	Fair / Unfair
Has shown interest in the things we like to do	1	2	3	4	5	Fair / Unfair
Has blamed us for what another family member did	1	2	3	4	5	Fair / Unfair
Has tended to favour one of us	1	, 2	3	4	5	Fair / Unfair
Has disciplined us	1	. 2	3	4	5	Fair / Unfair

Appendix III

Adult Sibling Relationship Questionnaire (ASRQ)

• This questionnaire is concerned with your relationship with your sibling with a learning disability. Each question asks you to rate how much different behaviours and feelings occur in your relationship. Try and answer the questions as your relationship is now, not how it was in the past or how you think it might be in the future.

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
1. How much do you and this sibling have in common?	1	2	3	4	5
2. How much do you talk to this sibling about things that are important to you?	1	2	3	4	5
3. How much does this sibling talk to you about things that are important to him or her?	1	2	3	4	5
4. How much do you and this sibling argue with each other?	1	2	3	4	5
5. How much does this sibling think of you as a good friend?	1	2	3	4	5
6. How much do you think of this sibling as a good friend?	1	2	3	.4	5
7. How much do you irritate this sibling?	1	2	3	4	5
8. How much does this sibling irritate you?	1	2	3	4	5
9. How much does this sibling admire you?	1	2	3	4	5
10. How much do you admire this sibling?	1	2	3	4	5

0	Please	circle	the	correct	response	for	you.
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	I am Usually Favoured	I am Sometimes Favoured	Neither of us is Favoured	This Sibling is Sometimes Favoured	This Sibling is Usually Favoured
11. Do you think that your mother favours you or this sibling more?	1	2	3	4	5
12. Does this sibling think your mother favours him/her or you more?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
13. How much does this sibling try to cheer you up when you are feeling down?	1	2	3	4	5
14. How much do you try to cheer this sibling up when he/she is feeling down?	1	2	3	4	5
15. How competitive are you with this sibling?	1 .	2	3	4	5
16. How competitive is this sibling with you?	1	2	3	4	5
17. How much does this sibling go to you with help with non-personal problems?	1	2	3	4	5
18. How much do you go to this sibling for help with non-personal problems?	1	2	3	4	5
19. How much do you dominate this sibling?	1	2	3	4	5
20. How much does this sibling dominate you?	1	2	3	4	5
21. How much does this sibling accept your personality?	1	2	3	4	5
22. How much do you accept this sibling's personality?	1	2	3	4	5

	I am Usually Favoured	I am Sometimes Favoured	Neither of us is Favoured	This Sibling is Sometimes Favoured	This Sibling is Usually Favoured
23. Do you think that your father favours you or this sibling more?	1	2	3	4	5
24. Does this sibling think your father favours him/her or you more?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
25. How much does this sibling know about you?	1	2	3	4	5
26. How much do you know about this sibling?	1	2	3	4	5
27. How much do you and this sibling have similar personalities?	1	2	3	4	5
28. How much do you discuss your feelings or personal issues with this sibling?	1	2	3	4	5
29. How much does this sibling discuss his or her feelings or personal issues with you?	1	2	3	4	5
30. How often does this sibling criticize you?	1	2	3	4	5
31. How often do you criticize this sibling?	1	2	3	4	5
32. How close do you feel to this sibling?	1	2	3	4	5
33. How close does this sibling feel to you?	1	2	3	4	5
34. How often does this sibling do things to make you mad?	1	2	3	4	5
35. How often do you do things to make this sibling mad?	1	2	3	4	5
36. How much do you think that this sibling has accomplished a great deal in life?	1	2	3	4	5
37. How much does this sibling think that you have accomplished a great deal in life?	1	2	3	4	5

	I Usually Get More Support	I Sometimes Get More Support	We are Supported Equally	This Sibling Sometimes Gets More Support	This Sibling Usually Gets More Support
38. Does this sibling think that your mother supports him/her or you more?	1	2	3	4	5
39. Do you think that your mother supports you or this sibling more?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
40. How much can you count on this sibling to be supportive when you are feeling stressed?	1	2	3	4	5
41. How much can this sibling count on you to be supportive when he/she is feeling stressed?	1	2	3	4	5
42. How much does this sibling feel jealous of you?	1	2	3	4	5
43. How much do you feel jealous of this sibling?	1	2	3	4	5
44. How much do you give this sibling practical advice?	1	2	3	4	5
45. How much does this sibling give you practical advice?	1	2	3	4	5
46. How much is this sibling bossy with you?	1	2	3	4	5
47. How much are you bossy with this sibling?	1	2	3	4	5
48. How much do you accept this sibling's lifestyle?	1	2	3	4	5
49. How much does this sibling accept your lifestyle?	1	2	3	4	5

	I Usually Get More Support	I Sometimes Get More Support	We are Supported Equally	This Sibling Sometimes Gets More Support	This Sibling Usually Gets More Support
50. Does this sibling think that your father supports him/her or you more?	1	2	3	4	5
51. Do you think your father supports you or this sibling more?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
52. How much do you know about this sibling's relationships?	1	2	3	4	5
53. How much does this sibling know about your relationships?	1	2	3	4	5
54. How much do you and this sibling think alike?	1	2	3	4	5
55 . How much do you really understand this sibling?	1	2	3	4	5
56. How much does this sibling really understand you?	1	2	3	4	5
57. How much does this sibling disagree with you about things?	1	2	3	4	5
58. How much do you disagree with this sibling about things?	1	2	3	4	5
59. How much do you let this sibling know you care about him/her?	1	2	3	4	5
60. How much does this sibling let you know he/she cares about you?	1	2	3	4	5
61. How much does this sibling put you down?	1	2	3	4	5
62. How much do you put this sibling down?	1	2	3	4	5
63. How much do you feel proud of this sibling?	1	2	3	4	5
64. How much does this sibling feel proud of you?	1	2	3	4	5

	Our Mother is Usually Closer to Me	Our Mother is Sometimes Closer to Me	Our Mother is Equally Close to Both of Us	Our Mother is sometimes Closer to This Sibling	Our Mother is Usually Closer to This Sibling
65. Does this sibling think your mother is closer to him/her or you?	1	2	3	4	5
66. Do you think your mother is closer to you or this sibling?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
67. How much do you discuss important personal decisions with this sibling?	1	2	3	4	5
68 . How much does this sibling discuss important personal decisions with you?	1	2	3	4	5
69. How much does this sibling try to perform better than you?	1	2	3	4	5
70. How much do you try to perform better than your sibling?	1	2	3	4	5
71. How likely is it that you would go to this sibling if you needed financial assistance?	1	2	3	4	5
72. How likely is it that this sibling would go to you if he/she needed financial assistance?	1	2	3	4	5
73. How much does this sibling act in superior ways to you?	1	2	3	4	5
74. How much do you act in superior ways to this sibling?	1	2	3	4	5
75. How much do you accept this sibling's ideas?	1	2	3	4	5
76. How much does this sibling accept your ideas?	1	2	3	4	5

	Our Father is Usually Closer to Me	Our Father is Sometimes Closer to Me	Our Father is Equally Close to Both of Us	Our Father is sometimes Closer to This Sibling	Our Father is Usually Closer to This Sibling
77. Does this sibling think your father is closer to him/her or you?	1	2	3	4	5
78. Do you think your father is closer to you or this sibling?	1	2	3	4	5

	Hardly Anything	A Little	Somewhat	Very Much	Extremely Much
79. How much do you know about your sibling's ideas?	1	2	3	4	5
80. How much does this sibling know about your ideas?	1	2	3	4	5
81. How much do you and this sibling lead similar lifestyles?	1	2	3	4	5

Appendix IV

Appendix IV Flowchart depicting Recruitment Procedure

Recruitment Procedure



Appendix V

Invitation Letter


Department of Psychology University of Southampton Highfield Southampton SO17 1BJ United Kingdom

Telephone +44 (0)23 8059 5000 Fax +44 (0)23 8059 4597 Email

Dear Family,

Can you help us!!

We are looking for people to take part in a study about the experiences of siblings of adults with a learning disability. Before you decide if you wish to take part we would like to explain why the study is being done and what it will involve. Please take time to read the following information. You may want to discuss it with family or friends.

Study title

The experiences of siblings of people with learning disabilities.

Firstly, who are we?!!

Our names are Simon Lloyd and Lindsey Rouse and we are training to be Clinical Psychologists in the NHS. We are particularly interested in working with people with learning disabilities and their families.

Why is this study being done?

We are carrying out this study with families in which one member has a learning disability. We are especially interested in your experiences as a sibling and we hope that this study will provide valuable information about your experiences that will be useful for developing family services in the future.

What will the study involve?

If you decide that you would like to take part you will be sent some questionnaires that will take approximately 30 minutes to complete. The questionnaires will ask about a number of different aspects of your relationship with your sibling. There will be no right or wrong answers! We are just interested in your personal experiences. You will be able to contact us at any time if there are questions that you are unsure about. If you would prefer us to meet with you in person to go through the questionnaires then this could be arranged. You will also be contacted by one of us who will ask you some questions over the telephone. These also ask about your relationship with your sibling. This should take no longer than 10-15 minutes.

Why have I been chosen?

You are being invited to take part because you are a sibling of an adult with a learning disability and our study will be about your experiences. We hope to involve 50 families from the Dorset area who can share their experiences with us.

Do I have to take part?

Of course, it is up to you to decide whether or not to take part. We hope you can find the time! If you are able to help us, you will be asked to sign a consent form but you will be free to withdraw at any time and without giving a reason.

What will happen to the information that I give?

The information that you give on the questionnaires and during the telephone conversation is CONFIDENTIAL. This means that this information will not be shared between different members of the same family or with services.

Who has approved the study?

The University of Southampton Research Ethics Committee has reviewed and approved this study.

Who should I contact for further information?

If you have any queries about the research or the questionnaires, please contact Simon Lloyd or Lindsey Rouse on tel. 02380 595321.

Or e-mail: <u>lr700@soton.ac.uk</u> sialloyd@hotmail.com

CONSENT FORM

The experiences of siblings of people with learning disabilities

Please tick box:

Na	ame	Date	Signature	
3.	I agree to take part in the above study.			
	free to withdraw at any time	2.		
2.	I understand that my participation is voluntary and that I am			
	for the above study.		,	
1.	I confirm that I have read and understand the information sheet			

4. It would be convenient for me to answer some questions over the telephone:

Day of week:

Time of day: ______(Morning, afternoon or evening.)

My telephone number is:

My address is (optional):

Please return this consent form in the enclosed pre-paid addressed envelope: (NB: You do not need to put a stamp on this envelope)

Sibling expressed emotion

Appendix VI

Instruction Sheet (Accompanied Questionnaire Pack) University of Southampton

Questionnaire Pack

University of Southampton Highfield Southampton SO17 1BJ United Kingdom

Telephone +44 (0)23 8059 5000 Fax +44 (0)23 8059 4597 Email

These questionnaires have been designed for completion by brothers and sisters of family members with developmental and/or learning disabilities.

How do I fill them in?

Please answer all of the questions as openly and honestly as possible. This is NOT a test and there are no right or wrong answers to the questions. Read each question carefully, but respond on the basis of your first reaction and do not spend too long on each question.

How long should it take?

It should take you approximately $\frac{1}{2}$ an hour to complete these questionnaires.

What if I have any questions?

The researcher you spoke to in the telephone interview is available for you to contact if you have any queries about how to fill in these questionnaires. You can contact Simon Lloyd or Lindsey Rouse on:

Tel: 02380 595321

Or

E-mail: <u>lr700@soton.ac.uk</u> sialloyd@hotmail.com

If you haven't returned the questionnaires within 2 weeks we will usually contact you by telephone to see if we can answer any questions you may have.

What do I do next?

Once you have completed the questionnaires place them in the addressed envelope you received with them and put them in the post! <u>You do not</u> <u>need to put a stamp on this envelope, it is freepost</u>.

THANKYOU FOR YOUR HELP IN THIS RESEARCH PROJECT.

Sibling expressed emotion

Appendix VII

Instructions to Authors (Journal of Intellectual Disability Research)

Journal of Intellectual Disability Research

Author Guidelines

Papers (in English) should be sent to: The Editor Journal of Intellectual Disability Research University of Wales College of Medicine Meridian Court North Road Cardiff, CF4 3BL Wales UK e-mail: winsladeb@cf.ac.uk.

Manuscript

Papers are accepted on the understanding that they have not been and will not be published elsewhere. The original and two copies of the manuscript should be submitted to aid refereeing and these should be typed (with a wide margin), double spaced, on one side of standard paper (A4: 30 × 21 cm). A title page should contain the author's name(s), place of work, address for correspondence, email address, full title and short running title. Authors should retain one copy of the text, tables and illustrations as the editor cannot accept responsibility for damage or loss of manuscripts. Final versions of accepted manuscripts should be accompanied by disks. The final disk should be accompanied by a file description form available at http://www.blackwellpublishing.com/pdf/fdf.pdf.

Each paper should be accompanied by a copyright assignment form.

A structured summary should be given at the beginning of each article, incorporating the following headings: Background, Method, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion. Pages should be numbered consecutively in arabic numbers, but tables, footnotes, figure legends, including magnifications and acknowledgements, should be submitted on separate sheets. Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

References

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic markers in Human Blood.
- Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* 24, 137-41.

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling

Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of SI units.

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